

George Johnson
"MY PROSTATE CANCER STORY"

Introduction

My profile includes long-term survival after radiation therapy, followed by recurrence and inappropriate salvage treatment. Severe side effects occurred but a change in doctors and a revised treatment program has been successful. I have an aggressive form of PCa; but, since joining this support group and becoming my own case manager, I have kept my PSA below 0.1.

Initial Treatment

Eleven years ago, December 1998, I received a mailed lab report from my doctor with a hand written note "Your PSA is high and you may have prostate cancer. You should see an urologist, Dr. X." I saw this new doctor and he told me my PSA was 9, but I may just have an infection. He gave me an antibiotic for two months. In these two months my PSA rose to 13. (I have since learned that this was a serious, aggressive doubling-rate of about three months.) He then did a biopsy of six shots. On my return for the results we had a brief discussion. By this time I had gone to the Internet to get informed and bought a bunch of books on PCa. He told me I had cancer and needed surgery. I asked about the biopsy metrics and he disclosed that I had a Gleason of 5 and my stage was T2a. I said "I think its T2c." He was shocked and asked how I knew that. I said "It's says in the lab report the cancer is on both sides of the prostate." He looked at the report and said, "Oh, it does say that. You're right." That began my concerns about urology and the need for me to become my own case manager.

I interviewed four more doctors/treatments and chose external beam radiation treatment, EBRT at Scripps Memorial. The reason for this selection was based upon the radiation oncologist analysis of the Parson Tables which indicated a high probability that my cancer had spread, and, as a result if I had surgery, I would still need radiation to catch it all. The radiation, 72 Grays, went great and my PSA stayed below 1.0 for eight years.

Recurrence

After treatment, my radiation oncologist turned me back over to my urologist, Dr. X. I wasn't impressed with him, or his replacement, Dr. Y, when Dr. X retired. I found a new internist for my general health who gave me my annual PSA tests, which were "low" for the next eight years. It turns out that my "low" was rising in recent years from 0.1 to 0.2, then 0.4 and finally 0.7. I waited two years before my next PSA in December 2009. It rose to 13.7! My internist and I did not know that, after treatment, the PSA baseline of cancer concern which was 4.0, shifts down to the decimals after the prostate is radiated and "low" is not a good indicator in itself. My calculated doubling-rate was at four months. In other words, my current PSA would rise to 28 in four more months. A year after that it would be over 200. Something had to be done. I was sent back to my previous urologist, Dr. Y.

New Treatment

I expected a review from Dr. Y and a retest of my PSA. Instead he gave me a urology standard "quickie" treatment, bend over for an injection of Lupron. That's it. He never checked my blood pressure, or did a DRE, etc. Before leaving his office I asked him if I should join a prostate cancer support group. He

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answered, "No." I asked why. He said, "They're a bunch of whiners." Of course I ignored his advice and went to the March IPCSG meeting and learned more in that meeting than in the previous ten years.

Lesson Learned from IPCSG

One of the things I learned was the prevalent controversy about Lupron side effects and the questionable effectiveness of testosterone reduction. My new friends in IPCSG strongly recommended I visit Dr. Bahn in Ventura, CA to get an accurate measure of my prostate cancer. His color Doppler ultra sound and 7 biopsies mapped the aggressiveness of my cancer. My new doctor was disturbed that Dr. Y made no diagnostic measurements and only gave me a troublesome injection without Casodex and Avodart to deal with the more critical cancer stimulus, dihydrotestosterone. At this time Dr. Y had stopped the Lupron injections, and placed me on an intermittent schedule. My PSA had dropped from 14 to 0.3 in three months. It was working. Why be concerned?

Well, Dr Bahn was concerned. He called me and said, "The reports are not good." After the exam and biopsy, I had a Gleason of 8 (4+4) in the prostate capsule and also in the seminal vesicles! Further tests, a CT scan and bone scan were negative. My cancer had not yet metastasized. In follow-up to Dr. Y's treatment I met with my internist; he found for the first time a heart problem, atrial fibrillation, a persistent heart beat fluctuation which can lead to blood clots. My urologist and cardiologist denied any correlation to my initial testosterone treatment and did not recommend any heart treatment. The two doctors had a rather unconcerned, cavalier attitude, apparently do to my age. Starting with, "Men your age (I'm only 78).

