

A Medical Tale—Taking Care of Your Own Future

By Gary Carls, CGCS



My story begins in late July of 2010. Like many others I have had high cholesterol for many years but with the use of Lipitor I have been able to maintain it at acceptable levels. As part of the regular cycle to renew my prescription my doctor requires me to get blood tests and urine every 12-18 months to make sure the Lipitor is not having any adverse affects within my body.

The blood tests showed my system was low in vitamin D so the doctor suggested I start taking Vitamin D tablets. I knew I had a passed a kidney stone just a few days before the urine test so I wasn't really surprised when the results indicated some blood in the sample. A follow up test came back clean but since I knew I had passed a stone the doctor suggested that I have a CT scan just to make sure that there weren't any additional stones.

On August 25 the results of the CT scan were back and I met with the doctor. The date stands out because it was my wife's birthday and we had planned a nice BBQ with our niece who was visiting from Colorado. I was hoping all would be good news so the day would be a happy occasion for all. The test actually showed three conditions that existed at that time.

First, the test confirmed a condition we were pretty sure I had but hadn't really investigated much, a hiatal hernia. It really wasn't much of a concern since it hadn't caused any other health issues. The second finding was that there were 3 kidney stones still in my kidneys, two of which were too large to pass on their own. The third finding was what at the time the doctors were calling a small one centimeter "cyst" on my pancreas. At that time the doctor said he didn't think it was cancer but there was a problem in about 1 in 20 cases and he would have me see someone more familiar with these types of cases. While I tried to keep a positive focus based upon what we knew at this point it didn't do much good for my anxiety level a short time later when we were watching the "Stand Up to Cancer" event on TV and they mentioned a statistic that over 90% of pancreatic cancer patients die within a year.

My primary doctor arranged the necessary referrals to see the specialists in their system regarding the kidney stones and the "cyst" on the pancreas. I actually met the doctor regarding the "cyst" first and he felt pretty certain that it was no big deal, assuring me that many people have "cysts" they are unaware of that show up in CT scans. He suggested that he would talk with their pathologist and see what he thought and get back to me about the next step. While comforting, it still wasn't certain that this wasn't a big concern.

In the interim I made arrangements to have a lithrioscropy procedure to "blast" the kidney stones so they could pass out of my system. That procedure was completed on October 6th and took about an hour. All went well and I was able to return home by noon the same day.

After a few weeks of hearing nothing back regarding my pancreas I got a call from the doctor who had looked at the original scan

asking me to come in and talk with him. He said that after discussing my case with their pathologist who would offer me two possible recommendations for what to do next. My first option would be to wait and have another CT scan in about 6 months and see if the cyst had grown or changed. The second option that he suggested was to schedule to have a biopsy done through an endoscopic procedure to get an immediate confirmation of what we were looking at. I'm not sure why anyone would want to wait another 6 months so I chose the option to have the biopsy done. That procedure took place on November 4.

During the course of all of this there were way too many trips to the lab for various tests of all types. Suddenly I had a blood test that showed high calcium in my blood. In some cases the fact that I had been taking high doses of Vitamin D for the last several weeks could be contributing to this but they weren't really certain. They recommended I see another specialist and go through another series of tests. After a few more tests this doctor concluded that they might be an issue with my parathyroid glands and suggested I do a parathyroid scan to detect which glands or glands might be causing the issue. He was suggesting that I also meet with the surgeon to discuss possible parathyroid surgery. Since my first priority was now dealing with the pancreas issues I told him I would probably wait a few months and then look into this further.

Meanwhile, since the first CT scan I had in July was focused on the kidneys I was scheduled for another CT scan to get a closer look at the pancreas. In the course of numerous visits to the doctors I got scheduled for the parathyroid scan without even realizing it. Since it was already scheduled I decided I might as well go ahead and have it done. I was told the results of that scan were "normal" yet they still were recommending I see a surgeon about possible surgery. None of it made any sense to me so I kind of put the parathyroid issue on the back burner once again.

Obviously these times were an emotional roller coaster for my wife and me. At times we were being assured that there was nothing to worry about and then being called back in for additional tests. It had already been a very emotional year since my mother in law had passed away from cancer on March 7 after battling the disease for many years and my wife spent most of the early part of the year in Denver to be with her mother. Still needing to be at work, I made several trips flying back and forth to Denver every other weekend to be with them. While I remained emotionally strong most of the time around others and my wife, there were also some private times where I was not so strong and would break down a bit and worry about what the future held. Most of the time I was more worried about the stress my wife was feeling than any medical issues I was facing. I found it important to remember that the love we have in our lives can help provide the positive attitude to get through these tough times.

