

Jim's Prostate Journey

To all the friends I haven't met yet who have discovered their PSA is rising.

Your blood test will include your PSA, prostate specific antigen, which is the gold standard for monitoring the health of the prostate gland. After a friend's Doctor missed his annual rise in PSA I began watching my own keeping copies of annual and semiannual blood tests. Good news, my PSA was in the 2.4 range for many years well within acceptable levels.

In 2008 things changed and my 2.4 became 4.2, then 4.8. My family doctor sent me to his favorite urologist and within seconds he recommended a biopsy. I reluctantly and suddenly became a freshman at "Prostate Cancer University". A biopsy removes 12 or 14 tissue samples from your prostate gland. They are sent to a lab to determine if you do or do not have cancer. If cancer is present, it is rated on the Gleason scale. The numerical values of that scale indicate the cancer's severity which determines a further course of action. There are some easy to understand explanations of the Gleason scale and you should be familiar with it.

I was not immediately accepting of this biopsy idea. I reminded myself that these doctors were just practicing and that I was actually in business. So I used my usual business approach, talking, reading, research and asking a lot of questions. I then sought out the top experts available and consulted them regardless of where I had to travel.

I became a patient at a premier medical institution in a renowned urology department. Another blood test was ordered and a DRE, direct rectal examination, where a urologist uses a finger to evaluate the surface feeling of the prostate. A pleasant surprise; my high PSA was not nearly as big a concern to them. At my age and with good DRE results they recommended that I wait and further monitor my PSA level by blood testing every six months.

In June of 2009 my PSA reached 5.22. This did concern them and they were also a little concerned about velocity, how long it takes for your PSA to rise. It was time for a biopsy. 12 samples were removed from my prostate and sent to the lab. Amazingly the results were all negative and I was reassured that I simply had a high PSA, but no cancer. It made for a very happy day. The six month interval blood tests continued.

More good news, my PSA starting dropping from over 5 to under 4 a year later, and to 3.0 in 2011. I was very happy about this downward progression. But then, in 2012, it rose again to 4.64 and then by the end of the year to 5.4. I was informed that a second biopsy would be wise just in case they may have missed something on the first one. After more samples and lab results I got the news, all samples were again negative once more! Again reassurance from one, if not the, most respected clinic in the country that I did not have prostate cancer. I was elated and so relieved.

Several years earlier I became a minor investor in a company, NuView Life Sciences. NuView developed a simple urine test to detect prostate cancer. The company is completing clinical trials and will seek FDA approval for this test. In 2015, my PSA had risen to 5.9 and I told my story to a couple of people at NuView including the founder.

Almost instantly they said, "We think, based on our studies, you may very well have prostate cancer." "How could that be after two biopsies from the best in the business?" "Well let's hope you are right" they said, "all you need to do is provide a urine sample and run our test to be sure".

I was fortunate to become one of the case studies for some of the early NuView clinical trials. First step, the urine test. I shipped my chilled urine sample overnight to Thomas Jefferson University in Philadelphia. If this test really was effective then I was confident my results would be negative. A couple of days later I got a phone call from the lead scientist himself. He told me my urine tested positive for prostate cancer.

Since I invested my money in this company I was torn. The investor in me wanted the test to work but I would gladly give up my investment if the test was wrong. I did not want to believe I had cancer especially after a quite a long journey that ended in finding no cancer. I booked flights for Philadelphia to find out.

I was given an MRI and then a PET/CT scan after being injected with radioactive copper 64. Two areas of cancer in my prostate lit up like a green blip on an air traffic control screen. Using these results as a guide a third, guided biopsy was performed and the tissue samples of these areas tested positive for cancer. On the Gleason scale my score was just over the line indicating immediate treatment versus waiting to see if the cancer was progressing. Waiting and monitoring would have been an option if my Gleason score was lower as prostate cancer is often a slow moving disease.

I went back to the clinic that had been treating me all along and announced that I did, in fact have prostate cancer. They looked at the scans and seemed a bit put out that they did not find it. I asked, "Why did you not give me scan years ago?" "You would have found it then." They explained that based on my two biopsies and current PSA they were just about to recommend a scan. As to why not earlier they had no answer. Herein lies one of the mysteries of prostate cancer treatment, why urologists don't use non evasive scans rather than biopsies as the first detection step. Biopsies are big business I guess. Perhaps the profit from a biopsy can make a Bentley payment.

The prominent urologist then did what almost all do, he immediately recommended surgery to remove the prostate. Urologists diagnose but they are also surgeons and they want to practice that as well. I stopped to regroup. It was very fortunate that one of the people with NuView recommended I read a book called *Invasion of the Prostate Snatchers**. Believe me the contents are much more serious than the title. If you are diagnosed with prostate cancer activate your Amazon prime or run to the nearest bookstore and get this book.

