

Bill Manning – Active Surveillance

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, I figured this was 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, 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, and I had a PSA of 4.33 – cutoff was 4.00.

Not willing to accept the rejection I went to my HMO, 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 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. A lot higher, as in 6.08. Little did I know what that would unleash.

I was referred immediately to an urologist who scheduled a biopsy. It wasn't long before I got the results and it wasn't good. When my wife came home that evening and asked about the results, it was as though I had slapped her in the face. The look of astonishment, the "this-can't be-true look".

I explained that they only found a very small amount and we would go in for a 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 my HMO didn't cover or endorse them. Oh yes, you could also do this thing called "watchful waiting".

Even though watchful waiting was explained and sounded to me like a possibility, as far as my wife was concerned that wasn't an option. 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 said yes, but we didn't really have enough information yet. She reluctantly went along provided I agreed to 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 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. In other words, there

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was risk. 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 my HMO was very helpful and suggested my attending 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 attendees ranged from men who had various treatments to people like me to one individual who admitted that after finding out he had prostate cancer it took him about 3 seconds to decide on surgery. Even though his 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 to 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 a couple of months. Then came the obligatory disclaimer; "oh and by the way here are the many things that can go wrong and potential permanent side effects..."

I was 70 % of the way toward a final decision when I was told about another support group from a member of my HMO. He said they met up in La Jolla and offered "other courses of action". The support group acknowledged their existence, but obviously wasn'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 so why not? He agreed and the next one came back 4.49. Music to my ears. This was the kind of breathing room I wanted and now it was off to the other group.

My IPCSG first meeting 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 name 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 gentleman named Lyle LaRosh. To say that Lyle was forceful in his sweeping assessments of the current state of prostate cancer treatment would be an understatement. Since I was strongly considering watchful waiting, which I was also told was now called "active surveillance", this was a great resource.

Over the coming weeks I learned about the color doplar ultrasound and how it had helped, maybe saved a few of the men in the group. After getting my wife's vote of approval I scheduled an appointment in Ventura to see the well-respected Prostate Specialist, Dr. Duke Bahn. In late Oct. I had my visit and exam. The results were good and I now had my second opinion from Dr. Bahn – and that was I was OK with active surveillance and I should come see him again in six months. I found the closest restaurant and ordered up a beer.

Since learning in June 09 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. The red meat was swapped for tofu and veggies. We already ate that way occasionally but now it was a lot. Oh yes

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– no dairy. That I’ve been doing for the past 20 years. Who knows, if I hadn’t maybe I’d be telling a much different story.

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 237) to 190. I had been changing my diet well before the diagnosis but it had never been that low. My blood pressure had dropped AND I lost 15 pounds. She asked what I had been doing different. I said one thing; same exercising, same sleep, maybe 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.

I followed up in March 2010 with another visit to Dr. Bahn. He tested me again with the color ultrasound and the results were the same. In fact his comment was I had advanced BPH with evidence of chronic prostatitis. A lot of other details followed by “the known cancer still appears too small to be seen and may be clinically insignificant at this time.” I had another PSA test at his office and now it had dropped to 3.8! He also ordered a PCA3 urine test just to add to our portfolio and it came back negative also. He stressed continued PSA monitoring and watch for any consistent PSA rising trends up over time, involving at least 3 PSA tests.

Summarizing this, I now had multiple pieces of evidence showing that for now and maybe for the next 3, 5, 10 years this might stay under control, particularly with my lifestyle changes. It also meant something else; if I had followed the urologist/surgeon/radiologist preference, I would no longer have a prostate and might have a whole lot of other problems. Doesn’t mean I might not have to do that some day but I DEFINITELY didn’t have to do it right now.

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 am improving and reinforcing my bodies immune system and even if I can’t reverse what’s happened, though I don’t think that’s impossible, I will at least stop it. If I can offer any help to someone going through the same turmoil I did in the beginning then I will be happy.

===== Updates =====

UPDATE 2011: bi-annual PSA’s and still below 5.

UPDATE 2012: In May of 2012 I went to see Dr. Bahn again for another color doplar ultrasound. This would now be my third and happily after the exam was done his report came back...everything the same. See you in a year or two.

UPDATE 2013: Well a funny thing happened in the exam room, but I’ll get to that in a minute. First, between 2011 and July 2013 my PSA has bounced up and down between a high of 5.42 and a low of 4.32. Was I worried? No. If my cancer was getting worse how would you explain my PSA going down? Which leads to the first part of my update. My urologist, who remember pushed for “treatment” since day 1, did start acknowledging that A.S. maybe be working ok. He still wanted a biopsy 2011-2012 and I asked why? If my PSA was steadily rising over time, well perhaps I would need a biopsy. However if it goes down how can you recommend the same thing? Defies logic. So by the end of 2012 at my annual visit to him, after another PSA and DRE, he did say, “I guess whatever you are doing is working”. Well thank you. I did mention I was still on my modified vegan diet (with better health tests BTW).

Now to 2013 and the exam room; I received a letter from Dr. Bahn recommending that I have another biopsy which I respectfully declined. It isn’t that I wouldn’t have one, I just wanted some compelling reason for doing so. I did make an appointment in July to see him, this now being my fourth test.

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Second part of update. Once he fired up his machine and invaded my space he discovered something “new”. As he outlined on his computer screen there was a new area that looked suspicious. Might mean nothing he said but... it might. He REALLY recommended a biopsy so this new area could be addressed either by him or someone else as long as they could do a “targeted biopsy”.