In mid-November after meeting with a surgeon in my regular medical group I scheduled December 15 as the date for my pancreas surgery. Like most of people, I was a bit unsure about what the surgeon had told me about the procedure but I felt like the doctors knew

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better than I. He told me that the surgery would require a large incision across my entire side to complete the procedure. I asked about being able to do it laproscopically but he said because I was a "large" patient it would be highly unlikely that anyone could do the procedure that way. I was also not comfortable with the fact that this was a procedure that he only did 3 or 4 times a year but again my first thoughts were that he knows better than I and I just wanted to get the surgery done and over with.

Once again fate and luck came into play in a very positive way for me. As I had been going through all my various tests and procedures I was giving my family regular medical updates via e-mail. It just so happened that my sister shared this information with my cousin, Linda Hageman of the Hageman Foundation. I had seen Linda's references to this foundation on Facebook numerous times but to be quite honest I had never really paid much attention to it and never associated my medical issues with the work they were doing. After my sister gave Linda my basic medical information I received an e-mail from Linda asking me to give her a call so we could discuss my situation. As I said, I was nervous about the surgery but I trusted my doctors to give me the proper care based upon their expertise.

After the e-mail I spoke with Linda by phone the next day which was the Wednesday before Thanksgiving. I learned that much of what I was experiencing was what she had been through in the past or was aware of others experiencing. She was fairly certain that what I had was MEN1 and she convinced me that I needed to see a specialist that knew more about this particular disease. To be honest about it, after talking with her it didn't really take a lot of convincing to make me consider seeing another doctor. During this conversation we talked about what options I might have and some possible medical centers that might be good places to go. Among those we discussed that first day were UCLA, the University of Michigan and the Mayo Clinic. I told her that my preference would be to stay close to home but I would consider other options if it got me the best care possible. I also suggested that Stanford (which was within 30 miles of home) had a lot of highly respected specialists although I wasn't sure if they did work directly related to this disease. She promised to get back to me as soon as possible regarding these medical centers after she made a few calls.

I heard within the next few days that I could get in to see someone at the University of Michigan if I was interested. They were still looking into UCLA and I restated my preference to be near home if at all possible so UCLA would probably be preferable to U of M. In the next few days she made some more calls and suddenly I got the e-mail that really made me feel a lot better. Dr. David Farley who was treating Linda at the Mayo Clinic recommended Dr. Jeff Norton at Stanford University Medical Center as the best in the west and suggested I contact him about my diagnosis and treatment. He even offered to make a call to Dr. Norton on my behalf if I was unable to secure an appointment with him before the end of December. I made the call the next day and even though Dr. Norton only does appointments on Fridays I was able to get scheduled to see him in less than two weeks.

I got copies of all of my medical records transferred to Stanford right away and hand carried a CD of my CT scans and my pathology slides to my appointment. The first 20-30 minutes of my appoint-

ment was spent with the Chief Resident for Dr. Norton. She went through all the basic medical symptoms with me and did the basic exam. She then left and met with Dr. Norton and a short time they came back to the examining room together. Dr. Norton got right to the point and pretty quickly told me that what I had was MEN1. He then went through all the various symptoms I had and explained to me how he had reached his diagnosis. He also explained to me how my parathyroid issues were related to everything else and then proceeded to let me know what his recommended course of action would be.

His plan was to address the pancreas tumor first and go from there. He was very confident that he could do the pancreas surgery laproscopically. His plan was to complete the pancreas surgery first and then assuming I was still doing okay he would proceed and do the parathyroid surgery immediately after that. Because of the location of the tumor on my pancreas there was also a 50/50 chance going in that they would need to remove my spleen during the surgery. It is important to note that my general overall good health was one of the main factors in his belief that he could do all the procedures during one session. The estimated time to do everything if all went well was between 3-3½ hours. By doing everything at once I would only face a single recovery period as opposed to doing one surgery, waiting a few months and then going back for the second procedure and having a 4-6 week recovery from each. I have to admit that one of my biggest fears going in was that some complication would occur and I would wake up to find out that they were only able to complete one of the procedures.

I can't describe how much better I felt about undergoing these surgeries when I left his office that day. He was so confident and assuring that I just knew I was in good hands and so did my wife. I only mean this in the most positive way but I knew he had an "attitude" about him which said "I am good at what I do and you couldn't be in better hands". It really lifted my spirits to hear him explain what he could do, and although I'm sure none of us ever want to have surgery, I felt like I was at the right place for me to get the best care possible. I went ahead and tentatively scheduled my surgery for January 6. We actually completed all my pre-op work that day.

Finally it was January 6 and time for my surgeries. I had the first time that morning at 7:30 A.M. although I believe there were about 12 or 13 other surgeries also taking place with other surgeons at the same time. Check in time was 5:30 A.M. and I was ready to go. After all the usual pre-op stuff I was taken in to the operating room right before 7:30 A.M.

