My Battle with Merkel Cell Cancer

My Battle with MCC

To David Shuster and the family he built.

Contents

I Discover a Mass in my Face

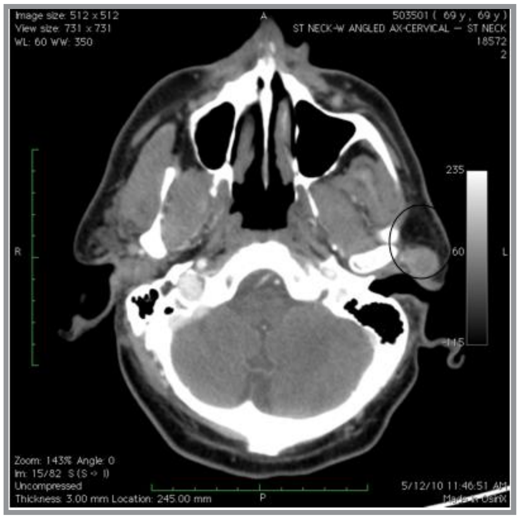
Friday, July 23, 2010

My Battle with Merkel Cell Carcinoma
About me. I am a 69 year old male diagnostic radiologist from Fresno. I have been in Fresno for almost 35 years, having left my radiology group a few years ago. I now work about half time as a pool physician at Kaiser. I am married 48 years. I have 3 sons, 4 granddaughters and a grandson on the way.
May 6 2010: I am visiting my mother in Montreal and I notice a lump in my face in front of my left ear. It is about 2 cm in diameter, firm, and mobile. It seemed to appear completely out of the blue, There is no pain. I can't feel any lymph nodes in my neck. May 11 2010: I am back in Fresno and get an informal ultrasound of the area. The mass is superficial to the parotid gland and is solid and vascular. In the superficial lobe of the parotid is another similar appearing mass of about 1 cm. I call my friend Richard Weinberg, an ENT specialist in Fresno. He tells me to come right over and he will take a look at it. He examines me and says he doesn't operate on the parotid, and has me seen by Dr Benjamin Teitelbaum. I have not heard of him before but Richard says he is the best for the parotid in Fresno. He examines me and sends me for a contrast enhanced CT scan of my neck. May 12 2010: I go for my CT scan. I review the images with Leyla Azmoun, the neuroradiologist at Sierra Imaging Associates.The scan shows the same findings as the ultrasound but there is a 1 cm lymph node in the neck. It is at the borderline between normal and suspicious.

Posted by docshu at 11:23AM (-07:00)

CT Scan Images

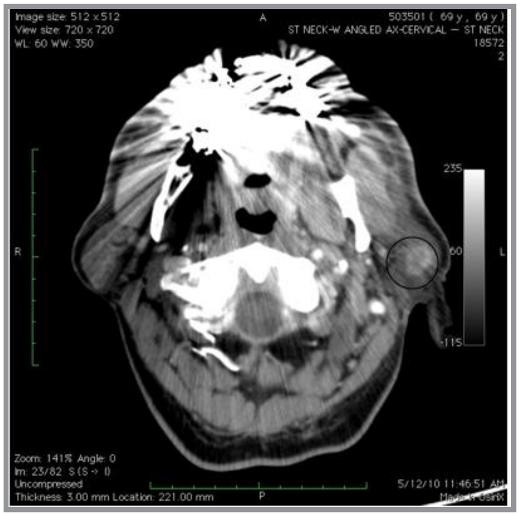
Friday, July 23, 2010



Posted by docshu at 11:40AM (-07:00)

Parotid Lesion

Friday, July 23, 2010



Posted by docshu at 12:00PM (-07:00)

Questionably Enlarged Lymph Node

Friday, July 23, 2010

Posted by docshu at 12:03PM (-07:00)

I Have Surgery

Saturday, July 24, 2010

May 13. Dr Teitelbaum does a fine needle biopsy of the superficial mass. I have to sweat out the weekend to get the results. The procedure was almost painless. He did two passes with a 21 needle. The first return was bloody. The second return was not visible to me.

May 17 or 18: The biopsy result is reported as a pleomorphic adenoma of the salivary gland.. This is a generally benign tumor although there are some malignant forms of it. I am very much relieved, but I have my doubts. Why would it arise outside the gland? This tumor can be multicentric.

We now have to arrange for surgery. The family is coming to visit for my Mother-in-law's unveiling. As the lesion is benign, there does not seem to be much urgency to do this. The earliest I can schedule the surgery is June 3, almost a full month after the mass was discovered.

June 3 2010: This is our 48th wedding anniversary. I arrive at the hospital 7:15 AM for the surgery scheduled for 9:15. The procedure is to be done at St. Agnes Medical Center in Fresno. I was on staff there for about 30 years in the radiology department starting in 1976. The assistant surgeon is to be Jerry Moore, who I have known almost that time. After some lab tests and an EKG, I meet the anaesthesiologist, Gary Grimes. He is very kind and reassuring. He gives me Versed and I wake up in recovery with no memory of even going to the OR.

Dr Teitelbaum checks me after surgery. I can smile with both sides of my mouth. (The dreaded complication of parotid surgery is facial nerve injury which leaves a person with weak facial muscles.)

He reports to me that the frozen section of the lymph node was benign. Things are looking good, but I still have reservations about the real pathology.

June 7 2010. I am feeling well enough to go to the bridge club. I keep my cell phone off. After the game I have a message from Dr Teitelbaum to call him. I get his office but not him. I page him. I call Judy and she says she spoke to him and although he would not give her any details, the news is “not good”.

Dr Teitlebaum calls back and says I have a Merkel Cell Tumor. All the lesions removed were metastases to lymph nodes. The frozen section was a false negative diagnosis.I look this up and find it is a malignant tumor of the deep layers of the skin. So where is the primary?

Posted by docshu at 10:49AM (-07:00)

Merkel Work-up

Saturday, July 24, 2010

June 8,2010 I have a post-op visit to remove the drain from my neck. The facial nerve was not overly damaged as I can smile with both sides of my mouth and raise my eyebrows. I do have some numbness in my left ear.

He sets up an appointment with a dermatologist to check me for the primary.

We have used Dr David Tashjian in the past. He is unavailable and his patients are being seen by Dr Edgar Macias. He checks me out but finds only a small lesion on my leg which he biopsies and sends to UCSF dermatopathologist.

During this visit, I have my first emotional response becoming very tearful. Dr Macias is very comforting. I surprise myself with the tearful comment that I feel like I have let everybody down by becoming ill.

June 9, 2010 I have noticed a red spot in front of my left clavicle. I return to have it biopsied.

I go to Valley metabolic Imaging for a PET CT

It shows one questionable lymph node in the left neck, level 2, possibly the same node as on the original CT. I have the CD of the images but it does not work well on my computer.

June 10, 2010. I play poker every month with a group that includes Tom Hackett, who is an oncologist. I call him and ask him to care for me. He refuses saying that he doesn't take friends as patients but strongly recommends his associate, Dr Marshall Flam. I have known Marshall for many years and have great respect for him. He ia a very knowledgable oncologist and I trust his judgement.I see him Thursday morning. He spends almost two hours with me going over the reports, calling my Docs including the pathologist, and doing my physical. He searches for a primary and suspects a lesion on my left cheek.

He recommends a radical neck dissection followed by radiation treatment. If the primary is not found, chemo before the radiation although he says he has no evidence that it will help. He says it may because Merkel is histologically similar to small cell carcinoma of the lung. He says he would not have a problem if I declined the chemo.

I return to see the dermatologist for a biopsy of my cheek, and he also biopsies a small lesion on my back.

June 11,2010. I go to work in the morning to try to get my mind off everything. I work 8-12 AM. It doesn’t work very well because all the other Radiologists come to visit and offer their words of encouragement.

I go to the bridge club and have a fine game, coming first of 9 tables. Bridge is more distracting than work.

My oldest son does some research on the internet and finds the MCC group.

Posted by docshu at 10:54AM (-07:00)

Gary Finds the MCC Group and Dr Nghiem

Saturday, July 24, 2010

June 14, 2010. Much has happened. Through the resources and support in the MCC group, I have been in contact with Dr Ngheim of the University of Washington who is a world exoert in this disease. He was good enough to call me Saturday morning, June 12, and spent 45 minutes on the phone with me.

The good news is that I have been spared a radical neck dissection, a procedure which involves an extensive removal of lymph nodes in the neck, together with the sterno-cleido-mastoid muscle, the internal jugular vein, a nerve which supplies muscles to the shoulder and risk to other important nerves such as the vagus and the recurrent laryngeal nerve.

In addition, chemotherapy is not recommended as this is not shown to be helpful at this stage of the disease. In fact it may be detrimental as it damages the immune system which is needed to fight the viral component of thes disease.

I will need radiation treatment alone for the time being.

The bad news is that at this stage, the risk of distant disease is 50% and the risk of local recurrence is 20%.

Tomorrow, I will contact Dr Teitelbaum to cancel surgery.

I will call Dr Flam to let him know of these developments.

I will set up appointments to see Dr Ngheim for Thursday, June 24, as well as Dr Parvathaneni, the Radiation Oncologist, for June 23.

I will need to see Dr Mahdu John in Fresno on Monday or Tuesday, so he can plan the treatment under the direction of Dr Parvathaneni.

Additionally there are exciting developments having to do with tumor antigens and injections of interferon into the tumor. Dr Ngheim has suggested injecting the site where the tumor was removed from as there is likely to be residual tumor there.

I will need flights and hotel. The plan is to leave Wednesday early AM and return Friday late or Saturday.

Mt first surgical wound is healing well, but there is some edema around my ear and swelling of the incision. Little serious pain and I am off all pain meds.

I must give great credit to my son, Gary who researched out the disease and made the initial contact with the MCC group and got me connected with Dr Ngheim.

Without his help, I would still be nervously awaiting a major surgery followed by chemotherapy, all delaying the most useful treatment, radiation therapy.

Posted by docshu at 11:06AM (-07:00)

We Go on a Cruise to Alaska

Saturday, July 24, 2010

June 13,2010 We leave on a long-planned cruise to Alaska, taking our nine tear old granddaughter Eva. This cruise is a great distraction, but it is difficult to stop obsessing about my condition. I often become tearful. I still am not sleeping well. Judy is very supportive but she is also very upset by all this.

Tuesday, June 15 2010

We dock in Ketchikan, Alaska.

I get up early because I will have cell service. I have a brief breakfast,go to the internet café, where there is good wireless signal, open my email and the phone rings. It is Dawson, the scheduler for Dr Ngheim. We have a long discussion during which time he gets Dr Ngheim conferenced in from Washington DC.

The bottom line is that I will need to go to Seattle Tuesday to see both Dr N and Dr P Wednesday. In addition, I will need to stay until Saturday so Judy can be shown how to inject the Beta Interferon. I will need to get my insurance to approve it as it is an off-label use for the drug. The cost is $3000, but I will pay if necessary.

I call Dr Teitelbaum’s office and tell them I need to cancel the surgery and to get copies of my records for me to pick up Monday.

Needless to say they call me back later in the afternoon to schedule the surgery.

I call Dr Flam and he has reservations about bypassing the surgery. Dr Teitelbaum also has such reservations when he returns my call later in the day. I promise both of them I will show them the literature I have from Dr Ngheim to support this decision.

I also arrange to pick up all biopsy reports from Dr Tashjian’s office.

Thursday June 17, 2010.

I am in better spirits after a good day in Juneau. My granddaughter Eva is such a delight to be with that I am able to get my mind off this. We watch her favorite movie including deleted scenes, and she has seen it so often she quotes the dialog with the actors. Ironically, the movie is The Titanic.

I have a large to do list for when I get home. I will see both Dr Ngheim and Dr Parvathaneni Wednesday morning and have arranged flights leaving Fresno late Tuesday arriving in Seattle Tuesday at 10:45 PM. Ironically, the flight back from the cruise originates in Seattle, nut Dr Nghiem can not see me until Wednesday and we decide we need to get Eva back to Fresno.

I have booked a room at SCCA House departing Saturday. I may receive injections of Beta Interferon into the site of the excised tumor mass as there is evidence this may control the disease in immune responsive patients.

In the absence of a tumor mass to inject, there is no precedent for this, but there are certainly tumor cells in the area. In fact, I may be feeling another mass in the area of tumor resection. Is this good news? They will have something to inject. Or bad news? Rapid tumor growth.

Posted by docshu at 11:15AM (-07:00)

My Visit with Dr Nghiem

Saturday, July 24, 2010

Sunday, June 20 2010.

We are back in Fresno from our cruise. I must admit that it was not entirely successful in distracting me from thinking about my condition. I think the tumor is already growing at the surgical site, only 2 1/2 weeks since it was removed.

I am busy getting material together for Seattle.

Tomorrow, I will visit Dr Teitelbaum and Dr Tashjian to get copies of my records. I will also visit Dr Flam and have a 2 hour appointment with Dr. Mahdu John, who will be my radiation oncologist in Fresno. I will try to find out about the off label use of Beta Interferon and whether my insurance will cover it.

I have a dentist appointment for a tooth cleaning and to get a prescription toothpaste to preserve my teeth during the radiation.

Tuesday June 22, 2010.

Yesterday was spent getting ready for the trip to Seattle. I have everything needed but quite disorganized. I will try to get it organized today.

Radiation will be no fun. It is likely to last 7 weeks. They make a mask which looks like a Fencer’s mask to hold you still. I hope it does not make me claustrophobic.

The most likely problems are skin burn, dry mouth from loss of parotid and submandibular gland function, loss of sense of taste, difficulty swallowing and hoarseness. The issue of damage to the mandible is reduced by their modern devices. There is also general malaise, fatigue and loss of appetite.

I have arranged with Kaiser to work when I can.

Treatment planning takes a week so I will not start treatment until July 6, exactly two months from the date I discovered the initial mass.

Friday, June 25, 2010.

We flew to Seattle on Tuesday evening and arrived at our lodging just before midnight. We stayed at a place called SCCA house. This is a residence which has been developed for cancer patients and many of the residents stayed for a fair length of time during treatment. The setup was very nice. Although rather Spartan, we had a nice room with queen bed, a separate area for a caregiver if needed, microwave, smaller for greater, flatscreen TV dishes so that we could prepare food if needed. The cost was very reasonable at $79 per night without any hotel tax being charged.

Wednesday was a very busy day. First appointment was with Dr. Nghiem. I was first examined by a visiting physician from Japan. Then Dr. Nghiem came in. He gave me a complete examination. We had a long discussion about the options. He felt that there was no recurrence of tumor mass in the region of recent resection. Because of this, he felt that it would be inappropriate to start injections in the area where the tumor had been removed. We had a frank discussion about what my chances are with Judy present. Basically, radiation treatment is expected to control local disease at least 80% of cases. However there is a 50-50 chance of having distant disease. At that time, chemotherapy may be an option for palliation. Injection of beta interferon may be an option if a mass appears, but this treatment is too untested to inject this material at the original tumor section site.

We then went for our appointment with Dr. Parvathaneni. We take a shuttle to the University Hospital which is about two or 3 miles away. We first met with a resident named dr Ralph Ermoian who is from Fresno. He examined me. We had long discussions about radiation treatment. Then Dr. P. arrived and he gave me a thorough examination including palpation of my tonsils causing me to gag. He felt that my tonsils were not involved. He is going to have discussions with Dr. John to organize my radiation treatments in Fresno. It looks like he will recommend only six weeks of radiation treatment.

Following this, we returned to the lab at Dr. Nghiem's location where they draw nine tubes of blood. We then returned to SCCA house, picking up bagels on the way back to have a late lunch. I checked my e-mail and discover that they want me to return for one more blood sample. That takes less than an hour as I take the shuttle in both directions.

We decided it would be best returned to Fresno immediately. The SCCA house is very good about this. They allow us to check out and credit us for the three days we did not spend there. Delta Air Lines, however, is not so cooperative. They want more money for the return flight to Fresno then they would charge if I just booked a one-way flight to Fresno. Instead, we book a direct flight from Seattle to Fresno on Alaska airlines. We arrived back in Fresno late Wednesday.

I will work half a day on Thursday and half a day on Friday which will more than pay for the additional cost of the flight.

It looks like the timetable is now as follows:

Monday, June 28: I have an appointment for the setup for radiation treatment at 9 AM. I plan to work Monday afternoon.

Tuesday, June 29: I plan to work all day.

Wednesday, June 30: I have an appointment with Dr. Person for a complete teeth cleaning, and consultation regarding keeping my teeth healthy during radiation treatment. At 11 AM, I have an appointment for follow up with Dr. Flam.

Thursday, July 1: I plan to work all day.

Friday, July 2: I plan to work in the morning.

Tuesday, July 6: radiation treatment begins and probably will last six weeks.
Posted by docshu at 11:23AM (-07:00)

Radiation Planning

Saturday, July 24, 2010

Monday, June 28, 2010. Today was a set up appointment for my radiation therapy. Everything was done very efficiently. I was placed on a simulator table which is actually a CT scanner and some images obtained. They use a mask which goes over your head which is not unlike fencers mask. It is warmed up and softened and then placed over your head, pressed into position, and then cooled so that it retains its shape. This allows them to keep you in the proper position during radiation treatments.Treatments will start on Thursday, July 8 and continue for six weeks, ending, ironically, on my birthday, August 18, 2010. I will celebrate my 70th birthday by ending radiation treatment. We reviewed all the complications which are possible and the precautions to take. The most annoying probably will be the need to gargle and rinse my mouth about five times a day with a mixture of salt and baking soda and water.Treatments will only take about 15 minutes and I should be in and out within half an hour. Every Monday, there is what they call a stat session which will involve reviewing my progress with the radiation oncologist. On the first Monday after treatment begins, we will also meet with the dietitian. Dietary restrictions expected will be as follows. I'll not be allowed to have anything which is too acidic, nor foods which are crunchy and which might tear the mucosa of the mouth. I will not be allowed to have hot coffee or anything too cold. I'll have to restrict processed sugars because of the risk of dental caries. I'm still feeling cautiously optimistic, but I have to say that reading the case histories on the Merkel website is quite terrifying. Right now I am essentially asymptomatic, except for some discomfort at the surgical site. However I am aware that this is a potentially devastating malignancy which could rapidly appear in the liver, brain, bone amongst other sites. I hope that I am not spoiling my last good months by taking the radiation treatments. However I have no choice but to follow with my physicians recommendations as they are the top experts in the field. Some interesting literature has come to light linking the virus which is involved with Merkel cell carcinoma and the Salk vaccine which was used to immunize me against polio. Apparently many early batches of this vaccine were contaminated with the polyamovirus. Who could have known? I plan to spend some my time in the future writing a separate blog which will basically be my memoirs. In the meantime, I feel that I am coping very well with my current circumstances.
Posted by docshu at 11:30AM (-07:00)

Pre Radiation

Saturday, July 24, 2010

Wednesday, June 30, 2010.

I have a dentist appointment at nine o'clock this morning. I'm nervous about this. If cavities are found, it is possible that I will need extractions prior to radiation treatment and in addition, it may change the treatment plan and delay the treatment. Fortunately, nothing is found. However I will have to return for additional x-rays of my mouth on July 7 at 11 AM.

At 11 AM, I have an appointment for follow-up with Dr. Flam. They do lab work which shows no abnormality. After about an hour and 20 minutes of waiting time, I finally get to see Dr. Flam. He has read the journal articles which I gave him. However he does not know very much about the virus associated with Merkel's. He gives me his e-mail address and later on in the day, I e-mail him some references. I have an appointment to see him again in about two months.

Gary has been doing some interesting research on the association of Merkel's and the polyamovirus. I will post his information later.

I am still feeling fine apart from some discomfort in the region of my incision, and some numbness in the region of my left ear. I'm in good spirits. I plan to work tomorrow all day, half the day Friday and then play bridge in the afternoon, and then work three afternoons a week during the early part of my radiation therapy unless I become too fatigued.

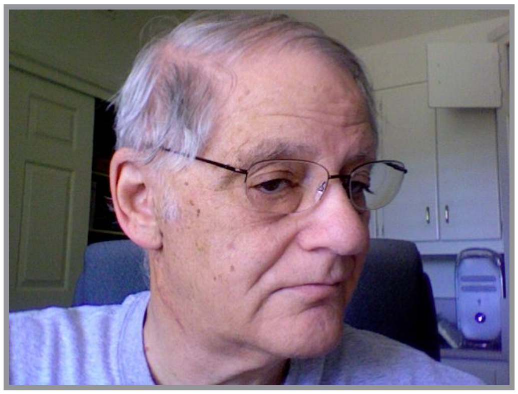
Monday. July 5 2010.

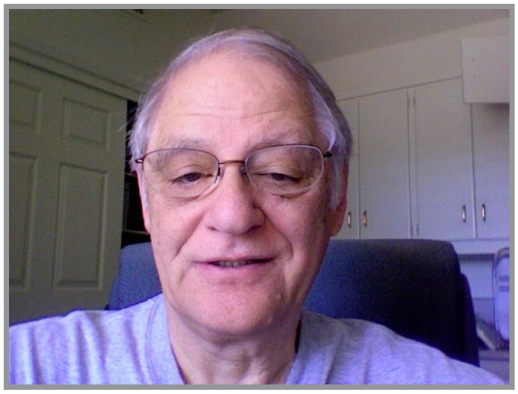
I have a piece of good news from Dr Nghiem. One of the blood tests done was a very sensitive assay for circulating Merkel cells. There were no such cells found in 7 cc of blood. They don't know what this means as there is little experience with this test long term but it is the best possible result. I am interpreting it to mean that my immune system is eliminating circulating merkel cells and this is a good prognostic indicator.

Posted by docshu at 11:34AM (-07:00)

Baseline Photos Before Radiation Treatment

Saturday, July 24, 2010





I plan to add photographs to this blog. They will be taken using my isight camera on my Macbook Pro.They will allow tracking of changes during radiation treatment

Here are the first, the baseline prior to beginning radiation therapy.

Posted by docshu at 11:39AM (-07:00)

I Begin radiation Treatment

Sunday, July 25, 2010

Thursday, July 8, 2010.Yesterday was a very busy day. I had received a call to switch my first radiation treatment to one clock on July 7, 2010. I had planned to work the afternoon at Kaiser. I had a dentist appointment for a complete set of x-rays to rule out cavities prior to beginning radiation treatment.I had noticed a skin lesion which look like a wart just at the edge of the inferior margin of my right orbit. It had turned red and was noticeably larger than it had been previously. This was very disconcerting as I was beginning treatment to the left side of my face and neck. The entire treatment plan would be incorrect if this turned out to be the primary Merkel cell carcinoma. I decided to start work early. I called my dermatologist. He was on vacation, but I set up appointment with his associate, Dr Simjee, who agreed to see me in the morning. I left Kaiser after working only about one hour. I was seen by the doctor who assured me that she was 99.9% certain that this was not Merkel cell carcinoma. She did remove the lesion superficially and sent it for her pathological examination.I went from there to the dentist who reported that my x-rays did not show any evidence of cavities.After lunch, Judy and I went to see Dr. John, to consult prior to beginning radiation treatment. The radiation plan is for five weeks of intensity modulated radiation to deliver a dose of approximately 51Sv which corresponds to 5100 rem or rads using the older units which I am more familiar with. This will be delivered over five weeks, and followed by one week of electron beam therapy to the specific area where the tumor was first discovered. Of interest is that the dose to my right sided salivary glands will be about 20% of the dose to the left. I presume this is because of scattered radiation. After five treatments, I should be able to judge the net effect of the radiation on my right salivary glands by the results of the treatments on the left salivary glands. On Monday, we will have a chance to speak to the dietitian. I have my first radiation treatment. Thy inclose me in a mesh mask which conforms to my face and keeps me from moving. There is only minor discomfort.After the treatment, I returned to Kaiser and work another 2 1/2 hours.After work, Dana, my daughter-in-law (Gary's wife) comes for dinner with Sarah, age 3 and Bel, almost one, This is a wonderful distraction. I barbecue steaks, thinking that while my taste buds are still functioning, I

might as well enjoy a good steak. Sarah has become something of a comedienne. She said that she will not participate in her day camp activities but was only going to stand around. She repeated that several times, and then with a big grin on her face she said "I was just kidding". She is learning to swim and Bel is also learning to swim. However allowing them to go in the pool is a big production. They have a wonderful time just using the wading pool. Just as were about to go inside, Rocky (our Goldendoodle) punctuates the evening by peeing in the pool. I sleep much better, having been reassured that the treatment plan is on track. I go for my Thursday morning radiation treatment. It is very quick and easy. I keep thinking as the radiation beam is traversing my body "take that you Merkel cells, I'm going to kill you. I'm going to get rid of every last one of you. You are my enemy and I hate you" .On Friday, July 2, I received notice that my drivers license is up for renewal. It will expire on my birthday, August 18, 2010. I'll have to take a written test. I checked with the DMV website, and the earliest possible appointment is August 12. This means that I would have to take the test after five weeks of radiation treatment and my drivers license photo will show my face probably bright red from the radiation. One of the three DMV offices in Fresno has been closed for about a month. I decide to see if I can take the test without an appointment. I drive to the DMV office in Clovis and get there about 830 in the morning. There were 75 to 100 people waiting in line outside the door. The parking lot was filled with cars and people searching for spots. Parking on the adjoining streets was also nonexistent, filled with additional vehicles along to people going to the DMV office. As I did not want to spend all day at the DMV, I decided to use my appointment. I asked Dr. John if I would be in mental condition to take the test and he said I would. If you have an appointment, you usually only have to wait a few minutes. I would hate to lose my drivers license. I asked Dr. John when I could travel. He suggests waiting three weeks after radiation treatment. I will make an appointment to go back to Seattle to see Dr. Nghiem at the end of September. Judy wants to plan a cruise.This Merkel tumor has forced us to cancel a trip to Philadelphia to visit our son and daughter-in-law and their new baby who is expected to be born in about a week. He will be our first grandson. I would like to travel to Philadelphia perhaps in the beginning of October to meet and greet him. They plan to name him Eli. Our oldest granddaughter, Eva, has written the following while at camp. I think she will be a wonderful writer someday.
"Friendship is the sprout of a new life. When you make a friend, you have a person who will be by your side, and love you no matter what. Your friend will always walk home with you. They will hug you when you cry. Without friends, there would be no peace. The world would not spin round.We need friends.
Eva Shuster-Arechiga Age 9
Posted by docshu at 02:01PM (-07:00)

First Week of Radiation Treatment, Eli is born.

Sunday, July 25, 2010

Friday, July 9, 2010.
My third radiation treatment was this morning. Yesterday in the afternoon, I felt some nausea. Otherwise I feel good and have no signs of radiation in my neck. I arrived at the office on time but had to wait about a half hour before treatment began. I met two interesting men in the waiting room. One was being treated for a brain tumor with radiation and chemotherapy at the same time. He was optimistic because half way into his treatment the tumor was slightly smaller. He had a history of thirty years of survival after testicular cancer and lung metastases. The second man was being treated in his left neck for skin cancer, I presume squamous cancer and had a very red neck with a white patch about three inches in diameter, which was a skin graft. He also had some neck

deformity and a facial droop on his left side. He must have had a radical neck dissection and probably facial nerve removal as he said the tumor infiltrated nerves. Both of these men seemed to be in very good spirits considering their conditions. It makes me feel things could be much worse for me.

Tuesday, June 13, 2010.

Yesterday, at about 2 AM, we received a phone call. Our first grandson was born by cesarean section in Philadelphia. He weighed 6 pounds, 7 ounces and was 19 inches in length. Unfortunately, he was positioned with the occiput posterior, sunny side up. After two hours of pushing, they decided to perform a cesarean section. Everyone is doing well. We were supposed to be traveling to Philadelphia both to greet the new baby and help out, but this will not be possible. Fortunately, Leanna's parents arrived in Philadelphia just before the baby was born. It appears that radiation treatment has not yet affected my bridge playing. On Friday afternoon, Bert and I came first, on Sunday afternoon, we also came first and on Monday afternoon, we came first of 12 tables and had the best score of all 24 pairs. Of interest is that Judy and Carol came second of East-West pairs. On Friday, Bert Rettner, my bridge partner and friend took me for an early lunch. He is a physician who is now retired. However he has a particular interest in alternative medicine. He gave me names of reference books one of which I took from the library. The book is called "Younger Next Year"by Chris Crowley and Dr. Harry Lodge. It basically gives you hints on diet and exercise to maintain your youth. I don't know if I can follow the advice at this time, but it is about time that I began a program of exercise which is more vigorous than merely walking the dog once or twice a day. On Monday, following my radiation treatment, they have what they call a stat session. This is the time when the radiation oncologist evaluates how I'm doing. So far, and had no symptoms. We had a brief meeting with the dietitian. I will have to apply Aloe Vera lotion to my face several times a day. I asked Dr. John about tips for improving my immune system. He recommended meditation. I don't know if I can do that, but today, while I was having my radiation treatment, I attempted to concentrate all of my thoughts on appreciating my heartbeat.

I have begun an e-mail correspondence with a former associate of mine. His name is Andy Osborne. He is much younger than me, and a world-class cyclist. He developed the mass in his neck which was diagnosed as carcinoma of the tonsil. He also underwent radiation treatment and I think chemotherapy as well. He has been doing very well and has resumed cycling and won races after recovering. He has given me three pieces of advice. Be aggressive! Don't think for a minute that you cannot beat this. Accept help when people offer. Keep a positive outlook. He said that he researched everything he could find on this cancer on the Internet and came up with 30 ongoing experimental protocols. He told his doctor that he wanted to be involved with all of them. He found a protocol which offered a 15 to 20% survival advantage but was experimental. He paid for it himself as it was not covered by insurance. One year later, it became standard treatment. I think, that without asking, I have been following Andy's advice.

Tonight, I am hosting my regular monthly poker group.

Posted by docshu at 02:12PM (-07:00)

Radiation Treatment Continues

Sunday, July 25, 2010

Here I am after 5 radiation treatments. The spot on my cheek is the biopsy site. I have the report of “Inflamed Suborrheic Keratosis”. No Merkels. Of interest is that the report does not show the name of the reading pathologist. I think I have a slight facial droop on the left as a result of my surgery.

Sunday, July 18, 2010.

This has not been a good weekend for me. I have begun to develop the symptoms of radiation treatment. Nothing unexpected has happened, with the exception that I think is happening sooner than I expected. I began to have a very sore throat, and some discomfort with swallowing. I have lost much of my sense of taste. This is the case after only 8 treatments, and have 22 treatments to go. I dread the next few weeks. As yet, have not taken any painkillers. Tomorrow I will discuss the situation with Dr. John. So far, I have noticed no skin changes. My beard is still growing on the left side. There's no redness or skin discoloration. I've had no itching or other symptoms. I have noticed some hoarseness. Reading of peoples experiences online, I fear now that when my symptoms become worse, I may require a gastrostomy. I also fear that my sense of taste will never return. I hope that this will all be worthwhile. It would be terrible to go through all of this only to have the cancer return. On a happy note, I got to spend a lot of time with Gary, Dana, Sara and Bel. Sara has been particularly delightful. She came over to me and kissed the location on my right leg which still shows some discoloration after a skin biopsy. We joked with her about her becoming the kissing doctor. In many ways, the kissing is better treatment than anything else. I spoke to my mother today. She is doing well. Ellie (my sister) visited her and just left today.While she was there,she was able to do a video chat with Mike and Leanna and had an opportunity to see Sammi and Eli. Tomorrow, the plan is that radiation treatment in the morning, and play bridge in the afternoon. I still plan to work in the afternoons next week.

Wednesday, July 21, 2010.

On Monday, I was examined by Dr. John. He thinks that I might have oral candidiasis (thrush). This is a yeast infection. when he looked in my mouth, he saw some white patches in the area where I was uncomfortable. He has given me a prescription for oral Nystatin.In addition, he gives me a prescription for a mixture which requires compounding. It includes sorbitol, lidocaine, hydrocodone, and acetaminophen. in order to receive these, I had to go to a pharmacy which does compounding. I go to the bridge club. When I'm done, I have a message on my cell phone from the pharmacy is saying that. They would like my permission to proceed with preparing this for me, in case the insurance doesn't pay. I go to the pharmacy, and the insurance does not pay. This is quite ridiculous, but it turns out that I have to obtain a retroactive formulary exception. Dr. John's staff is very helpful and this was taken care of yesterday.

The medications are actually helpful, and my pain has diminished. However I'm still very uncomfortable with throat pain, dry mouth, difficulty in swallowing, and loss of sensation

of taste.
I have now completed 11 of 30 radiation treatments. I am not looking forward to the next four weeks. For now, I feel that I'm still able to work, and will continue to work three afternoons a week. I will still play bridge on Monday afternoon and Friday afternoon. Last Monday, I feel that my bridge game was not up to par.
Posted by docshu at 02:23PM (-07:00)

Bel Turns One

Sunday, July 25, 2010

Sunday, July 25,2010.

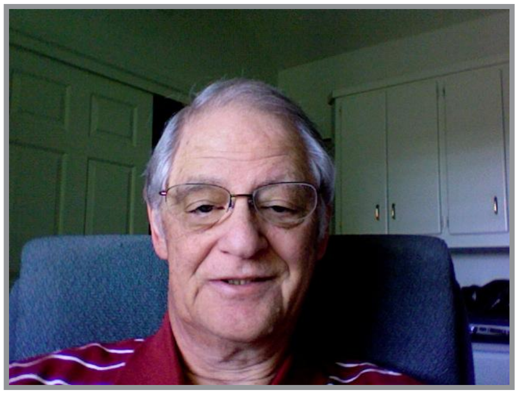
Friday was Bel's first birthday. We went to visit and have pizza and cake, She is on the verge of walking. We had a nice visit. here is a photo of her with cake face. I have now completed 13 treatments. I can report the following symptoms. Loss of taste. This perhaps is the most troubling. I can’t taste anything. I have no desire to eat as a result. I can taste no saltyness and no sweetness. I will have to force myself to eat to avoid a feeding tube. Dry mouth. I keep using the mixture of salt and baling soda to wet my mouth, but it does little good. At least it does not taste as terrible as it did. Sore throat. This has improved since last weekend, and it seems the medication has worked. Itchy skin, with some sensation of burning in my left neck. Constipation. This may be from the narcotic in the slurry given to me for treatment of sore throat. I stopped taking it yesterday. I have developed a quite severe low back pain. This has occurred in the past, but it is one of the worst I have had. When it started, my first thought was “could this be due to bone metastasis?” I don’t think so. I have taken NSAIDS today and I’ll see what develops. My bridge game is back to normal. Bert and I came first of 9 tables on Friday.
Posted by docshu at 02:51PM (-07:00)

Update at Halftime

Wednesday, July 28, 2010

Wednesday, July 27, 2010.
I am at the halfway point in my radiation treatments. My symptoms as previously listed are about the same. My back pain is manageable and my throat pain is minimal. Constipation is gone. The most troubling symptom is complete loss of the sense of taste. Mike and Leanna have suggested I try Miracle Fruit. This is a fruit which contains a chemical which alters the taste of foods to make them taste sweet. It acts on the taste buds. I have ordered this from Amazon in pill form, and will report on its effect on me. There were reports on CNN which looks encouraging. Here are the URL

http://www.cnn.com/2009/HEALTH/03/25/miracle.berries.weightloss/index.html http://www.miracleberrycafe.com/media_miracle_fruit_cnn_chemotherapy.html The research is being done at Mount Sinai in Miami, and a Dr Mike Cusnir was interviewed about it on CNN. I decided to call to discuss this. I had to call three numbers, all of which were answered by a very helpful HUMAN, and not by a machine. I did not get to speak with the doctor but I did speak with Monika Brooks, a nurse involved with the research. She reports good results in many chemotherapy patients in restoring some sense of taste, but not all patients. They have limited experience with radiation treatment patients.
Thursday July 28,2010
Here are the photos from the halfway point.



I can see a definite left facial droop. Otherwise there is little evidence that I have received radiation. My back has improved. My neck feels warm on the left. All food has no taste. There is a constant bad taste in my mouth. Others describe it as metallic. I have been advised to use plastic utensils. This doesn’t help.
Posted by docshu at 08:56AM (-07:00)

Update after 20 of 30 radiation treatments

Tuesday, August 03, 2010

Tuesday, August 3, 2010.
Today, I have completed 20 of 25 of the intensity modulated radiation treatments. This will be followed by five electron beam treatments. Before I get into a discussion of my recent visits to the radiation oncologists, I would like to discuss some of the activities which went on this weekend. Brian, my middle son, who lives in Vancouver, came to visit. We had a very nice visit with him. On Saturday, we went to visit with Gary and Dana, where we had another small party in honor of Bel's first birthday. Dana's parents were

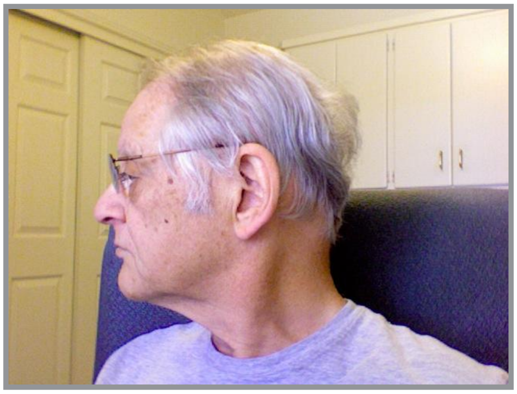
there. They visited from Valencia, California. Eva and Sara were there, of course, and Gary's first wife, Margaret Eva,s mother was also was there. We had a nice time and again, cake was served. Unfortunately, I could not enjoy the cake. On Sunday, we did video chats, first with Mike and Leanna, Sammie and Eli. Brian was also able to participate. This was followed by a video chat with my mother in Montreal. My sister Ellie was there visiting from Edmonton Alberta. Her daughter Cheryl was there with her newborn baby, whose name is David. He is not named after me. This was my first chance to see him. I have to say that the innovations in modern electronics are wonderful for families were separated by so much distance. Here, we were able to share video and chat with people living in Philadelphia, Vancouver, Montréal, and Edmonton. I can only imagine what my grandparents on my fathers side who left their families behind in Russia, and moved to the New World, would think. How they would have loved to have been able to communicate like this!

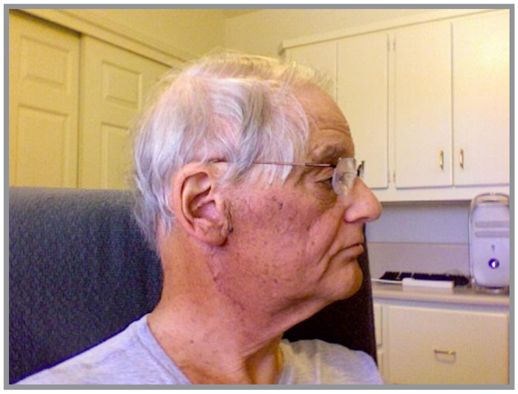
I have sufferred from most of the expected symptoms of radiation treatment. The one which I have managed to avoid is the fatigue described by many. The most distressing of all the symptoms is the loss of sense of taste. In fact, it is worse than merely the loss of sense of taste. Everything tastes bad. The way described it to my wife is for her to imagine that everything she ate tasted like cantaloupe. She hates cantaloupe. The next distressing symptom is a very dry mouth. In spite of multiple rinses, drinking lots of water, the dryness continues. This also seems to result in a sore throat, although my throat has markedly improved since the first week of radiation treatment. A new symptom which I have developed is some kind of painful lesion in my nose on the right. Dr. Lee, the radiation oncologist, who was filling in for Dr. John yesterday, thinks it might be a viral herpes simplex. I have had occasional herpes simplex infections on my lip, and I have had a similar condition and my nose two or three times in the past 10 years. I will try treating this with an antiviral ointment. My back pain is resolved almost completely. Last, but far from least, is the burning in my skin of my neck on the left. I have been applying aloe vera lotion to this four or five times a day, but I anticipate this getting a lot worse. This is particularly so as I will receive five electron beam treatments. These treatments are designed to add radiation to the skin. I asked Dr. Lee what were the chances that my skin would break down and that I would require skin grafts. He said that it was likely that my skin would break down, but that it was virtually certain to heal on its own. However, because this is the original site of tumor, the intense radiation to the skin is required.

On Saturday, I had a long talk with a fellow sufferer of Merkel's carcinoma in Minnesota. His name is Rich Kessler. He tells me that he is one of the founders of the group. He still has a non-healing lesion on his leg in the skin as a result of his radiation treatment four years ago. However I have to say that my discussion with him gave my spirits a big boost. He has survived eight years with Merkel's. Rich, this message is for you. I read on one of the other posts on the Merkel site that you can send blood for testing to Dr. Nghiem's lab.

My bridge game still has not suffered. Playing with Bert, in a game with 15 tables, we had the best score of all 30 pairs with 212 on a 156 average.

Here are the pictures. You can see the left side of my face is red and pigmented. My beard on the left is barely growing. The left facial droop appears more pronounced to me.





Unless there is some unexpected event, I will post in one week when I have completed the Intensity modulated treatments.

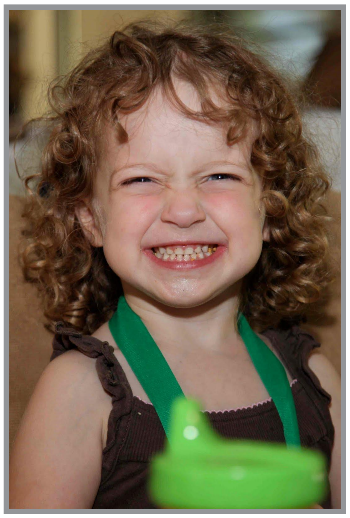
One additional note. My radiation badge at work is changed every month. Mine was changed today. How ironic! Here I am taking this huge dose of radiation and I wear a radiation badge at work monitoring me for trivial doses by comparison.
I have spent my entire career conscious of the hazards of radiation, and avoiding it to the best of my ability and now I willingly accept huge doses.

Here is a link to information about circulating tumor cell science. It is slow to load and references breast cancer, but I assume it will also apply to Merkel's. My result was zero circulating tumor cells.
http://www.veridex.com/media/CellsearchMOA.aspx
Posted by docshu at 11:40AM (-07:00)

What Do I Tell My Granddaughters?

Tuesday, August 10, 2010

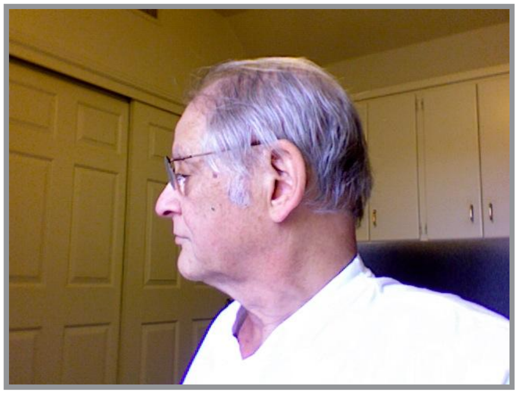
Tuesday, August 10, 2010.



SARA, age 3, The Kissing Doctor

What do I tell my granddaughter? She has been most interested in all of my injuries. When I had a healing biopsy site in my right leg, she noticed it and ask me what it was. I told her that it was a cut and it would get better. Then she insisted on kissing it. Similarly, a biopsy on my left cheek was cured. We have named her Sara, the kissing doctor. I don't know if she is any less effective than the other physicians that I have. I have a mark on my chest, which I plan to remove after I photograph myself today. This was a localizing marker for the radiation treatments. She asked me what that was not told her that it was like a tattoo that she sticks on her skin. As you can see from my photographs, I have green marks on my cheek covered with tape outlining the location of the electron beam treatments. In addition, my skin is quite red, and there is one area behind my ear which has broken down. I don't know how I am going to explain that to her. I also don't know what to tell my nine-year-old granddaughter. She has already lost her grandmother on her mother's side to a combination of breast malignancy and lymphoma. In addition, one of her favorite uncles was hit by a car and killed. We have told her that I have a condition that needs treatment. I don't know if I have to be more specific than that.

