Personal Experience
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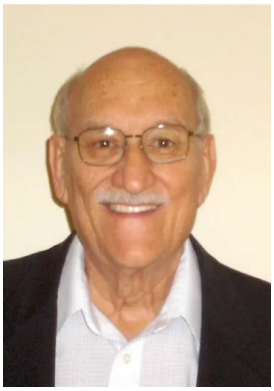

I have survived prostate cancer since first diagnosed in September 2002. My history might be useful to others as they learn their way into becoming their own case manager.

Involvement in the Informed Prostate Cancer Support Group (IPCSG) has given me insight to what I could have done differently as I made decisions along the way. Hopefully this will be useful information for you. I will sprinkle "I wish I had known" comments as I go along.

If you have done any research about the disease, you are likely overloaded with studies and statistics that talk about many types of treatment, their success rates, identifying the seriousness of the disease and prejudiced opinions on what you should do. One of the most difficult issues with Prostate Cancer (PCa) is to find out where you fit into the statistics. Are you in the high percentage of "not-to-worry" or the lower percentage of "get your affairs in order"? This is the most difficult question to answer about our disease.

Why PSA Testing? Beginning at the age of 59 and for a period of about 3 years I dealt with BPH (enlarged prostate). My PSA was 1.8. BPH is not usually a precursor to cancer but should be an alert to regular PSA testing—annually at least. Late in 2002, during a routine exam which included a digital rectal exam (DRE) my doctor felt an unusual lump in my prostate and referred me to a urologist for further examination. My PSA had moved upward to 4.3. The urologist performed another DRE as well as an ultrasound test which resulted in a recommendation to do a biopsy. "I wish I had known" about Color Doppler Ultrasound (CDUS) or multiparametric-MRI (MP-MRI which likely would have been a more accurate assessment of my cancer and certainly would have been less painful. To explain, a biopsy is a procedure of firing a number of needles (usually anywhere from 12 to 20) from a device inserted into the rectum that fires them in a matrix pattern into the prostate in order to take samples which can be analyzed by a pathologist. Imaging procedures not only identifies more precisely the area and size of a tumor but can be used to guide the biopsy process if a biopsy is deemed necessary. Another advantage of imaging can be to indicate no biopsy is needed. My biopsy resulted in a Gleason score of 3+4=7 Stage T1c. I began researching treatment options none of which could overcome my overwhelming sense that I needed to get that cancer out of my body. Also, being raised in the Midwest and in a generation in which doctor's analyses were considered next to gospel, I relied on what the urologist said. I HAD CANCER! THE PANIC BUTTON HAD BEEN PUSHED! To compound this, even though I thought I was being diligent in asking for a second opinion, I was unaware that the referred second urologist was a member of the same team as the first. Of course, his opinion was the same.

"I wish I had known" that removing the prostate was not necessarily a cure. I saw the statistics that showed that a high percentage of surgeries were successful and discounted the negative possibilities of impotence and incontinence. Unfortunately, most of us tend to believe we will be one of the successful ones in the higher percentages and focus too little on the negative aspects. In my opinion as you continue to look at studies and statistics you unknowingly are searching for ones that satisfy your wishes. I believe that my initial conclusion to have a radical prostatectomy could not have been overcome unless I had the benefit of the knowledge and experiences of men who have been through it like you get from our support group. "I wish I had known" about our group beforehand.

I had a retropubic radical prostatectomy (not robotic) in January, 2003. (Wow! My post-surgical pathology showed I was Stage T3b with seminal vesicle involvement! Cancer was already

outside the prostate! OOPS! I was misdiagnosed! The surgical process was unremarkable. I was out of the hospital in 3 days and used a catheter for bladder drainage for 3 weeks. I was back at work in 2 weeks. AAH! SWEET SUCCESS—I THOUGHT. Following the surgery, I experienced lessening degrees of impotence for about 3 months and thereafter I experimented with Viagra and tri-mix injection, either one was effective for me. Of course, Viagra is more convenient although its side effects were objectionable to me. Regardless of the mental stigma of a needle in the penis it really is not very painful. I discontinued injections because of the inconvenience and used Viagra when necessary. I have some incontinence that requires me to wear a pad to catch unexpected drips or squirts.

