

# A Prostate Cancer Patient's 24 Year Continuing Journey from Diagnosis to Mentoring

## Opinion

What has been successful for me may not be as successful for another. I expect it boils down to how much cancer was in development at diagnosis, where "all" was that cancer in development (biopsy indicates supposed areas, then removed gland indicates supposed areas, but neither can determine if, and how many, cancerous cells have migrated elsewhere away from the removed prostate gland, if removed, or radiation to the prostate gland and its periphery).

I have suspicions that pelvic lymph nodes are not given enough attention because of their deeper location away from the prostate gland, thus not usually extracted as part of surgical removal, as well as not included with sufficient radiation when any form of radiation is prescribed.

The surgeon who removed my prostate gland in December 1992 did remove lymph nodes adjacent to the gland, but not pelvic lymph nodes, and did remove the seminal vesicles and vas deferens, with none of these organs beyond the gland showing any evidence of cancer presence/development. But he did remark that an area of a tumor in the prostate gland had extended too far into some fatty tissue that he wasn't comfortable "cutting" any further. As a result of that decision and uncertainty that all the cancer was removed, I was scheduled and received a full series of salvage external beam radiation (SRT) as soon as I healed from the surgery. My radiation back in those days was much less precise as forms of radiation have improved over the years.

PSA following SRT dropped to <0.1ng/ml so the physician and I were of the opinion all cancer had been eradicated. However, three years later, in 1996, my PSA began slow but steady elevating and it was obvious cancer cells were left behind "somewhere" and both surgical removal and SRT had failed to find/eradicate those now developing cells.

Imaging was unable to identify any tumor activity so it was obvious that though somewhere in development, not sufficiently developed in cell numbers to have evolved into a tumor of sufficient size to show up in usual imaging.

With the uncertainty of where this development was occurring I began androgen deprivation therapy (ADT) with the antiandrogen Casodex (generic bicalutamide) to block androgen receptors from testosterone access and LHRH agonist Lupron to shut down testicular testosterone production. My PSA dropped again to less than 0.1ng/ml and my testosterone to near though not below 20ng/dl. And it was shortly following this recognition that I had a cancer that "didn't go away" that I realized I had better start studying what "Prostate Cancer" was all about!

And so began my educational journey. Over time I began to realize that my Urologist, though appearing to care for my well-

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being, actually knew little about just what androgen deprivation can do to a man's well-being (or at least didn't show much care), and when questioned about impotence and erectile dysfunction gave only the glib response that "we have medications that will help you get over that." I learned of ultrasensitive PSA testing so arranged that my future PSA levels were to have that form of testing and learned that my PSA was actually as low as <0.01ng/ml and remaining that low over the years since starting androgen deprivation. I learned that my neurovascular bundles on both sides of the prostate gland had been removed with the removal of the gland. I learned that at the time of surgery my prostate gland had a volume/size of 101cc, which is huge and should have been reduced in size with medications prior to surgery, since because of its size the Urologist performing open surgery was likely restricted in "feeling" his way in separating the bundles away from, and before, excising the gland thus had little option but to remove the neurovascular bundles along with the gland. This ignorance or lack of concern by the Urologist caused certain life-long impotence and consequent erectile dysfunction. I ultimately left this Urologist and moved to a Medical Oncologist I felt was showing interest in Prostate Cancer and evident concern for his patients and moved to intermittent androgen deprivation (IAD) and with future returns to ADT or to IAD I had learned the importance of a 5Alpha Reductase (5AR) inhibitor in ADT and added dutasteride/Avodart to my arsenal of appropriate medications.

As I learned more and more about appropriate treatment for prostate cancer depending on the patient's status from diagnostics and imaging, and posting comments in response to patient concerns on online prostate cancer support lists, others began to recognize that I was accumulating an abundance of reasonable information with reference material to back my comments, and more and more men or their caregivers were emailing me with their concerns. This dependence on my comments concerned me to the point that I knew I had to research even deeper and

study even more thoroughly our insidious men's disease so that the comments/recommendations I provided to these people could be supported by reference material, while at the same time telling them that the information I was providing was necessary for them to research even further to satisfy themselves whether the information was reliable, then discuss what they learned with their treating physician.

The more I researched and studied, the more I recognized that this disease can cause multitudes of side effects that were occurring to many, while less a problem for others, yet treatment methods were changing and improving regularly. The more I learned the more obsessed I became with having to continue daily research and study of medical and scientific information by way of monitoring several such informational websites in order to stay on top of changes/improvements occurring. I involved myself in scientific research regarding prostate cancer by serving two years in a row as a panelist with several research scientists reviewing research proposals submitted by other research scientists seeking funding for their research from the Department of Defense (DOD) Congressionally Directed Medical Research Program (CDMRP). I also made it a point to attend annual Prostate Cancer Research Institute (PCRI) Conferences on Prostate Cancer to meet and hear presentations from top medical professionals regarding prostate cancer and its treatment. I was fortunate, as well, to have been invited to attend a gathering of 600 top research scientists at an IMPaCT conference ("Innovative Minds in Prostate Cancer Today").

As I typed remarks addressing concerns of one patient or caregiver, I would receive an email from yet a different person with the same concern, and found I was repeating myself and typing addressing of these concerns over-and-over. I realized that with any new concern arising, it was better for me to research and study that concern and compile a paper addressing the concern so that I could simply provide that paper to anyone having the same concern. Thus began what has become my "Observations" webpage that is available on my personal website [www.theprostateadvocate.com](http://www.theprostateadvocate.com) currently containing over 200 papers on the many varieties of issues that have arisen over my many years mentoring/counseling patients and/or caregivers. All are listed alphabetically to hopefully aid the reader in finding the subject for which they have concern. Admittedly some subjects

contain information also available under another subject, since there is often information that can over-lap into other subjects of concern.

I have fortunately been successful with the several years I have been on/off androgen deprivation in making my own decisions as to appropriate medications, when to stop, when to resume, when to change, etc. and fortunate in having a Medical Oncologist who has become interested in better understanding prostate cancer and its treatment because of encouragement from me and what he has learned from me. He has remarked that from what he has learned and what he is aware I have learned, that he sees me as much a colleague as a patient. And he has been surprised on how well and how long I have been able to control and manage my prostate cancer. Another very prominent internationally respected Medical Oncologist specializing specifically in research and treatment of prostate cancer had this to say: "I wish all MDs were as responsive as Chuck. To me, Chuck represents what I call the CPR of what the medical profession should be all about, but rarely is. CPR (courtesy, professionalism, respect)." At another time to me he remarked: "... since I regard you as one of the few brightly shining lights in the world of PC support..." To the patient he remarked: "... In my 31+ years of working with men with PC, I find a minority of men who truly comprehend the basic principles/concepts of this disease like Chuck..."

To this day, imaging is unable to identify the location of my continuing cancer, and the Circulating Tumor Cell (CTC) test has determined that there are no tumor cells circulating in my blood. My thought is the cancer cells continue to lurk in my pelvic bed, but having had SRT many years ago precludes more radiation to that area since the radiation could cause more harm to healthy tissue/organs than possibly do good.

If interested, you can always determine my latest treatment/diagnostic results by visiting the menu word "About" on my website and scrolling down to the more recent date entry.

The foregoing is about as brief a relating of the story of my life as a continuing Prostate Cancer patient since 1992 and as a mentor regarding Prostate Cancer beginning somewhere following my recurrence in 1996.