While I pondered the next step, my new friends at IPCSG asked about my PSA results and testosterone levels. Dr. Y had not scheduled any follow-up tests, so after four months, on my own initiative I had both tested. My PSA had gone up from 0.2 to 14.0 and my testosterone from 29 to 857. Intermittent treatment did not work. Dr. Y said I had to go back on injections. Based upon my own case management lessons from IPCSG, I rejected this treatment and left his program.

A New Treatment Program

I switched from injections to pills, Casodex and Avodart. After one month my PSA dropped to 0.2, my testosterone went up to 927 but my dihydrotestosterone was down from a 30 average to 2.3. These great results have continued for the next 12 months. My PSA levels are less than 0.1. These results reflect the view that it is better to deal directly with dihydrotestosterone which is 5% of the full testosterone production. This targeted blockage has fewer side effects for me than the highly disruptive injections that caused permanent side effects for me.

In March '2011, a year after my injection and the start of my troubling persistent atrial fibrillation, I had a severe side effect, the whole right side of my body became numb. I had a cerebral blood clot that caused a stroke lasting 2+ days. I then learned the FDA had issued an alert on Lupron for potential heart problems, this occurred at the same time I brought up this issue with the two doctors the year before.

I now have a new cardiologist, am taking Pradaxa, a new blood thinner and feel great! My new cardiologist looked me in the eye and said, "George, a stroke is worse than any cancer." I took note.

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Lupron and other similar injections should not be used without thorough cardiac monitoring. In my case it was not the proper treatment and definitely it was highly dangerous to be suggested again after causing my atrial fibrillation.

The Outlook or Next Steps

I have now found my best plateau treatment, Casodex and Avodart. A key factor in my treatment program was to stop taking injections and change doctors by becoming my own case manager. The longer term question regards the duration of my current treatment. Should I take a holiday from the pills for a year as some doctors recommend to extend the effectiveness of the treatment and let my PSA rise, or because of my critical doubling rate, continue the daily dose and hope it remains effective?

On the horizon is the uncertainty of the cancer spreading from the seminal vesicles to my lymph nodes. Should I have a new, high-definition MRI 3T examination of my lymph nodes and/or the new CTC test, to check for circulating tumor cells in the blood stream? These tests could be performed to establish baseline measurements of possible spreading of this disease. I'm getting conflicting responses from different doctors. I will continue my current program a little longer before deciding.

IPCSG has made me well again and made me an effective case manager. I am more informed of my treatment options and also aware of new treatment developments. Recently doctors ask me, "Where do you get these questions?" Now you know.

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My recent profile

Date	PSA	Testosterone	DHT	Treatment
January 2010	13.2	?	?	Lupron (Trelstar), 3 month injection by urologist, no tests or DRE from urologist recommended by my internist
March 2010	0.2	29	?	"See it works, the testosterone is way down, We will go on an intermittent pause." No follow-up schedule. Had my own test performed as recommended by IPGSG.
August 2010	13.7	857	?	"Failed intermittent, see the correlation to testosterone, go back on Trelstar despite side effects." Refused treatment, Changed doctors and treatment. Had test performed by Dr. Bahn - T3c, Gleason - 8 including SV, negative CT and bone scan
September 2010	0.2	927	?	Casodex 150 MG, Avodart, Great results in one month. I see the lack of correlation to testosterone.
October 2010	0.1	975	?	Casodex 100 MG, Avodart, on my own, asked for DHT test
November 2010	< 0.1	900	2.3	Casodex 50 MG, Avodart, I see a correlation to DHT.
December 2010	< 0.1	910	2.3	Casodex 50 MG, Avodart
January 2011	0.3	?	2.3	Whoops, lowed my Casodex too much, 25 MG, moved it back up to 50 MG.
February 2011	< 0.1	?	2.3	Casodex 50 MG, Avodart, Back on track.
July 2011	< 0.1	?	2.3	Casodex 50 MG, Avodart, Tested each of last 4 months, same results. Will continue for the remaining year.