OOPS! After the surgery, my PSA went to <0.1 and stayed for about a year then began to slowly rise until it reached 0.4 in May, 2005. These seemingly minor rises are much more significant after surgery. I underwent pelvic MRI's and CT scans to determine if there was any evidence of metastasis, all with negative results. The urologist then recommended external beam radiation which would radiate the prostate bed and hopefully destroy any remaining cancer. I underwent 33 treatments, going 5 days a week from June to August, 2005. This was the now old-fashioned external beam radiation without the focusing capabilities of the modern techniques. Following this treatment my PSA dropped to 0.1. "I wish I had known" that this was a futile and needless procedure which I now know as salvation radiation that rarely resolves any problems. Such radiation can leave scarring and possibilities of future ramifications. Unlucky me, in May 2006 I ended up in the hospital for 5 days with a serious bladder infection, being aspirated every 15 minutes and twice having larger catheters inserted under anesthesia in order to expel clots and fluids. The urologist denied that this was a result of any radiation scarring! Alternatively, modern MRI imaging might have provided a precise target for treatment.

My PSA began to rise again and reached 4.3 in January 2007. My urologist's only suggestion was to see an oncologist.

Fate finally smiled on me when, through a casual acquaintance, I heard of Lyle LaRosh and the support group he heads up—Informed Prostate Cancer Support Group (IPCSG). I called Lyle and had a very eye-opening and comforting discussion about prostate cancer treatment possibilities. Prior to this, I was convinced I was headed toward a short-term existence. He convinced me otherwise. I went to my first meeting in February 2007. Through the group I learned about a more extensive insurance program that would allow me to leave the HMO program I had so that I could broaden my treatment capabilities. I learned about the positive aspects of diet, nutrition and exercise to help fight my cancer. I settled on a Mediterranean diet and began an exercise routine of 45 minutes 6 days a week. Having been raised in a rural community in the mid-west, I had a diet extremely high in meat and milk products. I read The China Study that is highly recommended reading by IPCSG which tells about the effect of diet on cancer. I lost 50 pounds very rapidly and brought my cholesterol and HDL within acceptable limits for the first time in many years.

Also, through the Group I learned of Prostate Oncology Specialists who focus only on the prostate. Surprisingly there are only about 100 such specialists in the United States and none in San Diego County. If the transmission on your car is broken, you wouldn't take it to a general mechanic. Why would you have a different attitude with your body? Take it to an expert on the problem! I became a patient of Dr. Lam who put me through the most extensive examination of my medical history and relevant CT and heart scans that I had ever had. Not only did he want to help with my cancer he wanted to improve my general health as well. Just as important, by networking with others, I learned of their experiences in controlling their disease. I BECAME INFORMED, I WAS LEARNING TO BE MY OWN CASE MANAGER.

After discussions about possible treatment alternatives, I first chose to try to contain the PSA by using only 0.5mg Avodart (Dutasteride) and 5mg Proscar (Finasteride). These agents help by blocking an enzyme which converts testosterone into a much more potent form called dihydrotestosterone (DHT). Unfortunately, my PSA continued to climb and reached 11.4 by February 2008. I then decided on antiandrogen therapy consisting of 150mg Casodex (Bicalutamide) daily, .5mg Avodart daily and 2.5mg Femara every other day. Casodex and Avodart help to keep cancer cells from feeding and growing and Femara helps lessen the possibility of breast tenderness/enlargement which is common in such therapies. Why did I choose this combination? I thought the side effects would be much less than Lupron because it didn't lower testosterone.

In 4 months, by June 2008 my PSA had dropped to .9 and I was having no noticeable side effects of the medications. My PSA reached its low point of .29 in October 2008.

In October 2008 I underwent a CT bone scan of the abdomen/pelvis that reported "sclerotic lesions likely representing metastatic disease" a condition we began watching and you will see many subsequent follow-up scans as we watch for further development of any metastatic disease.

In February 2009 I took a holiday from Casodex as is customary in hormone therapy. Unfortunately, my PSA began to rise rapidly and reached 11.8 in Jun 2009. I began taking Casodex again and my PSA dropped to 0.67 in 3 months. This time I developed breast tenderness and slight enlargement. To overcome this, I underwent 5 sessions of prophylactic radiation with Dr. A.J. Mundt of UCSD Radiation Oncology here in San Diego. The problem subsided and has not returned. About a year later, my PSA was still low at 0.69 so I tried taking another holiday. Within 4 months my PSA bounced back up to 5.2 so I started taking Casodex again. This time my PSA only went down to 2.28. Since the low point or nadir of my PSA score got higher each time after re-starting Casodex it was apparent that I was becoming resistant to the drug.

In August 2010, I underwent a nuclear medicine whole body bone scan which showed pretty much the same result as the bone scan in October 2008. I underwent a follow-up exam in April 2011 which showed no significant changes.