I have now completed the full five-week course of intensity modulated radiation treatment. Dr. John took upon himself to treat my left tonsil, although Dr. P. had not recommended it. I don't know whether to be grateful for this or unhappy with it. It seems that this has been the reason that I've had so much discomfort in my throat on the left. The PET scan showed some increased uptake in the left tonsil, but it was felt to be a normal variant. I now have the following complaints: 1. Sore throat on the left. 2. Worse than a complete loss of taste sensation, everything tastes bad. 3. Dry mouth. 4. Itchy and somewhat painful skin in my left neck, redness and increase in pigmentation. 5. There is some breakdown of the skin behind my left ear for which a silver sulfonamide cream has been prescribed.



On the plus side, my mental status is stable, I do not have significant hoarseness, and I have not suffered from the debilitating fatigue that other radiation oncology patients complain of. I plan to work this afternoon, and Wednesday afternoon, but not on Thursday, the day on which I have to take the written test to renew my California drivers license. I think I should not have trouble passing the test. My bridge game still has not deteriorated. Playing with a different partner as my usual partner is in the hospital with respiratory failure, we still manage to take first place in a 12 table game, where there was an overall winner. I have to take this opportunity to wish Bert Rettner a speedy recovery. He is not only my bridge partner, but a very good friend. Unfortunately, although he is a physician, he has been unable to kick the cigarette habit, and as a result, he now suffers from severe emphysema and bronchiectasis. Last night, in the middle of the night, I was awoken by a strange noise. It turned out that our pool sweep had become detached from the hose, and water was spraying all over the place. I had to go out in the middle of the night to turn off the pool pump and filter. After that, I had great difficulty in sleeping. When I finally fell asleep, I had a dream that I was using ultrasound to look for recurrent malignancy in my neck. I took the opportunity to put the ultrasound transducer on my abdomen and found a huge mass in my liver. I hope this is not predictive of the future. Tomorrow, I begin the first of five electron beam treatments. I anticipate that this will not have very much affect on any of my symptoms with the exception of skin symptoms, which should get significantly worse. I am hoping that other symptoms will begin to improve over the next few weeks. In spite of my nightmare last night, I remain very optimistic about my outcome.
Posted by docshu at 11:12AM (-07:00)

Hooray. I passed!!!

Friday, August 13, 2010

I passed the written drivers test. The photo will be weird with half my face red. I will put it down to bad lighting. Actually, if you have an appointment, the CA DMV is very efficient. I was in and out within half an hour.

Only two more treatments to go.

Bert is much better, home from the hospital. We will play bridge this afternoon.

Mike and Leanna sent us birthday gifts which we opened while doing a Skype video chat. That was a great way to keep close when travel is impossible. My gift was two wooden pieces onto which Mike printed some old photos. Judy's gift was coasters hand painted by Sammi, age 2 1/2. Great and meaningful gifts.

Our house is on the market. What a pain in the you-know-what. On Wednesday we had to vacate the place as a couple with two boys checked it out for an hour. Then our realtor says they can't afford the asking price. How inconsiderate. We were only given an hour,s notice to clean up and get out.I am having great fun following the Giants. They are a good distraction.

We recorded the HBO special, The Pacific. I have been watching that. If you are one of those who feel that we should never have dropped the bomb on Hiroshima, watch that series. It will change your mind. War is horrific. You can't imagine the courage it took for the marines to go from island to island in the Pacific to battle the Japanese. If anything, the error was to go to islands like Guadalcanal and Iwo Jima, rather than wait until we could use the bomb.

I will report on my progress again next Tuesday after my last treatment.

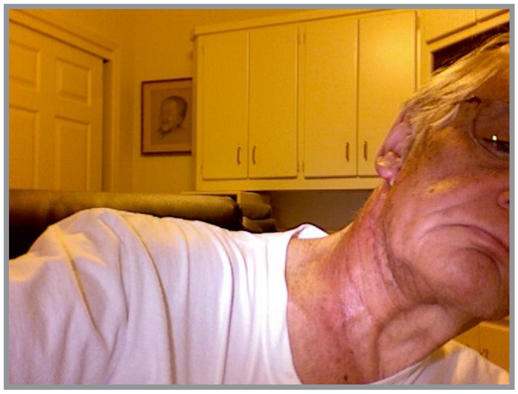
Posted by docshu at 12:28PM (-07:00)

I Know What Michael Douglas Has Coming

Tuesday, August 17, 2010

Tuesday, August 17,2010

I am done with the radiation treatments!!! I had my last treatment this morning. They gave me a certificate of completion like I had taken a Medical Education Course. Actually, I should get category 1 credit for all this as I learned so much. I know what Michael Douglas has to look forward to, as he will have radiation for throat cancer. His will be worse than mine. I hope his trophy wife will be half as nice to him as Judy has been to me. The printed information given to me says that after treatment ends, symptoms may still get worse for 7-10 days before there is any improvement. The electron beam treatments seem to be innocuous. The entire process takes only a few minutes. I lie on the same table with the same head holder, but no mask. They line up the machine with marks on my face which were drawn a week ago Monday by Dr John, and which have almost completely come off. They tape a stand-off pad to my cheek, generally running the tape onto my lips so I feel like a hostage. About 15 seconds of machine noise and I am done. Dr John checked my skin yesterday, and there is an area behind my left earlobe which has broken down. I am to cleanse it with Hydrogen Peroxide diluted to 20% and then with water, and then cover the area with Silvadine cream, three times daily. This will take weeks to heal, but is relatively asymptomatic as my earlobe is still numb from my surgery. The skin in front of my neck and just above the left clavicle is worse than it was, and the Aloe Vera stings when I apply it. I am afraid it will begin to break down.



My other symptoms are unchanged and I won't bore you with the details. At the bridge club yesterday, Judy surprised me by arriving with a birthday cake for my 70th which is on Wednesday. It was a lemon cake, one of my favorites. Needless to say, I tried some but it was tasteless to me although everyone else really enjoyed it. Playing with Bert who seems to have recovered nicely from his hospitalization, everyone must have felt it necessary to give me birthday gifts at the bridge table and we had a 72% game, one of the best in recent memory. For those who are unfamiliar with duplicate bridge, it means we had better results than others with the same cards 72% of the time on average. Usually, a score of around 62% will be a winner. On Saturday, Judy's birthday, she arranged her own party with Gary, Dana, Eva, Sara and Bel. Our sons presented us with a gift of two nights at the Martine Inn, a B&B in the Monterey area. We will likely go in late September. After cake and dessert, Eva announced that she had eaten a dozen strawberries. Not very smart to finish them all. Sara began to melt down, but I rescued Eva from parental anger and Sara from sisterly jealous anger by taking off to the store to buy more. Last night, I took Judy to the salad bar, (Sweet Tomatoes), I ate without enjoyment, but it was the first time in a while that we ate out together, and that was good for both of us. I plan to work three afternoons this week and likely will continue to work part time until I see some improvement in my taste buds, after which I want to visit Philadelphia to see Sammi and Eli, and Momtreal to see my mother, Seattle to see Dr Nghiem and perhaps some time in Vegas or a cruise or both. On a final, and somewhat sad note, Eva was asked to submit some meaningful photos as part of her first homework assignment. She submitted the photo below, taken when she was a baby, more than nine years ago.

In the top row are Judy, Eva and me On the bottom row are Eva's maternal grandmother Mary, her great grandmother Esther (GG), Judy's mother, and my parents, Eva's great-grandparents, Isobel and Samuel Shuster. Of the four on the bottom row, only my mother

survives.
Posted by docshu at 08:49PM (-07:00)

One Week After the End of Radiation Treatment

Tuesday, August 24, 2010

August 24, 2010
I had a brief appointment with Dr John this morning to check out my skin. As you can see from the photo, there is an area of depigmentation on my neck but my cheek looks fine. Not visible in tne photo is some skin breakdown behind my ear which I continue to treat 3 times daily with dilute hydrogen peroxide followed with Silvadine cream. Dr John says it is improving. I am feeling good. My throat is still sore but improved. No change in my taste buds.

I asked if there are any studies on neck radiation patients giving statistics about the time: dose: location: relationship to taste recovery. I could not find anything but anecdotal information on the internet. You would think some grad student would follow a large group of patients through the recovery period with either tests of taste or subjective quizzes to be able to construct graphs of the timeline to taste recovery. As it is, Dr John suggests that with my dose and using Intensity Modulated Radiation, I should expect substantial recovery in the next two months. He also says I should have no problems traveling in October so I will begin to make plans to go to Philadelphia and Montreal in mid October.
Our house is on the market. We have had two open houses and three visits by realtors with prospective buyers. We are asking $200,000 less than when we put it on the market 3 years ago, but no hint of an offer yet. I will continue working 3 half days in August and then go to about 2 1/2 days per week in September.
Bert and I scored 212 on a 156 average to win Monday’s bridge game. However our winning streak did end on Sunday, finally not finishing in the overalls.
I know that at one time Judy asked people not to call, as I was having a hard time reviewing all my history with friends and family, but I have adjusted well to my condition and my prognosis and am happy to speak to anyone who wishes to call.
I have found a back-up Doctor in case the kissing doctor is unavailable. Here is Dr Sammie, my granddaughter in Philadelphia.

Posted by docshu at 06:53PM (-07:00)

Taste Recovery

Friday, August 27, 2010

Here are some references to studies on the subject.
http://www.ncbi.nlm.nih.gov/pubmed/16798859
http://cat.inist.fr/?aModele=afficheN&cpsidt=3600133
http://www.thegreenjournal.com/article/S0167-8140(02)00025-7/abstract
http://www.ncbi.nlm.nih.gov/pubmed/16887272

These articles suggest that much of the sense of taste is recovered in six months after the end of treatment. One article showed recovery in all subjects in six months. The consensus is that the loss of taste is not due to salivary gland dysfunction but due to damage to the taste buds. Some patients never recover their sense of taste completely
Posted by docshu at 11:09PM (-07:00)

Update Two weeks after Radiation

Tuesday, August 31, 2010

Very little is new. My skin is healing well. My taste buds show very early signs of improvement. I had a follow-up appointment with Dr Flam who recommended Zinc, 50 mg twice daily and brushing my tongue which is coated.
Dr Nghiem has suggested a follow-up imaging study which I will have at the end of November, and I am in the process of setting up a follow-up visit around December 1. In the meantime, I will go to Montreal from about October 6-11, and then to Philadelphia Oct 11-17. Judy will go straight to Philadelphia October 6. At the end of October, we will meet friends from Montreal in Las Vegas.
We also have a Hawaii cruise from December 8-22. I hope the imaging results do not put a damper on that.
My weight has fallen to 166 lbs from about 176 when I first found my tumor mass. This weight loss is not unwelcome.
Here are the most recent photos. I did get a haircut.

Below is a photo of our dog, Rocky and our granddaughters Eva and Sara

Posted by docshu at 11:37AM (-07:00)

Wow! No Doctor Appointments this Week!

Wednesday, September 08, 2010

I debated whether to post at all this week as there is not much new to report. But I am elated not to have any medical appointments this week.
I feel good. (music) I thought that I would now. However I still have little taste sensation. My skin has improved, and the invisible area of breakdown behind my left ear must have improved as there is no blood on the pads I use to cleanse the area. My tongue is coated and I brush it several times a day.There ia an area of ulceration over my left tonsil visible and my throat is often sore. I wonder whether Dr John did me a favor when he included the area in the radiation field when Dr Parvathaneni in Seattle had not thought it necessary.

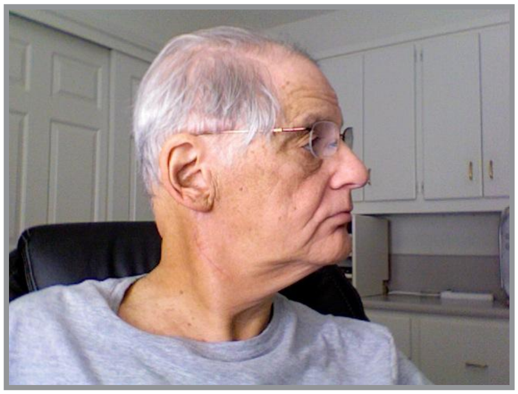
Most of the redness has disappeared. My beard has stopped growing on the left. My cheek feels like a baby's bottom. (Sorry for the cliche).
Here is the commercial for which I receive no benefit. Boost Plus (chocolate), the nutritional supplement has been my main source of calories and nutrition during this adventure. I can taste slight sweetness. It is really good for swallowing pills as it is thicker than water. I take 2-3 per day and my weight has remained at about 166 pounds.
Plans for travel are firm and flights booked. Judy and I travel together to Philadelphia on October 6. I continue to Montreal. I return to Philadelphia on October 11, and we return to Fresno October 17.
I hope I can taste the onion soup at Ty Breiz. I will be in Montreal the same time as Jon and Sandy (my brother and sister-in-law).
I have scheduled a follow-up Pet/CT for November 24. I had a nightmare the other night that it revealed liver metastases and I had to postpone our December Hawaii cruise to take chemotherapy. Oh well I can't dwell on that possibility. It is just over 4 months since I discovered the tumor mass and so far, so good.
Bridge results remain encouraging, 1st with Jill Woods, and 3rd with Steve Sharpe.
I close for this week with a photo of Eva, our oldest grandchild and the author of the poem on friendship I include with my emails. She and her family will be here tonight for a Rosh Hashona dinner.

This was taken on the Alaska cruise, before I started radiation treatments but after the diagnosis of Merkel's
Posted by docshu at 11:27AM (-07:00)

Not Much New

Thursday, September 16, 2010

There is not much new to report this week. I have worked 3 full days so far and will work another half day today. I must admit I was tired last night.



Here is my latest photo. It looks almost back to normal. my skin is so smooth, it seems like it isn't mine. No need to shave the left side. I have stopped using the aloe vera, and the ulcer behind my ear has healed. My throat is sore and I can still see an ulcer on my tonsil.

Slowly, but surely, my taste is returning. The most noticeable is that the constant bad taste some call metallic, is gone. There is a recommendation to use plastic utensils to minimize this but I thank that is not useful. I noticed no change between metal and plastic. Zinc may help. I have been taking 50 mg of zinc gluconate twice a day. Brushing the tongue may help, trying to get rid of the appearance of a coated tongue. I think the most helpful thing is patience, allowing the body to heal, without expectations of any miracles. I can now taste some sweetness and some saltyness. Last night I ate shrimp cocktail, and it wasn't bad. The cocktail sauce did burn my tongue, and it was the mild sauce.

All in all, I am doing better than I expected. Now, I have to hope for good news on follow ups.

Here is a photo of Eli and Sammie. I will get to visit with them (and their parents) on October 11. This is what life is all about.

Posted by docshu at 10:29AM (-07:00)

Five Weeks After

Wednesday, September 22, 2010

I completed radiation treatments 5 weeks and 1 day ago. Today I visited Dr Holmes, my Internist. My total cholesterol and blood sugar are down (good news), but my HDL is down 10 points and is way too low. This is because I have not gotten much exercise lately and have been getting niacin flushes due to having to take niacin without much food, as I have not much appetite.

I also had an appointment with Dr John, my radiation oncologist. My skin has healed, and the ulcer I saw on my tonsil has also healed. I feel like I am doing about as well as could be expected. My taste buds are slowly reviving. I invented a device to clean my tongue while in the shower last night. A toothbrush is too tall and makes me gag. Something flat and wide would work better. Before I tried to patent this, I found numerous devices already available, and have tried one and found it works better than a toothbrush.

Two weeks from today, I leave for Montreal and Philadelphia. I hope I can taste the Montreal bagels and the onion soup from Ty Breiz. The other day I did a test run on onion soup at Mimi's. It was not very tasty, but I still had seconds.

I have been spending a lot of time watching the Giants on TV, with the help of TIVO. I can thank them for helping me pass the time in the past two months. Go Giants. Still in first place as I write this.

Here I am. My neck looks like I never had the radiation. I have lost weight and today I am wearing size 34 jeans, and they fit. I will try not to gain it all back.

I like to include a photo of somebody better looking than me. This is Bel, Gary and Dana's youngest daughter. As you can see, she loves to eat.

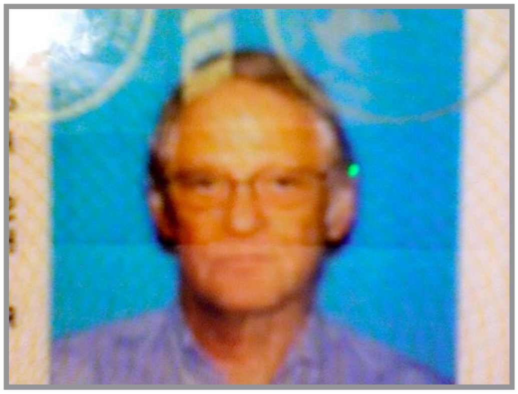
Posted by docshu at 05:09PM (-07:00)

Progress Report 5 Months After My Tumor is Discovered

Saturday, October 02, 2010

There is not much new to talk about. I have lost more weight, down to 163 1/2 today. This is about 15 pounds since May. I still have little appetite and although my taste buds are returning, most foods have some taste, but not to my liking. Boost plus, chocolate tastes good. Most other foods are not intolerable but not good.
Here is my photo, 50 days following radiation.

You can hardly tell which side was irradiated.
Here is my photo from the last week of treatment from my drivers license. Pardon the blurryness, as I used the camera on my laptop and it can't do close-ups.



I was a redneck.
We are on our way east on Wednesday. I go to Montreal to visit my mother and Judy goes to Philadelphia to visit our son, daughter-in-law and their two youngsters, including Eli, our first grandson.
I will join her in Philadelphia a week from Monday and we return the following Sunday.
My bridge results continue to be good, coming first in the last 4 club games played, with two different partners.
Go Giants. Can't you win ONE more game?
Here is a photo of me with Rocky, our Goldendoodle. He did not like sitting in the chair with me.

Next week, if technically possible, I will post from Montreal.
Posted by docshu at 05:51PM (-07:00)

My Visit to Montreal

Sunday, October 10, 2010

This has been a very enjoyable visit. My mother is in good spirits. She also seems to be in excellent health.

I got a chance to spend time with my two brothers. Jon lives in Florida and is a Professor of Biostatistics at the University of Florida. Robert is a retired teacher and lives in Montreal. Thank God for that as he has the responsibility to be the first line of defense for my mother. He brings her won ton soup every Saturday, carefully proportioned out to last the week. Is it a coincidence that when I was at my worst with side effects of radiation, I was living on War Won Ton soup? I think the apple does not fall far from the tree.

That's Jon on my right and Robert on my left.
We played bridge yesterday recalling many family bridge games when my father was alive.
It was very close but after 16 hands, my mother was the winner.

We went for dinner at Ty Breiz, with my niece, Andrea and her husband Ben. Also joining us was Sandy, Jon's wife. The onion soup was almost as good as I remembered it. I guess my taste buds are making a comeback. The mouth is still dry.
Everyone commented about how great I look. Is it because I don't look like I am dying or is it because of the weight loss. I think the latter. I recall a song by Gilda Radner who later died of ovarian cancer.The song was called Goodbye Saccharin and it lamented the recall of the sweetener because it caused cancer at huge doses in rats.
"Men prefer girls with cancer to girls with flabby thighs" (perhaps not a perfectly accurate quote).
I am off to Philadelphia tomorrow and will post again after that visit.
Posted by docshu at 11:20AM (-07:00)

I am presented at Tumor board while in Philadelphia

Sunday, October 17, 2010

We are back from Philadelphia. I finally met my grandson Eli. There is a slight culture clash here. It seems Eli is a Phillies fan and I root for the Giants.

Below is a photo of Eli, Sammie Mike and Leanna.

Here is a link to photos from Philadelphia.
http://picasaweb.google.com/radocshu/PhiladelphiaOct2010#

I was presented at Tumor board at St Agnes Medical Center in Fresno. I learned of this when my oncologist, Marshall Flam called me and asked if I wanted to attend. Of course, being out of town, I could not.
Dan Stobbe also called and offered to take notes. Here are extracts from those notes.

Not much new info from tumor board. Main point I learned was from pathologist, that these tumors are C-KIT positive on staining; that raised question of whether any possible relapse might be treated effectively with Gleevec. Nobody seemed to know of any literature re: that, might be good question to ask your doc at U. Wash. (I will ask. I see Dr Nghiem on Nov 30) Concensus was that local treatment with RT (radiation) was the way to go. Surgical resection alone higher relapse rate. Unknown if spontaneous regression of primary (suggested by multiple negative skin biopsies) is a positive prognostic factor or neutral. Another good question for U. Wash MD. (I asked Dr Nghiem this question and he had no useful information on this subject.) All agreed that follow up/surveillance with phys exam and PET would be wise. (My follow-up PET/CT is to be done just before Thanksgiving) All wondered/were curious if U. Wash will be drawing repeat circulating Merkel cell studies as surveillance. (I hope so) Back home, Gary met us at the airport with Sara. She gave me such a loving greeting. She is a real sweetheart. Go Giants! (posted while they are losing game 2)

Posted by docshu at 08:22PM (-07:00)

Six Months After

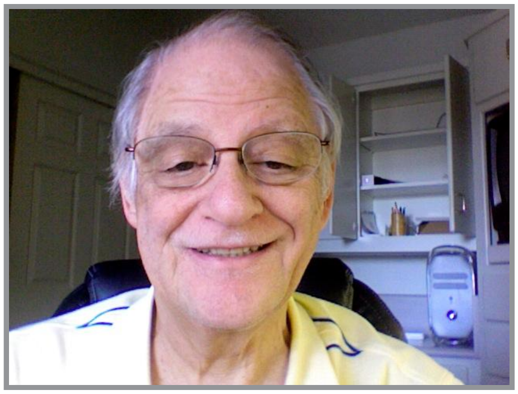
Wednesday, November 03, 2010

It is now about six months since I discovered my cancer. It appeared suddenly as a nodule in front of my left ear. After surgery and radiation, I am alive and feel well.
However there are residual symptoms. Taste is not completely restored. My mouth remains dry. My teeth have become sensitive. My left ear is numb. I have lost weight, about 15 pounds since May 2010. I was overweight so it is not all bad.
I have appointments for a follow-up PET/CT just before Thanksgiving and will visit Dr

Nghiem in Seattle on November 30. Until then, without much to report, I will not be posting.

I have made some plans for the future. Assuming the best, that no new lesions show up, I will cut my work week to three afternoons per week and go to the gym for aerobic workouts 6 days per week. We will cruise to Hawaii for two weeks in December. We likely will cruise to Mexico in February and I will visit my mother early in March. We are trying to organize a family cruise in June, but I am not optimistic about that. The last time I tried that, I ended up paying for a cruise nobody took.

I thank the San Francisco Giants for distracting me during the worst times. I still can't believe they went all the way.



Here is another photo, taken today, showing no change.

I see today that there are three new victims of Merkel Cell Carcinoma added to the Google support group. I wish you all the best. My advise is to be a strong advocate for your own care. Find a physician who deals with this disease all the time. Learn all you can about the disease, and remember that the research and study is rapidly advancing and what may seem hopeless today, may be easily treated tomorrow.

Posted by docshu at 12:23PM (-07:00)

Bad News on my PET/CT

Wednesday, November 24, 2010

Today, I went for a follow-up PET/CT. I have been feeling great, almost asymptomatic except for some dryness in my mouth and reduced taste sensation. I was optimistic that the scan would be normal and I could have a happy Thanksgiving and head off to my Hawaii cruise in a good frame of mind.

No such luck. The scans showed a mass in the posterior mediastinum measuring up to 4.5 cm, almost two inches in diameter. It is located just above the diaphragm behind the heart, next to the esophagus and spine, near the aorta. There was nothing there on my previous scan in June. The rest of this examination shows no evidence of significant abnormality elsewhere.

I put in a call for Dr Nghiem this afternoon, but it is Thanksgiving. I have an appointment to see him on Tuesday.

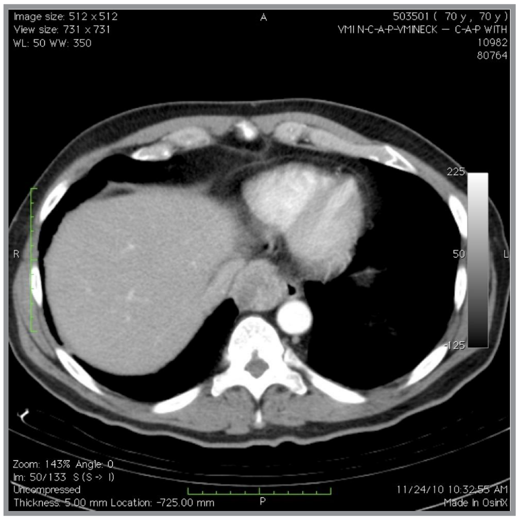
So what next? Surgery would be very difficult and dangerous, painful with a long and arduous recovery and no real expectation of success. Chemo is an option. Radiation is another option. The latter seems more likely to be successful. I await word from the specialists.

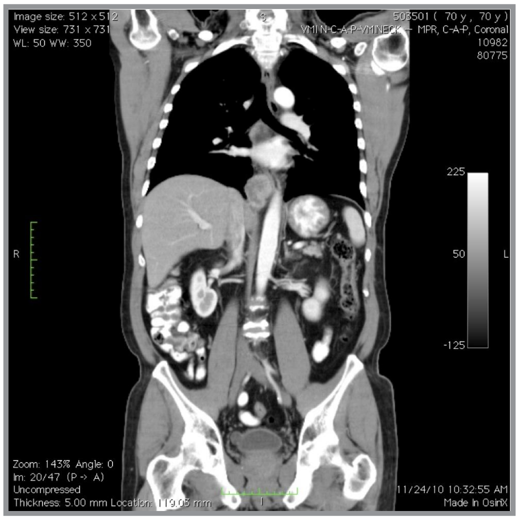
I will post more in the next few days.

Posted by docshu at 08:20PM (-08:00)

Images from my CT. The Dilemma of Treatment

Tuesday, November 30, 2010





The axial image is above, the coronal below.The coronal image shows the mass almost in the midline above the diaphragm. The axial image shows the mass in front of the spine. The little black dot beside the mass is air in my esophagus.The mass is behind the heart and liver in the axial scan. A large radiation treatment poses a risk to my heart and spinal cord.

This is the only evidence of tumor. However the consensus is that there are likely othe microscopic foci of tumor and this is apparently something seen with MCC.

So what are the options?

Surgery is ruled out by everyone. It would be a horrendous operation for me, and not likely to offer enough chance of prolonged benefit to make it worthwhile.

Radiation treatment alone is a possibility, likely to obliterate this mass and I would likely avoid serious long term side effects.

Radiation preceded by chemotherapy. This is Dr Flam's suggestion. The chemo might shrink the tumor so the field if radiation could be decreased. Also, without radiation at the same tome, the effect of the chemo could be assessed. Chemo could possibly delay or prevent new metastases.

Radiation followed by chemotherapy. Hit it first with the best shot, and use chemo to try to clean up microscopic distant disease.

The problem with chemotherapy is that it reduces the immune response to the tumor. Even killing 99% of the tumor cells won't prevent recurrence if the immune system is crippled.

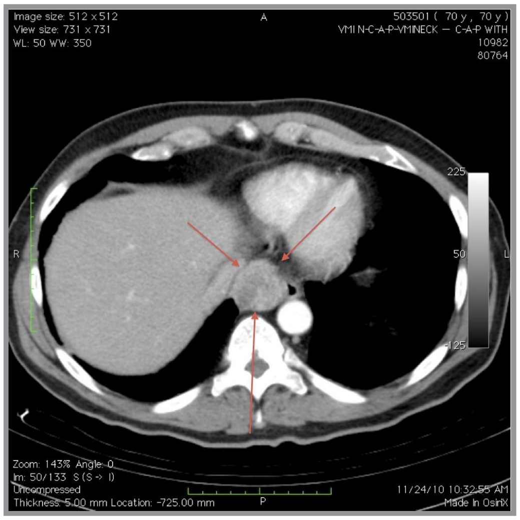
Dr Nghiem proposes a new treatment which has shown promise in animals, but I don't know if it has been tried in humans. Instead of 30 radiation treatments over 6 weeks, one triple shot given once. It would injure many cells rather than kill them. The hope is that these injured cells release antigens that the immune system will recognize as "not self" and create antibodies to kill the tumor cells all over the body.

There is little to lose with this approach. If it fails, the other possibilities above are still available, and in the meantime I may have several months of good quality of life. If it succeeds, I will be a pioneer patient.

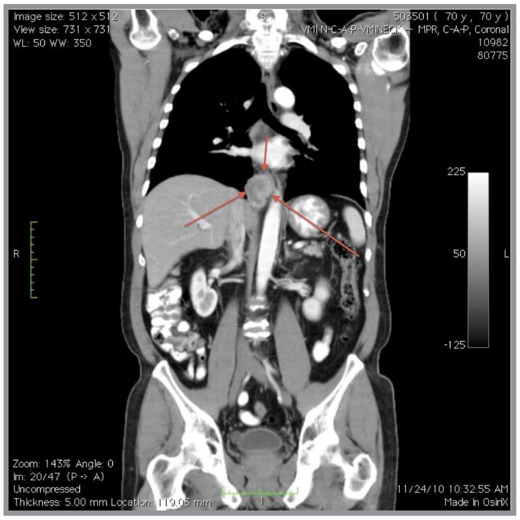
Posted by docshu at 07:20PM (-08:00)

PET/CT Images Annotated. Musings

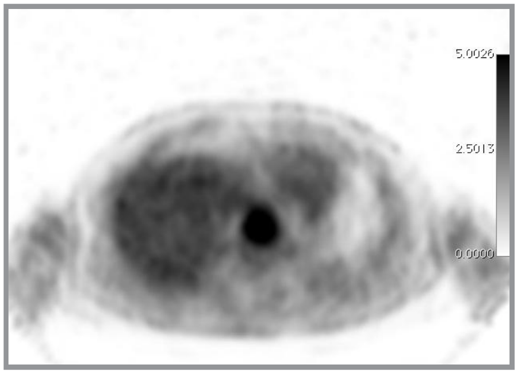
Saturday, December 04, 2010



Axial CT see arrows



Coronal CT see arrows



PET Scan I apologize to those people who looked at the images from my previous post and had no idea what I was talking about. Thanks to Mark Alson who pointed out that not everybody can interpret these images. I am reposting images from my CT scan with arrows to show the tumor mass. I am also posting a single image from my pet scan showing the tumor mass. On that image, the mass lights up and is black in the picture while everything else is a relative gray or white.The pet scan image shows a very high level of metabolic activity indicating a very high likelihood of malignancy. On the other images, the tumor mass is visible and is new. While I have no proof by biopsy, the odds are overwhelming that this all represents a recurrence of my Merkel cell carcinoma.

After discussions with Dr. Flam, Dr. Nghiem, Dr. John, and Dr. Parvathaneni and also with Dr Bhatia, the oncologist I visited at University of Washington, I have elected to proceed with the experimental treatment recommended. I think that there is little to lose, as it is highly likely that having chemotherapy and more aggressive radiation therapy will probably not be very effective. It is very likely that there are microscopic collections of tumor cells elsewhere in my body with the ability to rapidly grow as this mass did. While this would suggest that chemotherapy may be effective, Dr. Nghiem feels that the negative effect of chemotherapy on my immune system will allow those tumor cells not killed by chemotherapy to kill me.

So how do I feel being in this situation? It is highly likely that I will succumb to this disease. I may not have very much time left. Yet, I feel fine physically.

Mentally,it is very difficult. Like a song running through your head, thoughts of my condition, my treatment, and dealing with advancing illness and my ultimate demise are always in the forefront. I can't stop thinking about it. And yet, I am able to function quite well in day-to-day activities. I am continuing to work, play bridge,read, enjoy television shows, and particularly enjoy the love and support of my family.

Under the circumstances, we had a wonderful Thanksgiving weekend with the entire Shuster clan including Judy, my three sons, Gary, Brian and Michael, Gary's wife, Dana, Michael's wife, Leanna, and are five grandchildren, all together for the first time.

We were very concerned as to what we're going to tell our nine-year-old granddaughter, Eva. She was becoming very upset as she sensed that there was something wrong and nobody was telling her anything. She was concerned that there was something wrong with her, and was very relieved to learn the truth. Thanksgiving has not been a good time for her, as her maternal grandmother died on Thanksgiving day. Since learning the truth about me, she has been very loving and supportive.

So the question is, what should I do with my time that I have left. I do not plan to retreat into a world of gloom and self-pity. I have committed myself to spend some time working this month as long as I do not have substantial side effects from the radiation treatment. I think that I will continue to stick with my plan of working three afternoons per week beginning in January and additional time if needed at Kaiser. If I am feeling well, I would like to take a one-week cruise perhaps in the beginning of February. However I will only book last-minute, as I have canceled a planned two-week cruise to Hawaii, and will probably lose about $6000 which we have paid for this cruise. Additionally, I think I would like to go to Las Vegas for a few days.

I have had the goal for some time of becoming a gold life master of the American contract Bridge league. The requirement is to have 2500 master points. I need only about 90 more, and if I am feeling well enough, I will travel to some nearby tournaments to reach this goal.

I will also need to put my affairs in order. I always thought I had plenty of time to deal with issues such as drawing a will and making plans for my internment. I'll have to take care of these within the next month.

All this being said, in the words of the song from the Monty Python musical, Spamalot, I am not dead yet. I am by no means giving up the ghost to this disease. If this plan doesn't work, I will need a plan B. That may include more radiation treatment, chemotherapy, or enrollment in clinical trials.

My brother-in-law, Murray, has sent me links to clinical trials at the NIH. Thanks Murray.

In addition, I plan to try some alternative treatments to enhance my immune system as this seems to be the most promising avenue to defeat the disease.

Looking back on my life, I was always the sort of person who deferred immediate gratification looking toward the future. I still remember feelings of jealousy is my friends were going skiing while I was busy studying for exams or working nights and weekends during my internship and residency. The question is was that worthwhile. I think it was. I feel that I have accomplished a lot during my life. I still hope to accomplish a lot more.

I have to express my gratitude for the love, support, and good spirits of my wife, Judy. She recently went through a long ordeal with her mother, taking her for radiation treatments and a providing for her needs during her battle with colon cancer, from diagnosis to final hospice care and her death. Now, she may have to go through the same ordeals with me.

I also acknowledge the outpouring of love and support from friends and colleagues during this difficult time. So many people are praying for me. To all of them, I offer my thanks.

Posted by docshu at 11:40AM (-08:00)

Hope for the Best, Plan for the Worst

Wednesday, December 08, 2010

Today is a day of mixed feelings. This morning I went for my radiation treatment. A single radiation dose of six gray (GY). This is about 1/10 of the standard dose given to try to kill every cancer cell in the area. I had a dose of a total of 60 gray to my face and neck. This dose was given to my mediastinal tumor. The objective here is to induce an immune response to the tumor and hopefully to kill all the tumor cells in my body. I

Dr. John gave me a reference article printed in the international Journal of Radiation Oncology by Ganem et al, reporting on the mechanisms of low-dose radiation treatment for lymphoma. This article gives additional support to what we are attempting, and boosted my spirits.

This afternoon, we have an appointment with an estate planning attorney to update our wills, with a view to removing any complications which might result in passing our assets to our heirs. Needless to say, this is a downer.

On the bright side, a careful review of the insurance policy regarding cancellation of our cruise to Hawaii strongly suggests that we will either be repaid by the insurance company, or receive a credit for future cruises from Princess Cruise lines. I don't think that I want to plan a two-week cruise, but while I am still feeling good, I would like to plan a one-week cruise to the Mexican Riviera.

So many people have responded to this blog, e-mailed me, and called me, I feel very gratified by the outpouring of good wishes, prayers, support, and offers of assistance that I have received during this journey.

I plan to add some of my favorite songs, poems and limericks that I've written over my lifetime to my blog from time to time. Here is the first.

There Is No "C" in Shuster

A "C" belongs in candle In "cap" or "cape" or "coat" If you put a "C" in Shuster, You will really get my goat.

You can schove a "C " in schingle, In schop or schip or sche But there is no "C" in Shuster As you can plainly see.

I rarely lose my temper I'm a level-headed man But if you put a "C" in Shuster The schit will hit the fan.

BTW, my word processor thinks Shuster is misspelled.

Posted by docshu at 11:26AM (-08:00)

Thirteen. What Does it Mean?

Sunday, December 19, 2010

Last Friday, at about five o'clock, I received a telephone call from Dr. Nghiem. He reported to me that the circulating Merkel cell count measured in the blood that I had drawn on December 7 revealed 13 Merkel cells in 10 mL of blood. After my surgery and before commencement of radiation treatment for my initial tumor, the circulating Merkel cell count was zero. So is this bad news? Obviously it is worse than if the count was zero. However I expected there to be some circulating Merkel cells as I have developed a distant lesion. Dr. Nghiem did not seem to be disappointed or unhappy. In fact, he seemed to be almost elated, as this will provide him with a measurement of the effectiveness of the unconventional treatment that I have had. He has made arrangements for me to have a follow-up Merkel cell count done. The blood will be drawn next Monday, a week from tomorrow. That will be 19 days after my single dose of radiation which was intended to unmask the antigens in the tumor and to allow my immune system to react to the tumor as foreign material. I think that will be the crucial count. If it has returned to zero, it will suggest that the treatment is working. If it has gone up, that will not be good news. However I will allow the treatment more time to work before I do anything else.

We have signed up and paid for another cruise. This one will go to Mexico from Los Angeles, leaving on January 5 and returning on January 16. As long as I continue to be asymptomatic, I plan to take that cruise. In some ways, I feel like Charlie Brown, trying to kick the football. The football is the cruise. We already missed our two week cruise to Hawaii, and I'm not even sure if we will get any money back. However Princess cruises said that we will at least receive credit for the money paid. We still had to pay for this cruise as they have not had time to assess whether my medical excuse is valid or represents a pre-existing condition.

In the meantime, it is life as usual. I will work two days next week, and two full days and two half days the week between Christmas and New Year's. If I remain asymptomatic, following the cruise, I plan to work three afternoons a week.

Sometime later in January, I'm looking forward to visits from my brother Jon, and his wife

Sandy, and from my sister Ellie, with her daughter Cheryl and her grandson, David, who was not named after me.

If I said I'm not scared I'd be lying But there's no use sitting home crying My target's a circle Surrounding the Merkel I'll beat you or I'll die trying.

Posted by David Shuster at 10:43AM (-08:00)

There is a Suicide Bomber Living in my Body

Saturday, January 01, 2011

The suicide bomber living in my body is Merkel cell carcinoma. It lurks in hidden reaches and plans its terrorist attacks, with the potential that if it is successful, it will result in its own demise as well as mine. Just like the battle against terrorists, we have to use all the weapons at our disposal to destroy every single Merkel cell. To that end, I have undergone a somewhat unconventional treatment. When my Merkel cell carcinoma recurred as a large posterior mediastinal mass, instead of the suggested chemotherapy followed by a large dose of radiation, I have had only a small dose of radiation directly to the recurrent tumor in the hope that this will trigger an immune response. Prior to this treatment, my circulating Merkel cell count was measured at 13 cells per 10 mL of blood. I have just received a very encouraging result. After 2 1/2 weeks, the count has decreased to only one cell for every 10 mL of blood. At the end of January, I will have a follow-up assay, and perhaps my body will have successfully obliterated the terrorists.

I am feeling well, without any symptoms of the mediastinal mass. I have had no side effects from the radiation treatment. The only complaint I have is a dry mouth, and reduced sense of taste, all resulting from the original surgery and radiation.

Over Thanksgiving, we had a wonderful visit from all of our children. I have posted a collection of photos on Picasa. The link is below, and I don't know is how to place it so that you can click it. If it does not work, you'll have to copy and paste it into the browser window. I think I fixed it. You can click on "Here is the link" below.

I am sure that this collection of photos will bore many people, but for those interested, the photos are of my oldest son Gary, his wife Dana, and their three children, Eva, Sara and Bel, my middle son Brian, and my youngest son Mike with his wife Leanna, and their two children Sammi and Eli.

Here is the link

http://picasaweb.google.com/radocshu/Thanksgiving2010#5557290779026217122

We will be leaving on Wednesday for a cruise to the Mexican Riviera. It will be a 10 day cruise. We are taking this instead of the Hawaiian cruise which we had to give up as a result of my needing to have more radiation treatment.

You may notice that there are ads placed in this blog. Surprisingly enough, there have been over 3000 page views since I have begun posting. I have decided to monetize the blog. I think that if you view the ads, money comes to me. Any such money will be donated for Merkel cell research to the University of Washington. I will personally match any money donated.

My dear friend, Lenny Clayman, frequently suggested that Judy and I join him and his wife Bluma on exotic vacations, most of which we have not done. In the past few years, he urged us to do this by saying “We don't have that many good years left.” I may not have that many good years left, But I plan to live them to the fullest.

Posted by docshu at 11:42AM (-08:00)

From the Sapphire Princess

Friday, January 14, 2011

This post was written on the last day of our 10 day cruise to Mexico. We have had a wonderful time. We're going to do this again hopefully. Just before we left for this cruise, we learned that we will receive a cash refund from the insurance for the cruise that we had to cancel. This cruise has been a great distraction. Most of the time, I have been able to put my condition on the back burner and not think about it. We met some very nice people who were sitting at our table and introduced us to a new card game which they call "nines". It is different from the game of nines that we used to play. We have been playing this game with two decks of cards and six players. Judy and I have also played several sessions of bridge. In one session, we managed a 78% game, which, perhaps, speaks more to the quality of the opposition than to the quality of our game. There is food everywhere, but I have found that most of the time I have not had very much of an appetite. I am attributing this to the continued dryness in my mouth and the continued loss of much of my sense of taste, although I am able to taste foods to some extent. When I begin eating, the food taste pretty good, but it seems like my taste buds get tired, and the food loses its taste. The moment of truth will come at the end of this month. I'll have another blood test for circulating Merkel cells. If the cell count stays the same or goes to zero, I will have follow-up imaging at the end of March. If the cell count goes up, I will have follow-up imaging at the beginning of February. I was thinking yesterday about a very ironic event which happened not too long ago. Right after the passage of the health care legislation, I was trying to get a sandwich for lunch at the local subway shop, and I was accosted by a roving reporter for a local television station. They were trying to gather comments about the new tax on tanning booths. They asked my opinion and I said that they should raise the tax to help pay for healthcare for the people who ended up getting cancer from the tanning booths. The segment was aired on local television. The ironic thing is that it was not long after that that I was diagnosed with a form of skin cancer that is associated with sun and radiation exposure. This has been a very great escape from the world. Next week, it's back to reality, with two doctors appointments, one dentist appointment, and one appointment with an attorney to complete the details of our wills and medical directives. I also plan to work 3 half days. I also plan to play bridge two afternoons next week. It will be busy.
Posted by David Shuster at 12:57PM (-08:00)

Is This What it is Like to be on Death Row?

Friday, January 28, 2011

One of my colleagues working at Kaiser Permanente visited with me yesterday. I described to her and the feeling that in a way, my situation is similar to that of somebody on death row. Merkel cell cancer is the executioner. Dr Nghiem is my defense attorney. He is appealing my sentence to higher courts. Every time we have an interaction, he gives me hope that in some way, some judge will find merit in my appeal and commute the sentence. The only difference is that a death row inmate is given a definite time for his execution, and an attempt is made to avoid all discomfort as the sentence is carried out. I do not have a definite date from my demise, and I have no assurances that should my appeals be denied, I will have a painless and comfortable death.

I have in my possession the materials needed for my next blood draw for circulating Merkel cells. By the end of next week, I hope to have the result. If the cell count has risen, I expect that I will be undergoing chemotherapy designed to treat small cell carcinoma. That will be preceded by some form of imaging study. If the cell count has not risen, I can wait another month.

I have been feeling vaguely unwell. There's nothing that I can really put my finger on. There are some minor abdominal cramps and lower chest pains. My appetite is not good. This may be attributed to the lack of improvement in my sense of taste and continued dry mouth. My weight has stabilized around 160 pounds, almost 20 pounds less than what might average weight used to be prior to the diagnosis. Perhaps this is all psychological, as a result of my not looking forward to any future treatments.

I have been thinking that this posterior mediastinal mass should be visible on plain chest x-rays and I'm considering getting a plain chest x-ray for my own edification as to whether this is true and then to be able to follow the size of the mass with a very simple test. Of course this would not document any new masses involving lymph nodes in the upper abdomen or in the mediastinum.