I could understand his reasoning given it had been 4 years since my first and only random biopsy. He would be able to go into the new area and the area where my cancer had been found in the first place. So, I said go ahead and Dr. Bahn took 7 samples.

Several days later I got a phone call from Dr. Bahn – the lab results were back. He told me that the pathologist found...NOTHING. Nothing I asked? As in, nothing? Nothing he repeated, very good news, right? Oh, you might say that. After thanking him I couldn't call my wife fast enough. She was equally blown away.

So there you have it;

- **2009**, 12 random samples, cancer found in 1.
- **2013**, 7 TARGETED samples and zero cancer. There are issues, including chronic prostatitis, but no cancer. AND I STILL HAVE MY PROSTATE! Hey, maybe that diet thing has something to it!

I wasn't done though. I decided to have Kaiser double check the results, after all they were the ones who diagnosed PCa in the first place. I called the lab who had my samples and asked if they would send them down. No problem they replied, just have Kaiser request them. The Kaiser part started off a little rough because each person I spoke to at Kaiser thought I wanted results SENT somewhere else not the reverse. (I'm sure I am one of only a handful that has ever asked for a 2nd opinion FROM Kaiser). Anyway got to the right person, very nice lady in Pathology, gave her the details and she said she'd call if there was a problem. A week later I decided to follow up just in case so I called her (she gave me a direct line) and to my complete surprise not only had they already received the slides, they had reviewed them and sent the report to my urologist! In a week! I asked if I could get the results and with an email from me and a fax from them, I had the results; THEY CONCURRED with the original finding! How about that. Targeted biopsy, two labs = same result. No PCa.

A very exciting outcome that I hope will give some support to guys who may feel a bit of hopelessness and to those who are willing to avoid hopping on the treatment train urologists give you a ticket for.

UPDATE 2015: Still on Active Surveillance. Decided to switch gears and have a mpMRI done at Imaging Healthcare Specialists in San Diego. With all the advances in imaging and now having a specialist in San Diego it seemed like the best course. So I had the test in July 2015 and Dr. Schwartzberg gave my image a PI-RAD 2, pretty low classification – A.S. was still the way to go.

Still two PSA's per year, plus one DRE. Had another PSA spike this time to 7.1 in December.

UPDATE 2016: Still on Active Surveillance. PSA dropped to 5.9 then back up to 7.5. Looks like the 7's may be the normal for me. Years ago Dr. Bahn said based on my gland size, (large), my predicted PSA should be between 7 and 9. So later in 2017 I will have another mpMRI just to keep tabs on the good old prostate.

UPDATE 2017: Bi-annual PSA test: 7.7 – 6.8, DRE – negative. Second mpMRI @ Imaging Healthcare Specialists – results were negative. PI-RAD score of 2.

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UPDATE 2018: January PSA: 5.8. Active Surveillance the obvious choice. July PSA: 7.9. Not worried because back in 2016 it got as high as 8.7.

UPDATE 2019: January started Avodart for BPH. April PSA: 5.0. This is expected because Avodart lowers your PSA though my doctor was a little surprised it wasn't lower. Another test in July was 4.6. November didn't see any improvement from Avodart so switched to Flomax. PSA back up to 6.1. December had my 3rd mpMRI. No new findings; prostate gland volume of 95.7 cc (down from 99) and PSA density of 0.06 (normal <0.15). Test was graded PI_RAD2. More A.S.

UPDATE 2020: April PSA: 6.4. November PSA: 7.8, again at a level it's been several times before over the last 6 years.

UPDATE 2021: May PSA: 8.9 so its up again. June another mpMRI was ordered since my urologist was a *little* concerned about the rise. Results came back and I was downgraded to PI-RADS 1! So what about the PSA rise – this might explain it; “Nodular enlargement and inhomogeneous signal intensity throughout the transitional zone compatible with benign prostate hyperplasia.” Good ole BPH. Also worth noting; “volume of 111.2 cc. PSA density is 0.08 ng/ml/cc.” Density below 0.15 is considered favorable. November PSA: 9.1, up again though at a level it's been once before.

UPDATE 2022: April PSA: 7.9. A nice drop so we'll hold off on another MRI until next year. I asked about a micro-ultrasound and he said if anything new/concerning popped up yes we'd do one. Otherwise another MRI next year is OK. I'll have another PSA in November.

UPDATE 2022: Genetic testing history: 02/08/2022 - Exo DX demonstrates a score of 44.44, which is a higher risk for High Grade Prostate Cancer. I'm not concerned about this but my urologist wants another PSA done. Seems that ExoDX is very good at predicting very low and very high risk but not so good in the middle, like mine. April PSA: 7.9. A nice drop so we'll hold off on another MRI until next year. I asked about a micro-ultrasound and he said if anything new/concerning popped up yes we'd do one. Next PSA was in October – 10! Well, it was almost that high a year earlier so we'll wait and see with an MRI almost certain now.

UPDATE 2023: Feb. PSA: 8.7, down again. A scheduled MRI in May turns up good news, PIRAD 1, nothing remarkable other than Mr. Prostate has grown some more, 124cc now. August PSA: 8.2 down again plus another ExoDX test and results slightly lower than last time but my urologist still feels nervous but we'll see in 6 months.

UPDATE 2024: March PSA: back up to 10 again – however I believed there was an explanation; remember how they say no strenuous exercise the day before your test? Guess who forgot? My urologist laughed and said ok, let's do it again in a few weeks which I did. 8.3. I guess that old adage is correct. My urologist's take? See you in six months.

So, this June 2024, it will be 15 years since originally diagnosed when told I was an “excellent” candidate for surgery.