In April 2011, I tried Nilutamide, which is of the same family as Casodex, but I had a bad negative reaction of serious shortness of breath and extreme fatigue. I had to immediately discontinue taking it. My PSA had gone back up to 4.3, so in May 2011 after lengthy discussions with Dr. Lam, I agreed to start with a 30-day shot of Lupron to see how I reacted to it. I also took a 50mg Casodex pill with the first shot to alleviate the testosterone "spike" that occurs when implementing Lupron. My PSA dropped quickly to 0.23. I tolerated it well with no major side effects other than occasional minor flushing but no cold sweats or noticeable fatigue. I took two more 30-day shots of Lupron just to be sure I didn't develop bad side effects and then agreed to 90-day shots.

Dr. Lam emphasized the importance of resistance exercises to help overcome any muscle loss or fatigue that might occur while on Lupron. I began a program at my local YMCA of 45 min./day, 6 days a week and have continued that since with great results. Not only does it help overcome negative side effects, but I had also been on medication to lower blood pressure for about 20 years. I no longer need it!

In December 2011, as a follow-up to the previous bone scans, I underwent a sodium fluoride F-18 PET/CT whole body image to see if metastasis was developing. It again showed several small suspicious areas in bones that warranted watching, so in January 2012 I underwent a whole body Multiparametric MRI with and without contrast which utilized the latest 3 Tesla magnet. It mostly verified the findings of the sodium fluoride F-18 PET/CT scan.

In March 2012, I underwent another nuclear medicine bone scan with showed no significant changes, but we decided to do a bone biopsy of my sternum, one of the suspicious areas noted in the previous scans. It was negative

I May 2012, a year after my first Lupron treatment my PSA had been mostly consistent around .324, so I began a holiday.

In November 2012, we decided to do a biopsy of an area of the iliac, another of those suspicious areas noted in the scans. It was also negative.

Unfortunately, as my previous history has shown, when I discontinue hormone therapy, my PSA rises very rapidly and by December, 2012 just 5 months after discontinuing Lupron, it had risen from .324 to 13.6! So, we began with a 30-day shot of Firmagon (of the Lupron family) which alleviates concurrently taking Casodex to overcome the usual testosterone spike that occurs when first starting Lupron. I then started with the three-month Lupron shot again in January 2013. My PSA got progressively lower to 0.6 in July 2013. Dr. Lam and I had a discussion based on literature promoting the benefits of adding an additional drug to the primary drug being used. So, in July, 2013 I began taking a 50mg Casodex pill in addition to the Lupron shots. Remember I had good success with Casodex for a good period of time. This lowered my PSA to 0.25 close to the lowest it had ever been excepting right after surgery and subsequent radiation.

In September 2013, I underwent another sodium fluoride F-18 PET/CT scan to keep checking on any metastatic development. The result indicated things were stable.

In October 2013 we learned that Metformin (better known to be used for diabetes) had proven effective for breast cancer and could also be effective for prostate cancer, so I have continued to use it since then.

In July 2014 I underwent a general chest, abdomen & pelvis CT scan with contrast to assure there were no other areas developing issues. Results were all normal or stable.

In September 2014, I underwent another sodium fluoride F-18 PET/CT scan which reported stable conditions.

Even though I had been consistently following the possibility of metastatic development, I was concerned that it would develop further. Through IPCSG contacts, I became acquainted with Dr. Fabio Almeida in Phoenix who is an expert in imaging for recurrent prostate cancer. He became a welcome speaker at our meetings. He specialized in a relatively new type of imaging, Carbon 11 Acetate which utilizes a cyclotron to produce an injected fluid used to highlight cancerous areas throughout the body. I talked to him about my situation, and he agreed to take a look at my sodium fluoride F-18 PET/CT scans (he is expert in reading these as well). He determined that there were small spots of metastases but not of concern. He also thought I would not gain by doing the Carbon 11 Acetate imaging which is expensive and not covered by Medicare.

Dr. Lam and I had discussed on several occasions the benefits of a newer innovative medication (Provenge) that helps your own immune system fight the cancer. I was reluctant at first because there was no real way to determine it was working since it does not reduce PSA. Finally, after equating it to a flu shot, where you can't tell it is working---you just don't get the flu, I decided to undergo the treatment in April 2014. It is comprised of 3 sessions, 2 weeks apart, of blood draws at a local Red Cross facility which takes about 4 hours wherein white blood cells are removed and then shipped to a processing plant to be purified and Dendritic cells are added. Within 3 days of each process the "purified" blood was re-infused at Dr. Lam's office. I had no major reaction to any of the processes other than an onset of chills after the second re-infusion. This has been found to be a normal reaction of many. Can I tell you positively it works or does not work? No. I continue to believe it adds to my arsenal of treatments to control my disease.

