Month 87 – Adapting and Researching

February 11, 2018 By Dan Zeller

Ever since my December meeting with my doctor to review the latest uptick in my PSA reading to 0.10 ng/ml where he told me I need to begin to think about salvage radiation therapy, it's as though the clock has been turned back to when I was first diagnosed. That makes this all very real once again. We're getting closer to having to make a decision to move from monitoring to action.

My emotions have been all over the place—from mad as hell at the world to ready to bawl at the drop of a hat—and I felt compelled to research as much as I could, as fast as I could even though my next PSA and doctor's appointments aren't until April. On the good news front, the peaks and valleys on the emotional roller coaster have diminished some over the last two months. They're still there, but not as bad as they initially were.

I've been spending a good amount of time (perhaps too much) researching and hanging out in the advanced prostate cancer section of various online support groups. That's been both helpful and a tad frightening. It's been helpful because I'm new(er) to the advanced prostate cancer discussion, and I've been learning more about the different treatment options, protocols, and latest research. It's been frightening because reading the first-hand stories—while valuable and necessary—has stoked my fears of the treatment side effects.

I did come across one thing in my research that I'll definitely discuss with my doctor in April.

We know biochemical recurrence after prostatectomy has been widely defined at 0.2 ng/ml for quite some time, yet more and more research is indicating that salvage therapy should begin early in order to have the best chance of success. Some suggest starting SRT before hitting the 0.2 ng/ml threshold.

Of course, as we all know in the field of prostate cancer, nothing is clear-cut. You can easily find research that has conflicting recommendations.

I came across Stephen J. Freedland's 2005 study (co-authored by Alan Partin and Patrick Walsh—heavy hitters in the prostate cancer world from Johns Hopkins) that shows I may not have to do anything other than continue to be monitored given my status (PSA = 7, PSADT > 15 months, time to recurrence > 3 years). In fact, he writes:

"It is amazing to me that for a man who has all the low-

risk features – if his PSA doubling time is greater than 15 months, his Gleason score is below 8, his PSA comes back after three years – his odds of being alive 15 years later are 94 percent." These men do not need treatment, he adds. "If we know that 94 percent of these men are alive and well 15 years after surgery with no further treatment, anything we do to treat them is unlikely to improve on that, and probably would only affect the quality of life."

That's quite encouraging for someone fearful of side effects and loss of quality of life. Combine that with the Pound study done in 1999 that said it takes on average eight years to metastasis after BCR and, on average, another five years to death after metastasis without any additional treatment, and you're building a stronger case for doing nothing other than continued monitoring for those of us who are averse to treatment side effects. At least in my mind at the moment.

You can read an abbreviated summary of the Freedland study in the Johns Hopkins newsletter, Prostate Cancer Discovery, here, and the full study as published in JAMA here.

I'm slowly adapting to this new path that I'm on, and I'll work to find the right balance to stay away from the online support groups and the Google machine to maintain a sense of sanity. I fear, however, that controlling the emotional roller coaster is going to be far more challenging from this point forward (steer clear or pass the tissues). Just a hunch.

One related footnote. I've not yet met with a radiation oncologist since my PSA started going up in September 2015. If it stays the same or goes up again in April, I'll ask the urologist for the referral just to start the conversation and learn more from his/her perspective.

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