In my discussion with Dr. Ngheim regarding the planning of my experimental treatment, there is one thing which he said that stuck in my mind. He stated that there are no long-term survivors of Merkel cell carcinoma after chemotherapy. This is because the chemotherapy destroys the immune system which is the major defense against the spread of Merkel's. I think that his intention here was to dissuade me from having chemotherapy and to convince me to have this treatment. Reading posts to the Merkel cell message board, I see that there are several anecdotal cases of substantial survival of patients who have had what I would consider to be more advanced Merkel cell cancer than I think that I have. Because of this, if the disease is progressing, I will undergo the chemotherapy.

It is my hope that with this plan, I will not be trading the last days that I have of relative comfort for days of misery. Many patients are very sick following chemotherapy. I just read a post documenting rapid demise from infection during chemotherapy. On the other hand, when I was undergoing radiation treatment, I met a man who was having radiation treatment in the morning and chemotherapy in the afternoon, and he did not complain of significant symptoms.

In the meantime, I continue to work three afternoons a week. I plan to continue to play bridge twice a week. I look forward to a visit from my brother, Dr Jon Shuster, who is a professor of mathematical statistics at the University of Florida.

I'm also looking forward to a visit from my son Brian, who will be here just before Valentine's Day. I'm hoping to be able to travel to Montréal to visit my mother, perhaps at the end of March, depending on whether I will be allowed to travel assuming that I am undergoing chemotherapy, or hopefully, not needing chemotherapy before then.

In keeping with prior posts, I'm going to conclude this blog with a satirical song that I wrote many years ago, but I think that much of it is as true today as it was then.

MASTER OF THE HMO

To the tune of Master of the House From Les Miserables
Sung by the HMO President
Welcome, My friend Sit yourself down We are the best Provider in town As for the rest They don't compare They are obsessed With refusing care Seldom do you see Honest men like me Working in the health Insurance industry
Master of the plan Ads are on TV We show those smiling doctors But what you don't see

Show an MRI Make it look high tech You can’t even get one If you break your neck Glad to do a friend a favor Doesn't cost us to be nice When you sign up you will find out Everything has got a little price!

Master of the house Keeper of the gate Ready to deny 'em Or to make ‘em wait. Use generic drugs See your primary care If you use the ER You will be the payer Everybody needs insurance Everybody has to spend If you get diseases Jesus! We won't help you in the end!

Master of the plan Tumor to remove Never get it paid for ‘less its pre-approved Get a pre-op chest Help you to decide If it turns out normal Payment is denied Everybody's paranoiac Everybody's on his own

You all signed releases Jesus! Won't I skin you to the bone!

[To another new customer...]

Enter old man Pay your co-pay Doctor will see you Maybe some day. Charges are low They won’t go higher Unless you get sick Coverage won’t expire Join our HMO Get rid of Medicare And nothing's overlooked Till you’re on welfare

Care beyond compare Care you can’t resist See a nurse practitioner Not a specialist Kidneys, they don’t know Liver what is that Filling up their charts With this and that

Interns are more than welcome Residents we’ll keep occupied Reasonable charges Plus some little extras on the side!

If you have chest pain The ER you must disdain If its not a heart attack you'll end up payin' Here a little slice There a little chop You see a nurse practitioner and not a doc When it comes to fixing prices There are a lot of tricks he knows How it all increases All those bits and pieces Jesus! It's amazing how it grows!

Master of the Plan Tries to catch your eye Never wants a Healthy one To pass him by Service to the poor Equal to the rich Don’t need a Dermatologist To cure your itch! Everybody's capitated We make it all a closed shop Payment never increases Jesus! We just take ours off the top.!

Master of the plan Says precertify Call the number just to hear Deny, deny Never operate. Don't investigate Don't care if we find your cancer much too late CoPay for pharmacy Don’t Pay for MRI They all get diseases Jesus, its much cheaper If they die Don’t care who he fleeces, his nephews and his nieces Pack up their valises Never hear their sneezes They eat too many fatty cheeses Meats and all those greases Jesus it saves us money if they die.

Posted by David Shuster at 11:07AM (-08:00)

Good News. The Circulating Merkel Cell Count dropped to ZERO

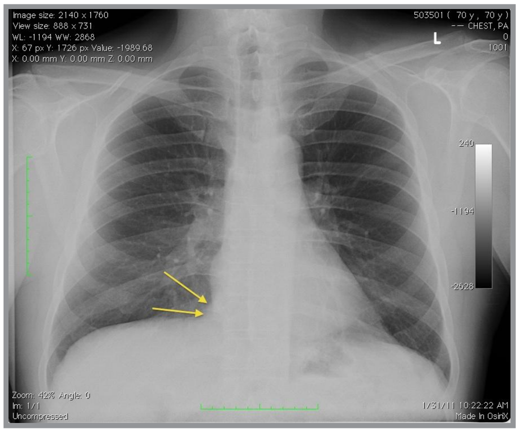
Friday, February 04, 2011

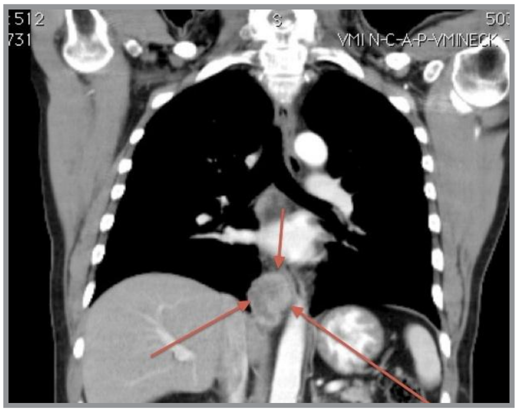
It can't go lower than 0. This can't be bad news. I can't let myself be too excited about this because the count was 0 before my initial radiation treatment and I still developed a distant recurrence, but this is the best possible result.

I had a chest x-ray and it doesn't show any large mass, although the location is such that it would take some growth from the previous to be visible.

There are no lung metastases visible. In fact my chest x-ray looks like that of a 40 year

old.
We had a very nice visit with my brother Jon last week-end and even got in a bridge game before he left.
My sister Ellie will visit from Edmonton next Monday, and our middle son Brian will visit the following week.





Comparing the CT image to the chest X-ray suggests a barely visible edge of the mass. This is a very questionable abnormality.
I would like to thank everyone for their kind words of encouragement and prayers. I am not a religious person but every little bit helps.
Posted by David Shuster at 11:30AM (-08:00)

Review of my Merkel Journey to Date

Tuesday, February 22, 2011

May 6, 2010, about three months before my 70th birthday, I discover a mass in my left cheek.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/07/i-discover-mass-in-my-face.html
I have a CT scan of my face and neck, links to images below.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/07/ct-scan-images.html
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/07/parotid-lesion.html

http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/07/questionably-enlarged-lymph-node.html

May 13 2010 I have a fine needle biopsy, false negative report. This delays surgery until June 3 2010, our 48th anniversary.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/07/i-have-surgery.html

June 7, 2010, I get the bad news.
Why the false negative, you may ask. I think it was a combination of factors. The tissue sample was wrongly sent as a parotid gland biopsy when in fact it was from a lymph node. It was read by a pathologist who had probably never seen a Merkel Cell carcinoma on a skinny needle biopsy. I have not asked for a review of the slides in this case, as it is water under the bridge. However, if the correct diagnosis was made, it might have resulted in sparing me the surgery of June 3.
A search for a primary site fails. Radical surgery is planned, possibly with chemotherapy

and then radiation.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/07/merkel-work-up.html

July 24,2010 My son Gary finds the Merkel support group on the internet, and I am in contact with Dr Nghiem. I cancel surgery and plan on radiation treatment alone.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/07/gary-finds-mcc-group-and-dr-nghiem.html

June 23, 2010. I visit Dr Nghiem in Seattle.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/07/my-visit-with-dr-nghiem.html

Aug 3, 2010 Radiation treatment continues. Here is a sample post.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/08/update-after-20-of-30-radiation.html

Aug 17, 2010. One day before my 70th birthday, I complete radiation treatments.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/08/i-know-what-michael-douglas-has-coming.html

My circulating Merkel count was ZERO and I am optimistic that the disease has been vanquished. Life returns more or less to normal and I continue to heal from the radiation treatments. We plan a cruise to hawaii for December, 2010, but on November 24, 2010, I have a follow-up PET/CT. Disaster! There is a large mass in my chest near my heart and esophagus, but not in the lung.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/11/bad-news-on-my-petct.html

Here are images from the scans.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2010/12/petct-images-annotated-musings.html

I visit Dr Nghiem again. My circulating Merkel cell count has risen to 13 cells per 10 cc of blood.
He proposes a unique treatment. A small dose of radiation to the tumor, about 10% of the usual treatment, all in one session. The object is to unmask the antigens associated with this tumor and allow my immune system to combat the tumor.
I have the treatment. My Merkel Cell count is down to 1.
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2011/01/there-is-suicide-bomber-living-in-my.html

We took a cruise to Mexico. My count dropped to ZERO again. We now plan a cruise to Hawaii, the one we had to cancel. This time I have learned my lesson. I will have a follow-up CT scan AFTER we get back from the cruise.
So, how do things stand now?
My weight is stable. I feel OK but not great. I have been having some vague discomfort in the abdomen, not enough to slow me down, but enough to make me worry. Of course with this disease, you have to worry. My best guess as to my prognosis is 20% chance of surviving 2 years from some date. I don't know if it is measured from the first appearance of symptoms, first diagnosis or the day I discovered I am stage IV. The statistics for stage IV are that. However if you make it through 2 years, the chance of long term survival is good.

I continue to work, although my schedule is cut back. I continue to play bridge and I continue to enjoy life.

For those afflicted with this disease, feel free to contact me through this blog or email me at dave@shuster.com

Posted by David Shuster at 11:13AM (-08:00)

Returning From Hawaii Cruise

Tuesday, March 15, 2011

Tomorrow, we leave the Golden Princess after a wonderful two week cruise to Hawaii.

It will be back to real life with a CT scan on Thursday and an appointment with Dr. Flam the following Tuesday. Once again, I am cautiously optimistic that there will be no new disease, but if there is, I am prepared to face whatever treatments will be required, likely Chemotherapy.

Wish me luck. I will post the results when I have them.

Posted by David Shuster at 04:18PM (-07:00)

The Emotional Roller Coaster

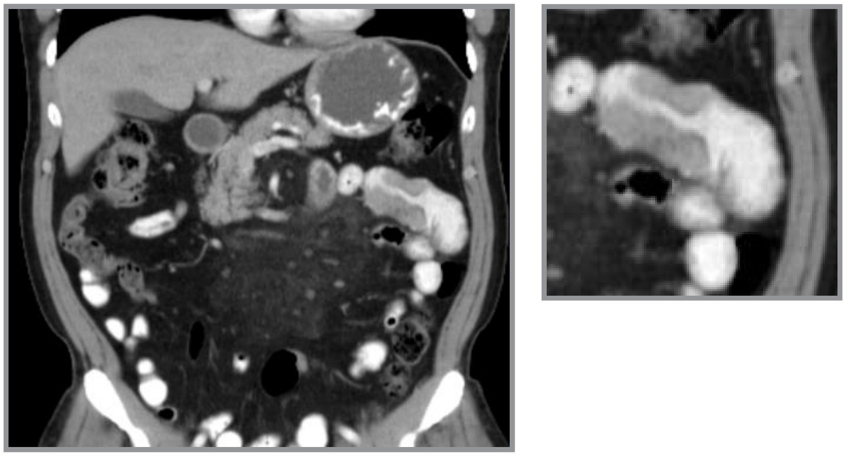
Thursday, March 17, 2011

Today, I went with Judy to Sierra Imaging in Fresno for a follow-up CT scan. On my last study, there was an unexpected new mass in my posterior mediastinum that was treated with a low dose of radiation in the hopes that this would stimulate my immune system to control the disease. I have been looking well and feeling quite well although I have commented in the past about some indigestion.

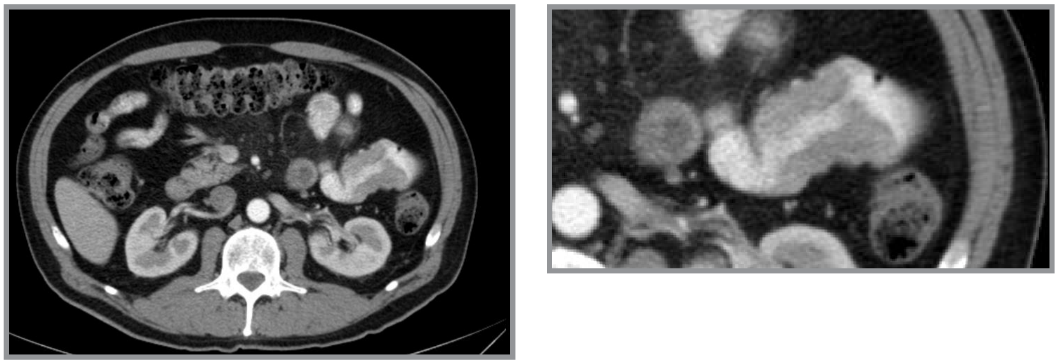
My CT scan was completed and I went to visit the Radiologist, Glen Hananouchi, a former partner of mine, to review the results, with Judy there as well. I realize this is always a difficult spot to put him in but I have been in this position many times. We reviewed the images and saw the mediastinal mass was smaller. There were no lung or liver metastases. I left the room elated and we sat in the waiting room as I had requested a CD of the images for my records.

Shortly Glen came to get me, appearing crestfallen and I knew the news was bad. There was a totally unexpected new finding. A new lesion had appeared in my small bowel, surrounding the lumen and thickening the wall, measuring about six centimeters in length and about three and a hanf centimeters in diameter. Well, at least the feelings of indigestion were not psychosomatic. There is no doubt that this is a real abnormality and I can't imagine it is anything other than a recurrence of Merkel Cell Carcinoma. This reminds me of the carnival game "Whack-a-Mole" where as soon as you whack it, it reappears elsewhere.

Here are some images from my CT scan. The mass is in the left upper abdomen. The magnigied view shows the bowel lumen (area through which digesting food passes) in white with the wall around it.



Those images are in the coronal plane. Below are axial images.



Again, the small image shows the tumor surrounding the bowel.

So, what next. I await a callback from Dr Nghiem. I have spoken briefly with Dr Flam. I have also spoken with Dr Ed Felix, a good friend, who is well known in the field of laparoscopic surgery and who has trained as an oncologic surgeon. I wii see him on Monday. I think he can remove this tumor using laparoscopic technique, with relatively little morbidity. Hopefully this will happen in the next week or so before I develop a small bowel obstruction. After that, who knows? Chemotherapy? Watch and wait for the next mole to pop up? It may be a while before I get some answers.

I would not have been surprised to see liver or lung metastases on this examination. In fact, I was almost expecting liver metastases to account for the indigestion. This was a shocker, and speaks to the variability of this disease.

Well, I still will not give up. If the bowel lesion is removed and is confined to the bowel, and the mediastinal lesion is not growing, maybe we can get rid of every trace of this bully for good.

Posted by David Shuster at 03:09PM (-07:00)

Surgery Wednesday 10:00 AM

Monday, March 21, 2011

The plan is to remove my small bowel tumor using the laparoscope. If successful, the morbidity of the operation should be minimal. Dr. Felix looked at my CT scan with me and thinks he may also be able to get the posterior mediastinal mass out.
Tomorrow, I see Dr Flam in the morning and will get labs done. EKG wednesday morning before the surgery. Colon prep tomorrow with Magnesium Citrate. I am not looking forward to that.
I will post again after my surgery, probably next week-end.
Posted by David Shuster at 06:15PM (-07:00)

A Brief Update

Friday, March 25, 2011

I came home from the hospital today. My laparoscopic surgery was done Wednesday morning. I came home today, Friday morning after only about 48 hours in the hospital. The small bowel mass was removed. I await the pathology report. The posterior mediastinal mass is still there, and could possibly be removed at a later date. I am feeling fairly well, but still have some gas pains. I am off all pain medications.
I thank all those who have wished me well. I will post a detailed narrative of the events as I remember them, hopefully this weekend.
Posted by David Shuster at 09:37PM (-07:00)

My Experience With Laparoscopic Small Bowel Resection

Sunday, March 27, 2011

On Monday, March 21, 2011, at 4 PM, I have an appointment with Dr. Edward Felix. Dr. Felix is somebody that I've known as a very good friend for more than 30 years. He has extensive experience with laparoscopic surgery having traveled the country teaching laparoscopic surgery. He has extensive experience with bariatric surgery and before coming to Fresno, was in practice as an oncologic surgeon. In fact, he was recruited by Dr. Marshall Flam to come to Fresno as an oncologic surgeon. I feel very confident in his abilities as a surgeon, and trust him as both a friend and colleague.

During this appointment, I find myself in the unusual position of acting as a radiologic consultant in my own case. I brought a CD with the images of my most recent CT scan, and we review the images together. One thing that surprised me was that Dr. Felix felt that he would have a good chance to remove the posterior mediastinal tumor at the same sitting, because he is frequently operating in this region repairing hiatus hernias in his bariatric surgery cases. Because I have not been feeling well, I urge Him to plan the surgery as soon as possible. He tells me the surgery will be scheduled for Wednesday morning.

On Tuesday, March 22, 2011, at 8:15 AM, I have my appointment with Dr. Flam. As always, it begins with labs. In addition to a CBC, a metabolic status panel has been requested. My labs have an unexpected result. I have become anemic. My hemoglobin is 9.5 g. This is down from about 13.5 g previously. This is quite a significant decrease and is presumed to be a result of occult bleeding from my small bowel tumor. the lab results or otherwise unremarkable. Now that I think about it, I did experience some shortness of breath, a symptom which has been unusual for me. This has occurred while debarking our Hawaii cruise when the ship arrived in Los Angeles. There was a fairly long upward sloping ramp which had to be traversed going from the ship to the terminal, and I noticed some shortness of breath while navigating this ramp. Before I am allowed to go home, I am given an intravenous iron infusion which lasts about 2 1/2 hours. Before the iron, I'm given some intravenous Benadryl in order to prevent allergic reactions. My understanding of the use of intravenous iron is that it will improve the level of hemoglobin in patients who are iron deficient, but the improvement occurs over several weeks. It is suggested that prior to the surgery, there will be packed red blood cells which have been irradiated available for transfusion if needed. Dr. Flam and Dr. Felix discuss my case.

On Tuesday evening, I received a phone call from Clovis Community Hospital. I am told to arrive late morning for a late afternoon surgery. I hate to do this sort of thing, but I have Judy call to Bluma, to get a hold of Dr. Felix for me, and it turns out that the hospital made a scheduling error and that indeed I am to arrive at the hospital by eight o'clock in the morning for a morning surgery.

On Wednesday morning, I arrived at the hospital by eight o'clock. Everybody is really very nice to me in the admitting department and I am brought over to the preoperative area where blood is to be drawn for type and cross match, and in IV is to be inserted. The technician selects a site in my left forearm, and inserts a needle and I can tell that she is not hitting the vein. She pulls back the needle and begins to apply compression without removing the tourniquet. I tell her she has to get the tourniquet off there, before removing the needle from the vein, but it is too late, and there is now a large black boot area on my forearm as a result. She makes a second attempt on the right arm which is also unsuccessful. A second nurse inserts the IV in my left forearm. I need the anesthesiologist who seems very nice. I've never met him before and have very little recollection of him. He obviously did excellent job because here I am. Dr. Felix arrives and we are all good to go. His wife, Bluma, also arrives, and when I am taken to surgery, she sits with Judy. We have some discussion about the possibility of removing the posterior mediastinal tumor, and that is left to his judgment that surgery. However the finding of anemia complicates the situation.

The next thing I remember is waking up sometime following the surgery, feeling quite comfortable except for some left-sided mid abdominal pain which it turns out to be located at the site of one of the incisions. There are four small incisions in my abdomen, the largest of which appears to be at the level of the umbilicus. The only one which is painful, however, is in the left mid abdomen. Dr. Felix visits and tells me that the tumor has been entirely removed. However, in view of my anemia, he felt it not to be in my best interest to perform the more complicated surgery. It could always be done at another time if necessary. I find myself in a hospital bed in a room by myself, attached to an IV which is plugged into the wall and which is on a pole with five wheels. There is a lighted yellow button, which I can press to administer a dose of morphine. As long as the button is lit, I can give myself more morphine. I give myself morphine injections, but they don't seem to do very much. On the other hand, I am not having very much discomfort unless I have to cough. I am placed on a liquid diet. Intravenous fluids are being administered. I need to call the nurse whenever I go to the bathroom which seems to be quite often as my bladder capacity seems to be limited. We await the important event, the passage of gas and a bowel movement. I go for a short walk with the nurse at my side, without incident.

Judy stays with me. I don't have much recollection of that evening. I do remember trying to go to sleep and having absolutely no success. The insomnia does not appear to be the result of pain. However I am lying in a rather uncomfortable position. This is one of these modern hospital beds which is designed to prevent bed sores. It inflates and then deflates and then re-inflates and the cycle is about every 35 seconds. The passage of time is excruciatingly slow.I'm reminded of the dripping faucet method of torture. In addition, I am having a small amount of post nasal drip which results in some coughing and abdominal pain. At times, I am unable to breathe either through my nose or through my mouth, although fortunately, not both at the same time. I get out of bed and sit in a chair which improves my respirations. I turn on the TV. I felt I did not want to wake up Dr. Felix and asking for sleeping medications. Instead, I watch for consecutive half-hour episodes of reruns of the TV show “Married with Children”.

Thursday morning finally arrives. I am greeted at about 6 AM by the lab tech who comes to draw blood. At about 7 AM, my breakfast arrives. The morning newspapers also provided. My breakfast consists of juice, Jell-O, and if there was something else, I don't remember. Later in the morning, Judy arrives. It is absolute the pouring rain outside. Dr. Felix arrives and by now, I have forgotten that I intended to ask him for sleeping pill for Thursday night. He seems to be satisfied with my progress. My hemoglobin has gone down to below 9 g. He explains this as viewed to improve hydration from intravenous fluids which results in dilution of the same amount of hemoglobin in a larger volume of fluid, and is not concerned by this at all. I again begin to go for short walks during the day. I'm given a device to encourage breathing. It sort of reminds me of a plastic pot pipe. You exhale as much as possible and then inhale through the mouthpiece. This raises up a blue marker which you have to get up to the arrow which is set at 1500. I'm having some difficulty at getting the marker up to the 1500 level. However I'm not terribly uncomfortable doing this. A small amount of post nasal drip, however, results in coughing which is uncomfortable. I am having some gas pains, and you're some gurgling from my abdomen, but still await evidence of colon activity. My diet has advanced to the full liquid diet. This allows the addition of sherbet, milk, and pudding.
I have visitors. My son Gary arrives with very touching get well cards from his three girls.Bert Rettner, My good friend and bridge partner also visits.
Thursday night is a repeat of Wednesday night. I have forgotten to arrange to have a sleeping pill. I spent much of the night awake in a chair. Since I woke up from my anesthetic, I have had virtually no sleep. I am making frequent visits to the bathroom to empty my bladder. With everything attached to the IV device, I am frequently getting things tangled and having to untangle them so that I can maneuver my way back and forth. I have completely stopped taking the morphine which doesn't seem to be doing any good whatsoever. I watched three more episodes of "Married with Children".
I may have mentioned before that I am not a religious man. However early Friday morning, my prayers were answered. There was an explosion of gas followed by a small amount of liquid stool. Thank God, My colon had begun to do its job. Friday morning, after a breakfast consisting of 1 ounce of cream of wheat, Jell-O, a half cup of milk, and some sherbet, and after having more blood drawn, I have an early visitor. It is Dr. Felix.

He gives me the wonderful news that I can go home. I will be able to leave the hospital about 48 hours after my surgery.

Here are a few other things that I did not mention above,

I was given two intradermal injections of Lovenox in the abdominal wall. I believe that this is a drug designed to reduce the incidence of thrombophlebitis and pulmonary embolism.

I received another intravenous iron infusion.

I had to wear a device that goes around the foot that regularly is inflated and deflated, also designed to reduce the incidence of pulmonary embolism. This device kept coming off of my feet, and I discarded it.

A hybrid stock/slipper was also given to me to be worn. It kept coming up, and it was not much fun reaching down to my foot to put it back on.

The intravenous device which was being used had a loud, shrill alarm system which would go off when the device detected increased resistance to flow, or when the volume of fluid remaining became low. Somehow, the nurses did not pay attention to this alarm, and frequently I would have to use the nurse call button. I would then place the microphone of the call button up to the alarm to let them know that the alarm was going off.

I was in room 322 of Clovis Community Hospital. I have to give kudos to the nursing staff and all of those people who helped take care of me during the two days that I spent in room 322 following surgery. I rarely had to wait any significant amount of time after calling the nurses. They went out of my way to be helpful and to answer all of my concerns. Whenever complaints I expressed above, I do not have any complaint about the nursing care that I was given.

Late Friday morning, I leave the hospital. I have to say that there is no place like home. However, I developed an unexpected complication of back spasms. These are relieved quite well with a heating pad which I alternate from my left upper abdomen to my lower back. I continue to be successful passing gas, but have not had a significant bowel movement.

Two quiet days have passed. My abdominal pain has substantially decreased. However there is still a small amount of residual discomfort in the left upper abdomen particularly on coughing. I have returned to a relatively light diet.

I continue to use the breathing device. I now quite easily get the marker up to the 2500 level.

Today, we were visited by our friends, Ray and Andrea Schwartz. Our dog, Rocky was visited by their dog, Joey, a full size poodle. They have been very encouraging to me. Many years ago, Andrea was diagnosed with breast cancer and was given only a short period of time to live. She is a shining example of what can happen when you stand up and fight your disease. I plan to emulate her example.

Posted by David Shuster at 05:04PM (-07:00)

I have my Pathology Report

Tuesday, March 29, 2011

The tumor is reported in a two page dissertation describing the specimen grossly and microscopic with multiple special stains.The bottom line is that the lesion is an ulcerated and necrotic focus of metastatic Merkel cell carcinoma, extending through the bowel wall and involving the serosal surface. The small bowel margins are clear. 6 lymph nodes in the mesentary have no Merkel involvement.There is no involvement of mesenteric fat. The entire specimen measures 10.5 cm in length and up to 4.5 cm in diameter. The tumor is described as ulcerating and fungating involving 85% of the small bowel circumference.

What that all means is that the small bowel tumor has been completely removed. The good thing is that the nodes are not involved. The bad news is that it got to the surface of the bowel and I am at risk for cells having been shedded from the surface taking hold in the peritoneum and growing there.

This was obviously the cause of my anemia and was close to causing a small bowel obstruction. It was also causing my weight loss.

My last Hemoglobin was 8 grams. I need to get this up. I have had 2 iron transfusions and have begun oral iron supplements as well.

My appetite has improved and my colon has begun behaving normally.

I was feeling very discouraged last night thinking I was having too much abdominal pain for this late after the surgery. This prompted a careful inspection of my abdomen. I realize that there is a 6cm horizontal incision in my right upper abdomen. This is larger than I had originally reported. I thought the largest was in the umbilicus. However it makes sense that the specimen was removed intact and measured up to 4.5 cm. This cheered me up, thinking that the continued pain is appropriate. I have taken some Advil for pain but did not fill my prescription for narcotic pain relief. A heating pad has been helpful as well for back spasms.

Yesterday, I called my accountant and asked him to get an extension for the deadline for filing my taxes for 2010. Then, in the mail, I get an audit notice for 2009.

I also got a Jury Summons. I requested a postponement based on the likelyhood of needing chemotherapy.

So here is the plan.

Follow-up with Dr Felix Monday afternoon. (April 4).

CBC Monday morning (to be drawn at Dr Flam's lab.

Follow-up with Dr Flam April 12

?Chemo? I don't think I can get away from it.

Posted by David Shuster at 09:46AM (-07:00)

12 Days Post-Op

Monday, April 04, 2011

Today I had my follow-up appointment with Dr. Felix. I never cease to be amazed at the way communications seem to fail. When I made this appointment, Dr. Felix wanted me to get a CBC. His office was supposed to fax a request to Dr. Flam's lab. When I arrived at Dr Flam's lab this morning to get my blood drawn, nobody had the request. They drew the blood and did the studies in any event. I requested that the report be faxed it to Dr. Felix's office. When I arrived for my appointment at 1:45 PM, of course, the results which take about 5 min. to obtain, were unavailable. I also learned from Dr. Felix that he had to read the path report on my blog. It was never sent to him from the hospital. Chalk one up for the universal medical record.

When the result was finally available, it turns out that my hemoglobin was 11.5 g. This is a substantial improvement from 8 g when I left the hospital.

All of the incisions on my abdominal wall are healing well. There are no stitches to remove, and I will be able to finally wash my abdomen with soap. Of interest is that although the pathology report suggested the tumor reached the serosa (outer lining) of the small bowel, Dr. Felix thinks that this is a result of the surgery. When the tumor is removed, it is actually placed within a plastic bag and then pulled through the incision. This trauma damaged the outer surface of the specimen, which showed no gross evidence of tumor infiltration at the time of surgery.

My apologies to Dr. Felix. I reported that the incision was about 6 cm in length. Actually,

the measurement is 4.5 cm.
My next step will be to confer with Dr. Nghiem and with Dr. Flam about chemotherapy.
The more I read about it, the more terrified I become.
Here is a link to Cisplatin side effects

These are the less common Cisplatin side effects (occurring in 10-29%) for patients receiving Cisplatin:
Peripheral neuropathy: Although less common, a serious side effect of decreased sensation and paresthesia (numbness and tingling of the extremities) may be noted. Sensory loss, numbness and tingling, and difficulty in walking may last for at least as long as therapy is continued. Neurologic effects may be irreversible.
High frequency hearing loss. Ringing in the ears.
Loss of appetite
Taste changes, metallic taste
Increases in blood tests measuring liver function.
Death from the therapy in about 2% of patients.

The following Cisplatin side effects are common (occurring in greater than 30%) for patients receiving Cisplatin:
Nausea and vomiting. Nausea may last up to 1 week after therapy. Anti-nausea medication is given before the infusion, and a prescription is also given for use after.
Kidney toxicity. Effects on kidney function are dose related, observed 10-20 days after therapy, and are generally reversible.
Blood test abnormalities (low magnesium, low calcium, low potassium)
Low white blood cells (this may put you at increased risk for infection)
Low red blood cells (anemia)

This will be a major undertaking and I will have to balance the potential gain with the risks of spending my remaining days in misery.

I would be very much interested in hearing from people who have undergone the treatment as to in their personal experience, it was worthwhile.

Posted by David Shuster at 09:05PM (-07:00)

A Plan

Tuesday, April 05, 2011

I had a long conversation with Dr. Nghiem today. He is not against my having chemo, but is also not strongly in favor of it. We discussed the pros and cons, and I have come to the conclusion that it is worth the risk and misery to try to defeat this monster of a disease. Judy has come up with a great idea. it is not an urgent matter to begin the chemo immediately. Unless Dr Flam is able to convince me otherwise, I will visit my mother in

Montreal and on my return, have a port placed and begin the chemo.
I will likely leave towards the end of next week and stay for about five days.
My Niece and nephew in Montreal just had a baby girl, as yet unnamed, and I will have the opportunity to see her as well.
This will be my last chance to travel for a long time so I will make the most of it.
Posted by David Shuster at 05:05PM (-07:00)

A Brief break, Then 3-5 Months of Chemo.

Thursday, April 07, 2011

My Pre-Chemo Photo First, the good news.
I have my reservations for Montreal. I leave Fresno April 15 and return April 20.
I am looking forward to spending time with my mother and meeting my new, as yet unnamed great-niece, as well as with my brother Robert my niece Andrea and her husband Ben, the proud parents.
I am recovering well from the surgery and should be feeling fine for the trip. When I get home, it will be down to business.
I called up Dr. Flam yesterday and he agreed to see me yesterday although my appointment was for April 12. He is on board with my trip to Montreal as I need time to heal from the surgery before the chemotherapy.
He patiently answered all my questions. I have discussed this with Dr. Nghiem and he is in agreement.
I did have the Pneumonia Vaccine at this visit.
I will get home April 20, a Wednesday.
On April 22, the Friday, I am scheduled for a PET scan to look for any evidence of new disease.
On Monday, April 25, I will go to St. Agnes Medical Center, my old stomping grounds and have a port inserted. I will also have lab work done.
On Tuesday, April 26, Chemo begins. Cisplatin and Etopiside IV.
On Wednesday, April 27, Etopiside and IV fluids to protect my kidneys.
On Thursday, April 28, repeat of Wednesday
On Friday, injection of a drug to stimulate my bone marrow. I didn't catch the name but will post it when I have it.
On Mondays, lab work to follow my red and white cell count and renal function.
Other than that, I have the next two weeks off and the next cycle begins May 17.
After three cycles, repeat imaging to try to determine if it is working.
A total of as many as six cycles is planned if I can tolerate it.
I have a package listing the side effects and how to mitigate them.

During the injections, drugs are given to combat nausea. I will lose my appetite, likely suffer nausea, vomiting, diarrhea and constipation. I may develop sores in the mouth and throat. There will be alteration of sense of taste, something I complained bitterly (pun) about when I had the radiation. Again dryness in the mouth.

Peripheral neuropathy, with numbness of the extremities is common. There can be liver and kidney damage.

Hair loss! That will be the least of my worries. I don't have that much hair left.

Dr Flam says I should be able to spend time with my grandchildren during the chemotherapy unless they are obviously sick. I should be able to go to the Bridge Club and even work during the off weeks. I am not planning to work at that time.

I am optimistic that I can get through all this with minimal side effects, as, apart from my cancer, I am in good health. In fact, since we made the diagnosis of Merkel's, I haven't had so much as the sniffles.

Posted by David Shuster at 04:08PM (-07:00)

My Visit to Montreal

Sunday, April 17, 2011

It is Sunday, April 17, 25 days after my laparoscopic surgery. The incisions are healing well. There is some discomfort in the area of the largest incision which is at the belt line. I feel more comfortable not wearing a belt.

I arrived late Friday, about 1 1/2 hours after the scheduled arrival time, delayed by a storm in Chicago. Lenny met me at the airport and took me home to have a snack of Montreal bagels and lox.

I met them again for brunch Saturday, and then they left for Toronto for Passover.

I arrived at my Mother's place and met my brother Robert and my nephew Peter. We went to Ty Breiz for lunch. I had my favorite Montreal Onion soup. It was great, Later in the afternoon, both Mom and I had GI upsets, perhaps because of MSG in the soup.

Today, I spent the day with my mother again. We spent the morning watching the 25th anniversary DVD of Les Miserables. It was wonderful, and I was in tears the whole show.

We were visited by Andrea and Ben and my new Grand-niece who is only 2 weeks old.

Her name is Alexandrea Lauren Urovitch, nicknamed Alex. My brother was also there.

They brought chinese food for lunch. After they left, Robert and Mom and I went for coffee at The Second Cup. I hung with my mother until 9:00 PM.

I have to say that I am not feeling 100%. I still am having GI upset.

My mother also seems as frail as I have ever seen her. She has also had GI upset and at dinner today, complained of dizzyness. I was somewhat concerned, but about an hour later, she ate a good meal of Won Tons, and I felt better about her.

Here is a photo of Alex and yours truly. She slept in my arms for about half an hour. You never forget how to hold a baby.
Posted by David Shuster at 06:53PM (-07:00)

An Innocent Man

Thursday, April 21, 2011

I read a book by Gresham, not a novel, about innocent men convicted of murder on death row. It was called "An Innocent Man". I think in some ways I am the Innocent Man. I may be on death row. My team of attorneys is my medical care providers. My appeals are through chemotherapy. The judge is God. I committed no crimes. I may be on my final appeal.

After a trouble-free day of travel, I am home. I will have pleasant memories of this trip. My Mother is frail and weak, but seems to be very stable for somebody who will soon turn 94. We had an unexpected visit from Willie Kravitz and his daughter Meredith on Monday. Willie is "the 4th son". He and his wife Elaine became very close with my parents when they lived in adjacent apartments. My parents baby-sat for Meredith when she was an infant, but she is now all grown up.

We had no Seder to go to because of issues which my brother's wife Gertie has with my mother, so we had dinner at Place Kensington. They did serve Matzah-ball soup, Gefilte fish and "Matzah Bread".

We saw an interesting movie called 'Gentleman's Agreement" with Gregory Peck, from 1947 about anti Semitism. A Christian writer pretends to be Jewish to research an article on anti-semitism. If you have a chance to see it, it is worthwhile.

Here is the countdown:

5. Today,
4. Friday. PET scan in the morning, CPA for my audit and to prepare my belated 2010 tax return in the afternoon
3. Saturday
2. Sunday, my last day of reasonable comfort
1. Monday. 7:00 AM to St Agnes for insertion of a port
0. Tuesday. Chemo begins.

I hope to be able to continue this blog through my chemo.
Posted by David Shuster at 12:05PM (-07:00)

My PET scan results

Friday, April 22, 2011

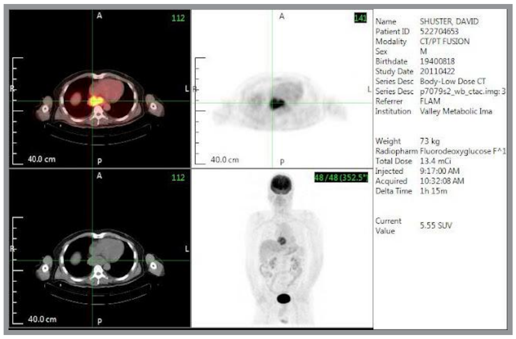
I went for my PET scan today. I have been having increasing discomfort in my lower chest and anticipated that my posterior mediastinal mass would be larger and pressing on my distal esophagus causing the symptoms. I was hoping there would be no evidence of new disease. This Merkel Cell carcinoma can grow as fast as any malignancy I know about.

I had to be on a sugar-free diet for 24 hours prior to the examination. Last night, we had Gary, Dana, Eva, Sara and Bel over for a mini-Seder. I could not enjoy much of the cooking, but everyone had a good time.

No breakfast this morning. I arrived for my scans at 8:15. They put me in a very cold room with a heating pad on my arm to start the IV. Of course, in the cold, your veins constrict, but the IV was started without incident. My blood sugar was 105, a good number. They injected the radioisotope without incident and then I had to wait 1 hour for it to spread through my body. It concentrates in areas of high metabolic activity, such as tumors, healing surgery sites, brain and kidneys. There was alot of activity in my brain, probably, like Cassius from Julius Caesar, I think too much.

After the hour, it is 35 minutes to be scanned with the warning to stay perfectly still to avoid image degradation. Of course, as soon as the scans began, my ear and my nose began to itch. I needed to clear my throat, and the blowing of cool air over me for ventilation made my face itchy and gave me the urge to sneeze. 35 minutes seemed like hours. I left at about 11:30 AM and returned at 2:00 PM to review the results with Dr. Dan Stobbe. He is a longtime colleague and friend.

Below are sample images from the scans.



Name	SHUSTER, DAVID
Patient ID	522704653
Modality	CT/PT FUSION
Sex	M
Birthdate	19400818
Study Date	20110422
Series Desc	Body-Low Dose CT
Series Desc	p7079s2_wb_ctac.img: 3
Referrer	FLAM
Institution	Valley Metabolic Ima
Weight	73 kg
Radiopharm	Fluorodeoxyglucose F^1
Total Dose	13.4 mCi
Injected	9:17:00 AM
Acquired	10:32:08 AM
Delta Time	1h 15m
Current Value	5.55 SUV

The image on the bottom right is a coronal image. The areas in black show high levels of activity. The brain at the top, the bladder at the bottom, and the tumor in the middle. The image at the top left is a color rendition in the axial plane showing my heart in gray, my lungs in black, and the tumor in yellow in front of the spine which shows up in white. The esophagus shows up on other images, pushed to the left. This is the cause of my symptoms.The tumor now measures 5.8x2.6x5.0 cm. On March 17, it was 2.6x3.8x3.7. The original measurements last November were 4.5x3.7x3.5.

There was no other convincing evidence of tumor growth.

So what does this mean to me?

The good news is that there is no new disease. This mass is causing my symptoms and there is no unexpected finding. It can be followed with serial PET scans to monitor the effectiveness of treatment.

Should the chemo shrink the mass, it might be removable by laparoscopic technique assuming no new disease develops during the chemo.

The bad news is that the experimental treatment with a small radiation dose was not effective, although the mass did initially shrink.
I received a call from Dr. Flam's office delaying the start of chemo to next Wednesday.
After visiting Dr Stobbe, I went to see my CPA who has my tax audit under control.
Some good news. I have made it to within 1-2 points of the 2500 I need to become a Gold Life Master at Bridge. I will get there before the Chemo begins.
I hope to post again to describe the insertion of the port from the patient point of view. I have inserted many ports, so the difference in perspective should be interesting.
This morning, there were flowers on our doorstep. Beautiful roses.
Thanks Bonna.
Posted by David Shuster at 07:31PM (-07:00)

Port Inserted Today

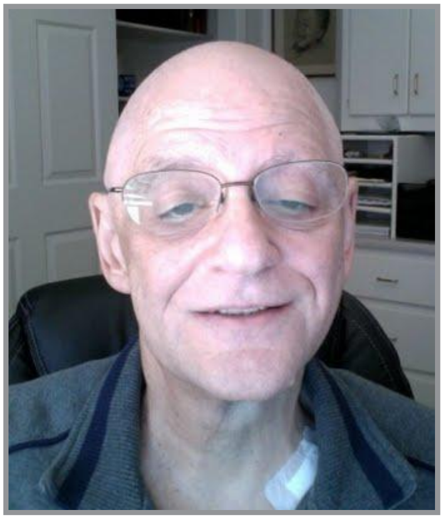
Monday, April 25, 2011

We arrived at St Agnes Medical Center at 7:00 AM.
I met Joe Cerillo, a longtime colleague with whom I have worked 20 years or more. He is a technologist who works in interventional radiology. He told me he just completed chemo for non-Hodgekins lymphoma. He had a port which was recently removed. I wonder if his disease is the result of radiation exposure. For that matter, I wonder if my condition is also caused by radiation exposure. I know there is a relation with sun exposure.
I met Dr. Nguyen, an interventional radiologist. He has placed more than 300 ports. He likes to place them in the subcutaneous tissues of the right upper chest. That was fine with me as the left jugular vein is scarred by the radiation treatments. The procedure went off on time and without incident. It is a duel lumen power port, meaning that there are actually two ports to inject, so two drugs which may not mix well can be injected simultaneously. It is capable of receiving injections from a pressure injector such as the type used to inject IV contrast for CT scans. It looks like it is made of plastic so it will not interfere with CT or MRI imaging. The port itself sits on my upper right chest wall. The catheter is tunneled to the lower neck where it enters the jugular vein.
Thee procedure was completed by 10:00 AM and I was able to leave shortly after 11:00 AM. It is now 1:00 PM and there is no pain from the incisions. I have no memory of the procedure itself, due to the effects of Versed and Fentanyl.
Joan Rivers described "Jewish Natural Childbirth" as follows. Put me out with the first pain and wake me up when the hairdresser comes.
This was the "Jewish Port insertion."
As I will not begin chemo until Wednesday, I will have a buzz cut of my hair tomorrow. That way, I will not have to worry about sweeping up falling hair.
I hope to post a picture of myself tomorrow, pre chemo with a buzz cut.
Posted by David Shuster at 01:08PM (-07:00)

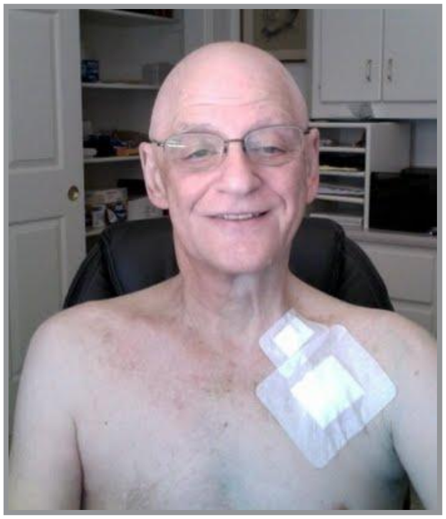
I get a Buzz Cut

Tuesday, April 26, 2011

Chemotherapy begins tomorrow. I decided that I don't want to wait for my hair to fall out so I got it all cut off today. Here is the new hairless me.



