

## Personal Experience

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It all started with life insurance in March of 2009. I wanted to change to a lower cost life insurance policy and being the healthy guy I was, figured this would be a slam-dunk. After enduring the normal amount of grilling over the phone, the insurance representative set up an appointment for the examiner to come by and run some routine tests. Piece of cake, after all, my last physical came out good even though my cholesterol was a little high.

About two weeks later I received a letter from the insurance company turning me down! The reason given for my rejection was because the tests showed elevated AST, ALT and GGT. These test results have to do with liver enzymes. I found out taking certain medications, including ones I was taking at the time for a respiratory issue, could elevate them. And oh yeah, I had a PSA of 4.33 – cut off for “within normal range” was 4.00.

Not willing to accept the rejection I went to Kaiser, explained what happened and they agreed to re-test me. I was done with the medication so; again, it would be a slam dunk.

Sure enough the new test results came back, which I checked on line, and all three enzyme tests had gone down well below the cutoff. However, the PSA was missing, so I had to call in for the results. What I heard stopped me in my tracks – my PSA was HIGHER. It was a lot higher, as in 6.08. Little did I know what that would unleash.

I was referred immediately to a Urologist who scheduled a biopsy. Two months later the biopsy was done and I waited for the results. Soon after, I got the results and they weren't good. My wife came home that evening and asked about the results. When I told her, it was as though I had slapped her in the face. She had a look of astonishment, the “this-can't be-true” look.

I explained that they only found a very small amount of cancer and we would both go to the consultation with the urologist soon. I continued on about the first options offered, either surgery or radiation. It was mentioned that there were other treatments, but Kaiser didn't do or endorse them. Oh yes, you could also do this thing called “watchful waiting”.

Even though “watchful waiting” was explained to me and sounded like something I would like to investigate, my wife felt that wasn't an option. After all, this wasn't something to play around with. Isn't your life more important than some stupid little gland in your crotch I was asked? I responded that we didn't really have enough information yet. She reluctantly agreed to consider that approach provided I would dive into this headfirst and find out everything I could and follow whatever the recommendations were religiously. I agreed.

First we saw the Urologist who explained in detail about what was going on and how the “treatments” were administered. The biopsy had resulted in a Gleason score of 3+3=6 Stage T1c. with 5% cancer cells found in one of twelve samples. The right side of the prostate gland, I was told, had the cancer while the left side “looked suspicious” but they wouldn't call it cancer. (I later found out how wide open the word suspicious was.) The doctor did admit the test results showed such a low level of cancer that “watchful waiting” was an option. However, because of the ambiguous results of PSA's, biopsies etc they, the doctors, couldn't really tell me 100% where I was at any given time. The doctor made it clear that if I followed the “watchful waiting” approach, I had to be ready to have the burden of always waiting for the next test results, wondering each time if the numbers had gone up. In other

words, there was risk, along with continued worry. The doctor felt that many men and/or their families had a difficult time dealing with an undefined course of action. Of course there was also risk with surgery, risk with radiation, risk of side effects. It came down to which risk door you wanted to go through.

The Prostate Cancer Manager at Kaiser was very helpful and suggested that I attend their group meetings held twice a month. As part of my program, I started attending the meetings and was very impressed by the fact there were so many men there, that they were so open and a lot of good information was exchanged. The men's stories were all over the map. It ranged from one individual who admitted that after finding out he had prostate cancer it took him all of 3 seconds to decide on surgery. Even though his cancer was not life threatening, actually closer to my situation, he couldn't live with the thought that this DISEASE was inside of him and he wanted it gone. I heard from the facilitator that this was common. Even my Urologist pointed out that if you decide against treatment that you have to be able to live with your decision 24/7. If that's going to drive you crazy then you better not wait. Made sense to me. I also heard from a man who had been on watchful waiting for over 10 years. So there you have it, all the way from yank it, burn it or watch it.

My wife and I met with the surgeon. Very informative, I was told I was a great candidate and he could get me in to his surgery schedule within a couple of months. This was accompanied by the obligatory oh and by the way here are the many things that can go wrong...

I had decided against radiation and was 70 % of the way toward a final decision of how to manage my cancer when I was told about another support group from a member at Kaiser. The name of the group was the Informed Prostate Cancer Support Group, IPCSG, and they offered "other courses of action". The Kaiser people acknowledged their existence but obviously weren't endorsing them. I wondered, what could be the big deal? Was there a big deal? Did they advocate voodoo? Magic potions? Howling at the moon? Figured I better check it out.

Meanwhile I ordered another PSA. My Urologist questioned why and I informed him I had read that there were a number of reasons for an elevated PSA that could have nothing to do with cancer. After all, he had also diagnosed me with BPH, an enlarged prostate, so why not? He agreed and the next one came back 4.49 (down from the previous 6.08). It was music to my ears. This was the kind of breathing room I wanted and now it was off to IPCSG.

My first meeting with IPCSG was in Sept 09. I was immediately impressed by the attendance. It appeared to be 60 or 70 people, mostly men. I was greeted by a gentleman named Gene Van Vleet, who took down my info and said he'd follow up later, which he did. The talk was informative but one of the most impressive moments was listening to another gentlemen, Lyle LaRosh. To say that Lyle was forceful in his sweeping assessments of the current state of prostate cancer treatment would be an understatement. For someone like myself on "watchful waiting", (now called "active surveillance") this was a great resource.

Over the coming weeks I learned about the color doplar ultrasound test and how it allowed a specialist to take color images of the prostate and see more clearly what might be going on. After getting my wife's vote of approval I scheduled an appointment in Ventura to see the well respected Prostate Oncologist, Dr. Bahn. In late Oct. My second opinion from Dr. Bahn was he felt I looked pretty good and to come see him again in six months. I found the closest restaurant and ordered up a beer.

Since learning back in June about my cancer, in addition to the meetings, I started on a crash course of reading and researching. One of the consistent threads that emerged was that there appeared to a correlation between animal fat and cancer, particularly red meat. Good enough for me. I still do some

chicken and fish but all the red meat was swapped for tofu and veggies. Our household already ate vegetarian occasionally but now it was a staple.

I went in for my physical in Dec 09 and my primary doctor was a bit shocked. In the last year my cholesterol had dropped from 206 (once was 220) to 190. It had ever been that low. My blood pressure had dropped AND I lost 15 pounds. She asked what I had been doing different. I said one new thing; same exercising, same sleep, perhaps more stress since 2009 was a bitch, still limited alcohol; it was the red meat substitute. She was flabbergasted. Now why should a doctor be so surprised? Oh and my PSA was 4.6.

So from here on out I have a life long course to fulfill. Health-wise I haven't felt this good in a long time. Mentally I don't dwell on the "C" word, only that I improving and reinforcing my body's immune system. Even if I can't reverse what's happened, though I don't think that's impossible, I will at least stop it. I might add that my wife is 100% behind what I am doing.

If I can offer help to someone going through the same turmoil I went through in the beginning, then I will be happy!