My PSA stayed in the 0.25 range until December 2014, when it popped up to 0.86. After discussions with Dr. Lam about how to aggressively attack my prostate cancer, I decided to do two things which I started in January 2015:

1. Undergo the Xofigo (abiraterone) treatment which is another relatively new one that is an injection of radium 223 that goes directly to bone metastatic areas to combat the cancer. It consists of a shot once a month for six successive months which I completed in June, 2015.
2. Add the newer antiandrogen drug Xtandi (enzalutamide) sometimes called super Casodex. It is 4ea. 40mg pills taken daily. I started this Jan 31, 2015. At my appointment in May 2015, my PSA was 0.04!!!! the lowest it has ever been! Major celebration!

Which of these things brought this about? Do I care? I don't know other than it/they must be working.

I had little reaction to these added treatments other than a slight increase in fatigue. I increased my exercise regimen to 1 hour. per day 6 days a week and take a daily nap to minimize fatigue.

In March 2016, my PSA began rising again, reaching .6 in September 2016 at which time Dr. Scholz of Prostate Oncology Specialists recommended the newly FDA approved Axumin (f-18 fluciclovine) scan. I underwent this scan in December 2016. This scan showed that the minor spots of metastases had all HEALED with the exception of one spot on the Ilium!!

I scheduled an SBRT (Stereotactic Body Radiotherapy) radiation scan March 3-6, 2017 (three successive high intensity treatments) with Dr. A.J. Mundt at UCSD.

Concurrently in March 2017, I began 8 tri-weekly Keytruda infusion treatments at Prostate Oncology Specialists. This treatment, not then approved for PCa, has shown success in some other forms of cancer and has shown some promise with PCa. It works by aiding your immune system in fighting the disease. After completing Keytruda infusions and remaining on Xtandi and Lupron, my PSA was 0.13.

In January 2018, my PSA began rising again so in August 2018, I began taking one Zytiga (Abiraterone) 250mg tablet and reduced the Xtandi dosage from 160mg (4pills) to 80mg (2 PILLS). This brought my PSA down to 0.06 in September 2018.

In December 2018, my PSA began rising again, reaching 1.3 in May 2019. I then did the newer Axumin imaging scan in June which showed that I had developed 2 small cancerous spots on the left hip. Also, in mid-June 2019, I reduced the Zytiga dosage to ½ pill and started on a very

new drug Olaparib (Lynparza). This is different from chemotherapy. It takes advantage of DNA damage so that cancer cells cannot get the help they need to survive. It has been very effective in treating women's ovarian cancer and has recently begun being used for prostate cancer.

In mid-August 2019 I underwent SBRT radiation under the guidance of Dr. Mundt at UCSD to clear the cancerous spots on the left hip discovered by an Axumin imaging scan in June 2019. Prior to this my PSA had risen very quickly to 10.16 (typical for me when recurring). After the SBRT radiation and Lynparza became effective, my PSA was reduced to l.2 in February 2020.

In April 2020 I took another Axumin imaging scan which showed another small spot on the right ilium. I did another 5-day SBRT radiation treatment of this area under the guidance of Dr. Mundt at UCSD. My PSA was l.5 at the time but began to rise and was 6.4 in early October so I took another Axumin imaging scan and the results showed more progression in the pelvic area. By this time my PSA had grown to 6.4----rising quickly as usual when recurring.

This caused great concern to both Dr. Lam and me. We met Oct. 20, 2020 and discussed the best course of action. We had discussed chemotherapy previously, but I thought it would make my neuropathy (which has made my feet useless) even worse to the degree I might require a wheelchair. All things considered we decided on Taxotere (Docetaxel) treatments which consists of an infusion every 3 weeks—six times. I discontinued all other pill drugs except Metformin, Avodart, Xgeva, and Prednisone.