The bandage is from the port insertion. Below is a photo of my chest to show the location of the incisions.



The larger bandage covers the incision through which the port is placed. The port lies under the skin. The smaller bandage covers the location where the catheter is placed in the jugular vein. They tunnel the catheter from the port to this incision and then insert it into the vein. It is all done with local anesthesia, but thanks to the magic of Versed , I have no memory of this.

This is the best photo I could find of the port itself from the Bard website. There are two wells into which the drugs can be injected. Each is delivered through a separate lumen in the catheter to the Superior Vena Cava. The ports are strong enough to take a pressure injection for contrast enhanced CT. Supposedly, the port does not degrade CT or MRI images.

I am feeling quite good. There is mild discomfort at the incisions controlled well by Extra Strength Tylenol, a drug which I rarely take as it usually does not work for me. I prefer Advil but they want me to stay off it for now.

I hope to be feeling well enough tomorrow to post my experience with the first day of chemo.

Posted by David Shuster at 12:18PM (-07:00)

Chemotherapy. Day 1

Wednesday, April 27, 2011

I arrive at The hematology Oncology office almost promptly at 8:03.

I sign in and sit and wait. Apparently Wednesday is the busiest day and they have added Dr Rao to the practice and he brings 125 patients.

After about 25 minutes, they call me to the lab. I refuse to submit to more labs because Dr Flam ordered the labs at St Agnes to be done Monday, just 2 days earlier, after a discussion which went something like this.

Dr Flam: You'll need labs before the Chemo. I could just get them here or at St Agnes since you'll probably need labs before they place the port.

Me: OK, let's get them at St Agnes.

Dr Flam: OK. I'll write the order.

And he did.

However, the labs are not immediately available, not having been filed in my chart.

Dr Flam: We can get them from the computer.

Nurse: The computer is down.

They did find my labs and my Hemoglobin is creeping up towards the normal range, at 11.8 from I think 11.1 three weeks earlier.

So they will draw blood from the port for serum iron and iron binding capacity.

9:00 AM. After a brief examination, I am sent to the small room for my Chemo. There are about 5 LazyBoy chairs down one side of the room. I grab the only vacant one. There are four sofabeds with elevated knee support on the other side of the room, all empty but soon to fill up. To my left are two very large bathrooms with folding doors. I decide they are not very private and will be used only in an emergency.

A very experienced nurse named Bill checks my port. He accesses it using a special needle called a Huber needle which has a 90 degree bend and tapes easily to the skin. Before inserting the needle, he numbs the skin with Ethylene Chloride spray, and I don't feel the needle. They draw my blood and begin treatment.

I am given Aloxi 0.25 mg bolus,

Next was Emend, 150 mg.

I am pre-hydrated with 500 cc of normal saline to which potassium chloride (KCl) and magnesium sulfate ($MgSO_4$).

Sorry, I don't know the doses.

At about 10:30, they bring in the big gun. Cis Platinum 170 mg with 40 mg KCl, 12 mg of $MgSO_4$

and 20 mg of Lasix. Lasix is a drug which increases urine production. It is used to prevent nephrotoxicity. (Kidney damage). 10 mg of decadron is also given. It is basically IV cortisone. This is in about 3000 cc of fluid, I think normal saline.

The infusion is about 3 hours. I sleep part of the time. Judy goes home and comes back at lunchtime with a sandwich from Subway, a soda and lemon yogurt.

Judy leaves to pick up my anti-nausea pills.

Zofram (generic name is Ondansetron) 8 mg twice a day.

Compazine (generic name is Prochlorperazine) 10 mg as needed 6 hours apart.

The insurance may not cover the Zofran, about $21 for 12 pills. No biggy.

At about 2:45, The second gun arrives. 100 mg of VP16 in 250 mg of normal saline.

I lost count of the number of visits to the bathroom, but my best estimate is 7. Fortunately, I found a more private bathroom.

I must say that the first day went surprising well. I was not sick. I had no nausea. I was comfortable and I got to meet new people.

To my left was a young man, about 35, with a lovely young woman, perhaps his wife or sister. He was also receiving cis platinum.

He has a rare testicular cancer, choriocarcinoma and they have given up on trying to cure him. The treatments for him are designed for slowing the spread of already widespread disease.

To my right was a man who was quietly playing cribbage with a woman, I presume his wife. Suddenly, he developed terrible chills and was in agony for about 20 minutes, perhaps because of an infected port. After the chills resolved, he was vomiting.

We left at about 4:15 PM.

I return Thursday and Friday for shorter sessions, just the VP16.

On Saturday, I have to go for an injection to stimulate my bone marrow. I think it is Neulasta.

I will post again about this.

After we returned home, it was a quiet evening. I have had no symptoms. I ate a good dinner, drank some fluids and we watched the Giants (they lost) and American Idol (James Durbin would get my vote if I voted).

I have now accumulated enough master points on line to become a Gold Life Master of the American Contract Bridge League.

So what did I learn today?

1. Chemo may not be as bad as I expected.
2. There are other patients who are much worse off than me.
3. I can find the bathrooms blindfolded while dragging my IV pole.

Posted by David Shuster at 11:24PM (-07:00)

Chemotherapy-Day 2

Thursday, April 28, 2011

Chemotherapy-Day 2

All went according to plan. I arrived at 8:15 AM and the infusion room was empty.

First was Solucortef and anti-nausea medication. Then 1000 cc of normal saline, followed by the VC16. I was out by 12:15. The needle was left overnight in the port but I had them pull it today so I can take a real shower tonight. The skin over the port seems to be healing well. The steri-strips stay until they start to fall off. During my treatments, several patients arrived for treatment needing new IV's. Watching the interaction between patient and nurse reinforced the conclusion that I had made a wise choice to have the port placed.

I am having very few symptoms. My voice is slightly hoarse and I am having some constipation. I managed to pass some rocks which seemed to help. I'll start Metamucil tomorrow morning.

I am getting the occasional hiccups. I was given a prescription for Reglan which I will try if

the symptom gets worse.
The generic for Zofram anti-nausea drug was not approved by by our Medicare Part D provider. $21.95 for 8 pills. An advisor at Dr Flam's office, Patty, who was very helpfull, established my right to coverage under Medicare Part B as I am having "in-office chemotherapy". This reduced the price to $7.30. Out of interest, she called Winton's Pharmacy in Fresno and got a quote of $1200 for 100 non-generic Zofram. What a racket.
Tomorrow should be a repeat of today, and then a brief visit Saturday for a subcutaneous shot of Neulasta.
Symptom to expect as a result of the Solucortef: Insomnia.
Symptom to expect as a result of Chemotherapy: Fatigue.
What a combination. Fatigue but insomnia. Can't stay awake, can't fall asleep.
So far it is a draw, as I fell asleep without difficulty, but my old man prostate woke me up after about 3,5 hours and then it was very difficult to get back to sleep,
Stay tuned for updates.
Posted by David Shuster at 06:42PM (-07:00)

Update Five Days After Cisplatin

Monday, May 02, 2011

It is Monday, May 2, 2011. On Friday, I had the third session of chemotherapy with VP16, along with all the other medications they routinely give. This went off without incident except that they wanted me to have labs drawn, and made me wait for the lab tech to draw the blood when I could have been starting the chemo. It makes no sense to stick a vein when the port is going to be used the same time for chemo. On days when there is no chemo, get the labs from a vein. On days when there is chemo, get the labs from the port. This resulted in a half hour delay in getting started, no big deal.
On Saturday, I went for my shot of Pelfilgrastim (Neulasta), a drug which stimulates the growth of healthy white blood cells. The shot is given into the subcutaneous tissues. I took mine in the left arm. There is a 30% incidence of bone pain from this drug but I had no symptoms.
Neulasta Link
On Wednesday, I have an appointment with Dr Flam. The following Wednesday, again, and the second round of chemo will begin May 17.
I am feeling fairly well at this time. The spasms in my chest have reduced. Could this mean the chemo is working? I am more fatigued than I am used to, going to bed at 10:00 PM instead of close to midnight. I am having some constipation without significant discomfort, and waking every 2 hours to void. I suspect this may be due to the Zofram, which I stopped this morning as I am not at all nauseated.
Zofran Link
The surgical site in the abdomen and the port insertion site have healed well.
I a trying to resume some activities, going to the bridge club today and tomorrow morning, driving, walking the dog and watching the inept San Francisco Giants blow baseball games.
I hope to post a follow-up after my visit with Dr Flam.
I thank the so many people who have offered their prayers and encouragement.
Posted by David Shuster at 07:34PM (-07:00)

My Visit With Dr. Flam

Wednesday, May 04, 2011

First, the labs were done. My Platelet count has dropped from 236,000 to 67,000. My white count has dropped to 3200 from 6400. My Hemoglobin is stable at 11.7 grams. When I saw these results, I was somewhat worried but Dr. Flam seemed to feel that this was a normal reaction to the chemo and that I was doing well. He is encouraged by the improvement in my symptoms, which he feels is an indication that the chemo is working. In fact, he is suggesting imaging after the second round of chemo, possibly with an eye towards following up with more radiation to the posterior mediastinal mass, assuming it is responding well to the chemo as verified with imaging.

This is all very encouraging.

Meanwhile, I am having only minor symptoms. Constipation for which I have started Colace (generic).

My sense of taste has lost something since I started the chemo. No metallic taste, but food does not have the full flavor it had recently. Part of this is a holdover from the radiation treatments. My mouth remains dry and there is some inflammation of the gums.

I finally have learned that I do indeed have evidence of the Polyoma Virus. I have antibodies to the T-Antigen of Merkel cell polyomavirus, according to Dr Nghiem. I suspect I received it in the mid 1950's when given the Salk Vaccine.

I have been interviewed for the the NCI Cancer Bulletin, a free online newsletter published every other week by the

National Cancer Institute. The interview was conducted by phone today. When the article is printed, I will post a link to it. The interview was conducted by Edward "Ted" Winstead. He has previously written about MCC for the NCI. Article 1

Article 2

Posted by David Shuster at 08:32PM (-07:00)

Polyoma Virus Information

Thursday, May 05, 2011

This stuff is beyond my ability to comprehend, but from what I can put together, the story is like this. In the 1950's, there was pressure to begin inoculating the general population against Polio. This came both from the general population as there was a high level of anxiety about the disease which caused paralysis and death among many of its victims, and also from the companies racing to get the vaccines on the market for financial gain. The initial doses of the vaccine were harvested from monkey kidneys and the virus was inactivated by formaldehyde. The Polyoma Virus was a contaminant, slightly more hardy and not inactivated by the amounts used. I have read some estimated of up to 50,000,000 doses of the vaccine were contaminated before they switched breeds of monkeys. The vaccine was given in the mid 50's. The evidence of a cause and effect relationship between MCC and the virus is circumstantial. The virus is present in 80% of MCC patients in the USA, but not more than 60% of the general population. People with a reduced immune response are more susceptible to the disease. MCC can be effectively treated locally by Beta Interferon, injected locally. Beta Interferon is an anti-viral drug. The Polyoma virus is not found in MCC cases in Australia. Please Note. The virus has mutated and there is no threat of human to human transmission of the virus. Below are some abstracts. **Merkel cell polyomavirus and MCC** 2008: Feng, Moore, Chang discovered a new human polyomavirus, the Merkel cell polyomavirus Virus integrates in the genome of most MCC tumors in a clonal pattern (Feng H et al., Science 2008) Viral

DNA present in ~80% MCC tumors MCPyV proteins are present and persistently expressed in > 50% of the tumors ~60% of US population has specific antibodies to the MCPyV capsid protein (Carter JJ et al., J Natl Cancer Inst. 2009) ~90% of MCC patients are sero-positive to the MCPyV capsid protein supporting a continuing role for this new virus in most MCC tumors Mutation pattern in the large T oncoprotein are highly suggestive of a role in this cancer (N terminal – pro-cell cycle portion is conserved: C terminal – genomic instability generating region is deleted in most tumors) (Shuda et al., Proc Natl Acad Sci U S A. 2008) Additional References: 1. Garneski KM, Decaprio JA, Nghiem P. Does a new polyomavirus contribute to Merkel cell carcinoma? *Genome Biol 2008*; 9(6):228. Click here for a PDF.

A review of polyomavirus biology and its possible relation to cancer.

2. Garneski KM, Warcola AH, Feng Q, Kiviat N, Leonard JH, Nghiem P. Merkel Cell Polyomavirus Is More Frequently Present in North American than Australian Merkel Cell Carcinoma Tumors. *Journal of Investigative Dermatology* 2009; 129, 246–248. Click here for a PDF.

North American and Australian tumor samples were evaluated for presence of MCPyV and a higher incidence in North American samples were positive for MCPyV when compared to Australia, suggesting a possible strain variant.

3. Feng H, Shuda M, Chang Y, Moore P. Clonal Integration of a Polyomavirus in Human Merkel Cell Carcinoma. *Science* 2008; 319:1096-1100

A technique called digital transcriptome subtraction (DTS) was used to identify a new virus, which is a previously unknown polyomavirus that we call Merkel cell polyomavirus (MCV or MCPyV). MCPyV sequences were detected in 8 of 10 (80%) MCC tumors (lower incidence in non-MCC tumors).

4. Carter J, Paulson K, Wipf G, Miranda D, Madeleine M, Johnson L, Lemos B, Lee S, Warcola A, Iyer J, Nghiem P, Galloway D. Association of Merkel Cell Polyomavirus–Specific Antibodies With Merkel Cell Carcinoma *Journal of the National Cancer Institute*2009; [Epub ahead of print]. Click here for a PDF.

Merkel cell polyomavirus (MCPyV) has been detected in approximately 75% of patients with the rare skin cancer Merkel cell carcinoma. We investigated the prevalence of antibodies against MCPyV in the general population and the association between these antibodies and Merkel cell carcinoma.

Posted by David Shuster at 02:43PM (-07:00)

First Round of Chemotherapy, Observations After Two weeks

Wednesday, May 11, 2011

A side effect of my chemo has been a dry mouth, loss of taste, and a lack of desire to drink much fluid. I began to note my bowel movements resembled small marbles, which passed without difficulty. However, for a few days prior to last Saturday, (May 7), nothing. No urge to go, no abdominal discomfort. I began to take oat bran, Metamucil and Colace. Still, nothing. Saturday morning, I finally felt the urge to go. Into the bathroom, seated on the toilet, and the struggle began. I am trying to push out a solid rock, hard as steel, painful and immovable. With due respect to all women who have delivered a baby, this must be as close as I can ever come to that. I wanted an epidural. I would have cheerfully done an episiotomy on myself if I could. It got to a position, halfway in, halfway out, and got stuck. I trained in ob/gyn as a resident for 6 months. I wanted to try obstetrical

forceps. After about half an hour of pushing, finally, success. I was bleeding. My rectum was on fire, I grew hemorrhoids I never knew I had. They still have not gone away, 4 days later. Every visit to the bathroom gives me a chance to relive this experience.
I visited Dr. Flam this morning. He has a cold and wore a mask and sanitized his hands. I hope I don't catch anything. All is going well.My white cell count has risen from 3.8 to 6.6 thousand. My platelet count has improved from 67 to 116 thousand. However, there has been a small drop in my hemoglobin from 11.7 to 11.2. I suspect this may be at least in part from my forcing fluids to keep from mixing more concrete in my colon.
Other symptoms include dry mouth, inflammation of the gums and nose, and leg cramps. The leg vramps seem to effect new muscles in the side of the calf rather than the usual calf cramps. They don't respond well to external squeezing, but seem to improve with walking and a heating pad.Dr Flam recommended
CO-Q 10, 200 mg for this. I will start with 100 mg.
I am also taking Colace, a fiber laxative and will try prunes.
I have to say that if I didn't know I have cancer, life would be pretty good right now. I am not working and am enjoying spending time in a non-productive way. I am still going to the bridge club and I have confirmed on the ACBL Web Site that i have attained the rank of Gold Life Master. On Monday afternoon, Bert and I came first of 11 north/south pairs.

All this has taken a toll on Judy who composed this small essay to describe her feelings.

FIND THE TIME
You're so busy.
Never enough time to do all the things you need to do.
Running here, running there, wishing you had more free time.
And then your life changes.
You're diagnosed with cancer.
Suddenly you have the time to run from doctor to doctor, being poked, X-rayed, Radiated and getting chemo.
Amazing how life suddenly changes and all those important things that kept you so busy
Can now so easily
Be put on hold.

Posted by David Shuster at 02:34PM (-07:00)

End of Round 2, I'm Still Standing

Thursday, May 19, 2011

Today, I completed round 2 of chemotherapy. I still have to go back tomorrow for a shot of Neulasta to build up my white count. My labs today were all good except my blood sugar which is about 175, bit taken after Rice Krispies, raisins, bananas, and Boost Plus. I think this accounts for the elevation. I am more nauseated this time than last, and have added generic Compazine to my list of medications. I think it is giving me a Parkinsonian reaction as I notice a tremor as I type this. My mouth is still quite dry, my taste buds have not deteriorated further, and I have been getting up every 2 hours to empty my bladder. Otherwise I feel well.
Judy has been having shoulder pain without any trauma but with a sudden onset. I presume it is bursitis.

Rocky woke us up this morning with vomiting. There's never a dull moment around here.
We went to a birthday party for Bob Savluk Saturday evening (May 24). He is a member of our Poker group and was celebrating his 60th birthday. It was a wonderful casual but eloquent party.
Another member of the poker group, Howard Watkins took photos. Below are two of Judy and Me, one with a hat and one without.

My hair has not yet begun to fall out but this is a preview.
Judy looks great in these pictures, and she has been wonderful during this battle. I couldn't ask for better care and support than what she has so cheerfully offered.
Posted by David Shuster at 02:32PM (-07:00)

The world did not end, so I will continue chemotherapy

Sunday, May 22, 2011

Sunday afternoon, 5 days after Cisplatin, 3 days after my last dose of VP16.
This week has produced more severe symptoms than round 1.
Nausea has been worse. I have still been able to control it fairly well with the medications. The Zofram seems to be associated with constipation and I am now on my third day day without any action. I will not make the mistake of straining and will await the effect of prunes and laxatives.
Yesterday, I treated the nausea with a product legal in California, and I must say it was very effective.
In fact, last night I had the best night of sleep in a few weeks.
Today is the first day I have not felt the severe fatigue of the past few days.
My taste buds are slowly fading away, but I have not completely lost my sense of taste. However, even after the "product", snacks did not taste as good as I might have expected.
I expect that in the next few days I will feel better, but round 3 will be worse than round 2.
I have an appointment with Dr. Flam Tuesday morning but he will be out of town, so I will see his assistant, Marina. The main thing will be the labs, and I will go fasting to the appointment to get a better idea about my blood sugar which has run in the 170's after Boost Plus.
I received a subpoena for tomorrow morning to testify in a trial where a former associate

of mine and St Agnes Medical Center are in a dispute. I received the subpoena Thursday night for Monday morning. I was never deposed or given any warnings. I called the attorney who was named on the subpoena, and after a brief conversation in which I played the cancer card, I was told they wouldn't need me. I guess having cancer isn't all bad.
Posted by David Shuster at 02:19PM (-07:00)

A Clarification About the Subpoena

Monday, May 23, 2011

Rereading my last post, I am afraid I may have left the wrong impression about who issued this subpoena. It came from the attorneys representing St. Agnes Medical Center of Fresno. It did not come from the plaintiff's attorneys.

The contact name is an associate at the law firm of Jones Day, Los Angeles office. The letterhead lists 32 locations including Beijing, Tokyo, Paris, Hong Kong, New York.

Posted by David Shuster at 09:20AM (-07:00)

My Follow-up Medical Appointment

Tuesday, May 24, 2011

Today, I went back for my appointment. Dr Flam is out of town so I saw his assistant, Marina.

I had labs done as per the routine. Today, I was fasting as I wanted to document a normal blood sugar fasting. The last was 176, and fasting, it was 110. This is an indication that I am not diabetic. Hemoglobin is 11.6, up from 11.2 two weeks ago, platelets normal at 162,000. The interesting result is that my white count is 20.8 thousand. This is elevated and raises the possibility of a significant infection. However, an internet search suggests that this is result of the injection of Neulasta.

I do not have symptoms of infection apart from mild sore throat and gum tenderness.

My constipation has passed, so to speak, after stopping Zofram, and there is no nausea.

My mouth is dry. Taste is diminished. We went to the salad bar last night for dinner. Most evident is the loss of the ability to taste sweetness. The tapioca pudding, a favorite of mine tasted like they forgot to put the sugar in it.

The mental fog and fatigue have disappeared.

My hair is still there. Perhaps I got the buzz cut prematurely. Hair growth has slowed, and I need to shave only every 3-4 days.

I plan to return to the bridge club to play Friday afternoon.

We are invited to a wedding on Saturday and we plan to go. The bride is our son Gary's first wife, Margaret, (Eva's Mom). They are all on good terms. I would like to see a survey of what percentage of people are invited to their ex daughter-in-law's wedding. I would guess not more than 15%. We were happy to be included.

Eva will be a junior bridesmaid, and I hope to grab a few photos for the blog.

Our very good friend, Andrea, sent me an email about playing the "Cancer Card". She is a miraculous 20 year survivor of breast cancer for which she was given only a short time to live.

"One day, when I was still in the middle of pretty heavy chemo, we decided to go to the Spaghetti Warehouse for dinner. The place was mobbed and people were all but hanging from the chandeliers. In horror, I mentioned to the hostess that we better not stay because I was so fatigued from all the chemo and couldn't sit up long enough to both wait to be seated and eat dinner. She assured me that there would be no problem, and

=Bingo!=we were the next ones seated. Hmmm, I thought to myself. Magic. This isn't all bad."
I don't plan on playing the card routinely, but will keep it in mind as my "ace in the hole".

Posted by David Shuster at 02:11PM (-07:00)

My Follow-up With Dr Flam

Tuesday, May 31, 2011

Judy went with me for this visit. The appointment was for 10:00 AM but we knew we were in for a long wait when we saw tho waiting room was almost standing room only. I guess when you have cancer, you better leave your type A personality at the door. In addition to being the first day of a short week because of Memorial Day, Dr Flam was just back from vacation.
I had the usual labs, and was seen about 11:45 by the doctor.
The labs were not bad. WBC back down to 10,000. Platelets 100,000 and hemoglobin down to 11.0.
Overall, Dr Flam was pleased. I showed him some irritation in the back of my scalp which he called small pustules, likely staph infection, and suggested I wash the area 3X daily with pHisoderm soap. He also suggested I stop wearing my baseball cap, the band of which could be causing irritation. He was quite surprised that my hair was not falling out yet. Perhaps I shaved it off prematurely.
We now have a plan of action. One more cycle of chemo followed by a PET/CT, most likely around June 24.
On a sad note, my mother seems to be doing badly. She is down to 66 pounds. She is becoming more and more withdrawn and depressed.
On a happy note, Saturday we went to the wedding of our ex-daughter-in-law, Margaret. It was very nice. We have some photos.
Rather than post the photos in this blog, I include a link to the
photos.

The photos include Gary, Dana who was a bridesmaid at her husband's ex wife's wedding, Eva a Jr. bridesmaid, Sara, age 4, Bel, age 2, Judy, me, and one which includes the bride.
Families are so much more complicated than they were when I was growing up.
Posted by David Shuster at 01:39PM (-07:00)

Round 3, day 1

Tuesday, June 07, 2011

We have a plan. It is obviously not set in stone.
Six rounds of chemotherapy. PET/CT before the 4th round. Assuming I have improved, that is the posterior mediastinal mass is smaller and there are no new lesions, Imaging again after the 6th round. Then additional radiation to the site of the posterior mediastinal mass. After chemo and before radiation, a visit to Dr Nghiem and a cruise. I hope I can work out the schedule to take the cruise out of Seattle.
Our 49th Anniversary was June 3. We went to red Lobster to celebrate although Judy has misgivings about the date since my first surgery was done on June 3, one year ago. I must say I was not impressed by the food although I am sure it was in part due to my

diminished sense of taste. We received a gift basket of Canadian chocolate bars, maple sugar and shortbread cookies from Gary, Dana and the girls. The Nestle Crunch bars tasted almost as good as I remember them.

I have been feeling pretty good this past week, so I am not looking forward to round 3. It starts with labs and an examination by Dr Flam. My hemoglobin remains at 11 grams. My WBC are 9,900 again normal and my platelets are 166,000. This is also normal. So far I have tolerated everything well, with only complaints of dry mouth, decreased taste and some tenderness of my gums. No hair loss although the hair on my head and my beard are growing only very slowly. I guess I got the buzz cut prematurely. I don't think I am significantly worse today than I was after round 1.

We arrive early, at 8:00 AM. I am done by 3:30 PM.

I am not uncomfortable during the chemo although I am running to the bathroom every 20 minutes towards the end.

About a week ago, Bert, my bridge partner and good friend suffered a stroke. He lost the ability to speak, but no other functionality. He was in the hospital for a few days and is expected to make a full recovery.

I spoke with him on Saturday and he was quite lucid, although he was often still unable to find the words he needed. We had finished first and second the two last times we played bridge. I played with Jill Friday and we won. I played with Byron yesterday and we won.

I will wait to play bridge again probably until a week from Friday, hopefully with Bert.

Our dear friend Bonna came for breakfast on Saturday and she brought us a chicken noodle cheese casserole which we will have for dinner tonight.

Eva slept here Sunday night. She will have her hair cut tomorrow and donated to Locks of Love to make wigs for cancer patients in my honor and also in honor of her grandmother on her mother's side who died of lymphoma and/or breast cancer.

We had dinner with our good friends Carol and Larry Saturday and then they came here to play some bridge. I see significant improvement in their game.

That's the news from here. We are trying to keep busy, but I am not looking forward to the next week.

Go Giants.

Posted by David Shuster at 05:19PM (-07:00)

My Hair's Still There!

Wednesday, June 15, 2011

My tongue is so dry
To my palate it's stuck
And the taste of food
Makes me want to upchuck
But my hair's still there.

I get so tired
I could sleep on nails.
My skin gets so dry
It's as if I had scales.
But my hair's still there.

For a week, I feel
Like I want to throw up

My colon feels like
It wants to blow up.
But my hair's still there.

I've become so clumsy
And I'm losing my hearing
I question the course
That I've been steering
But my hair's still there.

On the bright side, my doctors
Use every trick
And since I got Merkel's
I haven't been sick.
And my hair's still there.

I shaved it off,
But it didn't fall out.
Yet!
Three more rounds to go.
It will.
I bet.

Actually it is a fact that since I got MCC, I have not even had the sniffles (that weren't caused by allergy).

Yesterday, I visited Dr. Flam for follow-up.
Labs are good.
WBC up to 26,800 due to Neulasta.
Platelets down 166,000 to 80,000. This is still not too bad.
Hgb 11.5 up from 11.0
I have a symptom which has developed slowly and I don't even know if it is related to chemotherapy and that is hearing loss. I can hear sounds, but often cannot make out the words. This is especially so when watching TV. I have been resorting to closed captioning. I had an audiogram yesterday which showed mild hearing loss. We will see if it progresses.
Otherwise I am doing well.
I have a CT scan scheduled 1 week from tomorrow. That will be the moment of truth.

My Granddaughter Eva has donated her hair to Locks of Life, which provides wigs for cancer patients. She has done this in my honor and also in memory of her other grandmother Mary Arechiga, who passed away from the combination of breast cancer and lymphoma.

Here are the photos.

I am so proud!

Posted by David Shuster at 11:18AM (-07:00)

My Scan Will Be Done Tomorrow

Wednesday, June 22, 2011

My Scan Will Be Done Tomorrow
Bet your bottom dollar
That tomorrow
I'll be scanned.
Just thinking about tomorrow
It may be a day of sorrow,
Or a day that's grand.
It will be a day that's hot and sunny
This is the test for all the money.
Tomorrow, tomorrow, they'll scan me tomorrow
Tomorrow's the day I'll know.

With apologies to Annie

I had my appointment with Dr Flam today.
Labs are not great, but not terrible.
My platelets are 84,000 up from 80,000.
White count is normal at 6,900, down from 26,800 after Neulasta.
Hemoglobin is down to 10.5 from 11.5 last week.
Symptoms this week are mainly related to my hearing. The audiogram showed a mild high frequency hearing loss. This is manifest especially watching TV, where I can hear dialogue but have difficulty understanding it. This week, a new manifestation showed up. It feels like there is a low frequency tinny sound, accompanying speech like there is a defective speaker on a radio.
Dr Flam wants me to see an ENT specialist. I have called my friend Richard Weinberg who will try to see me tomorrow after my CT.

In any event, Dr Flam says I should not take any more Cisplatin and if more chemotherapy is needed, he will switch to Carboplatin, which causes less ototoxicity, but not none.

It seems like three possible scenarios depending on the CT scan.
1. Best case, the posterior mediastinal mass is gone and there is no new tumor.
The plan for this case is likely radiation treatment to the posterior mediastinum.
2. Most likely. The mass is smaller, or unchanged but there is no new tumor.
Continue chemo with Carboplatin.
3. The mass is bigger, or there is new disease.
Stop chemo. Look for an experimental protocol.

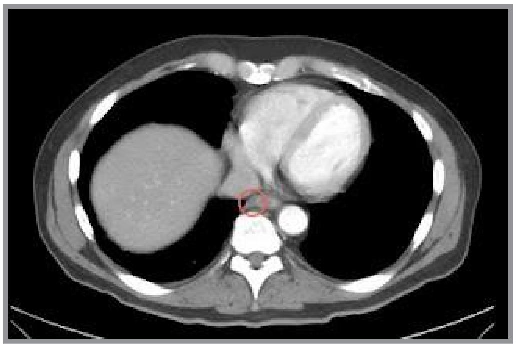
In other news, we had a very nice visit from my brother and sister-in-law from Florida, Jon and Sandy.
They took us out for dinner Monday night. The food was good, so I'm told. As good as could be expected, with loss of taste. On Tuesday, we had brunch with them and with Gary, Dana and the three granddaughters. Then Eva stayed over last night. She leaves for 2 weeks of camp on Sunday.

I hope to post again tomorrow with my results.
Posted by David Shuster at 08:37PM (-07:00)

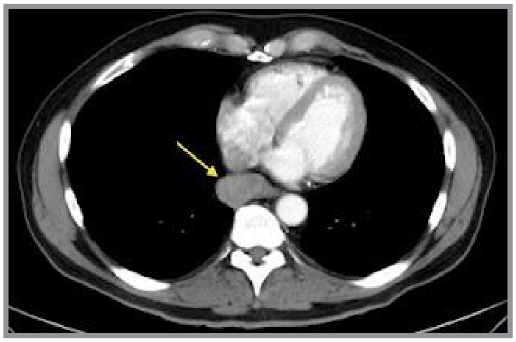
Good News!

Thursday, June 23, 2011

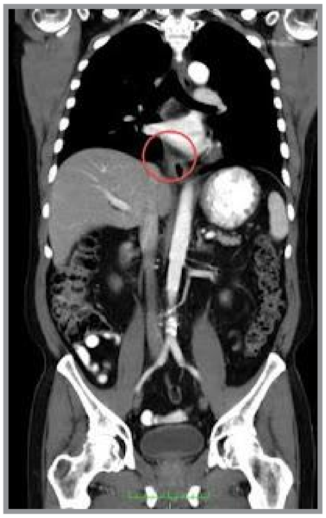
My CT scan today shows marked improvement from the previous studies.

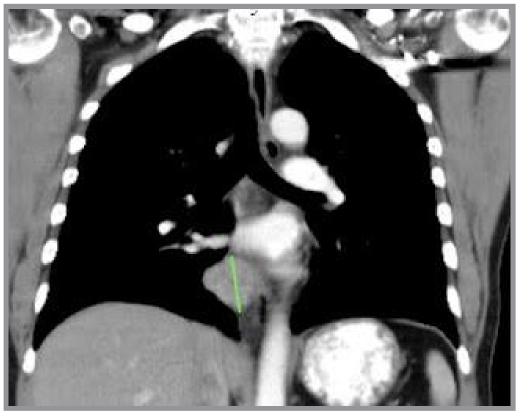


By comparison, here is the previous axial scan



Most of the soft tissue in the area on the scan today is the distal esophagus.
The coronal images are below.





Here is the previous for comparison.
This is about as much as I could hope for. I await my visit to Dr Flam next Tuesday at which time I expect him to stop all chemotherapy and we can plan some radiation treatment to the area.
The CT scan also shows no evidence of new disease.
I don't want to get my hopes up too high as I have been disappointed before, but I am very optimistic.
I also saw Richard Weinberg today about my hearing loss. He was very accommodating, squeezing me in between his regular appointments. They did a more complete audiogram on me and I have significant high frequency hearing loss. He says a hearing aid would not help at this time and feels that some additional hearing loss would be worth the price if I need additional Cisplatin.

Posted by David Shuster at 05:08PM (-07:00)

No More Chemo (for now)

Tuesday, June 28, 2011

Today, I had my appointment with Dr. Flam. Fortunately, I had the report of my CT scan with me, as the office claimed not to have received it. He read the report, and did not ask to look at the images, which I offered, as I had the CD with me. He said that the chemotherapy had accomplished its objectives, and it was time to clean up the residual tumor cells with radiation. Dr. John, the radiation oncologist was in the hall, and I brought him up to date on my case. I think he did not recognize hairless me at first, but I have an appointment for tomorrow at 9:30 AM for simulation and planning.

My labs are good. WBC is 5900, platelets are up to 182,000 and hemoglobin back up to 11.2.

My port was flushed and I have an appointment to see Dr. Flam in 1 month.

Additional discussion with Dr. Flam included the question of what might be available should the tumor come back. He said that he had additional chemotherapeutic regimens which might be effective.

I feel good. The side effects of hearing loss, bad speaker tinnitus and taste loss with dry mouth are still with me. I think I have largely avoided "chemo brain". I hope these side effects go away, although the hearing loss is irreversible.

I am delighted to avoid the expected additional chemotherapy, and I hope to be able to travel in another 6 or 7 weeks.

On the downside, I spoke with Dr. Nghiem yesterday. He was not particularly encouraging about the good response to chemotherapy. He suggested that this is the usual result, but there are most likely cancer cells in my body which would not show up on a circulating Merkel cell assay, and the remission induced by chemotherapy is unlikely to be a cure. He did say that should that be the case, there are experimental protocols for which I would be a good candidate. One using immunotherapy would be particularly promising for me.

In the meantime, I know of 3 cases of Merkel call carcinoma cancer-free after chemotherapy. Audi, Scott Hammond and an additional unnamed patient of Dr. Hackett who is a 10 year surviver.

If you know of others, please post the information.

Posted by David Shuster at 02:57PM (-07:00)

Or Was That a Premature Celebration

Wednesday, June 29, 2011

Dr. John, the Radiation Oncologist who will be giving me the treatment for my residual tumor next to the lower esophagus and perhaps extending into the esophagus wants me to have additional chemotherapy to enhance the effect of the radiation.

He proposes Taxotere and possibly also 5-FU. The Taxotere would be given once weekly over about 1 hour in a dose less than if it were to be used as a primary chemotherapeutic drug. The 5-FU would be given as a slow infusion over 3-5 days using a portable pump. These would be given at the same time as the Radiation.
I'm pretty bummed about this development.
I have reached out to Dr. N. and to my friend, Bill Podolsky, who is a Radiation Oncologist for additional opinions.
Planning is to be done Friday and treatment is tentatively set to begin July 11 and to last 5 weeks.
Meanwhile, we are at the Chukchansi Hotel and Casino near Oakhurst about 40 minutes from Fresno.
So far, I am down $80, but Judy is up $55.
Posted by David Shuster at 07:12PM (-07:00)

Decision Made

Saturday, July 02, 2011

I have heard from Dr. Nghiem. He is encouraging about the plan to enhance the radiation treatment with chemotherapy.
Dr. Podolsky is also encouraging.
I have had my set-up appointment and the treatments will begin on July 12 and continue for 5 weeks.
I have an appointment with Dr. Flam on July 5 to coordinate the chemotherapy.
My skin is marked with black marker ink and the marks are covered with tape. In the first session, July 12, they will place small skin tattoos for accurate targeting of the radiation.
The most feared complications will be related to the esophagus. Esophagitis, perforation and stricture are the most common, but the chance of stricture is less than 20%. It occurs as a late complication as a result of scarring, and can be managed by balloon dilatation.
The set-up includes low resolution CT. I looked at the images which were done with some barium in the esophagus. The residual tumor can not be identified with certainty and I believe it has shrunk since my last CT.
In the meantime, my body has a chance to recover from the chemotherapy. I feel quite good. My taste buds seem to have slightly improved. My mouth remains too dry. No hair has fallen out, but no hair grows on my head.
I have arranged to work at Kaiser on Wednesday morning and hope to be able to work more, both during and after my treatments. I must say I am going somewhat stir-crazy at home.
We are in the process of planning a family cruise in December and I am confident I will be healthy and fit so we can all enjoy it.

Posted by David Shuster at 03:40PM (-07:00)

The Plan is Finalized

Tuesday, July 05, 2011

I quote from my brother Robert. "The reason people retire is so that they will have time to visit doctors."

Between now and August 15, I will have 25 visits for radiation, 5 visits for chemotherapy, 5 evaluations by Dr. Flam, 5 status checks with Dr. John and a visit to by internist, Dr. Holmes. I think I also have a dental check-up coming up.

Today, it was Dr. Flam. You can't escape his office without labs.

The bone marrow suppression from my prior chemo continues.

White count is down from 5900 to 3500, Hemoglobin is down to 10.9 from 11.2. Platelets are still normal but down from 182,000 t0 158,000.

My symptoms are unchanged.

The most troubling is still hearing loss, with a buzzing sound when there is speech, particularly from male voices, including my own. Female voices seem to sound tinny. I hear the sounds, but its like a foreign language, of which I know many words but miss enough to often lose comprehension. The buzzing sound is something I can't find reviewing the web for hearing disorders.

The dry mouth and loss of taste continue.

The plan is to have radiation treatment with chemosensitization. I was reluctant to have 5FU, and the first words from Dr. Flam were "I don't want to give you 5FU." The drug to be used is Taxotere, with a generic name of Docetaxel. This is given at 1/3 of the dose which would be given for its chemotherapeutic effect.

Side effects include anemia, low white count,fluid retention, peripheral neuropathy,nausea, diarrhea, mouth sores,hair loss, fatigue, weakness,and infections. Less common side effects include vomiting,muscle and joint pain, low platelets, and abnormal liver function.

Because I am receiving a relatively low dose, I do not expect the side effects to be severe.

Here are some additional observations.

Since I was diagnosed with Merkel Cell Carcinoma, I have not been sick. No colds or flu.

Since chemotherapy, my patches of eczema, whith I think are probably mild psoriasis have disappeared.

I have lost about 23 pounds, and my cholesterol numbers have improved.

I have great health coverage. So far, between Medicare and Blue Cross, I have paid almost nothing out of pocket for all the care I have received.

I am looking beyond August. Between August 15 and the end of 2011, we have planned a family cruise in December. Judy and I will take a west coast cruise at the end of September.

We will also visit Mike and Leanna, Sammie and Eli, probably in October, and go to Montreal to visit my mother, perhaps on the same trip to the East.

In between, while in Fresno, I hope to work part time. (To pay for all this).

Posted by David Shuster at 02:48PM (-07:00)

Esophagus Radiation with Chemotherapy Enhancement

Thursday, July 14, 2011

This phase of my treatment has begun.

On Tuesday, I went for the first radiation treatment to the mediastinum. New markings covered with tape were placed on my chest. The actual treatments consisted of six short bursts of radiation, with the machine repositioned for each burst so the tumor is shot from many different angles. This is done to reduce the radiation dose to structures near the treatment site. These include my heart, lungs, spine and spinal cord, vagus nerve and liver.

My appointment was for 8:00 AM, but there is a new regulation from Medicare which requires the Radiation Oncologist to be on site during the treatment so it was delayed until after 8:30. The schedule has now been changed so treatments will be at 8:30.

Yesterday, I went for my radiation treatment followed by chemotherapy.

After the treatment, I went to Dr. Flam's office in the same complex, and the waiting room was as crowded as the Los Angeles Freeways will be this weekend. I had my blood drawn. The results are good. Platelets normal at 137,000, White count normal at 4,900, and hemoglobin low but stable at 10.9 g/l.

After a brief visit with Dr. Flam, my treatment began. Through the port, I was first given 32 mg of Zofran over 30 minutes to prevent nausea. then, over the next 2 hours, I received 57 mg of Taxotere. Because this was the first dose, they gave it slowly to make sure I did not have an adverse reaction. The only reaction was some flushing and a slight burning sensation around my ears. I did not get sick but was tired afterwards and was mildly nauseated.

I drove myself home, and rested in the afternoon.

Brian is visiting from Vancouver. Gary and Dana invited us for dinner and I was able to go and eat some BBQ chicken and a hot dog, with a small amount of strawberry pie for dessert, so the nausea was not a factor. I drove there and, being tired, drove myself home before Judy and Brian left.

Today was treatment #3 of 25. There was also a status check with Dr. John. There is nothing much to report about this, but I did ask him if I should show up on time for my 8:30 appointments, because if he was going to be late, so was I. He did admit to having a conference on Thursdays which do not end until 8:45, so I will not rush to be on time on Thursdays.

It looks like the main side effect to be aware of is esophagitis, with possible development of a stricture. (An area of narrowing from scar tissue which can obstruct the movement of food)

As a precaution against this, Dr. Flam wants me to take 20 mg. of Prilosec twice daily and Carafate Suspension, 1 tablespoon after meals and at bedtime. Somehow, my dead taste buds still think it tastes terrible.

Today, I am feeling well, mildly constipated, with no nausea.

I don't expect significant symptoms for the next 2-3 weeks.

Posted by David Shuster at 11:17AM (-07:00)

Not a Good Day Today, + Real Estate Discussion (off topic)

Wednesday, July 20, 2011

Wednesdays are the day for radiation and chemotherapy. Radiation Oncology and Dr. Flam are in the same complex, owned by St Agnes Hospital. The Oncology group rents space and is an independent entity while Radiation Oncology is owned and run by St. Agnes. Surprisingly, perhaps, the Oncology practice is much less efficient from the patient's point of view.

After my radiation treatment, I arrive for my chemo just after 9:00 AM. the waiting room and the adjacent corridor are filled with patients. I sign in and find a rare empty chair. The folks in the waiting room can talk of nothing except to express their unhappiness about the long wait. It made me feel guilty, because when I worked at a place called "La Clinique Medicale Des Groupes" in Montreal, in an average morning, a total of 25 fluoroscopic examinations were scheduled, with the last usually completed at 1:00 PM, and the latest appointment was 8:30 AM.

At 10:45, they finally call me to the lab, where they weigh me and send me back to the waiting room, because my blood draw is to be from my port. The blood draw and port access was done about 11 AM. I finally get to see Dr. Flam around 11:15. I am told he has 90 patients on the schedule for today.

My lab results are discouraging. the Hemoglobin is stable at 10.9, but my white count has dropped to 3380. My platelet count is not bad at 129,000.

Because of this, I will need shots of Leukine. This is given subcutaneously, for 5 days, after oral Tylenol, 325 mg tabletsx2, and Claritin. Potential side effects are allergic or flu-like reactions, hence the Claritin. and musculoskeletal pain, hence the Tylenol.

There are two areas where the chemo is given. One has about 16 chairs and two rooms with a nursing station between them. It is very busy and noisy, without internet access, and without windows. The second, called "The Clinic" is bright, relatively quiet, and has wireless internet. I ask to go to the clinic, and this is agreed to. However, when I get there, I am sent back because I reported a "Reaction" to the Taxotere last week. The reaction I reported was slight flushing and warmth around my ears. I return to the nursing station just after 11:30, but they have no empty chairs to give me chemo. I am seated at a bench to await an empty chemo chair. By this time, I am uncomfortable, getting hungry, and needing to use the bathroom. I get up and inform the nurses to call me on my cell phone when they have a space for me and that I am going home. We finally agree that I can go home and return around 1 PM.