I do not like surgery to begin with, and after reading a lot about prostate surgery I became even more surgery adverse. Often the surgeon is not as experienced as you may think, results are not as precise as advertised, and the side effects are often life changing.

To me prostate cancer is unique disease in two ways. First, unlike a lot of ailments where there is one obvious treatment, there are many options not just one. Second, each proponent of those options can easily convince you of the wisdom of that option. These doctors, most of them knowledgeable, great people, truly believe in the treatment

that have dedicated themselves to and will influence you into choosing it. With prostate cancer there are 6 or more good options and only you can make the decision which to choose. With all the experts and options you are literally forced to become your own doctor. My education at Prostate U continued.

So after reading Dr. Scholz prostate snatcher book and spending every evening entering every word related to prostate into all of the search engines, I told the urologist that I wanted to explore other options besides surgery. He referred me to the radiation therapy department. Again I met with a top doc. Much to my surprise he thought Proton therapy would be perfect for me rather than radiation. I had been reading about Proton therapy and it was one of my top options. I starting asking my typical list of questions, my doctor's appointments rarely end at the scheduled time. One thing I was convinced of is whatever treatment I chose I would get it from the very best and most experienced in that discipline. I asked, "How long have you been doing proton therapy?" And, "How many have you done for prostate cancer?" He said they got their proton machine a few months ago and had done three or four but their staff was fully trained and capable.

I hurried home for more research and found the best proton clinic around with an internationally known doctor who has treated almost 10,000 patients. I got an appointment and met with him. Proton is one option. There are many others including Radiation with Implanted Seeds, High Dose Radiation, External Beam Radiation, and the use of both heat and freezing. I won't bore you with all the scientific names and descriptions of these, they are readily available.

I adopted Dr. Scholz three goals, "The trifecta" for prostate cancer treatment. 1. Cure the cancer, 2. Retain good urine function, and 3. Maintain good sexual function. A lot of people panic when they find out they have cancer and per their Urologist's recommendation march directly into the operating room. For some strange reason I was confident that one of the available options would cure my cancer. I was focused on how to minimize these the two major side effects.

I consulted more experts thinking my Gleason score might be just a bit lower and then I could take the "wait and see" approach. Wouldn't be great if I didn't have to do anything right now, I thought. Perhaps I was in denial or at least avoidance. Through NuView I learned of a new, highly accurate scan which I had done at UCSD (University of California San Diego). I even had my third biopsy results sent to a nationally known uro-pathologist at Johns Hopkins University. Looked like avoidance wasn't an option, both the biopsy and scan confirmed the results and it became obvious I had to choose a treatment now.

In the end I chose HDR, High Dose Radiation. Several needle like tubes were inserted into my prostate and radiation was introduced down these tubes. This was done in one day and done again seven days later. The goal of HDR is to get your PSA down to less than 1, one year after treatment. I sought out the best HDR doctor I could find with the best statistics on cure rates and minimal side effects. I headed to UCLA (University of California Los Angeles).

Although I did a lot of research and consultation my ultimate choice of treatments was rather unscientific. I wanted to be cured, but at the same time minimize the side effects. Many treatments involve reliance on computers and other equipment. I rely heavily on

computers in business but have also been the victim of crashes, errors and problems with them. HDR is an approach where technology, scans and tests provide the map, but a highly experienced doctor is placing the radiation into the problem areas. The treatment is technology based but implemented by a skilled human.

The week before my first HDR treatment my PSA was 7.0. One year later it is .8, success and hopefully the end of Jim's Prostate Journey.

So that is my story. What about yours? If your PSA has risen to levels that require investigation and sought my advice, this is what I would say:

- Take personal responsibility for your own health
- Get a blood test at least annually, read it yourself and store copies in chronological order
- Enroll in "Prostate Cancer University" and do your homework
- Be cautious about accepting the first, second or third recommendations, fight to find the best answers
- Explore several options in depth, not just one or two
- There are many great doctors but you must make personal decisions based on how you interpret what they are prescribing
- Never make a decision based on your health insurance coverage – Find a way to get done what is best for you
- Know the stats – Number of procedures done, years of experience, success rates and incidence of side effects
- Take lightly all the recommendations of well-meaning friends, family members and patients – They suddenly become experts
- Once you choose a plan hire only the very best to implement it
- Your journey will be more successful if you have a copilot, a person you confide in, one that you really love, and truly loves you
- Regardless of your brand or depth of spirituality, or lack of it, do not underestimate the power of prayer