I had great concerns about the side effects of this treatment because most of the information you hear or read about is quite negative. Each treatment consisted of taking two anti-nausea pills the day before and the day after the infusion. The infusion takes about 2 hours and includes other medications including an antihistamine and another aid to help fight nausea. At each treatment I was given two ice packs to keep the tips of my fingers cold to prevent discoloring or breaking of fingernails and a cup of ice cubes to keep in my mouth—again to help deter nausea. There was no discomfort in the process other than the cold things. Also, of note, I was required to fast for 2 days following the treatment only drinking water—again to deter nausea. Of course, mentally, I was dreading what side effects I would begin to have. Guess what!! Almost nothing. Some fatigue, but not to the degree that some of the pills I had used. I never experienced nausea during the processes. I began to feel weakness in my knees likely because of the effect on my neuropathy, so I am undergoing physical training to help with that. None of this changed after each succeeding treatment. After the first treatment I did lose most of my already sparse hair, but not my mustache. I rarely needed to shave. I finished my 6th and last treatment February 2, 2021. My PSA was 8.22 when I started treatment and is now 1.88. I will meet with Dr. Lam in mid-March for follow-up. My PSA continued downward to .8 on September 2021, then began rising to 2.6 a year after first chemo infusion. In December, I underwent the newest imaging—PYL PSMA at UCSD. It showed spots in my clavicle, Vertebrae T1 & T9. Dr. Lam advised he had been contacted by UCLA that they had free openings for the latest new treatment they have been studying for years. He sent my information to them, and they responded that my involvement was not that serious "good for him". So, I had consultations with Dr. Mundt of UCSD about SBRT (which I have done before) and with Dr. Rossi of the Proton Center about Proton treatment. From their information I decided that SBRT would be preferable. I completed the SBRT treatments (5 visits) April 14, 2021, no significant aftereffects other than minor fatigue. I currently use drugs Metformin, Avodart and Lupron.

In June 2022, my PSA began rising rather quickly from 2.9 to 10.l in November. I communicated with Drs. Lam, Mundt & Kipper about getting the newly approved Pluvicto

(Lutetium 177 PSMA) treatment. Fortunately, with their help I began the first of 6 treatments on November 7, 2022. The treatments are six weeks apart which will end June 21, 2023. The treatment consisted of an injection of radioactive medicine into a vein in my arm, which took about 30 minutes to complete (late when undergoing treatment number 4, I was advised that infusion would be reduced to 1.2 minutes as research had proved the shorter time to be 97% effective as the longer time). The day following eacj treatment I returned for a PET/CT imaging procedure which took 50 minutes lying completely still in the machine. This is used to visualize the treatment. I was advised to not come closer than 3 feet to anyone or pets for 3 days and used the condom catheter to expel urine during that time. I use a condom catheter before each treatment and flush the toilet twice each time I emptied the urine bag and thoroughly washed my hands afterward. I have experienced no significant after affects other dry mouth and somewhat less energy.

On June 18, 2023. I completed the last of the 6 Pluvicto treatments. Just prior to this last treatment, my PSA had dropped from 10-1 to .87.

On July 26, 23 I had the Pylarify PSMA imaging test which showed no significant involvement. My latest PSA is 0.7. On August 17,2023 it was .9. Maybe recurring?

On 10/6/23 my PSA had moved upward to 2.0. I met with Dr. Lam about the issue and it was decided to take PSA tests each month for about 3 months to see how quickly it is rising. He has knowledge of what may be needed if PSA rises too quickly. We did monthly tests until 1/24/24 when it had grown to 10-1. After treatment possibilities were discussed, I decided on doing Jevtana chemotherapy which began at UCSD Infusion Center at the Mores Cancer Center on 1/25/24. Dr. Randall of UCSD oversees these treatments after conferring with Dr. Lam. There may be six treatments.

I have now been dealing with PCa for 21 years, so mine is an example of continued watchfulness and knowledgeable doctors.

An added note: As stated before I believe strongly in the benefits of working out. Although, I have not used a gym since Covid-19. I have some equipment at home with which I work out 6 days a week---as before and all during the treatments.

HERE ARE SOME IMPORTANT THINGS I HAVE LEARNED ALONG THE WAY

1. The PSA score is not an indicator of the aggressiveness of prostate cancer but rather should be used to monitor the disease. A high or increasing PSA score should be monitored closely by you and your doctor---hopefully one skilled in prostate oncology.

2. Imaging should be performed prior to a biopsy which can achieve results that help determine the need for a biopsy or help guide the biopsy procedure.

3. Be your own case manager. Do not let a doctor dictate what treatment is best for you. Get as much information as you can from research and networking with others that have the disease in order to make decisions best for you. This is the value of the Informed Prostate Cancer Support Group.

4. Once a treatment choice has been made, continue to monitor your condition. Too many find that their disease appears again after they thought they were “cured”.

5. Keep informed of the latest developments in treating PCa via IPCSG meetings, qualified Oncologists and personal research.

Since discovering IPCSG over sixteen years ago, I have volunteered my efforts to the group and have derived more satisfaction from it than anything I have ever been involved with before. The rewards justify the effort.

Respectfully submitted,
Gene Van Vleet
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Informed Prostate Cancer Support Group