I go home and have some lunch, and fall asleep for a few minutes. Judy goes to the Pharmacy and gets the Tylenol and Claritin. She also learns that my insurance will not cover the refill on Carafate, and they want $50 for a small bottle which, taken as directed, will last 1 week.

I return for my chemo and injection. I end up home about 3:00 PM.

It is now after 5 PM. I am having some pain in my lower chest and back. I presume this is from the Leukine and not from my esophagus, but I will be very nervous if the pain gets worse. I am also feeling mild nausea. I may need to self-medicate for that.

I have said that when you go to see Dr. Flam, you must park your "Type A" personality at the door and go with the flow. Today, I could not do that. I complained to the nurse, and that's how I learned that he had 90 patients scheduled for today. I complained to Tom Hackett. an associate of Dr. Flam, who looked in on me today, and I complained to Dr.

Flam. It was not all useless venting. I learned that they can see me at 7:30 AM, get my labs done, and start the chemo, and then get me to my Radiation treatment with the chemo running. If I wasn't so "Type A", I would never have learned about this.
Next Wednesday, I will be there at 7:30.
Why would Blue Cross deny payment for Carafate? Do they think it would be cheaper than treating me for esophageal perforation? I will try to contact them tomorrow to find the answer to this question.
I am wondering about the plan to have chemo with radiation to enhance the effect of radiation. Is it worth it? Is it going to be any different than if I had radiation alone? If Dr. Nghiem had not endorsed this plan, I think I would quit the chemo. I will talk about this with Dr. John tomorrow morning.

Real Estate Discussion (Off Topic)
We are hoping to move from our large 2 story home into a smaller house on one level with no pool. We have found 2 different homes which were suitable and made offers at what we thought were reasonable amounts. Surprisingly, other buyers came in at higher offers and we did not get the properties. There is an interesting trend in housing here. I called it a "Squeeze". Smaller homes are selling rapidly and values are going up. Larger homes are not selling and values are going down. For those trying to downsize, this is not a good trend. Perhaps the reason is the fear of rising interest rates, either from the stalemate on the government debt ceiling, of from the government printing money causing inflation.
Posted by David Shuster at 05:51PM (-07:00)

Not Feeling Well

Saturday, July 23, 2011

This has been a difficult week. I have been uncomfortable, probably due to the injections of Leukine. The constipation has disappeared and I am dealing with the opposite problem and with accompanying cramps. Last night I had shaking chills, and about 4:00 AM, the cramps woke me up and my nightshirt was drenched. My appetite and sense of taste are gone. I have to force myself to eat. I discussed the need for further chemo with Dr. John and he encouraged me to stay the course. I am not really convinced that the chemo is useful at this stage, but I plan to stick it out.
Today is my Granddaughter, Bel's second birthday party. I will make a brief appearance.
As to a replacement for Carofate, the generic that CVS found is $300, compared to $60. My insurance does not cover that brand and I can't blame them. They have another supplier which I think will be approved.
Thanks Patty at Dr. Flam's office for your help with this.
Posted by David Shuster at 03:58PM (-07:00)

Closing In On The Mid Point Of My Radiation Treatment

Wednesday, July 27, 2011

I have to say that at the end of last weekend I was getting very discouraged. I was taking daily shots of Leukine because my WBC's were down to 3100. I had a reaction of chills, and probably fever once. I was having nausea and almost constant diarrhea. My weight was down. I had no appetite. No food tasted good to me. I understand the need for the radiation, but the symptoms are mostly related to the Taxotere, being given to enhance the effect of radiation, rather than for its chemotherapeutic effect.

Today, I had my 12th of 25 radiation treatments and a visit with Dr. Flam. I also had the third of what I expect to be five infusions of Taxotere. I am feeling substantially better. I attribute this to my bowels returning to some semblance of normalcy. My WBC is up to 4400, not a huge improvement but better. My hemoglobin dropped from 10.9 to 9.9. Because of that, I was given a shot of Procrit, (epoetin alpha), to stimulate the production of red blood cells. Platelets were down slightly from 129,000 to 104,000.

I was feeling so discouraged that I wanted to discuss discontinuing the Taxotere and just going with radiation,but now I feel I can stay the course.

Thanks to Patty at Dr. Flam's office, the issue about the coverage for Carofate has been resolved. Apparently the insurance will only cover one generic brand, and I paid $7 for 3 weeks supply. The pharmacy originally obtained the wrong brand, and I asked what it would be out of pocket. $500. What a messed up system!

Dr. Flam suggested last week when I complained about the logistics of getting everything done suggested I come in at 7:30 AM today. He said I would have my labs done, see him get the infusion started and get to Radiation Therapy by my 8:30 appointment. This would work better than having the radiation first, and then coming to get the labs started after 9:00 in the usual traffic jam it his office. The techs at XRT were skeptical that this could be done and they were right. It all ran together at 8:30 when I was about to leave for XRT and Dr. Flam was ready to see me. Nevertheless, it worked out better than last week.

Judy has been wonderful. This week, she has been transporting Eva, our 10 year old granddaughter to Good Company Players acting camp, for 9:00 AM and picking her up at noon. Today, she woke up to take me to treatment for 7:30, took the dog to the park, picked up Eva to take her to her camp. Later, she picked Eva up and picked me up afterwards, and we had Eva here for most of the afternoon.

Tomorrow, I will drive myself.

Go Giants! It looks like we will get Beltran from the Mets.

Now, if we don't need to use Barry Zito we should have a good shot at a repeat championship.

Posted by David Shuster at 07:46PM (-07:00)

I Am Put On IV Hyperalimentation

Wednesday, August 03, 2011

I am writing this while receiving the third and last 2 liter IV fluid infusion over the past 3 days.

Since my last post, I have not felt up to writing down my thoughts and feelings. I will start with a litany of complaints.

Everything tastes terrible. It is very hard to force food into my body when everything tastes so bad.

My mouth is very dry. My tongue feels like sandpaper. It is white, with cracks in it. I don't think I have Candida, (Thrush).

I am having difficulty swallowing. I can get stuff past my throat but it does not go through my esophagus easily, and creates discomfort on the way down. I also have pretty much continuous heartburn.

I am having upper abdominal cramps. I had severe diarrhea earlier in the week. This has subsided.

As a result of these complaints, I have decided to stop the Taxotere, with the agreement of Dr. John who examined me on Monday. In addition to these complaints, it turns out my white count was down to 1900. The purpose of the Taxotere was to enhance the effect of the radiation treatments and I think they need no enhancement.

I continue to lose weight and am not ingesting adequate nutrition. I saw a dietitian yesterday morning and the choices or me are tube feedings, intravenous hyperalimentation, or to force enough food down by mouth. I opted for the latter, but failed. Tube feedings could be done through a naso-gastric tube or a percutaneous gastrostomy. I don't think I could take a nasogastric tube for very long so this narrows the choice to IV feedings or a percutaneous gastrostomy. This is a tube placed through the abdominal wall into the stomach. Bottom line: IV nutrition for me.

This will be set up this afternoon. Apparently Medicare does not cover all the cost, but I will only have to pay $35 per day.

I have only 8 more radiation treatments left and am off the taxotere, so I don't think this will go on for more than a month.

I am also back to another series of Leukine for my white count.

I am writing this after a meeting with the home infusion nurse. She has been very helpful in getting this all set up and will be back tomorrow to watch me set it all up for myself. As a trained physician, I think I can manage all this without great difficulty, but without such training, it would be a real challenge.

Supplies delivered this afternoon included multiple tubes and pre-filled syringes, vitamin doses to add to the fluids, plastic bags each containing 1900 cc of what looks like low-fat milk, a battery powered infusion pump, and supplies needed to test my blood sugar.

All went well except that I was concerned about a small amount of air in the infusion line. I removed it from a side port using the needle to add the vitamins to the infusion. All is set up and running. The infusions last 18 hours giving me only 6 hours free of the pump which is neatly housed in a back pack they provided.

The pump is not entirely silent and will take some getting used to, not unlike my dog snoring (he's much louder). I suspect it will be one reason I'll be sleeping alone tonight. The other is that I will have to shower during that 6 hour window.

I did manage to down 3 bottles of Boost Plus today so perhaps if I can continue that, I can shorten the infusions.

No IV pole, so I have rigged something up with a camera tripod. I'll ask for the pole tomorrow.

Thanks Karen for your patience and instructions in getting all this set up.

I am still hoping to get to Good Company Players to see Eva in the final performance of her drama classes. That will take place Friday afternoon about 1/2 hour after I remove the infusion during my 6 hour break.

Posted by David Shuster at 11:11PM (-07:00)

Into The Home Stretch. Review. Details of TPN

Thursday, August 11, 2011

I have only two more radiation treatments to go. It will be all over on Monday.

To recap, I originally found a lump in my face on the left in front of my left ear. There was also a small nodule in my left parotid (salivary) gland. Surgery and imaging showed one or two involved lymph nodes in my neck on the left.

After the surgery, I had radiation treatment only to the area of involvement. At that time, I was advised that the chance of complete eradication of the local disease was 80%. However, there was a 50-50 chance that the disease would appear elsewhere. If fact, I was on the wrong side of those odds, and the disease reappeared as a mass adjacent to my lower esophagus. An experimental treatment of a low dose of radiation was attempted in the hopes of stimulating my immune system to destroy the mass.

A follow-up CT scan showed the mass only slightly smaller, but a new tumor mass appeared in the small bowel. This was removed by laparoscopic surgery.

We then proceeded to chemotherapy and after 3 cycles of Cisplatin and VP16, the tumor was barely identifiable. No other tumor site could be seen.

The residual tumor site was treated with radiation and chemotherapy used to enhance the radiation. This was Taxotere. After 3 doses of the Taxotere I was too sick to continue taking it and it was stopped.

The result of all this is that, to my knowledge, there is no residual tumor in my body at this time. That's my story and I'm sticking to it.

I am recovering from the Taxotere gradually. My WBC have risen to 2900 from 1900. My Hemoglobin has decreased to 9.9 gms, and I was given a shot of Procrit for that. In my last post, I talked about inability to eat. I have been on TPN (Total Parental Nutrition) which is basically intravenous feedings.

On the first night after 3 days of 2 liters of fluid replacement and TPN, I developed ankle swelling. This rapidly resolved with elevation of the feet. I was having severe pain and burning in the lower chest when eating or drinking. This has largely resolved. I have had episodes of diarrhea, which have not resolved. Food tastes terrible, as if I have anorexia nervosa. This is due to the chemo and should begin to resolve. I am drinking 2-3 bottles of Boost Plus daily adding 700-1050 calories per day. Yesterday, I had 2 eggs. Today, I ate macaroni.

I expect no more than 3 weeks total of TPN.

This TPN is no simple matter. It began with delivery of 2 large boxes of material for one week's supplies. This included 7 bags of the fluid which looks like pale skim milk and has an odor almost like breast milk. 7 vials each of vitamins and other additives also were included. These need to be refrigerated and removed 1-2 hours before use. I set an alarm on my iphone to remind me.

A small infusion pump about the size of a paperback novel provides the power.It runs on a 9 volt battery which needs replacement daily. A disposable device is to lock in place which is part of the tubing that goes from the bag to my Medport. The procedure is as follows. The vitamins are added to the bag. The tubing is locked into the pump. The pump will often complain that it is not locked correctly. The pump is then primed. The port is flushed, and then the tubing attached to the port. The infusion is then ready to start. Needless to say, many things can go wrong. One night, the infusion pump thought it was still pumping from the previous night's residual and delivered only about 30 cc instead of 1800 cc.

I finally have it figured out, but a person untrained in medical procedures will find it easy to go wrong.

I also need to check my glucose 4 times a day. The device for that needs little blood. It is almost painless, but the first night, after 2 tries and error messages, I deferred further testing to the next day. I think I am still doing something wrong or there is a flaw in the device as far as sterility is concerned.

More on this in my next post.

I learned about the "Donut Hole" Because I have reached the donut hole in my Medicare Part D insurance, I am paying the full cost of this TPN. In another post, I hope to discuss the complexities of the donut hole and the inability to get straight answers from providers, one of whom told me it would be $4 per day and then called back and said $100 plus daily not including supplies. Total about $1000 per week. I can afford to pay (in spite of the falling stock market), but it is a powerful incentive to get off the TPN as soon as possible.

What happens to those who don't have the money to pay?

Posted by David Shuster at 07:43PM (-07:00)

Status After Final Radiation Treatment

Wednesday, August 17, 2011

My last radiation treatment was Monday, Aug 15. Take me out of the oven. I'm all done. My esophagus is cooked. In fact it feels like it was burned.

Yesterday was my visit to Dr. Flam. See the rant below.

My labs were OK except for my Hemoglobin which was 9.8. I needed another shot of Procrit, which insurance wouldn't pay for as the appointment was 6 days and not 7 days after my last shot. No big deal. I had that done today.

I have gained 4-5 pounds since my last appointment and we agreed to stop the TPN, tapering it off with the last treatment on Friday night. Saturday morning, I get to remove the Huber needle myself and will have just skin covering my port.

I have had some burning in my esophagus and heartburn at night. This should resolve as my esophagus heals. Food still has no taste. I seem to have a form of anorexia nervosa.

My tongue was white and Dr. Flam diagnosed Candidiasis (Thrush). He put me on Mycelex, Generic.

It comes in "lozenges", which are actually white chalky pills to be sucked until they dissolve, three times daily. Surprisingly, they are not as obnoxious as they look. Perhaps getting rid of the candida will help restore my sense of taste.

I have no ankle or foot swelling. My blood sugars have been behaving, as I have been self-testing as required 3 times daily.

I have been drinking up to 3 bottles of Boost Plus daily and eating a small amount in addition.

I have noticed that my hands are always dry and there is slight numbness in my fingers. I have become clumsy, dropping things and with slight tremor with small motor tasks. (Including typing this). This seems to be a mild peripheral neuropathy as a result of the chemo. I think I have similar but less obvious neuropathy in my feet. Dr. Flam told me to take Vitamin B complex for this but I doubt this will make a difference, as I have been taking multivites all along and vitamins are added to the TPN. Nevertheless, it couldn't hurt.

Dr. Flam offered two possible plans for follow-up. CT in 1 month if I absolutely had to know if all this worked as soon as possible. PET/CT in 2 months as the PET would not be accurate because of residual inflammation in 1 month. I prefer to wait until after our cruise at the end of September so will have the PET/CT in mid October.

Meanwhile I see the nurse in 1 week and Dr. Flam in 2 weeks.

Sunday afternoon, we had the Fresno Shusters for birthday cake to celebrate Judy's birthday. That was a nice distraction.

Last night I went to our monthly poker game, It was great to get out even with the TPN running. I left early, ahead by 80 cents. Before I left, I had a small slice of Mary Callender Lemon pie. It tasted like they forgot to put the sugar in it.

Friday, I plan to return to the Bridge Club.

Here is the rant.
My appointment was for 10 AM. At 11, I was weighed. At 11:50, I was called back for the nurse to draw blood from my port and replace the Huber needle. I was not seen by Dr. Flam until 1:30, and did not get out of the office until close to 2:00 PM.
Late in the afternoon, Judy went to pick up the prescription, which was supposed to have been called in to the pharmacy. They didn't have it.
There were many patients grumbling in the waiting room, some very sick and waiting to have chemotherapy.
There has to be a better way. Even the Cheesecake Factory gives pagers to those waiting for a table.
In Dr. Flam's defense, his Physician's Assistant recently left and has not yet been replaced, and he was seeing about 100 patients that day. I pointed out to him that the waiting times were excessive, and he shrugged it off to being very busy. He gave instructions for me to be the first patient of the day when I see him in 2 weeks. This does not change the fact that the office could be organized to reduce waiting times for all.

Posted by David Shuster at 04:27PM (-07:00)

My 71st Birthday Photo

Thursday, August 18, 2011

This is what it is all about. Here is a photo of me with 3 of my granddaughters, Eva (age 10), Sara (age 4) and Bel (age 2).
Posted by David Shuster at 05:29PM (-07:00)

Substantial Improvement Since my Last Post

Thursday, August 25, 2011

Last Tuesday, I had a brief visit with the nurse. My labs are still not great, but my Hemoglobin is up to 11gm from 9.9. My white count and platelets are slightly low. I have been off parenteral nutrition since last Saturday morning and have begun eating much better. I am still losing weight but I suspect much of that as retained fluid. My taste buds are improving daily. Last night I had a small steak and it tasted like, well, you know, steak!
The white coating on my tongue has improved, but not disappeared, so I renewed my

prescription for the lozenges for another 10 days.

I definitely have more energy. I hope I am not going to overdo things, but I have decided to accompany Judy to Philadelphia on September 9 to visit Mike and Leanna and our grandchildren Sammi and Eli.

Pet/CT in about 2 months.

Visit to Dr Flam next Tuesday.

After we get back from our coastal cruise on Oct 1, I will plan a visit to Montreal to see my mother who continues to lose weight.

Posted by David Shuster at 02:58PM (-07:00)

Things are Looking Up, Lots of Travel Plans.

Wednesday, August 31, 2011

Yesterday was another visit with Dr. Flam. I was his first patient and things ran like clockwork.

My labs were encouraging. WBC is still slightly low at 4200. Platelets are still slightly low at 101,000, but hemoglobin is up to 11.9 grams. I am feeling much better. My taste buds are recovering, but my mouth is still dry. The candida has almost disappeared. I have to brush by tongue 2-3x daily. It makes me gag. I still have hearing loss which I am afraid will be permanent but I have a follow-up ENT appointment. I have mild peripheral neuropathy, manifest by slight numbness, dry skin and clumsiness. I guess I should be grateful there is no associated pain. I hope it gets better, but I am not optimistic. Vitamin B complex does not seem to make a difference.

The good news is that I have made new travel plans.

Montreal, October 10-15. I will combine a visit to my mother, my brother and family and old friends, Bluma and Lenny, with Mcgill class reunions, 50 years from undergraduate, and 45 years from medical school. Judy will not be accompanying me on this trip.

Plans previously made include Philadelphia Sept. 9-15 and our coastal cruise September 24-Oct 1.

When I get back after Oct 15, the moment of truth will be upon me. That is a follow-up PET/CT.

Posted by David Shuster at 05:17PM (-07:00)

Philadelphia on 9/11/11

Sunday, September 11, 2011

A new post to my blog 9/11/11.

I am writing this on the flight from San Francisco to Philadelphia, on 9/9/11. I am so grateful to be able to take this trip to see Mike, Leanna, and our 2 grandchildren, Sammi and Eli. I hope to have a photo to add to this post. Things are rapidly improving. My sense of taste is coming back. For the first time in months, I was able to taste the slightly sweet minty taste of Glide Dental Floss, something that makes Rocky, our dog, salivate. Today, at the airport, I ate a bagel, and while I found it dry, I almost finished it. Most foods still do not taste as good as I remember, and leave a bad taste in my mouth. My peripheral neuropathy is unchanged. I am trying a Vitamin B fat soluble product which is marketed as having a 90% success rate. I am skeptical about this, but it can't hurt. I will report on my progress and you can respond by email if you need the details. I have been able to work. At Kaiser, I did 2 half days last week and 2 this week. I do note that while walking at a rapid pace from the car to the terminal, I was short of breath. Hopefully, this is due to lack of exercise and remaining anemia. Here is a report of a conversation between Gary and our 3 year old granddaughter a few days ago. Gary "What do you want to be when you grow up?" Sara "A doctor" Gary "So you can help people?" Sara "Yes, I'm going to be Dr Sara" Sara "Wait, I'm not going to be Dr. Sara, I'm going to be a different Doctor. You know Papa? I'm going to be whatever kind of Doctor he is. They say grandchildren are your reward for not killing your children. Here is proof. A brief comment about American Airlines price gouging. I booked flights from Fresno to Montreal to visit my mother, Oct 10-15. I later found out my brother Jon will visit from Florida, and my sister Ellie will visit from Edmonton. In addition, there are McGill class reunion activities going on that week. I thought it would be nice to extend my trip 1 day to leave the 16th. So the question is "how much for the change?" $150 change fee. OK, High, but I'm willing to pay it. $350 in addition as the fare structure at the time of this new booking has increased. Like I said, price gouging.

On 9/10/11, I called American Airlines again after learning that a one way flight from Montreal to Fresno on October 17 was only $300. I was able to do the change for less than $100.

Today is 9/11/11, the 10 year anniversary. I think back to where I was at the time the disaster unfolded. Judy and I were at Lake Tahoe with Judy's mother, staying at a condo at Lakeland Village. We actually owned the condo which management rented for us most of the time. Our son Gary called and we turned on the TV shortly before the second plane hit the World Trade Center. We were talking about the changes in the past 10 years. Judy's mother died of colon cancer. My father developed dementia and died of bile duct cancer. Brian, our middle son was married and is since divorced. Gary, our oldest son was married to his first wife, Margaret, and our first granddaughter, Eva was an infant. Gary has since remarried, and has two more daughters. We have since sold the rental condo in Lake Tahoe. I didn't have cancer. So many changes in our lives in just 10 years. We took photos but because we left the cable to connect the camera to my computer, the photos await my next post.

I am having a new symptom. Recently, I have had some dizzyness on standing. Today, I stood up to walk a short distance from one sofa to another, and briefly lost consciousness. No injury. I am presuming this is a vaso-vagal reaction. I will need to be careful getting up.

Posted by David Shuster at 11:07AM (-07:00)

Back From Philadelphia

Monday, September 19, 2011

It was great to have the opportunity to visit with Mike, Leanna, and Sammie (age 3) and Eli (age 1).

Here is a photo of me with Sammie and Eli. As you can see, there is some new hair growing on that chemo head of mine.

I am feeling pretty well these days, and have agreed to work Tuesday and Thursday mornings this week. I have an appointment with Dr. Flam on Wednesday. That should be a courtesy visit, labs, flush Mediport, set up appointment for PET/CT quick physical, and out. Probably, I will be there less than 4 hours.

On Saturday, Judy and I leave for a 1 week coastal cruise. I wanted to drive to LA from Fresno to take the cruise, but common sense prevailed, and we will fly there.

After we return, I have one more week in Fresno, with visits to Dr Weinberg (to check my hearing) and Dr John (follow-up of radiation treatment). I plan to work 2 half days that week.

On October 10, I leave for Montreal to visit my mother. My sister Ellie will visit from Edmonton and my brother Jon, from Florida. Robert lives in Montreal, so we will have a reunion of all 4 siblings with my mother. It will also be the 45th reunion of my McGill medical school class and the 50th year reunion of the McGill undergraduate class, with a dinner planned with fellow alumni of the Honors (Honours) Math Physics class.

I return home to reality on October 17, with my PET/CT to be scheduled for that week. That is when I find out whether I have another reprieve or whether I will be looking for an experimental protocol.

We have a family cruise planned for mid December with all our children and grandchildren, and I am determined to be on that cruise.

Posted by David Shuster at 09:20AM (-07:00)

Update From At Sea

Friday, September 30, 2011

Actually this post is sent from in port at Ensenada Mexico but "at sea" sounds better.

A new post to my blog 9/24/11. I am writing this on the Sapphire Princess as we await debarkation from the Port of Los Angeles. Tomorrow, we stop at Santa Barbara, San Francisco on Tuesday, San Diego on Thursday and beautiful downtown Ensenada on Friday. I had my appointment with Dr Flam on Wednesday. My hemoglobin is down to 11.2, my white count down to 4300, but my platelets are normal. I told him I am having mild shortness of breath, which he attributes to anemia. He was disappointed that I have continued to take zinc for my saliva production, although he never asked me to stop it. He says zinc can promote anemia and low WBC by interfering with copper metabolism. I have stopped the zinc. I am also having a little more discomfort related to eating and drinking. I think this is related to my esophagus. I think it is most likely due to scarring from the radiation and not due to recurrence of Merkel Cell Carcinoma, but this will await imaging and other studies. I would like to postpone any more evaluations until I get back from Montreal on October 17. Meanwhile I have planned to work about 3 half days per week while in Fresno. My neuropathy has not changed. It is manifest by relatively painless numbness in my hands and feet. there is dryness of my hands and loss of fine motor coordination. I have had a few episodes of dizziness on standing up (postural hypotension). Once, I had to quickly sit down or I would have lost consciousness. Dr. Flam says the neuropathy can effect the autonomic nervous system and this may account for it. My blood pressure was 90/65 at his office. I am to increase the amount of salt in my diet. I have been taking a Vitamin B product advertised on the internet said to have a 90% effectiveness in relieving peripheral neuropathy. Week 1. 2 capsules twice daily Week 2. 3 capsules twice daily Week 3. 2 capsules 4x daily Week 4 . 3 capsules 3x a day Week 5. Well, you get the idea. the dose increases until there is a response or you give up. A 3 month supply of 360 capsules cost over $140. At this rate it isn't even a 2 month supply. I have just started week 3, without any improvement. There is supposed to be a money back guarantee. Without much faith in the product, I have little to lose by trying. Dr. Flam did recommend Vitamin B complex for neuropathy. Well, it is time for the mandatory safety drill. This is our 14th cruise. I think I know what they are going to say. For the next week, I plan to concentrate on having a great time and put this Merkel business out of my mind.

September 29, 2011 This cruise has been delightful. A chance to get away from the day to day activities. There is plenty of food, and my appetite has been pretty good. My taste buds are almost normal and my dry mouth has improved. I continue to have mild symptoms of mild pain presumably in the radiated area of my lower esophagus, which is worse on eating. The food does not stick in the esophagus, and it does not diminish my appetite. I also have less exercise tolerance than I did, and when I take a deep breath, I almost feel like I need to cough. There will be a big meeting in Seattle involving researchers and patients with Merkel Cell carcinoma, on Tuesday, October 25, which Judy and I would like to attend. Because of this and my symptoms, I have called Dr. Dan Stobbe and inquired about the timing of a PET/CT after radiation. He said I need to wait six weeks. Since my treatments ended August 15, I can have the scan. I have arranged this with him for October 5, next Wednesday. I am waiting to hear back from Dr. Flam to get the official approval of the study. I am hoping to see Dr. Nghiem, particularly if my scans are positive, around the time of this meeting.

September 30, 2011 I thought I could put all thoughts of Merkel Cell carcinoma out of my mind for the week of the cruise but this is not possible. Once you have a diagnosis of cancer, every little ache or pain makes you think about the spread of the cancer as the cause. I have to know sooner rather than later whether my symptoms are caused by scarring or by Merkel cell carcinoma growing back after chemo and radiation. All is arranged with Valley Metabolic Imaging and with Dr Flam to proceed on Wednesday. This will leave me with a very busy week. Saturday: Fly back to Fresno Sunday: Work a half day reading CT scans at Kaiser. Monday: Bridge in the afternoon Tuesday: Work a half day at Kaiser. Appointment with Dr. Weinberg (ENT) for follow up on my hearing loss. Wednesday; PET/CT, ZZTop at the Fresno Fair7 Thursday: Work a half day at Kaiser Friday: Bridge, Yom Kippur Saturday: Work a half day at Kaiser (I am not very religious, but I hope to go to Yertzeit services in memory of my father in the afternoon) Sunday: rest Monday: Off to Montreal for a week.

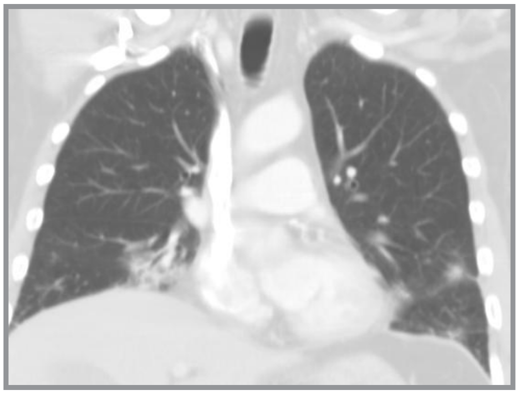
Posted by David Shuster at 10:34AM (-07:00)

My PET/CT Results: Good News and News of Unknown Significance

Thursday, October 06, 2011

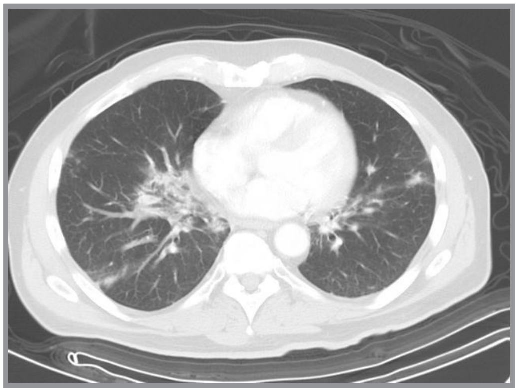
This will be a long post.

I have been complaining of increasing shortness of breath lately. The symptom is not disabling but is disturbing. I have been thinking I might have lung metastases, and because of this, I have pushed up the timing of imaging to have my scans done yesterday. Before I get into the findings, I would like to fully describe the symptoms. I have little tolerance for exercise, getting short of breath with rapid walking. When I take a deep breath, it seems to catch and make me want to cough, I have difficulty modulating my voice and sometimes have to stop speaking to cough. I am not short of breath at rest.



Coronal CT Image On this coronal image, there is air space consolidation adjacent to the heart, more right than left. There is also some focal peripheral consolidation.
(Right in patient is on viewers left)
Consolidation means fluid or other tissue where lung should be)

Here we can see that there is consolidation on both sides.



Axial CT Image

Here, we see a large abnormal area of air space consolidation to the left of the heart and several additional abnormal areas of lung consolidation on both sides.

This image shows some similar areas in the left upper lung.

These areas are described in the PET report as showing uptake of the tracer (the indicator of abnormal activity) which probably indicate infectious or inflammatory origin.

The areas adjacent to the heart are described as also taking up the tracer, most compatible with post radiation inflammatory change.

There is no uptake in the area of the original mediastinal tumor, reported as a "Positive response to interim therapy".

Both the PET and CT reports attribute all this to inflammation and not neoplasm. My experience with almost all forms of cancer is that metastases are smooth round nodules in the lung without inflammatory changes around them.

However, I am not yet jumping for joy.

I have called Dr. Flam to discuss this and expect to hear from him tomorrow. I have also tried to reach Dr. Nghiem to get his take on this. Nobody I have talked to has ever seen what metastatic Merkel Cell Carcinoma looks like in the lung. We also need to find an explanation for the findings assuming they are not MCC.

In the meanwhile, I expect to go to Montreal as planned on Monday and deal with this when I get back.

To sum up, at first look, this seems like good news, but after many disappointments, I retain a guarded optimism.

I will leave Monday for Montreal, where I will see my 94 year old mother, perhaps for the last time. She has lost weight and recently weighed as little as 63 lbs. While there, I will have a chance to visit with my sister Ellie, her daughter Cheryl and grandson David (not named after me) from Edmonton, my brother Jon, visiting from Gainesville Florida and my brother Robert, his daughter Andrea, her husband Ben, and granddaughter Alex.

In addition, it will be my 45th medical class reunion and my 50th undergraduate reunion at McGill.

These can not be missed.

It seems like only yesterday, and yet also like an eternity ago when, on a visit to Montreal, I put my hand on a spot right in front of my ear and fount a mass. It was only 17 months ago. I have been through two major surgeries, 3 episodes of radiation treatments, 2 courses of chemotherapy, a port insertion, innumerable blood draws, and about half a dozen sophisticated imaging studies. These are all further documented in my earlier blog posts.

I continue to fight!

Posted by David Shuster at 03:29PM (-07:00)

Radiation Pneumonitis, No Evidence of Cancer!!!!!

Friday, October 07, 2011

Today I spoke with Dr. Nghiem. He told me that Merkel Cell Carcinoma looks like any other malignancy when it spreads to the lungs, round smooth nodules. It typically goes to the lungs only late in the disease when there is cancer which is widespread. He will look at the images on my last blog and have Dr, Parvathaneni look at them also and get back to me. I so much appreciate his responsiveness.

I called Dr. Flam this morning and he agreed to see me on an urgent basis. I had labs done and my counts are improving. HGB is up to 12.3, WBC up to 5500. We did a baseline chest X-Ray and I must say that it looked almost normal. It amazes me how much more we see on a CT scan of the chest than on a routine X-Ray. We reviewed my PET/CT images. He examined me and I went for a walk while measuring my O2 Sat. This is a simple measurement with a device clipped to the finger which measures the percentage of oxygen in the blood compared to the maximum. It should run in the high 90's. It was 95% at rest and on walking, went up to 97%. These results indicate good function.

Dr. Flam has come to the conclusion that this is radiation pneumonitis, and the predominant area of involvement is the area which was irradiated. There are other areas involved also which he says is not uncommon. It is more common when chemotherapy is given at the same time as I had. The treatment if symptoms require it is with steroids. We would like to avoid steroids because of the immunosupressive effect which is not desirable with MCC.

He is fine with me sticking with my plans to go to Montreal and I will bring pills for a course of steroids with me in case they are needed. He suggested I delay my flu shot until I get back but wants me to wear a mask on the airplanes.

I have to thank Dr. Flam for seeing me in the middle of an exceedingly busy day.

Bottom Line: No Evidence of Cancer. As good a result as I could hope for. Radiation Pneumonitis. A temporary inconvenience.

On to Montreal.

Posted by David Shuster at 02:53PM (-07:00)

I'm Back!

Tuesday, October 18, 2011

I am back from Montreal. It was a wonderful visit. There is much to talk about and I will do it in a future post.
Here is a photo of my mother, Isobel who weighs only 62 pounds but seems to otherwise be in good health. I am on her far left, Jon on her right, and Ellie and Robert standing.

Posted by David Shuster at 03:35PM (-07:00)

Peripheral Neuropathy: An Explanation

Tuesday, October 18, 2011

I have symptoms of peripheral neuropathy, which I would like to discuss in detail. This is a condition in which there is damage to peripheral nerves, both sensory and motor. The common causes are diabetes and chemotherapy but there are other causes. At its worst, patients can develop severe arthritis in the feet which is caused by repeated trauma, because the protective mechanism of pain sensation is not present. This is termed "Charcot Joints". Symptoms include pain and numbness in the hands and feet. The distribution in the feet particularly and to a lesser extent in the hands is described as "Stocking numbness". This is numbness that goes from some point in the leg to the toes like a stocking or sock, rather than in the distribution of peripheral nerves and allow distinction from other causes such as a slipped disc or nerve injury or in the hands to distinguish from neck disc or carpal tunnel syndrome. In my case. there is also dryness and clumsiness of the hands due to motor nerve involvement and more subtle sensory deficiencies such as loss of proprioception which allows your brain to know where your fingers are. I find simple tasks somewhat challenging, such as turning the pages of a newspaper or separating one coffee filter from a stack, or buttoning my shirt. It has also resulted in spilling a cup of coffee on my lap and shattering the glass coffee mug. fortunately, I have had little pain but there is the occasional shooting pain in my feet. Dr. Flam suggested Vitamin B Complex which I began taking. I searched the internet and found a company that claimed to have 90% success treating this condition with their fat soluble version of Vitamin B. I bought a so-called 3 month supply for $145. they suggested 4 capsules daily, but upping the dose if it did not work, so the final dose would be 12 capsules a day or $140 for one month supply. This has not been effective and as they offer a 3 month money back guarantee, I will try to get my money back, without much optimism. So, its back to the pharmacy for Vitamin B Complex. At least it is an inexpensive treatment which I don't think will work. Oh well, better to live with peripheral

neuropathy than die of Merkel Cell carcinoma. Here is a link to a Mayo Clinic artticle about peripheral neuropathy. Link to Mayo Clinic Article
Posted by David Shuster at 03:55PM (-07:00)

Latest Update

Wednesday, October 26, 2011

Today was the day for my follow up visit with Dr. Flam.
My labs are stable. My shortness of breath is slightly worse, but I can walk at a good pace and climb stairs. (thank goodness for that as we live in a 2 story home). I am not short of breath at rest, and I can sleep lying flat. I have the unusual symptom of being unable to speak for very long without coughing. I can not take a deep breath without coughing. This slows me down at work when dictating radiology reports and limits my ability to carry on a conversation. The treatment advocated by Dr. Flam is a short course of steroids, beginning at a high dose and rapidly tapering over six days. because of the immunosupressive effect of corticosteroids, I will run this past Dr. Nghiem. In the meanwhile he wants me to take a cough suppressant containing codeine. As there is the Fresno Sectional Bridge Tournament this weekend, I will delay this until the Bridge tournament is over.
My neuropathy is unchanged, and when the supply of pills I obtained from a web site promising 90% success rate runs out, I will discontinue them. I would doubt the accuracy of the 90% number.
My weight is stable and my hair is growing back. It is almost long enough to brush.

Here I am, no longer hairless although certainly showing more baldness than when this ordeal began.

I promised to write about my visit to Montreal, so here it is,
My Mother is doing as well as can be expected given her age and loneliness after the death of my Father after 65 years of marriage. Although she has been a widow for about 5 years, who can blame her. Her appetite is not good, but the food at Place Kensington is not the best, so she doesn't eat very much.
Here is the question. At 62 lbs, and at the age of 94, Is there another human on this planet whose weight in pounds is less than 2/3 of her age in years? Somebody not effected by some sort of developmental dwarfism?
Bluma and Lenny Clayman were wonderful hosts for the first 3 days I was in Montreal. Lenny picked me up at the airport and hardly complained about the plane being late. He cooked dinners and drove me around. Truly, they are the best of friends.

My brother Jon Shuster arrived Thursday and we shared a room at the Residence Inn in Westmount. We had a chance to spend time together and catch up. He lives in Florida and We are in California so we don't get to visit very often.
My sister Ellie Shuster came with her daughter Cheryl Cruikshank and grandson David (not supposed to be named after me). He is about 14 months and very cute. He had been walking only 2 weeks but getting around very well.
My brother Robert is in Montreal and is the go to person for my mother. We got to spend time with him Saturday and Sunday.

We met Alex and her Mom and Dad Saturday for a family Chinese lunch. She is very cute. Her Mom Andrea and dad Ben Urovitch are doing a great job parenting her.

From L to R: Me,Cheryl,David,Andrea,Alex and Ben.
We got to spend time with Robert and his wife Gertie Sunday for brunch.
Afterwards, Mom, Jon, Robert and I sat down for a game of bridge. My mother held her own most of the time.
Friday evening was the McGill Reunion Dinner.It was at the Omni Hotel and one had to step over the protesters to get inside. This did not seem to make much difference as the place was jammed. I sat at a table with old classmates from the Honours Math Physics class. It was the 50th reunion.
Ralph Roskies, who organized the table was stuck first in Newark and then at immigration and didn't make it. Doug Beder was there. He and Ralph were instrumental in my career change from Physics to medicine. I knew I could never compete with them. David Mayerovitch, Barry Frank and Lorne Mendel were also there.
On Saturday night, we had a mini reunion of members of the McGill 66 medical school class.
About 15 members were present. Hopefully I will be there for the 50th when many more classmates have promised to be there. Thanks to Peter Humphreys for organizing this.
We had a delicious dinner at Le Caveau, near the Mcgill campus. It was raining very hard after dinner, and I thank Arnold Zidulka for the ride back to the hotel.
We had a Friday brunch at Place Kensington, for which I ordered food from Snowdon Delicatessen.
We had Montreal smoked meat, pickles, chopped liver, eggplant salad, cole slaw party sandwiches and potato knishes. Oh wait! Ellie left the knishes in the oven and they burned to a crisp. David ate half the party sandwiches (not me). Still, there was plenty to eat and some leftovers.
Many family members took the time to be there.

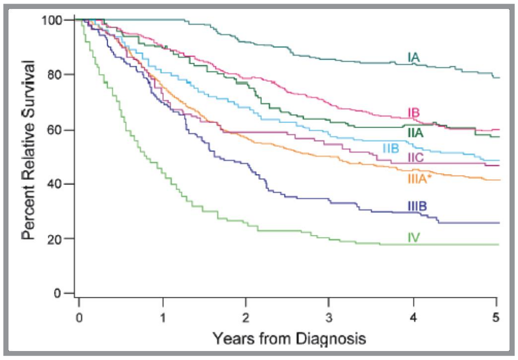
Posted by David Shuster at 03:02PM (-07:00)

Some Random Observations About MCC and Me

Saturday, November 05, 2011

This is my 100th post.

Here is a graph showing survival of patients with Merkel Cell Carcinoma by stage at the time of diagnosis.



Relative survival for 2,856 Merkel cell carcinoma patients by stage according to the 2009 AJCC staging system. Percent relative survival was calculated for cases in the National Cancer Database using age- and sex-matched control data from the Centers for Disease Control and Prevention. Stages are as indicated in the figure except for Stage IIIA which could not be derived using this dataset. The curve marked "IIIA*" represents pathologically node positive patients, with the clinical node status unknown or negative. It is anticipated that true Stage IIIA patients (clinical node status negative) have better survival than the line marked with "IIIA*." Total number of patients was 2,856, and individual substages were as follows: IA = 266, IB = 754, IIA = 124, IIB = 414, IIC = 84, IIIA* = 794, IIIB = 143, IV = 277. From AJCC Staging Manual 2009. This refers to stage at the time of initial diagnosis. I was stage IIB at the time of diagnosis, but I would classify myself as Stage IV diagnosed on November 24, 2010, about 11 months ago. If I can survive another 13 months, I will fall into that 20% who survive long term. Those who survive 2 years almost all are long term survivors.
These patients who survive stage IV undoubtedly have had chemotherapy, so I submit my thesis that, in spite of what Dr. Nghiem says, chemotherapy can prolong survival in Merkel Cell carcinoma.

Al Davis, famed and notorious owner of the Oakland (and Los Angeles) Raiders died last week. I have seen his death certificate on the internet. He supposedly died of heart disease and he had a history of cardiomyopathy. He supposedly died of ventricular fibrillation. He also had Merkel Cell Carcinoma, and had undergone a procedure for dysphagia (difficulty swallowing) a few days before his death. I submit that the full story has not been told. I suspect he died of complications of Merkel Cell Carcinoma.

Bridge. The Fresno Sectional Bridge Tournament was held last week. I played in all 8 sessions, and for the first time since I came to Fresno in 1976, I won the Presidents Trophy for winning the most masterpoints. Thanks to my partners, Bert Rettner and Mark Stern.

So how am I doing? I feel pretty good these days, but my shortness of breath has not improved. The worst symptom of this is inability to speak very long without coughing. This bothers me most when working, as I spend all the time dictating reports into Dragon 10 Medical. The software does a good job of ignoring my coughing. I am using cough drops and taking cough syrup at night, and have few symptoms when not speaking.
My neuropathy has not changed.
I will see Dr. Flam next Tuesday and will discuss possible treatment with corticosteroids.
Posted by David Shuster at 07:25PM (-07:00)

Not Much New, So I Tell the Story of Sadie Cohen

Sunday, November 20, 2011

It has been a while since I posted to this blog. That is because there has not been much change. I did visit Dr. Flam on November 9. My labs were unchanged, and my chest X-ray showed little change. because of continuing cough and shortness of breath, he ordered a CT scan of my chest. That was done on Nov 10. I looked at the images but do not have them to post. I would describe the findings using a term I coined. "Mixed Change". That is, somewhat better in the right upper lung annd somewhat worse in the right lower lung and the same on the left. No change was seen in my posterior mediastinum, the site of the only known tumor, which I hope is totally inactive. No liver metastases are seen. I will get the full report when I see Dr. Flam on Wednesday. I still have shortness of breath and a cough, The cough responds well to Hydrocodone/homatropine cough syrop. It allows me to dictate reports with little interruptions for a coughing break. Drug Info
This is a narcotic with potential for addiction. Apparently the Homatropine is added to stop people from taking too much at a time. It also helps me sleep all night as the homatropine prevents bladder spasm. Constipation is a side effect but so far has not been too much of a problem. My other symptoms are stable. Dry mouth, arm and leg numbness and hearing loss have not changed and are not too debilitating.
I have been working half days at Kaiser and even worked a full day at Sierra Imaging.
I was taking Vitamin B Complex, tablets from CVS. On my CT scan, I could see the tablets intact in my colon. Needless to say, they could not be very effective in treating peripheral neuropathy.
We have an addition to the family, sort of. Our oldest granddaughter Eva has a baby (half) brother born yesterday to her mother and stepfather.