The next thing I remember was being in post-op and it was somewhere around 2:30-3:00 P.M. There was an issue with the hospital being very busy that day and I ended up staying in post-op waiting to get placed in a room until almost 7:30 P.M. Because I was in the post-op so long they were kind enough to let my wife come back and visit me a couple times while we were waiting.

It turned out that they found a couple of additional tumors during the surgery so they had to take a little more of the tail of my pancreas then they had originally planned. They also ended up removing the spleen since these tumors were very close to it. The good news was that despite all of this the pancreas surgery was still done laproscopi-

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cally with a total of 5 incisions with the longest one being less than 3" long. This meant the surgery took a lot longer than they originally planned, in fact it was almost 6 hours and I wasn't out of surgery until 1:30 P.M. that day.

After spending just one night hooked up with an IV and oxygen they removed all of that the next morning and I was actually up for my first walk by 10:00 A.M. that day. After that I was taking regular walks and even went to the hospital cafeteria with my wife that same night. My incisions were healing very well and my pain level was tolerable for the most part although the Vicodin I was being given didn't set well the few times I took it on an empty stomach. In total I spent only three nights in the hospital and was able to go home on January 9. The first week or so I was sleeping in our spare room as I adjusted to being at home, dealing with the pain medications and just the general fear of moving the wrong way or my wife accidentally hitting the incisions. After a short time things were back to normal.

The weather was great so I was able to walk almost every day after returning home. I think this helped my recovery time greatly. I had my follow up with Dr. Norton on January 28 and he was very pleased with my recovery, perhaps even a bit surprised at how well it was going. I asked him about returning to work and he told me to try it and see how it goes. I was back at work in my office only 25 days after my surgery. I'll admit my side got a little sore sitting at my desk those first few days but after that everything seems to be recovering nicely.

My long-term prognosis is very good. While MEN1 is something I will need to live with the rest of my life I think of it as just another lifestyle adjustment I need to make as I get older. Because my surgery went so well and everything was detected so early my next follow up will be a CT scan sometime late this year to make sure there are no new tumors showing up.

In summary I guess there were several lessons I learned during this whole experience. Those lessons were:

1. Always consider getting a second opinion on any major medical decisions. Remember it is your life and you need to do what is best for you.
2. Don't be afraid to ask questions if you have them. If the answers you hear make you uncomfortable ask more questions or seek another opinion.
3. Be comfortable with those that will be treating you. I can't begin to describe how much better I felt when I met with the doctor who eventually did my surgery as compared to the first doctors I had met with.
4. Do everything you can to maintain a positive attitude. It can be very difficult at times but a positive attitude will help get you through the tough times. Keep your life as normal as possible and spend lots of time with those you love.
5. Don't be afraid to share your story with those around you. If I hadn't shared my medical information with my family and others I would have never gotten connected with the Hageman Foundation that made sure I got to the right medical center and the right doctor to get me the best care possible.
6. Have faith and seek comfort in prayer. I know I had hundreds praying for me during my diagnosis, surgery and recovery and have no doubt that it was a huge factor in me getting through all of this as well as I did both emotionally and physically.

Thank you for listening to my story. I hope it can give hope and inspiration to those who may be facing similar circumstances now or in the future. I want to thank all the doctors and medical personnel who helped get me through this. I want to thank all my friends, family, co-workers and those who had never even met me who prayed for my recovery. My most special thanks and love to my sister Sharon who shared my story with my cousin Linda at the Hageman Foundation. Without the assistance of the Hageman Foundation my outcome would most likely have been quite different than what it is today.

Editor's Ramblings

Brian Nettz, CGCS

Hello everyone. There are a couple of new and interesting things for TTG this month. We are happy to have these non-traditional items. First, a rebuttal from Gale Love, Class A life member from Alta Sierra Golf Course. Thanks for the rebuttal, Gale.

Second, the answer to a question I heard a couple of dozen times at the annual meeting, "What happened to Gary Carls?" This is the real deal, a candid and sobering view of Gary's ordeal and triumph over Multiple Endocrine Neoadasia Type-1. It's about this time of the year when things are firing way up, rounds are up, temperatures are up, cost of goods is up, expectations are up and tempers are up. We get the same old yada yada about enjoying life and not taking it so seriously. Well my friends, this article is sure to inspire us all to take the yada yada a bit more seriously. Things could have turned out very differently for Gary, so let's heed his advice and listen to our bodies and make regular medical visits happen. Thanks, Gary! Also, our prayers are with you.



Ace

Greg Hall, Supt. at McGinnis Park up in San Rafael, made a hole-in-one at Stanford GC on the 17th hole (185 yards.) It was witnessed by Ken Williams, John Grund (the sprinkler yardage guy) and McGinnis Park General Manager Erick Jensen.