Since I have no more news, I will tell the story of a patient from my internship who I will call Sadie Cohen.
Sadie was an elderly Jewish diabetic being treated for an ulcer in her foot, with the hope of preventing an amputation. She had Alzheimer's disease and was in pain She would lie in bed constantly moaning oy-oy-oy-oy-oy as only an old Jewish lady could. It was my job to keep her IV running and she would be constantly pulling at it until she dislodged it. There were no ports or PICC lines back then. They were calling me at all times to restart

the IV. When I would stick her with the needle, you would hear "oy-oy-oy-oy-GEVALT-GEVALT-GEVALT! Because of this, I invented the decoy IV, some tubing taped to the arm above the real IV. When she pulled this off, the nurse could replace it.

One day I was called to see her because she was in a coma. I checked the IV fluids and there was an error in pharmacy. Too much insulin had been added to the IV. I gave her an injection of Glucose, and a few seconds after I gave the injection, I heard "oy-oy-oy-oy-oy". I knew she was back to normal. (for her).

Posted by David Shuster at 05:23PM (-08:00)

Hurray! I don't have a Doctor's Appointment for Today

Wednesday, December 07, 2011

It's a Wednesday, and I don't have to see Dr. Flam today. In fact, I don't have to see him for another 6 weeks. I will need my port flushed 2 weeks from today.

I am feeling somewhat better. Although I am still short of breath, I can take a deeper breath without coughing. The cough syrup helps. It does contain a narcotic, so I try to take it only in the morning.

My neuropathy has changed a little. Occasionally, I do have some pain in my feet. This is new. However, there appears to be less numbness above the ankles than there was previously. My hands show little change. My mouth is still quite dry, and it makes many foods unappetizing. This includes bread, cake, and cookies. However my sense of taste has substantially improved, and is close to normal.

On Friday, we will drive to Los Angeles and stay over at the Holiday Inn in Long Beach. On Saturday, we will embark on our family cruise to the Mexican Riviera. (These days, the Mexican Riviera includes only Ensenada and Cabo San Lucas.) There are no other stops. Whether this is because Princess Cruises is trying to save money, or because of unrest in Mexico, is uncertain. This is a vacation we've been planning for some time. It is a real family cruise. It will include our 3 sons, 2 daughters-in-law, and 5 grandchildren. When we planned this, I was hoping I could go, but I was not very confident that I would be in good enough health to enjoy it. It seems to have worked out well.

We have now booked another cruise, this time, to Hawaii, at the end of February. I am very optimistic about this one.

I have been working about 3 mornings a week at Kaiser Permanente, and plan to work 4 full days at Sierra Imaging at the end of December.

In other news, the IRS has disallowed the deduction I took for the Ponzi scheme that I was a victim of. My file was sent to Atlanta, but the agent who reviewed my tax return did not have the entire tax return but only the numbers to review. They didn't bother to give him the supporting documentation. Of course, he disallowed what was classified as a miscellaneous deduction. The IRS then stalled the case until the deadline for me to go to Tax Court was so close, that the case would not be reviewed in time. I think that the agent who receive the case in Atlanta did not want to have anything to do with it, and so just delayed to force me to go to Tax Court. This is an annoying bump in the road, and I would be much more upset, I'm sure, if I did not have the experience of having to fight a malignant neoplasm. That helped put these minor annoyances into their proper perspectives.

I will conclude this post, and hopefully future posts, with an anecdote from the past.

One day I was doing a carotid angiogram. These examinations are done with the patient awake, although sedated. We were most interested in the region of the origin of the internal carotid artery in the neck, but had some interest in the branches at the base of the skull. When the catheter was in place, I was giving instructions to the technologist as to how to position the patient. The conversation went as follows.

Me: "It's important that we get the neck in this patient and not so important that we have the entire brain."

Technologist, after setting up the equipment, “Is this okay?”

Me: “No. I don't care if you cut off the top of the patient's head. Just make sure you get the neck on”.

Patient: “I care. Don't cut off the top of my head!”

The moral of this little story is: Be careful of what you say, because you don't know who may be listening.

Posted by David Shuster at 09:49AM (-08:00)

We're Back!!!

Monday, December 19, 2011

We're back from the cruise. I'm going to divide this post into 2 portions. The 1st will deal with my health status. The 2nd will deal with a description of the cruise and associated events.

Part 1. My health status.

A few days ago, I was thinking to myself that since I began radiation treatments, I have never felt better. My cough and shortness of breath have significantly improved. My exercise tolerance has improved. I even climbed 3 flights of stairs at one point during this cruise. But peripheral neuropathy has changed little, but I think that the extent of the neuropathy has decreased in that there is less loss of sensation in the mid-calf level than there was. Before the cruise, I complained of some pain which appeared to come from the area one of my right lower ribs. Of course, whenever there is unexplained pain, one immediately thinks that it may be metastatic disease. However I think that I must've pulled a muscle while coughing, as the pain has gone away.

At the end of the cruise, on Friday night, I began to have severe heartburn. This became substantially worse on Saturday and Saturday night. I have had some difficulty explaining this. It felt like heartburn in that it was a burning pain centered on the lower chest, just like heartburn that I used to have before I began taking Prilosec. However it did not seem to be related to acid reflux as I have been on full doses of Prilosec, and the pain seemed to be at its worst right after and during eating. On about 2 occasions, the pain was so severe that I was postulating that may have torn the mucosa of the esophagus. Of course, when this happens, one immediately becomes convinced that there is now metastatic disease or that the tumor in my lower esophagus has again begun to grow. However I am now theorizing that this was due to viral infection as I was exposed significantly during this cruise as I will describe below. In fact, I am feeling significantly better, and this pain has almost completely gone away.

In summary, I am back to thinking optimistically, that, knock on wood, I'm feeling about as well as I have ever since I began radiation treatments.

Part 2. The Family Cruise

The photo above was taken on the 2nd formal night of the family cruise. Standing from left to right, are Mike, our youngest son, Leanna, his wife, Brian, our middle son, Dana, Gary's wife, and Gary, our oldest son. Sitting are Judy and me. To my left is Eva, our oldest granddaughter, Age 10 1/2. The bottom row consists of Sara, Eli, Bel, and Sammie. Sara, 4 1/2 and Bel, 2 1/2 belong to Gary and Dana. Sammie 3 1/2 and Eli 1 1/2 belong to Mike and Leanna. The cruise began with numerous fiascoes. Mike and his family together with Judy and I all stayed at the Holiday Inn in Long Beach. There was supposed to be a free shuttle going to the terminal from the hotel, and we could park the car for a week at no additional charge. It turned out that the shuttle only went to the Long Beach port and our cruise was taking off from San Pedro. we needed to get a shuttle to take us to the cruise terminal, and it was quite a job fitting all the luggage into that shuttle, (not free). There was a virus going around, and Sara was sick, and we were not sure that we would be able to get onto the ship. They do have a health questionnaire, and they have the right to bar access to the cruise if they feel that a person may be a health risk to passengers. However everybody managed to meet on board ship and get underway. The premise was that for the family cruise, everybody would be on their own, but we would all meet for dinner. In fact, most of the time, we were together. This was very nice, but did involve more babysitting for Judy than she had anticipated. The 1st two family dinners were terribly disorganized. The wait staff was particularly slow, and this exceeded the patience of the grandchildren. There were lots of requests for special orders for the small children, and this somewhat overburdened the waiter and his assistant. By the time we had the 3rd dinner, after I spoke to the maître d', the situation was fairly well resolved. However there were many instances where grandchildren had to be taken out of the dining room and food for the parents was sent to the room. There is an excellent children's program on board the ship. However 2 of the grandchildren were too young to stay there without adult supervision. Much of the time, the adult supervisor was Judy. In the middle of the cruise, Sammie ran a fever of up to 104. She did not seem nearly as sick as that number would indicate. However clearly, there was a virus involved. In Cabo San Lucas, Brian took Eva ziplining, and that was a highlight for them. On the last night, there was another fiasco. Eva and Sarah disappeared and were nowhere to be found. There is nothing so terrifying as the disappearance of children. We had the whole ship's crew searching for them, and they turned up at a dance club, where they were having a great time dancing as everybody else was searching. At the end of the cruise, we all went our separate ways. However everybody but Brian ended up meeting for lunch just south of Bakersfield on the way home. Mike and his family stayed over at our house as it would be too long a trip to drive all the way to San Jose where they were going to stay with her parents for a week. This is the time when Eli became ill. He spent the whole night crying and could not be soothed enough to get some sleep. On Sunday morning, they took him

to a pediatrician, who said that this was a viral infection. We had suspected that it might be an ear infection. By Sunday at noon, our house was finally quiet. The cruise was over. We were left with fond memories, and viral infections.
Posted by David Shuster at 11:22AM (-08:00)

First Update for 2012. Google Ads Pay Out!

Tuesday, January 03, 2012

I received a check from Google for ad revenue from my blog. $100.95 was sent to me as a result of people reading my blog and clicking on the ads Google places on the right side of the posts. As a result, I am matching the amount and sending $201.90 to the University of Washington care of Dr Nghiem to be used for research into Merkel cell carcinoma.

I was home alone for almost a week as Judy went to the Renaissance meeting in Charlotte mainly to take care of Eva, Sara and Bel. She left last Tuesday and came back yesterday. I worked 4 full days while she was gone, and managed to handle the work well, although I was tired by the end of the day. While at home, I watched a DVD of Season 3 of 24, all 24 episodes, and read a book of 850 pages, 11/22/63, a science fiction thriller by Stephen King.

I am feeling quite well, but there are some symptoms. Apart from the dry mouth, hearing loss and neuropathy, I have gradually been developing discomfort on swallowing, particularly dry foods. There have been episodes of heartburn. I thought this was due to a virus as I was in contact with my contagious grandchildren during our family cruise. However, I now think I am developing a radiation stricture of my esophagus. I will mention this to Dr. Flam when I see him on January 18. I think there is little to do now, unless it gets worse. If it is due to new tumor growth, the area has had a full dose of radiation and I doubt if any more chemotherapy will be effective. Right now, it is not a quality of life issue.

Treatment, if needed would likely be balloon dilation of the esophagus, which I am reluctant to undergo at this stage.

My shortness of breath and cough have improved but I continue to take a narcotic every morning for the cough. (Just a small dose, I am not addicted.)

Here is a story from my youth. It teaches about life and death.

The Mouse and the Minnow Trap. When I was about 10 years old, I used to go to the country with my parents and my brothers. My parents would rent a cabin by the side of the lake and there were quite a few children of similar age to me we spent the summer there. One day, we found a mouse in a minnow trap. We kept the minnow trap and a small locker when it was not in use. There was still some bread inside it, and when in the water, was very efficient at catching small fish. It was somewhat cylindrical in shape, with conical openings at either end. These openings allow the fish to swim in, but then they couldn't find the openings to get out. It worked very well on this little mouse which got caught inside. We had a long discussion about what to do with this mouse. I think the consensus was that we would submerge the minnow trap in the lake until the mouse drowned and then dissect it. You have to realize that this time, we were young children who had no significant ideas about life and death, pain and torture. At that age, you thought you would live forever. Time subjectively seem to pass much lower. A week off from school was a very long time. All summer away from school was an eternity. My mother saw this group of children in serious discussion, and decided to intervene. She

asked what was going on and we told her. She made the decision. We had to let the mouse go. We argued, but my mother was the boss. So we opened the minnow trap, and the mouse scurried away. He didn't get very far, as the dog, who was watching this with some interest, pounced on the mouse, and within a heartbeat, the mouse was dead. There is a lesson to be learned from this. Men may be cruel, but nature can be just as cruel.
Posted by David Shuster at 04:10PM (-08:00)

Another Complication of Radiation Treatment

Wednesday, January 11, 2012

As I reported in my previous post, I am having difficulty eating. I get spasms of pain which appear to come from my lower esophagus. The pain is worse later in the day, and is worse with eating dry solid foods. Liquids go down better, and in the morning, I can eat my Rice Krispies with raisins, banana and blueberries without these spasms. Pudding, ice cream and yogurt are OK. Today, I called Dr. Flam and asked to see him. He had come back from vacation earlier than I thought, and I was there at 4:00 PM. The office was surprisingly busy. I got my port flushed and had labs which are stable. I have not lost weight. A chest X-Ray showed improvement from the previous, and I was better able to take a deeper breath. I realized that in that respect, I am significantly improved. Dr. Flam is quite certain that this is not due to recurrence of Merkel Cell carcinoma but is a stricture of the esophagus due to radiation. He called my gastroenterologist, Dr. Robert Lewis to set up an appointment for an esopho-gastroscopy and dilatation of the stricture, but it was too late to reach him. I expect this to be scheduled tomorrow, and hopefully to be done by early next week. In the meanwhile, I am to have only liquids and "pureed food". "No bagels and lox" in the words of Dr. Flam.

Stricture of the esophagus is a relatively common complication of radiation treatment and usually responds well to balloon dilatation. The major complication of rupture of the esophagus is relatively rare, less than 1% for all strictures, but greater for radiation strictures. The procedure may have to be repeated more than once as the stricture has a tendency to recur.

I think it will be an out-patient procedure.

It is of interest that I am feeling otherwise quite well and am functioning at a good level.

I will report a follow-up when I have more information.

Posted by David Shuster at 07:39PM (-08:00)

Dilatation for Today, Almost an Emergency

Friday, January 13, 2012

This morning, after taking my Hydrocodone-Homatropine cough syrup and 2 small pills, I tried a mouthful of well chewed Rice Krispies. It would not go down, In fact, for the next 45 minutes, nothing would go down, not even my own saliva and I was having severe pain. There were lots of oral secretions which I had to spit out, and with coughing, some of the cereal came back up. I could not even drink my coffee.

This is significant progression of symptoms. Yesterday, I was able to eat a whole bowl of cereal without much discomfort.

I attribute this to flow dynamics. The flow through a tube is related to the 4th power of the diameter. Reduce the diameter by 1/2, and the flow rate is reduced to 1/16.

The symptoms now have abated somewhat.

My appointment with Dr. Lewis is for 3:00 PM but he has thankfully moved me up to 1:00

PM.
I will post again when I get home.
Posted by David Shuster at 10:42AM (-08:00)

Post Esophagoscopy Uppdate

Friday, January 13, 2012

It was done. I am somewhat improved but still have epigastric pain. Dr. Lewis will see me in 2 weeks. In the meantime, meat (except for ground meat) is off the table. I did burp tonight, for the first time in weeks.

I have been able to down pudding and Boost Plus, which would have been impossible this morning.

I will post a full description of the experience in a few days.

Posted by David Shuster at 09:36PM (-08:00)

Esophageal Dilatation: My Experience

Monday, January 16, 2012

On Friday, the 13th of January, my breakfast got stuck in my esophagus. Nothing would go down, and nothing would come back up. I had severe pain in my chest, and hypersecretions. My nose ran, my eyes watered, and my mouth filled with saliva. I was coughing and sneezing, and eventually, some food appeared in my mouth. After about 45 minutes, the symptoms abated. I had scheduled my esophagoscopy for 3:00 PM, but Dr. Lewis was able to get me in for 1:00 PM. By that time, the symptoms were gone.

I arrived at noon as requested. I was taken to a cubicle and changed into a gown. It was cold (or I was cold). They started an IV (2 tries). My veins were tiny because of the cold. I asked the nurse to use a heating pad on my hand to allow the veins to expand, but they had none available. I am left with hematomas at both sites, left hand and anticubital area.

Dr. Lewis arrived shortly after 1:00 PM and they took me to the room. We talked and then the sedation was given with me lying on my left side. After that, I remember nothing.

It was like Joan Rivers said about giving birth. "Put me out with the first pain and wake me up when the hairdresser comes".

Dr. Lewis was surprised that he didn't find it as narrow as he expected. He didn't see signs of tumor infiltrating my esophagus. I have not yet had a chance to discuss the findings in detail. I will have an appointment with him in 2 weeks and may need the procedure repeated. I guess they don't want to stretch the area too much at a time for fear of perforation. I am to take 2 teaspoons of Lidocaine Viscous before meals, 20 mg of Prilosec twice daily, and to eat meat only if cut into tiny pieces.

So, what is the result? That's hard to say. I still have some esophageal spasm with eating, but no repeat of the Friday episode. Epigastric pain has diminished. I have a sore throat, either from the procedure or I am getting a cold. I am eating mostly yogurt, pudding, soup and other predominantly soft foods with little solid food. I have lost 3 pounds since last week. I didn't get much sleep last night, but I feel somewhat better this morning.

The plan is to carry on with my usual activities for now.

Posted by David Shuster at 10:01AM (-08:00)

Another Esophageal Dilatation Scheduled

Wednesday, January 18, 2012

Today, I had a follow-up appointment with Dr. Lewis. I am still having symptoms of my esophageal stricture. This morning, I ate some cereal for breakfast and 3 small pills, after which even coffee would not go down. Presumably the pills were enough to block the esophagus.I was uncomfortable all morning, with esophageal pain and some pain referred to my back. For lunch, I had a bowl of soup and a bottle of Boost Plus and that went down OK. Dr. Lewis told me he dilated with Bougies, which are tapered tubes, up to 56 French, which corresponds to almost 19 mm. The most he will go to is 60 French or 20 mm. He could tell that there was a fairly long segment, about 4-5 cm of narrowing, andI had some bleeding and pain from the dilatation. Fortunately, I don't have any memory of the pain.

So why do I still have symptoms? It could be largely spasm, which could be treated by Beta Blockers or Nitroglycerine. The latter would have a major side effect of headaches. His inclination is to dilate again, and this will be done Monday afternoon. Sorry, Bert, our bridge game for Monday will be cancelled.

In the meantime, it is going to be a mainly liquid diet, ingested very slowly for the next 5 days.

Apart from this, I have developed an upper respiratory infection, the first since I was diagnosed with Merkel Cell Carcinoma. This has not helped, but it seems to be improving.

Hopefully, this will all be taken care of before mid February, as I have two bridge tournaments planned, followed by a cruise to Hawaii.

Captain, O Captain, don't go too close to shore.
I love to hear (from a distance), the ocean's soothing roar.
Use the Tenders as Tenders, I love those Tender rides,
Don't use them as lifeboats, with the ship listing on its side.
But if the ship were to unfortunately go down,
Rather than die of Merkel's, I would choose to drown.

Posted by David Shuster at 02:41PM (-08:00)

I Need Help Today

Friday, January 20, 2012

Last night at dinner, I tried to eat a fried egg, and got blocked up. I expected the blockage to ease off as it has in the past, but it is now 16 hours, and nothing goes down. I have to spit out my saliva. I am having constant pain. I have had no sleep. Dr. Lewis is off today, but Dr. Cano, his associate, will try to take care of me today at noon.

Poor Judy. Everyone has problems. One son will have sinus surgery soon. Another will have cystoscopy for occult hematuria. Another will come to Fresno Monday to have endoscopy Tuesday for what I think is gastric outlet obstruction. Her sister probably needs to have multiple teeth pulled and a second hip replacement. On top of all this, the dog has a severe limp and had great difficulty getting down the stairs this morning.

Posted by David Shuster at 09:56AM (-08:00)

Only a Little Improvement

Friday, January 20, 2012

Repeat endoscopy and dilatation today by Dr. Cano has resulted in mild symptomatic improvement. I don't think he dilated any more than Dr. Lewis. He removed some food impacted in the distal esophagus, and the spasms have improved, but attempts to eat small amounts of chicken broth, chocolate pudding and Boost+ have resulted in only mild success. I have regurgitated some of these, but without as much pain as yesterday, and some seems to have gone down. I don't think he dilated as much as planned as he was concerned with inflammation in the esophagus. You can't appreciate how we take for granted the ability to eat, chew, swallow and digest food. I don't know if I will ever be able to do so. It is very depressing. If my Merkel cell cancer is "cured', the cure may be as bad as the disease.

I will see Dr. Lewis next week, and maybe he will have something else to offer. I have heard of esophageal stents being used but there is a very high rate of complications, and they are not recommended for benign strictures.

In the meantime, I will stay home, trying to distract myself. Sorry, KP Docs, I will not be up to working tomorrow.

GO 49ers!

Posted by David Shuster at 09:43PM (-08:00)

Sunday Morning Coming Down. Two Days After Dilatation #2

Sunday, January 22, 2012

I have had two decent nights sleep, with mild back pain (likely esophageal in origin) and without much regurgitation. This morning, I could down a bottle of Boost+ in about 15 minutes. Yesterday, it took much longer. My weight is down to 147 lbs. I was at about 180 when I first discovered my tumor 20 months ago.

On the bright side, people are telling me I look good.

I have stopped taking the Hydrocodone-Homatropine cough syrup, without withdrawal symptoms. In fact, with no solid food going down, my colon has been surprisingly active. Although the 20 mg generic Prilosec tablet is tiny, I have not taken it yet today, fearing it is enough to block my esophagus. I am looking into finding the liquid form.

I think there is slow improvement, and I might be able to start eating food again, perhaps after more dilatations.

I will follow up with Dr. Lewis.

Taking a step back, I think I need to see Dr. Flam, to get his input. It is probably important to get a repeat CT scan to make sure I do not have a recurrent tumor around my esophagus or elsewhere. Will I need a PEG tube? (Percutaneous Gastrostomy) for feeding? Sometimes, radiation strictures require multiple dilatations, up to 6 before there is relief of symptoms. Sometimes there is no relief. The latest treatment is biodegradable stents. These have been tried in Europe with good success. There is a product on the market in Europe called the SX Ella BD Biodegradable stent, by UK Medical. I have emailed the company, but I don't think the stent is FDA approved. Another study is being done led by Dr. Alessandro Repici in Italy, a multi-country trial. I emailed Dr. Repici and he responded today. The stent is in clinical trials and will not be available in the USA for 2 years. These stents are placed across the stricture and hold it open for 6-10 weeks before degrading and being absorbed by the body. Most patients get long term relief, but many need restenting. There are few complications.

In the meanwhile, I hope to go to the Bridge Club tomorrow and to work Tuesday morning at Kaiser.

Go 49ers

Posted by David Shuster at 12:48PM (-08:00)

Steps in the Right Direction

Monday, January 23, 2012

While I slept very well Friday and Saturday nights, but not so well last night as phlegm was coming into my mouth all night. But it was not enough to have to spit it out. I continue to lose weight, down to 147.5 lbs. However I am getting down more nourishment. 3 bottles of Boost+, ice cream, mushroom soup after it was put in the blender and chocolate pudding so far today. I was able to down a 20 mg Prilosec pill. There has been some discomfort, but it is not unbearable. In spite of the lack of sleep, I played Bridge with Bert today and we had the second best score of 25 pairs. I then briefly visited my 2 younger granddaughters. On Sunday afternoon, I got to spend time with Eva.

I will see Dr. Lewis tomorrow morning at 10:30. I moved up my appointment with Dr. Flam to Wednesday morning. I am scheduled to work at Kaiser tomorrow morning, and will do 2 hours early and then return after my appointment for another 2 hours.

Good news. My son had a negative cystoscopy today. My son Brian just arrived today for his appointment tomorrow with Dr. Lewis.

I asked an Interventional Radiologist who used to be an associate of mine, Dr. Marty Rindahl who was too busy climbing Mt. Everest to put in my Mediport about esophageal stents but he has little recent experience with them. He defers that to the gastroenterologists.

Posted by David Shuster at 08:32PM (-08:00)

Esophageal Dilatation #3 (or is it #2?) Tomorrow

Wednesday, January 25, 2012

Yesterday was my appointment with Dr. Lewis. It turns out that my last endoscopy showed food wedged in the lower esophagus. I saw a picture. It looked like nothing I ever ate, but I guess the main component was egg. After that was removed, Dr. Cano felt it was too inflamed to dilate significantly.

Dr. Lewis is confident that my ability to eat can be restored with dilatations. He does have experience with removable stents if needed. It is still a struggle to get even liquids down, and I get little sleep because of fluid in the esophagus coming back to my mouth at night and making me cough. Last night, I slept in the bed and not in the recliner. It was a little better. The head of the bed was elevated by cushions under the mattress.

Tomorrow, I go for another dilatation. In the meanwhile, I have been living on Boost+, 4 bottles today, 360 calories per bottle.

Today, I saw Dr. Flam this morning. He is very optimistic. He feels that this is benign disease, and doesn't even want to do a follow-up PET/CT for another two months. However, he did suggest that I would benefit from hyperalimentation if I lose another 5 lbs.

I am told I look good. My hair has come back, although the baldness has also come back. I look slim as if I am getting lots of exercise. My response is "I am half way between obesity and emaciation." One of these days, I will get a haircut, something I often thought I would never do again.

I plan to work at Kaiser tomorrow morning, go for my procedure tomorrow afternoon, play bridge Friday afternoon and work Saturday morning.

Posted by David Shuster at 06:57PM (-08:00)

Pseudo-Achalasia: A New Diagnosis

Friday, January 27, 2012

Yesterday, after my repeat esophagoscopy, Dr Lewis came to the conclusion that I do not really have an esophageal stricture, but a form of achalasia. This is a condition where the esophagus does not contract and the sphincter at the distal end does not relax. In layman's terms, the esophagus does not propel food towards the stomach, and the muscle of the lower esophagus does not relax to allow the food to advance from the esophagus to the stomach. The result is accumulation of food and saliva in the esophagus that needs to go somewhere. When upright, it can eventually trickle into the stomach by gravity. When lying down, it can go back into the throat and even possibly get aspirated into the lungs.

My search of the internet does not reveal much about this condition acquired as a result of radiation.

Dr. Lewis will consult with a colleague at UCSF and get back to me on Monday.

Possible treatments are:

1. Drugs which relax smooth muscle. These may not be right for me as my blood pressure is already low and this might make it worse.
2. BOTOX! This can be injected through the endoscope and might paralyze the sphincter.
3. Some form of myotomy in which the sphincter is cut, probably also done endoscopically.
4. Major surgery to remove the involved segment of esophagus and pull the stomach into the chest or replace the segment with colon. This would be a last resort. However, it might be best if there is no Merkel Cell Carcinoma lurking in my body.

Last night, I did get some sleep, but today, the second bottle of Boost+ does not want to go down easily.

Most people, when depressed, complain they can't eat and can't sleep. I am becoming depressed because I can't eat and can't sleep.

It is amazing that this has all come on within less than a month.

Posted by David Shuster at 11:40AM (-08:00)

I am Going to the Hospital Now

Friday, January 27, 2012

Nothing is going down, not even saliva.

I expect to be admitted to the hospital.

Posted by David Shuster at 06:06PM (-08:00)

Saturday Afternoon At St. Agnes Medical Center

Saturday, January 28, 2012

Just a brief update. It has been frustrating, but I have been in my hospital room since 3:00 AM. I had a Barium study this morning and will post pictures when I get home. Hyperalimentation will start tonight. I will be seen by Dr. Flam Monday morning, I presume in the hospital and go home Monday to continue hyperalimentation at home. Surprisingly, the Barium went down to my stomach passing around a huge glob of goo un my upper esophagus. The lower esophagus is very narrow and tortuous, but no evidence of malignancy there.

The last piece of the puzzle will be a scan, either PET/CT or CT to see if there is malignancy in the area. I am optimistic there is not. We will then need a strategy to deal with the lower esophagus.

Judy has been a Jewish Saint during all of this. Thanks to well-wishers.

More details to come, depending on the degree of insomnia tonight and my mental status.

Posted by David Shuster at 04:06PM (-08:00)

Brief Update I am home

Monday, January 30, 2012

Monday Evening.

I am home from the hospital finally.

I have a PET/CT scheduled for tomorrow morning.

With nitroglycerine to relieve esophageal spasm, I was able to have Boost+ tonight.

Continue hyperalimentation tomorrow.

Depending on the results of the PET/CT, perhaps a removable esophageal stent is in the offing.

It will take some time for me to chronicle the events of the week-end and to post images from my esophagram and hopefully from my PET/CT.

This all awaits a future post.

Posted by David Shuster at 06:43PM (-08:00)

The Bad News Doesn't Stop

Tuesday, January 31, 2012

This morning, while being prepped for my PET scan, I answered my cell phone. It was Dr. Flam. He had just received the pathology report on biopsies of my distal esophagus done by Dr. Lewis on Thursday. The biopsy material contains Merkel cell carcinoma.

Shortly after arriving home, Dr. Stobbe called me with the results of the scan. There is a large mass of tumor around my lower esophagus, up to 6 cm in length. There are also positive nodes in my upper abdomen.

I have an appointment with Dr. Flam tomorrow at 3:00 PM at which time he will recommend more chemotherapy. Dr. Lewis agrees with that, but I will await the opinion of Dr. Nghiem. I spoke with Dr. Blom, who works with Dr. Nghiem. He was in Washington but will be back in Seattle tonight. I will fax or email the path report, and images from my Barium Swallow tonight, and images from my PET and the report tomorrow.

I began home hyperalimentation today.

Last night, I had the most sleep I've had in a week. It was the peaceful sleep of the ignorant. I wonder if I will sleep that well tonight.

I am not in pain, and the nitroglycerine helps me drink fluids. I have had 2 bottles of Boost Plus today.

I am hoping there is an experimental protocol which will offer me potential benefit, because it seems that more chemo will buy me a period of misery without any guarantee of a period of normalcy to follow, and may preclude any effective experimental protocol.

It should all come together in the next few days.

Posted by David Shuster at 06:17PM (-08:00)

The Short Of It

Thursday, February 02, 2012

Last night, I did have a fairly decent nights sleep, for me. At least I was able to sleep in bed, and not in a chair. The IV feeding ran during the night. However, today, the Boost Plus is not going down easily.

I had my visit with Dr. Flam yesterday afternoon. We had conversations with Dr. Nghiem and Dr. Lewis during this visit. Dr. Flam wants me to start chemotherapy again and made a compelling case for it. He wanted me to begin as soon as today and felt that that would open my esophagus so I could begin eating again. However it would take some time for this and I am in too much distress to wait for this. Dr. Nghiem suggested injecting the esophagus tumor with Beta Interferon endoscopically and then giving radiation to the area of 8 Gy. The second mass near the gastrohepatic ligament might also be treated in similar fashion. However, my esophagus has already had 56 Gy and this is getting close to the maximum. We decided to hold that approach for the time being. I did not want to have any more cisplatin as I want to preserve my hearing and my peripheral neuropathy has not improved and at times is quite uncomfortable.

The plan now is as follows.

Tomorrow, Dr. Lewis will insert a removable stent. Stent Review Article On Monday I will begin chemotherapy with a drug called Topotecan. Information about Topotecan

The drug will be administered by continuous infusion for 5 days, and repeated after 2 weeks off. I don't know how many cycles will be used, presumably this depends on the response.

The drug is available to be taken orally. Perhaps after the first cycle, if my swallowing function has improved, I will be able to do that. More on Topotecan

Nobody discussed the response rate with me, but it seems to be in the 25-40% range, with only rare complete remissions.

Posted by David Shuster at 10:51AM (-08:00)

Too sick to post much

Monday, February 06, 2012

I can't put coherent thoughts together to post. Today, I will see Dr Flam and decide whether to start Topotecan today or delay a few days. The stent is working but I have no desire to eat. Lots of pain, but getting better. Nausea. No desire to eat even though the food goes down. Still on IV nutrition.

Posted by David Shuster at 10:13AM (-08:00)

Another "The Short of It"

Sunday, February 12, 2012

Because I still am not up to writing "The Long Of It"
I have been home since last Wednesday when the Topotican was started, as a continuous drip. I am able to swallow with the stent, albeit not without pain. The pain has been controlled with Vicodin needing less and less, but still needing it at bedtime. I am sleeping better, but not well. At night and at other times as needed, Marinol was prescribed. It is basically synthetic marijuana, supposedly without the psychotropic effects but with the anti nausea properties. So far, it does make me drowsy and does reduce nausea.
Although I am able to eat, I have no desire to do so. I have to force myself to eat food, and I am still on the TPN. I have not had a bowel movement in about a week, but I do pass gas. Sometimes I burp up feculent gas.
Listening to the Grammies tonight, I notice that my hearing is again deteriorating. I am also noting more neuropathy in my feet.
I continue to have shortness of breath and coughing while trying to speak.
With that parade of complaints, I am still optimistic that this drug, the Topo will kill enough tumor to allow me a remission, where I can have some snippets of normal life.
I hope to have the energy to post again, likely Wednesday after I see Dr. Flam.
Goodbye Whitney.
We will always love you. YouTubeVideo
Posted by David Shuster at 11:20PM (-08:00)

Dictated But Not Read

Monday, February 20, 2012

My dad asked me to update his blog. He has been in the ICU for about the past 24 hours, and is about to spend his second night there. His voice, wit and personality have come through beautifully in his blog posts. I cannot emulate those qualities, but I hope to at least accurately convey the ideas he shared with me. If I get some of the ideas wrong, I hope he will soon correct them in a post of his own.

He first asked me to express his deep appreciation for the support he has received from all of you.

He then asked me to share his current status.

Since his last post, his energy had declined. He was given a week of chemo as planned, but then his cell counts became too low to continue. The new plan was to take a week off and then restart. During this time, he was in significant pain (seemingly from the stent, but there was some generalized pain). There were plans for him to have the stent removed on Tuesday and replaced (if necessary) by a smaller stent. The plans were worked out late in the week, but given the long weekend the surgery was scheduled for Tuesday. He was given a 72 hour Fentanyl patch for the pain. My mom changed the patch on Saturday, and a few hours into the second patch, he began to experience shallow, somewhat labored breathing and a drop in alertness. He also had a slight fever in the just under 100 degree range.

My daughter Eva was sleeping over with my mom and dad on Saturday night. As he has done frequently since having the problems leading to the stent, he was sleeping downstairs in a chair. During the early morning hours, after Eva was asleep, my mom heard my dad call for her. She came downstairs and found my dad on the floor with blood everywhere. My dad remembers clearly what happened, and told me today that he had tried to walk to the bathroom but fell. He tried to get up and then fell again, this time hitting his head on the door to the bathroom. While telling the story, he smiled and said "after the second time, I figured I should ask for help." The blood was from the cut on his head. My mom stayed downstairs for the rest of the night, staying awake to keep watch over him. Thankfully, Eva slept through this and only saw a somewhat cleaned up scene when she awoke.

Eva's mom Margaret is my ex-wife, but over the past few years she has become best friends with my current wife Dana and we have been blessed with a strong co-parenting relationship. My mom called me in the morning, before Eva awoke, and after briefly speaking with Dana, we called Margaret. There was a little difficulty reaching her (understandable, she is remarried and has a newborn baby and was probably enjoying the hour or two of sleep her newborn affords her). After a little delay, she got the message and quickly called. She got right in the car and picked up Eva. Eva was well aware that her papa had fallen and was experiencing a turn for the worse, and her mom spent most of the day comforting Eva and crying together with her (Margaret has known my dad for almost 20 years).

I was out of town with Dana and scheduled to come back late Monday. However, it was Sunday and I was going back and forth by phone with my mom as to whether to return early. I told her that the only priority was honoring her wishes and my dad's wishes, and doing what would make things easier for them. She said she did not want me to come back yet, but she would let me know if that changed. She was holding off on calling Dr. Flam because she did not want to wake him so early on a holiday Sunday. I strongly encouraged her to just wake him up (if you're reading this, Dr. Flam, thank you for taking the early call). She did wake him up, but he did not seem to mind. He said to hold off on going to the hospital and just monitor him for changes. I asked my mom to call me immediately when anything changed. I'm afraid I didn't give her quite that much courtesy, though, since I called her a few times just to check in (although to be fair, my cell coverage was spotty so I wanted to make sure she hadn't called and failed to get through).

Some time later that day (probably mid-afternoon, but it is kind of a blur) she called to say she was in the car going to the hospital with my dad and Herb Boro. Basically my dad's temperature had gone to just shy of 101 degrees, which I am told for patients in my dad's condition is a level indicating possible serious problems (as we learned later, probably sepsis). I asked whether I should drive home but my mom said I should hold off. She didn't think things were critical at that point and she said she without a diagnosis of an imminent medical problem, she didn't want me driving home with my wife and two younger daughters at night. I said OK.

Around dinner time, perhaps a bit later, my mom called saying that my dad was not going to just be admitted, but was going to be sent to either the cardiac ward or the ICU. His heart rate was ranging between 110 and 130 and his blood pressure was way up and down. He had also seen his fever rise to 103 degrees. At this point I was gripped with uncertainty and self-doubt. I could drive home right away, but if things progressed even linearly, he would be unconscious or worse by the time I got there (it was about a 4 hour drive). My mom hadn't slept on Saturday night for more than an hour or two, and was heading into a Sunday night without sleep. My mom said the best thing was for me to rest and return in the morning. I went with her request and decided to try to sleep and drive in very early on Monday morning. My thinking was that the best thing I could do was arrive ready to relieve my mom so she could sleep. If I drove home right away, my mom and I would both be going into Monday with no sleep, and if things continued to worsen, we might both start to have our function impaired by lack of sleep some time in Tuesday's early morning hours.

It was the worst feeling I've ever had going to sleep. I was going to sleep knowing that my dad might pass away before morning. I had two dreams that I can recall that night. In one of them, my dad called to say hi and I stopped him after a few sentences and said "dad, you're ok!". In the other dream, it was morning and my dad had stabilized. I woke up well before the alarm and was gripped by a need to know how my dad was. The phone hadn't gone off during the night, so my worst fears hadn't been realized. I hoped that my dad had stabilized enough that my mom was able to sleep for a few hours. I didn't want to wake her, so I painfully waited for an hour before calling her.

I know that the portion of the story I just told is entirely unlike the other blog entries -- it is told from my perspective, and focuses on the experience of trying to react when a loved one is hurting. It is one thing to say that you should expect to make hard choices, have ambiguous feelings about the choices you make, and force yourself to do what you think, on balance, is best for the well being of your loved ones even if it is hard for you. It is quite another to live the experience. I laid out my decisions, the reasons for them and the ambiguity because even if I got it wrong or others would have done it differently, I think it is important for people caring for people in my dad's situation know that they aren't alone in making decisions that reflect their best guess, based on limited facts, about the right thing to do. Had the worst come to pass while I slept, I would surely have felt guilt that I made the wrong decision. I was lucky, or (I hope) rationally reached the right decision in that I arrived sad but rested and I was able to provide the love and support that my parents both needed after a truly awful night. Caregivers, you are not alone in repeatedly rethinking the decision you made that you thought 60% likely to be the right one. Be guided by your love for others rather than your own needs and at least you can tell yourself "I honored the wishes of my loved ones, and took the path I thought was most likely to do right by them."

I jumped a bit ahead in my effort to keep contiguous the portion of the post about the decision to return sufficiently rested to help rather than return 8 hours earlier. So I'll rewind to Sunday evening. I had held it together really well, talking my mom through some of decisions she faced, trying to figure out the right thing to do, even packing up so I could leave without delay in the morning. Dana had been offering to hug me for hours but I just needed to talk with her, and we talked until I'm sure she was well past the point of exhaustion -- but she is an angel and never let on. I was talking to Dana when mid-sentence I said "I need that hug now", she held me in her arms, and I cried. I wish I was better at crying when I need to, because it really helped. Dana made it safe to cry and I did. I realize now how strange it was that my ex-wife was holding my daughter and crying together about my dad probably at the same time as my current wife was holding me and crying together about my dad. Strange, but in a positive way.

While I was driving home, I talked a couple of times with my mom. She told me of the harrowing night they had. Essentially, she was up with my dad all night. They finally got him settled in the ICU and transfused him with 2 units of whole blood, at which point he improved a bit (the platelets they gave him earlier in the process may have helped, but if they did help, they didn't help enough). They had him on IV antibiotics, and that also helped. She was exhausted, and neither parent had slept that night.

I learned something else during that drive that completely surprised me: People don't normally have a copy of their advance medical directive document available. The doctors had asked if there was an advance medical directive, and in the middle of the night my mom was only able to say "yes, at the lawyer's office". Indeed, my dad's was at his lawyer's office (along with mine). We had all made the mistake of not making sure our loved ones had copies of our advance medical directive available. I don't know why I didn't realize that illnesses don't always strike when law firms are open, and that even keeping a single copy in one person's file cabinet doesn't mean that the person who will need it can get it. Luckily, the will was done by the same firm where a terrific person, lawyer, and friend works (Ken Price). I emailed the three lawyers I knew well at that firm, and despite the pretty early hour got a prompt reply from Ken. Of course (as I should have known after doing that whole law school/bar exam thing), the complication was that my mom was the person named to make medical decisions, so only she could approve the release of the document. Ken had the document scanned to a PDF and emailed it to my mom. She forwarded it to me and I printed it when I got home. Lessons here? Give copies of your advance medical directive to anybody who might need it, and realize that even if you have terrific, responsive lawyers they might be ethically limited in their ability to rapidly get you a copy.

I got in the car, copy of the advance medical directive in hand, and drove to the hospital. My mom was home resting and eating a meal. When I got there, I walked in and held my dad's hand. It had only been 24 hours since that first call, but it felt like I had spent a month on the trek there. I didn't let go of his hand for what seemed like an hour (likely about a minute), and in that moment he was my daddy and I was his little boy. I wished with all my heart for my daddy to be better. I looked up, told him I love him, and took a seat next to him.

He had beard stubble, was thinner than when I last saw him, but his eyes were alive. Not just literally alive, but *** alive *** in the way that all humans recognize as the sign that somebody is really there, ready to engage with the world. His body was suffering, but he was still very much himself. I suspect I had been breathing for the minutes leading up to that realization, but I felt like like it was the first time I exhaled all day.

We spent hours talking or just sitting with each other. My mom arrived, and the three of us just talked and enjoyed each other. As you can guess from his blog entries, my dad doesn't keep that much secret. My dad wasn't able to drink easily, and his mouth was very dry. As a result, his voice was crackly and quiet. He turns to me and says "Gary, I've got something I want to say to you". My mom kind of looked up and asked him "is this something I should be here for". He said "no, just Gary". I thought, "this is like one of those moments in the movies where the patriarch leans over and in a weak but firm voice and shares something of great importance." My mom walked out and I leaned in to hear every word. My dad looked in my eyes and said "so here is what I want you to write on my blog...." He proceeded to lay out his thoughts. At first I thought that this was one of those funny moments in a really tense setting where you've misunderstood a fundamental thing. But then it dawned on me that this blog has been an amazing resource to those suffering with similar afflictions, to his family and friends who get to see his wit and learn new things about him with each entry, and to himself in a cathartic way. So it was in fact a moment of immense importance for us -- he had entrusted me with writing an entry in a document of true importance in his life. He shared what I wrote below, but (to again take things out of sequence), we did share some intimate thoughts outside of the blog before my mom returned.

So this blog entry is very much dictated but not read. I listened carefully to what he said, and this is my best shot at conveying it.

He told me that he was very depressed last night, feeling that there wasn't hope for him. But today he has a ray of hope. He said his brain function "is not that great right now", but he is more optimistic based on the fact that we don't yet know if the chemo worked, and it may well have worked. He then laid out two scenarios:

The optimistic scenario: The chemo worked. In a few days he finds out that it worked and the stent comes out, he goes home, he has a chance to beat this thing.

The pessimistic scenario: The chemo didn't work. In a few days he finds out that it did not work and there is not much hope.

He says that everything is based on whether the chemo worked. I then asked him whether there was a third scenario, a middle ground where the chemo didn't work, but he feels better for a time. He doesn't get more chemo, but with pain management he is able to go home and enjoy some quality time before he passes away. He agreed that the middle ground scenario was possible and agreed that I should add it to his blog entry.

As for his current status, his blood pressure is still relatively low (88/50 earlier, but when I left it was around 80/50). I believe his ability to concentrate was cycling with drops in blood pressure, but that might just have been coincidental (he hasn't slept a reasonable amount in couple of days so there are plenty of reasons he might have trouble concentrating). They gave him IV steroids just before I left to try to raise his blood pressure. The risk is a secondary fungal infection, but they said that his blood pressure was just too low and they could control the risk with anti-fungals.

They confirmed that he had sepsis. Blood drawn yesterday was cultured and showed gram positive cocci in clusters. They continue to give him antibiotics, although they're going to monitor his renal function since the antibiotics can create renal function issues.

It turns out that the ICU has a rule that between 7:00 (am and pm) and 8:30 (am and pm, respectively), no visitors can be present. This is to allow the staff to brief each other more effectively during the shift change. We were sent home at 7:00 pm, and my dad indicated that we should come back in the morning. I asked the nurse to call me if he thought that my being there overnight would improve the treatment outlook, and he promised he would. He hasn't called yet, and assuming I don't get a call I'll return to the hospital after the morning shift change.

My dad remains cognitively strong, and the observation he made about his "brain function" being "not that great now", I'm convinced that it is due to difficulty remaining fully awake. When he does focus in, he's sharp as ever. His hands shake when he reaches for things. He is not getting IV nutrition, but he is on a liquid diet and has no desire to eat it. They probably put him back on IV nutrition tomorrow. His temperature is more or less normal (perhaps slightly high, like 99.2 or so). The nurse was laying out the treatment plan for the next few days, which is a signal that at this point the nurse is thinking things are improving.

I hope that my dad is well enough to post for himself soon, but while we wait for that I will do my best to take his dictation.

I know I led off with this, but it is important enough to repeat: My dad is truly appreciative of all of the support.

He has his iPhone with him and is reading email at times when his concentration is good. He may not have time or the concentration to reply to emails, but rest assured that they are reaching him.

-- Gary Shuster
Posted by Gary Shuster at 10:22PM (-08:00)

It's Heavy

Friday, March 02, 2012

My dad has spent the last 12 nights in the hospital. The urgency of the first days has given way to a different world where the hours, days, nights, even weeks seem to run together.

As much as we try to empathize with others, we never really know what they are feeling or thinking. I do know what my dad has seen, heard, and had done to him since coming to the hospital. I've taken a photograph of the view my dad has had continuously for the past ten days. We've taken time to decorate the wall for him with the pictures we think he would most like.

The view from my dad's hospital bed.

On the left is a group shot (taken on the cruise in December). On the right is a grid of photos, arranged as follows:

[Eva] [Sara] [Sammie]
[Bel] [Eli]
[Family] [Rocky]

Eva is my oldest daughter (now 11); Sara is my middle daughter (now 4); Sammie is my brother's daughter (turned 4 a few days ago); Bel is my youngest daughter (now 2); Eli is my brother's son (now 1). Rocky is my parents' golden doodle. Along the bottom of the photo is a banner my 2 and 4 year olds made for him.

I've spent more time with my father in the past two weeks than in any other two week period since I was a child living at home. Over the years, we've talked work, family, and politics, but this is only the second time I can remember that every conversation and moment of silence we shared has been either about a single emotionally important event (in this case, dad's illness) or discussed with an unspoken awareness that we're not discussing that event.

The tenor is captured well by a conversation we had a week ago. My dad was lying in the bed, covered with quite a few sheets. He was shuffling his feet a bit, then stopped, looked over, and said "It's heavy." I leaned in and asked "what's heavy? The blankets?" His response was "no, it's heavy, the stuff I'm thinking about." I asked if he wanted to discuss it, and he said "not now".

His dry wit still shows. A few days later, he was having a tough night, and I said "I'm sorry, dad. I know this isn't how you would have wanted to spend your evening." Without pause, he said "evenings".

Last night my dad said I could update his blog going forward, so I'm putting up this post to bring the blog up to date with what has gone on over the past two weeks. First off, a technical note: I found the long URL for this blog made it nearly impossible to get people to remember how to find my dad's blog. Rather than keep telling them to "search Google for mcc and shuster", I created a new URL that redirects to it: http://mcc.shuster.com/ The blog continues to be hosted on the old URL, but http://mcc.shuster.com/ takes you there.

Since I last updated the blog with the post "Dictated But Not Read", there have been a lot of changes, but the bottom line is that my dad's immediate condition is improved and we have no definitive data on what is going on with the cancer.

The initial issue with sepsis was probably caused by compromise to the immune system as a complication from the chemo with Topotecan. My dad's last blog post before going to the ER noted the various side effects of the Topotican, but noted that "*With that parade of complaints, I am still optimistic that this drug, the Topo will kill enough tumor to allow me a remission, where I can have some snippets of normal life*." Nothing in the time between then and now has worsened the chances of that optimistic outcome.

While I don't have the blood counts from before he was hospitalized, I do have the counts for the last several days:

	2/26/12	2/27/12	2/28/12	2/29/12	3/01/12	3/02/12
WBC count	0.3	0.4	0.5	1.3	2.6	7.1
Platelet	12.0	105.0	76.0	38.0	31.0	27.0
RBC count	3.09	3.10	3.01	2.93	2.75	2.65
Hemoglobin	9.6	9.5	9.2	9.2	8.5	8.2
Neutrophil	0.10	0.10	0.30	1.10	2.30	6.70

Normal ranges:

WBC count 4.5-11.0 K/mcL
Platelet 150-400 K/mcL
RBC count 4.70-6.10 M/mcL
Hemoglobin 14.0-18.0 g/dL
Neutrophil 2.60-8.20 K/mcL

Dad was hospitalized on Feb. 19, so a week after his hospitalization, his counts had not yet recovered. His immune system (apparently Neutrophil is a key thing) was essentially non-functional until 10 days after hospital admission, and not normal until 12 days after admission. His blood (taken upon admission) was positive for gram positive cocci in clusters, and eventually cultured to show presence of a particular strain of staph. He was given broad antibiotic coverage initially, then the coverage was reduced to target the identified strain of bacteria. After he developed a new fever, his coverage was again broadened.

Dad was moved out of the ICU around midnight on Feb. 23. He was moved into a regular room with neutropenic isolation because of the compromised immune system. This meant lots of hand washing and wearing a mask. Note to caregivers: Do not try to drink hot tea with a mask on -- I did it twice before I realized I should just not bring drinks into the room.

Because it was unclear what the initial source of staph was, and because of concern that the port was either the cause of the infection or had become infected, the port was removed on Feb. 26.

His heart rate went from 80 to 90 around Feb. 26, then from 90 to 100 on Feb. 27. On Feb. 28, he stayed awake from mid-afternoon more or less all night. Around 2:30 am he developed sinus tach at 120 beats per minute, and around 3:00 am he developed atrial fibrillation at around 140 beats per minute. When dad heard that, he said "oh shit". Some say doctors make the worst patients, but I think it must be scariest for doctors when they are patients. They know exactly what they should be scared of.

At that point, I called my mom and let her know what was going on. I intended to let her know to come in early, but of course she instead decided to come in immediately.

They gave him an IV medication to restore normal rhythm, and his heart rhythm became normal and his rate dropped back to around 102 to 105 beats per minute. The rate became normal shortly thereafter. On top of everything else, his pain from the stent was spiking at that moment. His temperature went from 38.1 to 37.7 back to 38.4 that night. By the morning, his fever was down to 99.7 (yes, I'm aware that switching between centigrade and Fahrenheit is confusing) and his pulse was 89.

His antibiotic coverage was broadened, and his temperature returned to normal (or a bit below normal actually). By February 29, his immune system had recovered enough to discontinue the isolation precautions. Finally, I can sit next to him and smile without having a mask covering it all up.

On the morning on March 1, after a few days of rainy, cloudy weather, the sun rose to a beautiful purple sky that quickly transitioned to blue. There were some clouds, but they were distant on the horizon. It was an unexpected but wonderful metaphor.

There has been a lot of difficulty with IV lines. After the port was removed, he needed to get PPN (the weaker version of TPN, IV nutrition) in a regular IV line. This irritated his veins. Same thing with some of the antibiotics. He needed three IV lines at one point, but then one went bad. He was suspecting it would go bad, and one night after starting the PPN in that IV line, he experienced a profound hot flush, lasting for about 5 minutes. They pulled that IV. Another IV went bad later that day. They put in a new line. The new line and the third "old" line went bad today. He currently has only a single line. There is an open question about whether or when they will put in a central line, such as a "PIC" line.

The pain from the stent has been continuous. He had the stent removed at 3:00 p.m. today, March 2. The removal went very well. His esophagus was fully open. The doctor reported seeing material that had the appearance of necrotic tumor. He took a biopsy, and results of the biopsy should be available either Saturday or Monday. The esophagus remaining fully open and the observation of potentially necrotic tumor are both positive signs. The stent removal was just a few hours ago, so we don't yet know whether the esophagus will remain fully open.

I leave it to my dad to discuss his feelings about all of this, and I hope he will resume blogging soon. I can say that he has experienced some days when he is very positive, and some days when he is very negative, and those feelings do not always correlate to how well he is doing physically. There is a lot of uncertainty -- will his esophagus remain open? Will his esophageal neuro-muscular function be good? Will he be able to eat enough to get off of IV nutrition? When will he get a PET scan? What will it show? What will the biopsy show? What will it be like to go home? How much care will he want? If the tumor did shrink, what would another round of chemo be like? Of course, there are also the important big picture questions.

Dad is still groggy from the anesthetic, but he reports a reduction in pain after removal of the stent.

Tonight my mom is staying at St. Agnes with dad. My middle brother, Brian, goes in for surgery tomorrow afternoon (Saturday). It is surgery for something causing esophageal issues. My youngest brother, Michael, arrives tomorrow evening. I expect to spend tomorrow night with my dad, and my mom expects to spend tomorrow night with Brian. That is a whole lot of activity in a short period of time. Thankfully, my wife has been amazing about watching the kids so I am free to be there for my dad.

Dad isn't yet feeling up to having visitors or taking calls. He greatly appreciates all of the friendship and support.
Posted by Gary Shuster at 02:10PM (-08:00)

There's No Place Like Home

Monday, March 05, 2012

Last night dad said he was hoping to go home on Tuesday or Wednesday. I told him that it lined up pretty well with my guess that he would be going home by around Thursday. As it turns out, we were both wrong: Dr. Flam just signed the discharge papers.

Doc Dave is going home today.

It is such great news. There are dozens of little details that we will need to take care of in the next few hours and days, but they all seem trivially easy compared to the battle my dad just waged and won.

Dad's war with Merkel Cell Carcinoma continues, and every battle he fights shows his courage and serves as an example and inspiration to me. It should come as no surprise that we discussed how to proceed with dignity and comfort should this battle have gone badly, and dad's ability to initiate that blunt and difficult discussion speaks to his inner strength.

I realize I paid very good attention to how my dad interacted with my grandfather when my grandfather was ill, because I had a rich reservoir of observations to model my care taking behavior on. When I face a serious illness, as we all eventually do, I now have a heroic fighter to model my response to illness on as well.

There is a story they used to tell students on their first day at Harvard Law, and I suspect I'll tell it a bit wrong. My recollection is this: Two hunters are sleeping in their tent in the woods. An enormous bear comes crashing through the forest and roars. One hunter starts putting on his shoes. The other, still barefoot, says "Why are putting on shoes? You can't outrun the bear!" The first hunter says "I don't need to outrun the bear. I just need to outrun you."

Of interest is that my dad considered himself stage IV on November 24, 2010. According to his post last year, he had only about a 25% chance of being alive today, and some people in fact do outrun and eventually survive the bear. Every new day that my dad outruns the MCC is a victory we will celebrate.

On a practical note, my dad is surely going to be exhausted for the next few days and will be very unlikely to take visitors or phone calls. The transition from hospital to home is one that we will all need to focus on.
Posted by Gary Shuster at 10:54AM (-08:00)

Two Steps Forward, One Step Back

Tuesday, March 06, 2012

Dr. Flam signed my dad's discharge papers early yesterday morning, and he was discharged mid-afternoon yesterday.

After the stent was removed, my dad actually enjoyed chicken noodle soup. He put away quite a few lemon yogurts and bowls of cream of wheat. His eating was less enthusiastic yesterday, but I wrote that off to jitters about going home. Last night he said he had no appetite, but managed to eat some soup and a lemon yogurt. I didn't see the pattern, but in retrospect, it was an echo of the earlier pattern that preceded acute esophagus issues.

This morning started as a really normal day for me. Amid the buzz of my three daughters getting ready for school, I called my parents around 8:00 am to see how dad's night went. Me: "Hey, mom, how did dad do last night?" Mom: "I can't talk. I'm on the other line with Dr. Lewis." Me: "Is everything OK?" Mom: "No, he can't swallow again, he's going to the hospital. I'll call you back in a minute."

I wanted to cry, and I did tear up, but that is all I had time for. It was time for the team to pull together. The day went from normal to high gear.

My youngest brother, Michael, helped my mom get my dad ready to go to the hospital. In the meantime, my other brother, Brian, was still recovering from his Saturday surgery. Brian wasn't feeling great. In the midst of it all, my mom had to go to the doctor. To top it off, my youngest daughter, Bel, stopped getting ready for school and started complaining she didn't feel good. She was off to the doctor. I had a regularly scheduled doctor's appointment.

My dad was scheduled to have a PEG feeding tube and a new (smaller) stent put in at noon, and was supposed to be at the hospital for 10:30. So the morning went like this:

8:45 My wife, Dana, took Sara to school
8:45 I took Eva to school
9:00 I went to Home Depot to buy a wireless doorbell for dad to use as a call button (press downstairs, rings upstairs)
9:15 Mom went to the doctor
9:40 I went to the doctor
9:45 Mom drops off an antibiotics prescription at CVS, they say they can't fill it fast enough so she can get home in time to take dad to the hospital.
10:00 Michael had arranged to have a supplier come over and evaluate whether a chair lift can be installed on the staircase. Michael handles the visit, but it doesn't look like it is going to be something that makes sense to do.
10:10 My wife Dana volunteers to pick up my mom's prescription at CVS and take it to the hospital.
10:15 I pull up at my parents' house as they're putting my dad in the car
10:16 Youngest brother Michael drives my dad's car to the hospital; I drive my car to the hospital; my mom drives my dad in her car to the hospital. Turns out we actually needed the flexibility of multiple cars, so lack of carpooling was good
10:30 Shuster caravan arrives at hospital
10:45 Dana arrives with the prescription. CVS gave her my dad's prescription, not my mom's. My mom needs those antibiotics. Dana heads back to CVS to get the prescription. Dana doesn't complain at all, which is more than I could have pulled off.
11:15 Dana arrives with the correct prescription. We discuss registering Sara (our middle daughter) for Kindergarten, which apparently requires camping out at the school by 6:00 a.m. tomorrow in order to avoid getting assigned to a school all the way across town. We realize that we have a problem because Bel's doctor appointment is 2:00 pm and we won't have a free person to pick up my oldest daughter Eva at 3:05 p.m. Dana calls Margaret (Eva's mom, my ex-wife) and she cancels her doctor's appointment so Eva can take the school bus to her house. I'm super-thankful for a very functional blended family.
11:45 Dad is having pain and gets a painkiller via IV (the IV went it without much difficulty, a good thing)
12:00 Dad is taken to the endoscopy suite, then a bit later to radiology where the procedure will be done.
12:05 We all talk with Dr. Lewis. Michael, mom and I are sent to the waiting room.
12:10 We wait.
1:00 Dr. Lewis gets us, and tells us the procedure went well. He walks us back to where dad is. We ask him what the biopsy results were from the sample he took on Friday when removing the stent, and he said he didn't have them yet, but that Dr. Flam would have them. Mom puts in a call to Dr. Flam asking for them.
1:10 Michael goes home to keep an eye on Brian. Mom and I wait for dad to wake up.
1:30 Dad wakes up, we visit with him, he's barely awake. We go back to the waiting room

so he can sleep.
2:00 Dana takes Bel to the doctor. Dual ear infection. Dana's third trip to the pharmacy is underway.
2:00 Mom and I are shown a really bad video of a woman with "flock of seagulls" hair explaining (incorrectly, it turns out) how to use a feeding tube. There are 20 minutes I'm never getting back.
2:30 Dad is ready to go, mom goes to get the car. Dad tells me that he has a vague recollection of fighting the doctor's efforts to get the tube in. That probably explains the extra anesthetic he got and the longer than expected groggy period.
3:00 Nurse helps dad get into the car.
3:15 We arrive at my parents' house. (I think I might have gotten about 30 minutes off on this schedule, since 3:15 seems earlier than it really happened).
3:30 Dad is in his bed, exhausted.
3:35 Dad is scheduled to see Dr. Flam at 8:30 tomorrow, but we think today's events probably make that appointment unnecessary. Mom calls Dr. Flam again asking for biopsy results and whether he needs to go to his appointment.
4:00 First Super Tuesday results come in. Dad turns it on and watches for a few minutes, then naps.
4:55 Mom places third call to Dr. Flam, and he's already on the exchange. So we still don't know if we have biopsy results or an appointment tomorrow.
5:30 In the ironic moment of the day, I get a call from St. Agnes billing about a bill I got and apparently didn't pay quickly enough -- because I was too busy caring for my dad as a St. Agnes inpatient. The message said to call them back and that they were open until 6:00 p.m. I called back right away, but it turns out that they were only open until 3:00 p.m. Very annoying.
6:00 Dad is settled. He has some pain related to the PEG, but he seems OK. I head to the store to get dinner.

Dad wants to have a few days without a doctor or hospital visit, and we will try to accomplish that. Today we had one doctor visit for each generation (my mom, myself, and my daughter) -- plus my dad's outpatient procedure.

My wife has been great. My oldest daughter, Eva, has been a terrific help. My youngest daughters have been solid. My youngest brother took control of what needed to be controlled. My middle brother soldiered through his discomfort. My ex wife helped. My mom was amazing, fighting through her infection. There is no substitute for a family that pulls together. My dad must have done something right because he built the framework for all of this since becoming a parent in 1967.

I'm tired just looking at the list of what happened today. I wish there was some witty closing sentence I could use, but I have to recycle the one thing I said today that got my dad to smile. While we were waiting for Dr. Lewis, I told my dad "you know, just three more of these surgeries and the fourth one is free." It was nice to see him smile.
Posted by Gary Shuster at 08:09PM (-08:00)

Ignoring the Sword of Damocles

Monday, March 12, 2012

Dad wrote a post a little more than a year ago asking "Is This What it is Like to be on Death Row?" He posited that "in a way, my situation is similar to that of somebody on death row. Merkel cell cancer is the executioner. Dr Nghiem is my defense attorney. He is appealing my sentence to higher courts." It was an apt analogy then, and intervening events have unfortunately brought another level of accuracy to the analogy. A year ago (even a few months ago), dad could forget he was on death row for long stretches of time. He could play with his grandchildren, dine and go on cruises with his wife, play bridge, and work. By contrast, a death row inmate may forget from time to time that he is on death row, but he remains imprisoned, unable to enjoy even a moment of normal life. The physical impact of the cancer is now making it harder to enjoy normal life.

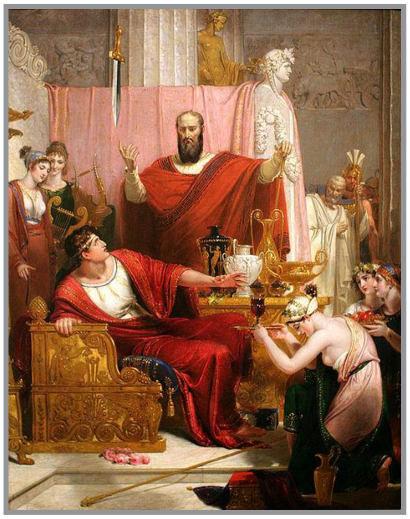
My dad isn't a lawyer, so I doubt the distinction was intended, but when he wrote about death row, he said that he is "appealing my sentence to higher courts." Until now, we were hoping his conviction would be overturned, eliminating any accompanying sentence. I'd still love to see a full cure, but at this point we're through most or all of the appeal and a lengthy stay of the sentence pending appeal would be a welcome outcome on its own. The battle isn't over yet, but the most promising appeals of the conviction are behind us. I'm sure every death row inmate listens until the last second for the phone to ring with a pardon from the governor or a stay from the Supreme Court, and sometimes it does.

Hope remains, but as it diminishes we cross into another problem and another legal analogy: The chilling effect. At some point, the death row inmate in my dad's example may stop studying for the GED, stop learning new skills, and toward the end may even refuse to start a book so lengthy he might not finish it before his scheduled execution date.

While we wait, hoping for a stay from the Supreme Court of medical progress and treatment outcomes, dad battles daily with the question of how to spend the time he knows he has, regardless of treatment outcomes. Unlike the death row inmate, dad is home from the hospital, released from the confines of the death chamber's anteroom. He is free for now, but some of the trappings of his sentence remain -- a PEG feeding tube, weakness, and pain. All of the trappings can, for now, be managed (the pain with Vicodin, the weakness with physical therapy). The knowledge of his situation, however, is not quite so simple to manage.

Thurgood Marshall wrote in a dissenting Supreme Court opinion "That this Court will ultimately vindicate [somebody] ... is of little consequence - for the value of a sword of Damocles is that it hangs - not that it drops."

Our challenge is to find moments we can ignore the Sword of Damocles. The Sword of Damocles is a sword, suspended by a single hair, hanging above a ruler's throne, casting such a pall that the ruler soon begs to cede the throne (see footnote 1 below for a more detailed description).



Cicero says of the Sword of Damocles, "Does not Dionysius seem to have made it sufficiently clear that there can be nothing happy for the person over whom some fear always looms?"

In the days following dad's diagnosis, we understood Merkel Cell Carcinoma to be so deadly and aggressive that it seemed a Sword of Damocles, destruction a hair's breadth away. I struggled to accept that there was nothing to be done, but that was not in my nature. I found the MCC Google Group. George, and soon others in the group, reached out. Dr. Nghiem got involved. We soon realized that the sword may be hanging, but by something far more robust than a hair. Indeed, it was by no means certain that the sword could not be removed. Nearly two years later, the rope holding the sword may be fraying, but dad and the family have enjoyed birthdays, vacations, and good times even in the shadow of the threat.

Unfortunately, the chilling effect of the threat is settling in. I can't imagine what passes through dad's mind, but I know pain keeps him awake many nights. I doubt even he knows whether it is physical pain or emotional pain that is behind the insomnia. He does not feel up to having visitors, updating this blog, or engaging in anything that requires extended concentration. His cognition seems fine, but the weight of his circumstances surely makes concentration a hard task.

My oldest daughter, Eva, has visited him a few times. He spent a few minutes with 4 year old Sara yesterday. Sara said "I wish you could feel better."

The question is whether dad can feel better. Physically, it seems on balance that he does feel better. There is new pain on the left side under the lung (pleural pain), but it is somewhat less than the now-discontinued posterior mediastinal pain was. Dad is still using a walker for infrequent walks, but he is now sitting in a chair regularly, which wasn't happening last week. Dad is engaging in discussions more frequently, but he is becoming short of breath more quickly than before. His voice has been raspy and almost godfather-like since his stent replacement surgery. Dad is refusing most food and water by mouth, but he getting nutrition via a PEG tube.

Physical improvement aside, the sword still hangs, and the chill it casts has become quite strong. Other than those who die young and suddenly, the Sword of Damocles will one day hang over each of us. That dad has enjoyed nearly every day since his diagnosis is a testament to his strength. That he is having trouble enjoying the early days of his release from the hospital is not surprising.

He is scheduled to see Dr. Flam again on Friday, March 23. They will likely schedule a PET scan at that point. Dad saw no point in doing a PET scan earlier -- if it was good news and the chemo worked, he wouldn't be strong enough for another round yet anyhow. If it was bad news, learning it earlier wouldn't be helpful either. The esophageal biopsy that was done in conjunction with the removal of the original stent showed dead and dying tumor cells, so there is some objective evidence that the chemo worked. The closure of the esophagus after removal of the first stent and the new pain are of concern to dad. So we live with a couple of weeks of uncertainty. There is some thought that the left pleural pain may be pneumonia-related, so there may be some intervening diagnostic tests.

I wish there was some positive note I could conclude on, but it eludes me. It was three weeks ago yesterday that my dad went to the ICU, and so it has been three weeks since the reality of what is going on has solidified. If dad gets to feeling well enough to have some normal days, I'm sure he will take advantage of them. The appeals aren't yet exhausted either, and nobody refuses a pardon.

Footnotes:
1. From Wikipedia's description of the Sword of Damocles: The Damocles of the anecdote was an obsequious courtier in the court of Dionysius II of Syracuse, a fourth century BC tyrant of Syracuse, Italy. Pandering to his king, Damocles exclaimed that, as a great man of power and authority surrounded by magnificence, Dionysius was truly extremely fortunate. Dionysius then offered to switch places with Damocles, so that Damocles could taste that very fortune first hand. Damocles quickly and eagerly accepted the King's proposal. Damocles sat down in the king's throne surrounded by every luxury, but Dionysius arranged that a huge sword should hang above the throne, held at the pommel only by a single hair of a horse's tail. Damocles finally begged the tyrant that he be allowed to depart, because he no longer wanted to be so fortunate. Dionysius had successfully conveyed a sense of the constant fear in which the great man lives. Cicero uses this story as the last in a series of contrasting examples for reaching the conclusion he had been moving towards in this fifth Disputation, in which the theme is that virtue is sufficient for living a happy life.
Posted by Gary Shuster at 02:20PM (-07:00)

I'm Still Alive

Wednesday, March 28, 2012

The events of the past 6 weeks or so have brought me close to death but failed to do me in. Although my head is not as clear as it was, I will attempt to recount my brushes with the grim reaper.
About 5 11/2 weeks ago, sleeping on my recliner, I needed to get up, for some reason. I was sedated with a phentonyl patch. I remember losing my balance, getting up and then falling head first into the glass door to the back of the house. Helped back onto the recliner, I slept the night, with a lump the size of a lemon on my forehead. Herb Boro called Judy the next morning and asked if there was anything he could do. He came to the house and immediately he and Judy took me to the hospital.
I was admitted with no platelets and no white blood cells, low hemoglobin. A CT scan showed no intracranial bleeding but I am sure I had a concussion. A blood culture

revealed Staph Aureus, but not the antibiotic resistant type. My port had to be removed and I went on vein destroying IV nutrition. Every venipuncture was agony.

I had blood transfusions, platelet transfusions, drugs to encourage WBC production, labs, regular blood sugar measurements with oversized lancets, insulin.

After 2 weeks I was ready to go home, but my esophageal stent had been removed and I could not swallow. The day after discharge, I was back for a PEG tube and stent replacement.

I was home again, relatively comfortable for about 2 weeks when my heart rate went up to 180. No chest pain or other symptoms. In Dr Flam's office, he diagnosed atrial fibrillation and converted me to sinus rhythm with drugs.

Today, I saw Dr. Dale Merrill, an old colleague and cardiologist who confirmed I am on the right track.

Biopsies of my esophagus showed Merkel Cell cancer, but the repeat biopsy at the time of insertion of the smaller recent stent showed a lattice of connective tissue without living Merkel cells. Dr Lewis thinks it is an optimistic sigh that the Topotican worked. Dr Flam thinks it is an artifact of crushed cells.

Probably I will have a follow-up PET scan in the next 2 weeks to learn more.

So, after lying in my hospital bed conjuring up methods to hasten my demise, I now have room for optimism.

Tonight, I plan to briefly appear at the Lady Antebellum concert at the Save Mart Center.

I hope to be alive to celebrate 50 years of marriage to Judy, who has been a rock in support of me.

Posted by David Shuster at 04:15PM (-07:00)

Status Quo except increasing right sided pain

Monday, April 09, 2012

Here is the latest update of my physical and mental status.

I am awake and oriented, relatively alert although with decreased ability to concentrate.

Last Friday night, we had a miniature Seder with Gary, Dana, Eva, Sara and Bel. A very much abbreviated service in which the Four Questions were asked and the Afikomen was hidden was followed by a great dinner, of which I was only able to partake of a small amount. The highlight was gifts given to the girls for returning the Afikomen.

Judy worked very hard to make this a success.

We went to see the Trans Siberian Orchestra on Tuesday at the SaveMart Center and I was able to stay for much of the show. Brian was in town for a follow-up visit with his Doctor so we got an extra ticket for him. It was a great show.

I have been able to climb the stairs with some difficulty and to take showers in our upstair shower, much better than sponge baths in the downstairs bathroom. I was also able to lie down in our bed, a pleasure very much missed in the past few months.

We have had a few close friends come for brief visits.

My heart rate is generally well controlled in the mid 80's by Amiodarone, 200 mg bid. I am also taking Prilosec, 200 mg BID as well as medication to shrink my prostate to combat occasional urgency incontinence, a sleep aide, and pain medication. Aleve twice daily seemed to work well, but I have been having worsening right sided upper back pain and right rib pain for which I have just resumed taking hydrocodone. I seem to be improved this morning. My shortness of breath also seems improved.

I fear this pain is due to bone metastases, and will have a PET scan next week to shed some light on this problem and determine the extent of disease.

Although with the esophageal stent present, I can eat almost anything, but I have little desire to eat. Perhaps it is because of dry mouth, for which I am using Biotene with some relief. Most of my calories are ingested through my gastrostomy tube. I do have some symptoms of gastric overfilling and worry about the cancer pressing on my duodenum. But enough drowning in self pity.

The sky is clear. It's warm ouside. I shall sit out and catch some rays.

I can get around quite well with my walker.

It is only 1 1/2 months until Judy and I celebrate 50 years of marriage.

Sara turns 5 today. She and Bel will visit this afternoon.

Posted by David Shuster at 11:38AM (-07:00)

PET Results

Saturday, April 14, 2012

Friday, I had a PET scan. it looks like the Topotican did me no good. A 3 cm node in the gastrohepatic area now measures up to 8 or 9 cm, pressing on my stomach. The esophageal mass is also larger, and may be compressing my left main bronchus. I have had respiratory difficulties with 2 episodes at night of what seemed like acute asthma. I am now on home oxygen and with it, attempted to go upstairs for a shower. That was a failure as I had the third asthma-like attack.

It looks like I have a choice of waiting to die or going on Votrient. I somehow doubt my Insurance will pay and I think it will cost a lot of money.

Dr. Nghiem is encouraging about this, saying it helps in about 50% of cases and if Dr Bhatia and Dr Flam agree (Appointment with Dr Flam Monday), this seems to be the last arrow in my quiver.

Posted by David Shuster at 05:13PM (-07:00)

About the Author -- Curriculum Vitae

Monday, April 16, 2012

CURRICULUM VITAE
DAVID N. SHUSTER, M.D.
PERSONAL DATA:
Date of Birth: August 18, 1940
Place of Birth: Montreal, Canada
Marital Status: Married (Judy)
Address: [redacted] Fresno, CA 93720
Telephone: Business: [redacted] Home: [redacted]
EDUCATION:
COLLEGE: McGill University B.S., 1961
MEDICAL SCHOOL: McGill University M.D.C.M., 1966
INTERNSHIP: Jewish General Hospital-Montreal June 1966 - June 1967
RESIDENCY: Jewish Hospital-Brooklyn, N.Y. Obstetrics and Gynecology June 1967 - December 1967
Brookdale Hospital-Brooklyn, N.Y. Pathology January 1968 - June 1968
McGill University-Jewish General Hospital Radiology July 1968 - June 1971
PRACTICE: Diagnostic Radiology St. Mary's Hospital, Montreal June 1971 - August 1976
Saint Agnes Hospital, Fresno, California September 1976 - April 1993

Fresno Imaging Center Medical Group May 1993 – December 2004
Sierra Imaging Associates Medical Group January 2005 to present

[Note that this version of the CV predated his work at Kaiser]

LICENSES/CERTIFICATIONS:

L.M.C.C. 1968 National Board of Medical Examiners 1967 Certified Specialists of Province of Quebec 1971 Fellow of Royal College (by examination) 1971 Royal College certification (Radiology) 1971 Diploma of American Board of Radiology 1972 California Certificate Number [redacted]

MEMBERSHIPS:

Fresno-Madera Medical Society California Medical Association Central Valley Radiological Society California Radiological Society Radiological Society of North America American College of Radiology

CLINICAL ASSISTANT PROFESSOR: U.C.S.F. 1980 - 2000

LECTURER IN RADIOLOGY: McGill University 1973 - 1976

PUBLICATIONS: Shuster, D., Palayew, M.J., "Accordian-Like Compression of a Calcified Splenic Artery: A Plain Film Roentgenographic Sign of Splenic Enlargement". AJR 116:423-425, 1972.

Posted by Gary Shuster at 01:26PM (-07:00)

Following an ambulance

Wednesday, April 18, 2012

It is a surreal experience to follow an ambulance with your father in it.

I got a call around 9 am from my mom saying that my dad is in severe respiratory distress and he doesn't think he can make it to the hospital in a car. My mom said she was probably going to call an ambulance. I told her I agreed, call the ambulance. I arrived there just as the paramedics (full fire truck + ambulance -- I paid my taxes yesterday, and all of my annoyance at writing that check is gone with this demonstration of what those taxes pay for) were getting there.

My mom and I filled the paramedics in.

My dad is currently in the ER being seen. There is a one-visitor-at-a-time policy, and I'm sure my dad would be more comfortable with his wife at his side, so I'm patiently waiting in the waiting room. The doctors are confirmed atrial fibrillation. They also hear a wheezing noise they don't like and they're taking him in for a chest x-ray. I assume the cancer impinging on the bronchi is making them worry about pneumonia, but I'm not even close to being a doctor so that is just guessing.

I'm post more when there is more. At this point, it is all scary, sad, and a great unknown.
Posted by Gary Shuster at 10:57AM (-07:00)

Back in the ICU

Wednesday, April 18, 2012

Dad is back in the ICU. His situation is very serious.

CT scan results showed that the left lung is better than the right, but the left bronchial branch is completely closed off (presumably tumor pressing it shut). The right bronchial branch is fully open, but the right lung is very compromised with pneumonia. There is some pleural effusion.

One of the nurses and one of the doctors, on different occasions, said that the outlook was very bad.

Other than the Dilaudid causing him to be a bit loopy, he is very cogent when his O2 saturation is good. When it isn't good, he is very out of it, eyes rolling back, etc. His O2 saturation ranges from 70% to 100%. He is on a BPAP mask as he refused intubation. He has also given a very broad do not resuscitate order. In relation to the intubation refusal, he said, paraphrasing, "instead of intubating me, just shut me down with morphine. I've just about had it. I've had enough."

His breathing is very labored. It reminds me a lot of when my daughter Eva was a newborn and developed RSV. You can see his stomach trying to suck in to help draw air into the lungs.

He seems to be cogent, at peace, and just wants to stop hurting.

I love him. I hope tonight goes the way he wants it to.
Posted by Gary Shuster at 06:46PM (-07:00)

Dead

Friday, April 20, 2012

Dad died at 10:58 p.m. on April 18, 2012. He was 46 days away from his 50th wedding anniversary. In the week prior to his death, he conducted a Seder, watched his granddaughter open birthday gifts, watched Stanley Cup hockey, considered treatment with Votrient, and saw his doctor. He even saw a concert a couple of weeks ago.

When he first got to the ICU on April 18, he asked me to please update his blog if he died. I promised I would. I will expand this post further as I get my thoughts together. I don't want to post too much until I can do so cogently.

I miss him already.
Posted by Gary Shuster at 12:59AM (-07:00)

Obituary

Saturday, April 21, 2012

The following obituary ran in dad's hometown newspaper:

DAVID NORMAN SHUSTER, M.D.

Dave Shuster died on April 18, 2012 after fighting a courageous battle with Merkel Cell Carcinoma. He was born on Aug. 18, 1940 in Montreal, and moved to Fresno in 1976. He was a talented diagnostic radiologist well respected within the medical community.

Dave met his wife, Judy, more than 50 years ago. He was a loving father to his three children, Gary and his wife Dana, Brian, and Michael and his wife Leanna. He was blessed with 5 grandchildren, Eva, Sara, Sammie, Bel, and Eli. He is also survived by his mother, Isobel and his siblings, Jon, Robert and Ellie.

In addition to his professional and family accomplishments, he achieved the rank of gold life master in bridge. He also always had a fun time with his poker buddies. He never missed an opportunity to play with his grandchildren.

A memorial service honoring his life is scheduled at Temple Beth Israel for Sunday, April 22 at noon. In lieu of flowers, remembrances may be made to Merkel Cell Carcinoma Research (details at http://donate.shuster.com) or to Temple Beth Israel at 6622 N. Maroa Ave., Fresno 93704.

The world is a better place for Dave's being here. He lives on through his children, grandchildren, and kind deeds.

Posted by Gary Shuster at 12:50PM (-07:00)

Thank you, MCC Google Group

Sunday, April 22, 2012

I wrote an email to the Google Group for MCC (http://groups.google.com/group/merkelcell), which is a private group for those battling Merkel Cell Cancer and for the people fighting alongside them (if you have MCC or are supporting somebody with MCC, you really need to join that group). I realized after writing it that my dad would have wanted me to share my thanks and thoughts for this group more broadly. The email I sent is as follows:

Thank you all for your wishes and your kind praise of dad.

I've linked the obituary at his blog http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2012/04/obituary.html

His memorial service is today, and while I'm not going to be distracted with technological issues, I do plan to set up a video camera to capture the event. Since you've become his family in the same way that soldiers fighting a battle side by side become family, In a war, there are many battles. Some warriors are felled in battle. Some throw themselves into the path of danger to protect others (as with experimental surgeries). Some mentor other soldiers, preparing them to survive their part in the way (a role my dad took on). Some get lucky and survive, and some powerful warriors are less lucky. But in the end, spending years with a band of brothers and sisters fighting a heartless, inhuman beast turns strangers into family. And so it was for my dad. He implicitly sought a promise that I'd care for my mother, but the only explicit promise he asked of me on his last day was that I update his blog if he didn't make it. This family, forged in a shared, frightening common battle against a heartless beast, this family forged in common support and empathy, this family that met not in person but in heart, this family was on his mind on his last day. As well it should have been. He died with me at his side, with his wife at his side, with his children and grandchildren in his heart, and with your thoughts and presence surrounding him. Thank you for that.

I'd like to post the memorial so you can watch it. I'm not going to be babysitting the video camera, so if there is a technical failure to record the video, so be it. But if things go as planned, after a few days I'll be able to put up a link to the video.

I see about 3 more posts to the blog. "Eulogy", "Dying", and "The Future" are likely titles. I intend to post the eulogy I wrote for him after I deliver it today. I've been drafting a pretty detailed account of his last day called "dying" (incredibly hard to write, but he found it so important to bluntly share his experiences to help others prepare for what they might face). I then intend to close with a post about the future, although the ideas about that are kind of amorphous so I'm not sure if that post happens or if it happens the way I'm thinking about it today.

After the last substantive blog post, I'm considering a fundraising and patient support blog post. This would be links to a PDF version of his blog, a print version, and perhaps a Kindle format version. They would be available at cost (so PDF free, ebook free, if distributed via Amazon the minimum cost, physical book probably expensive even sold at cost). Patients need support, and family, friends and patients would be encouraged to use the book without paying. For those who find value in the book and who are able to afford it, I would include information about how they can pay what they wish, donating to MCC research donate voluntarily in exchange for the book.

I'm off to prepare to bury my father. I'm having a hard day, but having just read this thread of comments [a set of emails sent by MCC group members in response to my post that he had died], my day is that much easier.

The power of community cannot be overstated, and the power of this community is particularly strong.

Thank you for your love. I know my dad was grateful for your support to the end, since he went out of his way to expressly say so. He was fitted with a BiPAP mask much of the day, so he spoke perhaps a thousand words or less on his last day and he reserved some of those for you. I'm glad he did so. You deserve it.

Now I ask each of you to honor him by beating your own MCC. Please make my father one of the last to die by this disease. You've described it as a beast and a bully and by all manner of other names, as my dad did, but ultimately it is just some cells in your own bodies making the horrible mistake of thinking that they should keep on reproducing. It isn't an intelligent enemy or even a powerful enemy. It is nothing more than a biological mistake. This isn't to underplay how virulent it is -- it took my dad, a powerful, determined, brilliant man. But this isn't an intelligent enemy or even a particularly crafty enemy. It is a mistake of biology, and it will be beaten. I know it is disheartening to see a warrior like my dad lose his battle, but it would be a tragedy if his death were to do anything but strengthen each of your resolve to beat this thing.

I know that this group has been very civil and avoided language that wasn't family friendly, but in the heat of the moment, waiting to be let in to see my dad, I posted something to facebook that captured my feelings about MCC. In the law, we make an exception to the hearsay rule for an "excited utterance", under the theory that when somebody is experiencing an enormously emotional, critical moment, they aren't going to lie and they will speak what they're really thinking. So here is the post, which expressed in no uncertain terms what I was thinking at the moment: "Just had the surreal experience of following an ambulance carrying my dad to The hospital. spO2 well <80% possible atrial fibrillation, irregular heart rate ranging from what I saw up to 180. Fuck you, cancer." As I prepare to bury my father, let me say that "Fuck you, cancer" was, if anything, too kind to cancer. Cancer, you're taken my dad away from his grandchildren. You've robbed his MCC group family of his wit, advice and love. You've made my mom a widow. You've made me the patriarch of my family at 45. You've sent a man who could have saved hundreds or thousands of lives practicing medicine for another decade or two to the grave. You, cancer, must die. You faced a resolute foe in my dad and beat him, but he wasn't your only enemy. There are leaders like George and Audi who are organizing forces against you. You have smart and creative enemies like Paul Ngheim who are preparing to crush you as surely as you've crushed lives and families. Your days are numbered, and when they write your obituary, I'll be proud of my dad's role as a member of the force that fought against you helped put you in the ground.

I love my dad and I'll miss him. I know you all feel the same way. Thank you, on his behalf, not just for the strength you provided him, but for the opportunity to give him to chance to beat MCC if not in himself, at least in the others he helped along the way.

Posted by Gary Shuster at 08:08AM (-07:00)

Eulogy

Wednesday, May 02, 2012

I wrote the following as the eulogy I intended to deliver at dad's funeral. I ended up delivering a somewhat different version (the reality of speaking at a funeral is that it is a rare person who delivers written remarks without giving in to emotionally-driven spontaneous changes).

* * *

I am planning to cry, so please bear with me if I need a minute during this.

I've given eulogies before, but I've stuck with facts, praise, and prose. Dad deserves that kind of praise and prose, and he'll get it from me and others. But I had the privilege of spending weeks living with him in the hospital, switching nights with my mom, and helping him as he did thing after thing for the very last time. It was hard to watch him suffer, but I am grateful I was able to give him the gift of companionship, the gift of making sure the hospital followed his wishes, and to enjoy the gift we gave each other of leaving nothing unsaid between us. So instead of talking about how great a dad he was – and he was, and you'll hear that over and over today – and instead of offering a biography, I want to share his last moments with you.

I'm coming to grips with the fact my grandfather was the patriarch of the family just five years ago, dad was the patriarch until Wednesday, and that role now rests with me. But that also means that dad isn't 71 years old anymore. He isn't old, or sick, or worried, or battling cancer. I see him reflected, as if he were still alive, in the things my daughters do day to day, in my brothers' kindness, in my mother, and frankly in my drive to do the right thing no matter the personal cost – particularly when the right thing involves keeping my family happy and safe.

We die as we live, and his last day told the story of his life.

He lived as a strong man, a man who knew what he wanted. On his last day, he knew he was going to die, and he didn't want to suffer. In the morning, he told mom he was in respiratory failure, and she called for an ambulance. As he left his home for the last time, even struggling to breathe, he was having a technical discussion with the paramedics about his condition, he liked the details of stuff and he loved medicine.

Mom and I drove to the hospital and after a long wait they let her in to see him. Mom came out and said they only would give one pass and asked if I wanted to use the pass to go in. Mom was the love of his life and I knew he needed her by his side. I told her that and she just nodded. Of course, she knew it too.

Mom is crafty, and eventually got the doctor to give me a pass. When I got back there, I insisted that the doctor talk with us about dad's DNR wishes. Dad was a bit out of it, but immediately engaged. "I do not want to be resuscitated under any circumstances." The doctor said intubation would help him breathe. Dad said "I refuse to be intubated. Instead of intubating me, just shut me down with morphine. I've just about had it. I've had enough." This is a man who was wrote on his blog that he was going to shoot the last chemo arrow in his quiver days before – but today a man who had finally concluded he was beyond any reasonable chance for a meaningful recovery. I leaned in and promised him that we would take good care of mom no matter what happened. You could just see him relax.

Dad always knew what he wanted in life, and it was no different in death. The greatest gift mom and I were able to give dad was making sure his wishes were honored. It was also the most expensive gift I ever gave, since I loved him so much and he was asking us to let the doctors let him die. But he was a good man, a good father, and he had long ago earned the right to have me fight to make sure he would be able to exit in the way of his choice. I gave him my word, and I made sure the doctors and nurses followed his.

We waited for a chest x-ray. Dad was interactive, even smiled a bit. Then the results, pneumonia confirmed. The doctor offered a BiPAP mask, which is a non-invasive mask that covers the mouth and nose and when you breathe, kicks up the pressure to force air in. Dad was cogent and said he wanted it. They fitted him with it, and he couldn't talk easily once it was on. Just as bad, he couldn't wear his trifocals over the mask's seal. I knew he expected this to be his last day when he refused intubation, but I saw impatience in his eyes when he realized he couldn't talk or even see properly.

They took him to the ICU, but didn't let us in for a while. By the time we got in, dad had asked for Dilaudid painkiller. He was still cogent, but his plan was in action. He looked each of us in eye. He responded when we held him. The details from then on aren't critical – he eventually lost consciousness. Dad would never wake up again, but this is where the real story of dad's life was told.

His left arm was covered with IVs, tape, and other medical stuff. His right arm was clear. My mom was standing next to his left arm, and I was holding onto his right. It didn't seem right, and I asked her if she would switch so she could touch his skin more easily. She paused, then walked to the end of the bed and said "no, he always loved when I rubbed his feet. I want him to feel me rubbing his feet." She knew him so well, and loves him so much.

Eva had asked that I tell him she loved him, so I kissed him and said “Eva wanted me to tell you she loves you, and I love you too.” Mom said “I love you” and kissed him.

I’d spent so much time at the hospital that I knew how to read a lot of the machines, and I saw dad was about to go. The nurse said “it’s happening”. Mom rubbed his feet, held him. I held his arm and cried softly. He died the way he lived – with his family at his side, respecting his wishes, and on his own terms.

I looked up and saw mom sitting in a chair at the foot of the bed. I kissed dad once more on the forehead – his heart had stopped but I hoped he could still feel my love – then I walked to mom, hugged her, and asked her what she needed. In a strong, painful voice she said “I need them to take all of that stuff off of him so I can hug him, so I can hold him one last time.” I told the nurse and he complied in seconds.

Then I saw the most terrifying and beautiful thing I’ve ever seen. Something that was simultaneously the stuff of nightmares and the stuff of the endings of the most beautiful Disney princess stories. My dad’s body, his mouth slightly open, still, not breathing, and my mother holding him. She was holding him lightly in a physical sense, but it was the strongest hug I’ve ever seen.

I know that in intense situations people see things that aren’t real, but what I saw next I will believe to my grave to be real. Dad’s body looked full. It will still, he was dead, but even in death it was full. And with every second mom held him, dad’s body emptied and mom’s grew fuller. I could see him going into her. She held him until I saw that migration finish, then, like she knew it was complete, she looked up, let go, and told me that that was the last time she would ever be able to hold him.

Not true, mom. I’m not a religious man. I do know that nothing in the universe is ever destroyed; it can change form, but is never gone. I don’t know how I saw what I saw, I don’t know if it was really visible or just my realizing what it means to spend 50 years madly in love. But what I do know is that dad is with you, whatever spirit he has, however it manifests, you carry him with you for the rest of your days.

I don’t expect you to suddenly follow the NCAA. I know it isn’t literally that there are two people in your body, but the story of your lives was so intertwined with your love that at the moment of his death your merger became complete. At the time I couldn’t figure out why you had such an urgency to give him a full body hug, with all the medical stuff gone, but when I saw what happened, I knew.

You hold in you all of the love you share. Everybody should be so lucky to draw that much love, enough love to sustain you the rest of your days.

I love you dad. I’ll honor you by being the best dad and the best man I can be. * * *

The funeral was recorded on video and was uploaded in three parts. Many voices spoke about my father, and each deserves to be linked from his blog. Parts one, two, three.

Posted by Gary Shuster at 01:37PM (-07:00)

Dying

Wednesday, May 02, 2012

I woke up on Wednesday morning and all seemed well with the world. I had just spent the weekend in Yosemite, was loving my time with the family, and was enjoying an apparent respite in my dad's illness.

I dropped Eva off at school at 9:00 a.m., and I had Sara and Bel in the car going to preschool. The phone rang at 9:11 a.m., and it was my mother. Everybody with a sick relative knows that there are times when your heart drops when the phone rings, but this wasn't one of those times. I figured she was calling to see if one of the kids wanted to visit after school. Not so.

Her first words were ominous: "I didn't want to call you until I was sure you'd dropped Eva off." My heart drops. I have a speaker phone in the car, so I warned her that Sara and Bel were in the car and could hear. I'll never know how the conversation would have gone if she could have spoken freely, but she was fairly blunt: "Dad is having troubling breathing and we called the pulmonologist but its been a couple of hours and he hasn't called us back. I'm thinking about calling 911 and getting an ambulance." I told her "hang up right now and call an ambulance, I'll drop off the kids as quickly as I can and I'll get right over to your house." She did.

At 9:13 a.m. I called my wife and let her know the situation (I'm using the phone records so these are actual times). I called my mom back at 9:19 to confirm she'd called the ambulance, which she had. I called and updated my wife at 9:20.
My mom called back at 9:25 a.m. and she told me the back story -- when she woke up and came downstairs, my dad was awake and told her he was in respiratory failure. I had outfitted his chair with a button connected to a chime that rang upstairs, but he never pressed the chime. I later confirmed the chime was working and dad was pretty cogent.

At 9:26 I called one brother; at 9:27 I called the other. I gave them the little information I had.
I was over at the house around 9:30 (I'd stopped at my home, just around the corner, to get my bag and stuff I'd need assuming I'd be at the hospital for a few days). As I pulled up, the firetruck was there already and the ambulance was parking. That will make it real in a flash.
I asked if my mom could ride with my dad in the ambulance but they either refused it or discouraged it. Either way, we drove separate cars. She wanted to pack some things she would need so I left first. I followed the ambulance, and their siren and lights weren't on. I thought that was a positive sign. I tried to follow the ambulance through the lights, but it turns out that ambulances run an awful lot of very yellow lights, siren or no siren. I arrived perhaps two minutes after the ambulance, but they had already taken dad into the hospital. This meant he was on the inside of the impassible doors to the inner emergency room and mom and I were on the outside. We tried to go in through the ambulance bay doors, but that didn't work.
We walked to the front desk in emergency. My mom explained that ...

* * *

Ok, that mid-sentence stop above is not typo. It is an event-driven discontinuity. I was writing the post during down time before the post-death activities hit a fever pitch. I don't know if it is designed to distract the survivors or just a mismatch between the things our culture expects and the things the survivors need, but we got so busy with dealing with funeral plans, out of town relatives, condolences, even things like canceling Amazon Subscribe and Save subscriptions that all normal activity slowed to a crawl. So I continue this post where I left off, my memory both dulled and sharpened by the passage of time. I wrote the earlier portion of this post well over a week ago.

I sent emails to family all day with updates. Excepting for things personal to family, I will intersperse this post with those email updates at the time when they were sent. They are hard to read, even for me (and I wrote them). But dad never pulled punches. He was brutally honest. And Merkel Cell Carcinoma cells are a practiced fraternity of assassins, operating quickly and brutally. As my dad documented his transition from vital, healthy 69 year old to an injured but spirited 71 year old with stage 4 cancer, I feel I owe it to him to document the final part of that transition, the one that ended with his release from a pained and infested body. He asked me to post about what his last day was like, and I feel my contemporaneous emails perhaps best capture the type of chaotic uncertainty that others facing MCC (and their families) should prepare for. I hope it is wasted preparation and a cure is soon found, but this is here as a resource while we await the success of the work of Dr. Ngheim and others.

Contemporaneous posts are found in courier text in a quotation box, prefaced with "Email". The first of them is immediately below this box. Note that the subject line tried to keep format of "Update" with 24 hour time following. I didn't keep that up the whole time.

** Email sent Date: Wed, 18 Apr 2012 10:07:59 -0700
subject: "Update 10:06"
He has arrived by ambulance. He is in the ambulance bay. We are not yet allowed to go back to see him. We expect the go in a few minutes. Will then be more to let you know.Sent from my iPhone **

** Email sent Date: Wed, 18 Apr 2012 10:24:02 -0700
subject "Dad"
Just arrived via ambulance to st Agnes. Irregular heart rate andrhythm. Low spO2. Did [SIC, should be did not] feel he could tolerate car ride to hospital.More if there is more. Please share with his siblings.
Sent from my iPhone **

We walked to the front desk in emergency. My mom explained that her husband had been taken in by ambulance and was in self-described respiratory failure. The man staffing the desk seemed like he wanted to be helpful but was overwhelmed with responsibilities (emergency rooms, even on a weekday, are partly emergencies and partly primary care for the uninsured, so the front desk staffer is the front line recipient of a lot of angst and conflict). When he said, more or less, that they had things well in hand back there and we'd be called in at some point later, I felt something in me that happens once every few years. The last time it happened was during the 2008 presidential campaign when I was managing a voter registration drive and we were illegally instructed by law enforcement that we weren't allowed to register voters in a public place: I flipped into intense, personally impacted lawyer mode. I felt myself compelled to stare, unblinking, into his eyes and say "understand that my mom has been married to him for 50 years. He worked at this hospital for decades. He is a doctor and thinks he's in respiratory failure. I need you to go back there, tell them that, and tell them that the family refuses to let him die alone and we need to be let back there." I'm normally pretty non-confrontational (at least in person), but if the intensity of my words were translated into physical force, the guy would have been unconscious on the floor. He said, basically, "take a seat, I'll let them know."

We sat down and I watched him rush back to the inner sanctum of the ER. When he returned to the desk my mom went up to follow up. I don't know what she said, but she came up to me with a badge on and said that they could only get one visitor badge. I told her to head in.

** Email sent Date: Wed, 18 Apr 2012 10:50:22 -0700
Subject: Update 10:44 am

Mom is in there with dad. I'm in waiting room due to "one visitor at a time policy".

He's confirmed to be in atrial fibrillation. He is already on amioderone, which is the drug that previously fixed it, so I assume they're going to up the dose or use something in addition.

They hear a wheezy noise they don't like in his lungs. They are taking him in for a chest x-ray. Obvious candidate is pneumonia (fits with with low blood oxygenation level), but given the cancer impinging on the bronchi, who knows. Mom thinks (hopes?) they'll let me in after the x-ray. I think dad is more comfortable having his wife with him, so I encouraged her to stay by her side and that I'd be fine patiently waiting in the waiting room. I didn't tell her about the very loud annoying woman eating something on the order of 40 pounds of Fritos who is sitting next to me, but she doesn't need to know everything.

My guess is that they'll admit him at least overnight, if for no other reason than defensive medicine to avoid a lawsuit if they release him and he has a fatal heart attack. But no decision has yet been announced on admission.

I think it is a bad sign that I've gotten good at this. I have my laptop, my TOR browser (to get around the hospital filters), my iPad with hotspot (in case Tor fails) and my iPhone with megacharger. I also have meal replacement drinks with me.

I should create a macro for the term "this sucks", since I'm writing it a lot. This sucks.

More when there is more to share. **

Mom came out a few minutes later and said dad was still ok and cogent, but they hear something they don't like in his lungs and he's going for a chest x-ray. She wanted to know if I wanted a turn in there. I said no, you're his wife and I know he wants nobody more at his side right now. She just nodded and headed back in. In a different world, my mom would have been a lawyer, because within a few minutes she appeared in the waiting room with a second badge, saying something about how she insisted that the doctor issue one for me. And with that, we were both able to get back to the ER back area.

We had some time waiting for x-ray and dad called me over. he said something to the effect of "If I don't make it today, I want you to make sure to update my blog with what happened." Until that point, I thought the blog was partially cathartic for him, and partially an effort to help others battle not just MCC, but the weird, scary, unexpected things that accompany it. When facing his own death and knowing that he wouldn't get to enjoy the catharsis of writing about it, I learned that (at least by the end) he was providing his fellow travelers down the "life with MCC" path with the kindness and protection of the type he had spent 50 years providing his family (68 if you count protecting his siblings). I promised him I would keep the group updated.

Dad was, by now, switching between being very aware and closing his eyes. During the first eye close following that discussion, I quickly updated the blog with the current situation and sent an email:

** Email Date: Wed, 18 Apr 2012 10:59:01 -0700

Subject: docdave back at hospital
To: [mcc google group]
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2012/04/following-ambulance.html
New update, dad is back in the hospital. **

We immediately started getting supportive messages back from the MCC group. At moments like this, every message of support is worth ten messages of support during more stable times. They were all read and appreciated.

My mom was shaky and hungry, and was worried about taking the time to go to the cafeteria. I remembered from the prior hospitalization (you don't want to do this enough to know how to work the system like this) that nurses will bring family a plain but sufficient sandwich if you ask nicely. I tracked down a nurse and my mom was spared the anxiety of being away from dad (and he was spared the anxiety of being away from her). She did need to go to the restroom, though, and I took that opportunity to tell my dad that whatever happened, he had good sons and we would make sure mom got all the support and looking after that she needed. He visibly relaxed. He knew it, of course, but it is important to say it, particularly when somebody is experiencing poor concentration or high pain.

Another thing that happens in these situations is that you seek a tiny bit of normal in the day. Perhaps it keeps you moored. I emailed the local camera shop and asked what kind of lenses they rent. I know, the very strangest thing you might imagine doing. But dad had his eyes closed, mom was deep in thought, and I needed to remind myself that life would go on regardless of the outcome. You **will** be tempted to feel guilt over such moments. Don't. I took a few such moments, and they gave me the strength to be well moored when the time came for the really hard stuff.

At some point that day, the Votrient we had ordered via next day delivery was to be delivered to his home. His final post was made just days before he died: “it looks like Topotican did me no good…. I have had respiratory difficulties … [and when I] attempted to go upstairs for a shower … that was a failure as I had [an] asthma-like attack. It looks like I have a choice of waiting to die or going on Votrient … I somehow doubt my insurance will pay and I think it will cost a lot of money…. This seems to be the last arrow in my quiver.” He wasn't home to sign for that first shipment of Votrient because he was in the hospital, dying. Dad was a realist, but a fighter -- he was ordering ammunition to use against the cancer the day before he succumbed to it.

We were still waiting for the x-ray at 11:46. We were getting impatient, but they wanted to stabilize his heart first. First things first, I guess. I'm not a doctor, but it didn't seem to surprise my dad, who was a doctor.

I realized I hadn't been keeping my ex-wife (and oldest daughter's mom) up to date. I emailed her along with my brothers:

** Email: Date: Wed, 18 Apr 2012 11:46:50 -0700
Subject: FYI

Dad is alive, alert, and describes himself as restless. They won't X-ray him until they stabilize his heart. spO2 is ranging 88% to 92%. Pulse 120. Blood pressure scares me at 90/38.
He expects to be admitted overnight.
Sent from my iPhone **

My ex-wife wrote back "Thank G-d!" when learning my dad was alive and alert. Divorces are tough on families and there is a temptation to demonize the ex. My dad never gave in to that temptation, and was probably the most even-tempered of the lot of us during that time. I've previously posted about the benefits of a happy blended family, and this was one of them: My ex-wife stood by the ready to help, and when my dad died, she was able not just to comfort our daughter, but to comfort her from a place of empathy.

Turns out I read the blood pressure wrong. There will be errors, and when reporting to remote family members correcting the errors quickly is pretty important:

** Email: Date: Wed, 18 Apr 2012 11:50:49 -0700
Subject: Re: Update 11:43
Correction. I misread blood pressure. 113/47
Sent from my iPhone **

In retrospect, I'm not sure that I misread the blood pressure, since it kept swinging pretty widely, but in the moment I wanted it to be 113/47 more than 90/38, so when I saw that reading, I was pretty willing to assume an error rather than volatility.

I told the nurse that we wanted dad to speak with the doctor directly about his instructions regarding "do not resuscitate" ("DNR") and similar issues. The nurse said she would get the doctor.

By noon, I was starting to feel a real risk that dad wouldn't make it out of the hospital. On the one hand, I was thinking they might send him to a regular room, but in my gut I was worried he wouldn't even make it to the ICU. I didn't want my out of town family to be caught by surprise (more than they already would be) by getting "he's at the hospital" emails followed by a "he passed away" email. So I sent an email offering a pretty frank assessment:

** Email: Date: Wed, 18 Apr 2012 12:03:49 -0700
Subject: Re: Update 1201
O2 saturation took a nosedive before recovering.
Dad is kind of out of it on and off.
I'm not an MD so my intuition means little scientifically, but I have a very bad feeling in my gut about this one.
Sent from my iPhone **

The emails are, by now, getting harder and harder to send, but I'm getting to the point where I am getting teary-eyed and I fear having a phone conversation would be a very hard thing to do without becoming incoherent. So emails it was.

We got word that the ER doctor wanted to admit him to the ICU, but they first whisked him off to x-ray.

** Email: Date: Wed, 18 Apr 2012 12:07:28 -0700
Subject: Re: Update 1206
On his way to X-ray.
ER doctor wants him admitted to ICU. we'll see if there is an available bed. **
The doctor came in and I asked him to ask my dad for his specific DNR and related instructions. I was aware that my mom and I knew them, but I knew they would be followed more accurately if given directly by the patient. It also would save my mom, if it came down to it, from having to say the words that dad would have wanted her to say but that would be very hard to actually say with regard to somebody she's loved for over 50 years. I also recognize that writing instructions in a lawyer's office, or even discussing them in the abstract even in a hospital bed, is only a simulation. When faced with the reality that the instructions are likely to actually be followed that day, people often need to tweak their instructions.

He said he did not want to be resuscitated "ever", regardless of the event or the severity of the event. I got him to clarify whether he would want to be resuscitated even in the event of a minor event, and he said "no" with clarity and purpose.

** Email: Date: Wed, 18 Apr 2012 12:31:43 -0700
Subject: Update 12:28
He has been admitted to ICU.
he just gave the doctor an order that he does not want to be resuscitated "ever" regardless of the event, respiratory, cardiac or otherwise. So given he has abnormal cardiac rhythm, terrible O2 sat, probably needs to be intimated [SIC, should be intubated], and has tumor impinging his lung, the DNR instruction gives a very high risk of death in the next few hours or days. A hope I'm wrong.
Sent from my iPhone **
The x-ray came back around 12:15. I don't recall dad reading it himself, it is one of the few memories that aren't still totally clear for me:

** Email: Date: Wed, 18 Apr 2012 12:22:16 -0700
Subject: Update 12:20
Dad read his own chest X-ray. Described it as bad, bilateral pneumonia.
I'd be shocked if he isn't in the ICU overnight.
Sent from my iPhone **

My dad was visited by the doctor who was to admit him to the ICU. I prompted this doctor to make sure he knew my dad's wishes, and to ask my dad directly. He did:

** Email: Date: Wed, 18 Apr 2012 12:58:57 -0700
Subject: Re: Update 12:58 bad news. Possible rapid development.
He just refused intubation. He instructed doctor "instead of intubating me, just shut me down with morphine. I've just about had it. I've had enough."
He is giving instructions that make it highly likely he will not live much longer.

He is peaceful, tired, kind, and entirely unemotional.
Sent from my iPhone **

I was getting a lot more anxious. My mom was getting anxious as well, although both of us began to feel an increasing split between the reality unfolding in front of us and the reality as we wished it were. Dad was clearly preparing to die, and that was the objective reality. The analytical Harvard-trained lawyer knew this, and he was the one drafting the emails. The scared little boy watching his daddy suffer, watching his hero lose his last battle, watching his role model pass in and out of consciousness, that scared little boy believed that his daddy would make it. That scared little boy knew nothing could beat his daddy, his protector.

Ultimately, both the lawyer and the scared little boy in me were right. Dad was dying, but he was dying on his terms. Merkel Cell Carcinoma wanted to torture him into the darkness, to chase him scared into the wildness of death. He stood his ground as long as he could, then metaphorically said "fuck you, cancer, I may not be able to stop you from hastening my death, but I'll be damned if I let you dictate how, when, and with what degree of pain." Dad was a doctor, and a good one at that. He knew he had pneumonia, and he was bringing up morphine, a respiratory depressant (like hydromorphone, trade name Dilaudid). He was unable to dictate the terms of his entry to the world of cancer, but he had just laid out the path for his exit. There would be no horrific final days of pain and suffering.

My brother Michael wrote back at 1:36 (4:36 in Philadelphia, where he lives) "I wish him good luck. Bon voyage, dad. I love you." Reading that, from my youngest brother, made things even more real. We were really all saying our goodbyes. The rational part of my brain was holding out hope even as I knew hope was fading fast.

They were ready to move him to the ICU, they had his room, but the doctor with the paperwork was busy with another patient. We waited quite a while before he was moved.

** Email: Date: Wed, 18 Apr 2012 13:46:13 -0700
Subject: Update 13:46
Dad about to be moved to ICU 12 on the B side
Sent from my iPhone **

Before they moved him, they wanted to do something about his oxygen saturation. It turns out that while he refused intubation, he accepted a "BiPAP" mask. This is a mask that covers the nose and mouth and when it detects the patient breathing in, it ramps up the pressure to force in the air. It also allows oxygen to be intermixed with the air, up to 100% oxygen. My guess is that dad knew dying from pneumonia would be horribly painful, emulating drowning in some ways. The BiPAP mask may have been his way to avoid some of that pain. Unfortunately, it had two huge drawbacks. First, dad's glasses wouldn't fit with the BiPAP mask on. He had trifocals, and while I could get them in place, they were slightly off in height, just enough to be non-functional. I later learned that they could have fit the BiPAP mask around the glasses (although I asked about it at the time and was told no). Later that day I would rush out briefly to pick up my medications (in case I had to stay overnight a few nights), my dad's PEG tube feeding food (he never used it), some stuff for my mom, and materials to modify his glasses to fit the BiPAP mask. He never did wear his glasses again -- by the time I had the materials to modify the glasses, he never got to the point where he was interested in wearing them.

The thing I think he didn't consider about the BiPAP mask is that it is like a mini hurricane when the patient tries to lift the mask to talk. If the patient doesn't lift the mask, the sounds are muffled. So once they fitted him with the mask, there would be no intimate whispers, no final lengthy conversations. Communications reduced to signs, words, sometimes sentences. We, of course, talked with him a lot. His inability to respond was probably more frustrating to him than anybody else. He couldn't see clearly or talk clearly due to the BiPAP mask. Layered on top of the hearing loss from the earlier chemo round, he was limited in his interactions with the world. Perhaps it was how he wanted it. He started to close his eyes more often, and at times he looked like he was dreaming peacefully. My heart imagines him dreaming of good days during those moments.

They finally took dad to the ICU. This marked the second time my mom and I were forced to spend time away from dad. We followed his bed to the ICU, but they stopped us at the door and said they needed to be alone with him to get him set up and do the intake. We waited in the ICU waiting room. The ICU waiting room was decorated with borderline-depressing images so bland they were probably unnoticed by the others in the room. The television was blaring with an A&E show about a bounty hunter. Mom and I sat next to each other. We were told we would be called back soon, but it took nearly 45 minutes. Ultimately, we got back in by following a nurse through the doors. Not following protocol, but nobody complained.

When we got in, I introduced myself to the nurse and asked the questions I had learned to ask during the last stay. The first question -- did he get Dilaudid yet? Yes. In better times, dad wasn't a big drinker and didn't use painkillers in a serious way. In fact, he often ignored his Vicodin prescription during the weeks leading to this day in favor of a simple Advil. So he was very sensitive to painkillers. And he'd asked for more than he usually asked for during his prior hospital stay. A smart doctor, in respiratory distress, very responsive to low dose Dilaudid, yet receiving a higher dose than normal. He wasn't going to suffer on the way out, and cancer wasn't going to get extra days of artificial life support during which it could torment him.

Soon they wheeled dad out for a CT scan and again banished us to the ICU waiting room. They again took a long time before letting us in to see him. I suspect he was instructing the nursing staff at this point and wanted privacy to give some blunt instructions to them.

** Email: Date: Wed, 18 Apr 2012 17:11:24 -0700
Subject: Ct done
Dad just got back from ct scan. They wont yet let us in to see him. No real news for the moment but hopefully know more soon
Sent from my iPhone **
We were in no mood to remain banished to the waiting room, so we were appreciative when the cardiologist came by, got us from the waiting room, and took us into the ICU so we could participate in the conversation with dad.

As I wrote two months ago, during dad's past hospitalization, around 2:30 a.m. one night he developed a sinus tachycardia of around 120 beats per minute, and around 3:00 a.m.

the nurse came in and said he had developed atrial fibrillation at around 140 beats per minute. When he heard that, he said "oh shit". On that night, the atrial fibrillation scared him, because he held out hope of beating the cancer, or at least delaying death, and he was starting to feel physically better. He was right, by the way. He had some good times after that night, cancer be damned.

This night was different than that night in a key way: The cardiologist took us in, and told him that he was experiencing not just atrial fibrillation, but atrial flutter. The top of dad's heart was beating around 300 times a minute, but only about 1/3 to 2/3 of those impulses were being transmitted to the bottom of his heart. This time, dad didn't say "oh shit". In fact, he had little reaction at all. His body had already told him more than the cardiologist ever could. I again recited my understanding of dad's DNR instructions in front of dad and the cardiologist, and made sure that everybody understood his wishes.

** Email: Date: Wed, 18 Apr 2012 17:34:48 -0700
Subject: Update 17:27
No ct results yet
The cardiologist was just in. He said the prognosis was bad. He apologized for not having "anything good" to tell us.
The top of dads heart is beating around 300 times a minute. About 1/3 to 2/3 of the electrical beat signals do not get transmitted to bottom of the heart, and they're trying to reduce that number. He says this condition doesn't usually yield cardiac arrest. The bigger problem he says is no oxygen from the lungs. Without oxygen "nothing works". So cardiologist is quite pessimistic.
My subjective evaluation of his appearance and affect is also pessimistic.
Mom and I are both having trouble seeking a path that ends with him going home, but of course we're hoping.
Sent from my iPhone **
The medications dad needed to stabilize his heart were too much for his chemo-weakened veins. They had nothing but trouble putting in IV lines during dad's prior hospitalization, and this time they needed to put some medication in that was not well suited to a regular IV anyhow. They wanted to put in a central line (an IV that goes directly into a very large blood vessel, in this case a subclavian central line). He appeared to consent, but the nurse was no longer sure that dad was sufficiently alert to consent. Mom and I knew dad better than the nurse, of course, and we were able to see that he was sufficiently cogent to consent. Mom said to do it. Interestingly, dad then engaged in a conversation (such as he could, pulling the BiPAP mask to the side) asking the nurse about the preferred placement of the central line. The nurse's concern regarding dad's ability to consent was not without basis, however. He was periodically losing concentration, with his eyes rolling up or closing.

** Email: Date: Wed, 18 Apr 2012 17:56:06 -0700
Subject: Re: Update 17:27
They are putting an emergency central line in. We are being sent out since it is a sterile procedure. Nurse refuses to accept dads consent because he's too sick and out of it. She is looking to mom for consent.
They won't say it out loud, but he's crashing.
Sent from my iPhone **
Blood oxygen saturation. It seems like a rather arcane thing, but it turns out to be critical in situations like this. The math is pretty simple -- if there is enough oxygen in your blood,

your brain and body work. As the oxygen level drops, your brain stops working right and your body takes measures to protect the organs and brain. Dad's blood pressure and pulse, combined with the increasing chill in his extremities, made it nearly impossible to get an accurate blood oxygen (SpO2) reading. The pulse oximeter stopped working on his left hand fingers. They tried the right hand fingers, but no luck. I suggested his toes, since the socks were keeping his toes warm, but that worked only for a minute or two. They tried his ear lobe. Ultimately, they fitted him with a special SpO2 measurement device that read from the forehead. Since we were non-doctors, our focus was only on the machine readings we knew to be significant -- pulse, blood pressure, and SpO2. I was relieved to have the SpO2 reading available again, but it was dropping steadily and that was pretty distressing. I don't remember quite when in the sequence of all these things that the pulse oximeter stopped working, but it seems like it was around here, give or take an hour.

The CT scan results were back and they were not good. The doctor took us back to the computer, spent some time logging in, and then walked us through the results. I've looked over my dad's shoulder at the x-rays and CT scans he would read since I was old enough to look over his shoulder, and I never quite figured out how he saw what mattered in those images. Just like my dad would sometimes do, the doctor walked us through my dad's CT results.

I know that MCC is a terrible cancer, but at that moment it seemed to be possessed of a primal malevolent intelligence, and decided that if dad was going to rob it if the ability to inflict more pain, it would at least make his death as frustrating, inflicting one last round of bad luck or even irony. Dad's left lung wasn't sick. It showed some possible signs of slight pneumonia, but was in pretty good shape. It would be able to get plenty of oxygen to his brain and body -- if only the Merkel Cell Carcinoma had not wrapped itself around the left bronchial branch and squeezed it shut. The right bronchial branch was wide open, easy airflow in and out, and would be able to get plenty of oxygen to his brain and body -- if only it wasn't filled with fluid from pneumonia. So MCC left him with a functioning lung he couldn't use, and a compromised lung he could use. His SpO2 kept falling, and now we knew why.

** Email: Date: Wed, 18 Apr 2012 18:29:33 -0700
Subject: Ct results
Left lung better than right, pretty clear but left bronchial branch is totally blocked so he can't use that lung tissue. Right ling quite bad, lots of infection but open bronchi. They may insert left bronchial stent tomorrow. Central line going in now.
Sent from my iPhone **
Dad had refused intubation but said (in very brief words due to the BiPAP mask) that he would consent to a bronchial stent. Such a stent would open up his left lung. I'm still not sure why a stent wasn't put in on an emergency basis. My non-medical guess is that with his heart in atrial flutter, they didn't think the additional anesthetic would be tolerated -- but I really don't know. I don't even know if he was still in atrial flutter.

At this point, they were approaching a shift change. The ICU nurses work 12 hour shifts, and they usually kick out family members for an hour around shift change so that the outgoing shift and properly brief the incoming shift. I really didn't want dad to be alone at this point, and was starting to worry about how I would deal with the shift change "please leave for a bit" request. They required us to leave because they needed to create a sterile environment so they could put in the central line. That took care of the question of whether I would object to having to leave during the shift change. We were again banished to the ICU waiting room.

I took the forced time away from dad as an opportunity to pull out my laptop and update dad's blog. I wrote "He seems to be cogent, at peace, and just wants to stop hurting."

** Email: Date: Wed, 18 Apr 2012 18:47:17 -0700
Subject: Another post, doc dave doing worse
To: [Merkel Cell Google Group]
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2012/04/back-in-icu.html **

** Email: Date: Wed, 18 Apr 2012 18:48:30 -0700
Subject: Another post, doing worse
To: [Large bcc list of Dad's friends and relatives]
http://docshu-mybattlewithmerkelcellcancer.blogspot.com/2012/04/back-in-icu.html
This has already been a long day. Going to be a long week no matter howtonight turns out. **

Soon enough the doctor came and told us the procedure went well. We were briefly allowed into the ICU and then kicked out so that they could x-ray dad to confirm the placement of the central line.

Mom was starving and agonized over whether to get food downstairs. The x-ray was clearly going to take more than a couple of minutes. We asked around and going downstairs to the cafeteria was the only option. Although she ran down and was back with food in minutes, I regret not insisting that I pick up food for her. For a day filled with hard decisions and intense stress, it was one of the few things I think I should have known, at the time, to do differently.

In the meantime, the room had cleared out and I took the opportunity to change the blaring waiting room TV channel to something I could ignore and turn the volume down to a level just loud enough that others would not feel the need to turn it up if they wanted to listen. I originally wanted to turn it off, but I was sure it would just get turned back on and then the person turning it on would of course crank up the volume. I wanted time with my thoughts.

** Email: Date: Wed, 18 Apr 2012 19:21:05 -0700
Subject: Re: Ct results
Central line went in OK. They kicked us out (again) so they could xray him to confirm that the line was placed properly.
His breathing is really labored. He is also getting serious discomfort with the BPAP [SIC should be BiPAP] mask. The doctor ordered another dose of hydromorphone with the goal not of eliminating pain but of relaxing dad enough so that he can allow the machine to breathe for him. Mom went to get dinner. She's rattled but seems to have accepted things are serious. **
They finally let us back in. We met the night shift nurse, and I was glad we had a nurse

who seemed competent and caring. The oxygen level in dad's blood was dropping, and the nurse bumped the oxygen percentage in the BiPAP mask up to 75%. He mentioned that because dad didn't want to be intubated, once the oxygen percentage went to 100%, we would be out of options to bring up dad's SpO2.

I again went over the DNR orders with the nurse during one of the periods when dad was cogent. He told the nurse "I don't want you to code me under any circumstances." This was apparently hospital shorthand for calling a code blue and trying to resuscitate him.

Dad was working pretty hard to breathe, and the nurse would periodically speak his name quite loudly to make sure that he could be awakened.

I told dad I loved him, and that his granddaughter had asked me to tell him that she loved him. My mom told dad she loved him. I kissed him on the forehead.

I told the nurse that dad is a doctor, mom has spent 50 years married to a doctor, and I grew up in a doctor's family -- and we wanted him to not dumb down or soften the truth. My mom suggested we have that discussion outside. We walked outside, and I bluntly asked the nurse about whether I should go home. Basically, I told him that I knew it wasn't the kind of thing he could give accurate percentages for, but I was trying to figure out if it was more than 20% likely dad would pass away that night. If it was less than about 1 in 5, I would go home so that my mom could stay with him overnight and I could be with him the next day (I didn't want us to both be up for 24 hours, both fall asleep at the same time, and have my dad pass away then -- so the question was whether it was appropriate for us to keep him company in shifts). The nurse said that he had seen patients in my dad's condition recover, but he'd also seen them decline very quickly and pass away. He thought dad would probably make it through the night, but there was a real chance he wouldn't. He then said that in my shoes, he wouldn't go home. I thanked him then for his blunt advice, and I thank him now. Mom was also weighing taking shifts, but at this point we were both expecting to be there all night.

** Email: Date: Wed, 18 Apr 2012 20:36:41 -0700
Subject: Update 20:33
He has central line and foley catheter. He is working extremely hard to breathe.
I spoke with the nurse outside the room and told him I didn't want to go home and have my dad die while I'm home. He said in that case I should not go home. He said he didn't think it more likely than not that dad dies tonight but that it wasn't a remote risk either.
Sent from my iPhone **
At some point, the nurse sought clarification of the DNR orders. He said that he understood my dad did not want to be intubated or resuscitated, but suggested that if his heart went into a bad rhythm, he "could be paddled" back into a normal rhythm. He asked my mom what she thought, as she was the person with the final word when my dad couldn't consent. I waited for a while, but I saw in her eyes that she knew my dad's answer was "no" but that it was too hard to say that about somebody she loved so much. I'm sure she would have eventually said it, but I stepped in and said "my understanding is that dad wouldn't want that, isn't that right mom?" She just nodded her head in agreement.

My dad's SpO2 kept dropping, and the nurse increased his BiPAP oxygen to 100%. The SpO2 continued to drop. Some time around 9:30 dad stopped responding to the nurse with anything but perfunctory acknowledgments, and by 10:00 he was not responding at all. The nurse squeezed a muscle on his upper shoulder as hard as he could, yelled "Dr. Shuster" several times, asked dad to squeeze his finger, blink or open his eyes, but there was no response.

At this point, I was regularly streaming tears. My mom warned me about her propensity to faint in really seriously bad situations -- I'd spend the night looking out for that.

** Email: Date: Wed, 18 Apr 2012 22:09:13 -0700
Subject: 22:07
Unconscious. Unable to awaken him. Non responsive. No longer BPAP [SIC should be BiPAP] candidate per nurse. Nurse says death may be imminent.
Sent from my iPhone **
My dad's left arm had the IV and a bunch of other stuff attached. His right arm was clear. Mom was sitting on his left and I was sitting on his right. I said something like "you're his wife -- would you like to switch places so you can hold him skin to skin without all this medical stuff in the way?" She started to amble around the bed, but stopped at the foot of the bed. She grabbed his feet and said "no, you stay there. I'm going to rub his feet. He always loved when I rubbed his feet." So there we were, me silently crying, holding his hand and arm, my mom with a sad, fixed determination, rubbing his feet and deep in thought.

** Email: Date: Wed, 18 Apr 2012 22:17:22 -0700
Subject: Re: 22:07
The nurse just brought Kleenex. So the nurse thinks we're at the about to need Kleenex phase.
Mom says she is near vomiting.
Sent from my iPhone **
My brother Michael responded almost instantly with an email "Me too. Its late here, but sleep isn't happening."

I was fighting to strike a balance between feeling my emotions and retaining enough control to be there for my dad and my mom.

The nurse observed the skin on dad's head and said that it had taken on a distinctive look that often is associated with impending death. I have no idea if that is a documented medical thing or just the nurse's experience, but he was right.

It is worth observing that from the time that dad lost consciousness, he had a look on his face that was really peaceful. He had a look that was entirely consonant with his remembering the great times in his life, running down the beach with his wife, enjoying family birthdays, all good stuff. His body may have been shutting down, but he wasn't suffering. He sure looked like his consciousness was in a good place, a place the pain couldn't reach but where the good memories were easily found.

The nurse said "it's happening". I was holding dad's hand. I looked up at the EKG machine and saw a single, final heartbeat and then a flat line. I looked back at dad. I said "I love you, dad" and leaned in and kissed him on the forehead. After some time (seconds? a couple minutes?) I stood up, tears running down my cheeks, and walked over to my mom, who was sitting on a chair against the wall, a few feet from the foot of the bed. I hugged her and asked "mom, what can I do here, what do you need?" My said, in a voice I'd never heard her use before, "tell them to get all that stuff off of him so I can hug him one last time."

I walked to the nurse and told him, my words by now interspersed with sounds of crying. The nurse said he was on it, and within seconds my dad's body was clear of all of the medical equipment. She held him. I described what I observed in my eulogy, and the written version is part of this blog as a separate post. This post is about my dad's last day of life, and sadly he died at 10:55 p.m.

This isn't the kind of news you can deliver to your wife or brothers by email, so I called them. I called my youngest brother first, since it was the middle of the night there already. My phone bill shows it was a 3 minute call, and I'm sure I spent the first two minutes of that just sobbing, unable to say the words he knew were coming. The remainder of the calls were more cogent but no easier to make. Finally, I let dad's online family of fellow MCC fighters know the bad news.

** Email: Date: Wed, 18 Apr 2012 23:13:51 -0700
Subject: docdave passed away
To: [Merkel Cell Cancer Google Group]
Will be a blog post after I get my thoughts together. He died 10:55 pm **
Dr. Nghiem played a critical role in dad's care, and while I focused strongly on family in the days and weeks following dad's death, I wrote Dr. Nghiem first thing in the morning the day after my dad's passing:

** Email: Date: Thu, 19 Apr 2012 08:16:56 -0700
Subject: Dave Shuster
From: Gary Shuster []
To: Paul Nghiem []
Dr. Nghiem
Thank you so much for the support you provided my dad. He died last night. Some people would like to make donations to MCC research in his name. Could you please provide me with the information I need to put into obituaries to instruct people as to how to make those donations?
Again, thank you for what you did for him. I don't think anything could have extended his life beyond the years he had, but thanks to you the treatments he underwent were not the debilitating and ultimately unhelpful ones such as a radical neck dissection. Thanks to that, he was able to take many cruises and vacations and enjoy birthdays with his grandkids. **
His response, as always, was prompt and written from the heart.

** Email: Subject: Re: Dave Shuster
From: Paul Nghiem []
Date: Thu, 19 Apr 2012 09:36:39 -0700
To: Gary Shuster []
Dear Gary,
I am so sorry for your loss.
It was a pleasure and an honor to take care of your Dad & to follow his remarkable journey/battle as chronicled by such a humanistic, articulate physician.
Thank you for thinking of others with MCC at this time regarding donations in honor of your Father.
Relevant information is below, and can be obtained directly via:
http://www.merkelcell.org/help/index.php

Paul Nghiem **

I made many promises to my dad on his final day, but three stood out. First, I promised to make sure the medical staff would honor his wishes with regard to treatment, and they did. Second, I promised to make sure I would be there for mom, and it is a promise I carry with me, and intend to keep for the remainder of her life. Third, I promised to document his last day for his blog.

This extremely lengthy post attempts to keep that last promise. I know that dad understood the cathartic nature of posting to the blog, and at some point writing this entry, I realized I was as much keeping my promise to him as I was helping myself to understand the enormity of that day. I suspect the promise to update his blog was intended not just to make sure the ending of his story was told, but to help his eldest son heal in the telling of it. It was as much a gift to me as a promise to him.

We spent weeks together in the hospital, and there was little left unsaid between us. I loved him as a father. I loved him as a friend. I will miss him.

I sign this post using the same Jewish nomenclature I used when I signed the memorial book at his funeral:

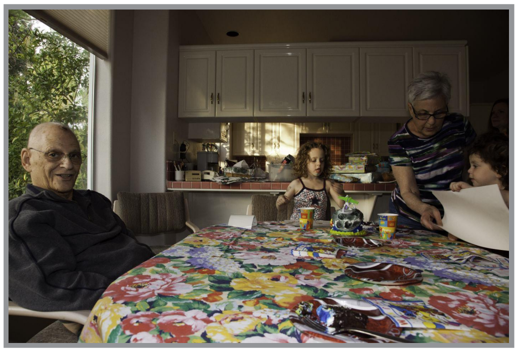
Gary, son of David; Gershon ben David

Posted by Gary Shuster at 02:12PM (-07:00)

Living

Wednesday, May 02, 2012

Dad changed fundamentally in his two year battle with Merkel Cell Carcinoma. He discovered the first lesion on May 6, 2010, almost exactly two years ago. As he came to understand the profound danger he faced, he allowed things that didn't matter to simply fall away. He got in touch with his love for his family in a way that was far more intense than before he started the battle. He enjoyed every moment with his grandchildren. He took his wife on cruise vacations as often as possible. In the weeks before he passed away, he celebrated a grandchild's birthday and conducted a family Seder.



Dad enjoying Sara's birthday on April 9.

In facing death, dad decided to truly live his life. I love how he embraced what is important, and allowed the distractions from a happy life to fall by the wayside. None of us need to wait until we face a terminal illness to live the way dad lived his final years.
Dad left behind a great family, a family that will live a better life thanks to the legacy and lessons he leaves behind.

Grandma, Poppa, and their five grandchildren on the family cruise, December 2011

Dad and family on a cruise, December 2011

We each remember dad -- and allow that memory to enrich our lives -- in our own way.
His passing allowed me to reflect on whether I was the man he was, or at least the man I wanted to be. Dad had always loomed large -- a man whose shoes I could never hope to fill. He was a man who would hoist a canoe over beaver damns, a man who would step in to fix anything that went wrong, a man I turned to for rock solid advice. He was in so many ways not just a father, but a father figure. He was a hero to his mother when his father was sick and later died. He was a hero and role model for his children. Like any respected father figure, he cast quite a shadow.
Even to the end dad projected strength, regardless of the cancer's weakening of his body.
A few days after he passed away, I looked in his closet and was drawn to his shoes. I had always assumed his feet were far bigger than mine, so I had trouble believing what I saw. I stared for minutes. His shoes looked the same size as mine. And they were. I sat down, picked out a pair of shoes I had seen him wear dozens of times, and put them on. I literally filled his shoes.

I sat, reflected, and realized that dad may have passed away, but he left his children ready to take on the world.

Dad often listened to the Kingston Trio. In the days after he died, I found myself tearing up when I played their song "Reverend Mr. Black":

It's been many years since we had to part. I guess I learned his ways by heart. I can still hear his sermon's ring, down in the valley where he used to sing. I followed him, yes, sir, and I don't regret it and I hope I will always be a credit to his memory 'cause I want you to understand. The Reverend Mr. Black was my old man!

The sun sets during the last family vacation with dad, December 2011

Posted by Gary Shuster at 04:31PM (-07:00)

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