



INFORMED PROSTATE CANCER SUPPORT GROUP INC.

“A SAN DIEGO 501 C 3 CORPORATION ID # 54-2141691”

IN MEMORY OF WILLIAM “BILL” LEWIS

BILL FIRST CAME TO OUR GROUP TO TRY TO LEARN HOW TO DEAL WITH HIS OWN ISSUES WITH PROSTATE CANCER.

AFTER ATTENDING MEETINGS AND LEARNING OF OUR PURPOSE, HE BECAME MORE INTERESTED IN HELPING US DO WHAT WE DO. HE BECAME PRESIDENT OF OUR ORGANIZATION. HE WAS THE PRIMARY PERSON THAT FOUND SPEAKERS TO HELP US LEARN OF WAYS TO DEAL WITH OUR COMMON DISEASE. FURTHER HE ESTABLISHED MARKETING EFFORTS TO BROADEN OUR EXPOSURE ABOUT HOW TO DEAL WITH PROSTATE CANCER.

THANKFULLY HE MOVED ON PEACEFULLY BUT WILL BE THOUGHTFULLY REMEMBERED.

GENE VAN VLEET
DIRECTOR
INFORMED PROSTATE CANCER SUPPORT GROUP



My prostate cancer began to show itself in a PSA test I purchased in 2014, after I had lost my health insurance a few years earlier. I have a strong family history of prostate cancer but had not had a PSA test since 2009. That result was 1.14 – quite normal. Since then, I had had a heart attack (99% main coronary artery blockage), a bankruptcy and ongoing business stress, antidepressant medication-induced anxiety, frequent urination, and loss of insurance coverage. Life stresses can lead to disease!

The new PSA value was 18, but I had no financial options for getting a biopsy or starting any needed treatment. I began attending IPCSG meetings after noticing a newspaper ad. In the Fall of 2015, I was able to afford insurance, but ended up paying out-of-pocket for an (IPCSG-recommended) mp-MRI, then for an MRI-guided biopsy, because the insurance copays were actually higher. The Gleason score was 8, re-evaluated to a 9 at Johns Hopkins. A subsequent bone scan (Technetium-99) showed dozens of bone metastases. A doctor-friend thought he could cure me with an olive leaf extract, IV vitamin C, and ozonation of my blood. After 6 months, my PSA was 73, and another bone scan showed over a hundred metastases. Such a scan is called a Super Scan -- doctor-speak for “Awful!” That gave me a life expectancy of six to nine months.

So instead of continuing to hope that alternative medicine would suffice, I took a comprehensive approach. My friend helped me select about 15 supplements that “muscle testing” indicated could be helpful, including turmeric, vitamins C & D, flaxseed oil with cottage cheese and seeds/nuts/berries, berberine, “Airborne” tablets, tocotrienols and tocopherols, agaricus blazei mushroom extract, apricot kernels, and oxaloacetate. I’ve gradually added many others with the guidance of a holistic medicine doctor – list available on request. I also followed the lifestyle factors listed in a book called Radical Remission, including eliminating negative emotions, accentuating positive ones, spirituality (hugely important to me) and reasons to live, lots of service, food choices (no sugar, no drinking milk, little meat, many veggies, and little fruit, later corrected to lots of fruit), following intuitions, and exercise. Four-page book summary available on request.

I also followed the best allopathic/Western medicine protocol I could find – Triple Androgen Blockade – consisting of Casodex (bicalutamide, “duct tape” over cancer cell growth stimulation receptors), Lupron (leuprolide injections, to block testosterone production) and Proscar (finasteride, to block conversion of testosterone to a more active/dangerous form). By this time, I was “my own case manager,” telling my doctor what to prescribe for me.

Side effects were mild – mainly a few months of warm flushes (not very hot), and of course erectile dysfunction and loss of libido. After nine months, my PSA was 0.2, and only two barely detectable bone metastases remained. My radiologist, Dr. Ross Schwartzberg, said that he had never before seen such a dramatic improvement. Due to fears about its cardiovascular side effects, I stopped taking Lupron, and my insurance refused to cover Firmagon (degarelix), which is safer. After trying a few new doctors, accessible because I became eligible for Medicare, I settled on Dr. Leibowitz (whom I later learned was the originator of the Triple Androgen Blockade protocol I had found on the internet, but who is now retired), and his partner, Dr. Shahrooz Eshaghian, originally having a practice called Compassionate Oncology Medical Group, but now part of the LA Cancer Network. Since 1998, Dr. Bob and Dr. E. have focused on prostate cancer, and their Triple Hormone Blockade, Finasteride Maintenance, Three-Pronged Approach to treating Prostate Cancer, and High Dose Testosterone Replacement Therapy.

I was drawn to them because of my interest in BAT (bipolar androgen therapy), where testosterone levels are cycled between high and low, to kill cancer cells with feast/famine cycles. They were willing to give me Firmagon (degarelix) to replace the Lupron I had only used for 9 months. My PSA had risen to 5.8 by December 2017 without ADT. Having learned about Zytiga (abiraterone) and its effectiveness, including the advantages of taking it with food, I also wanted to add this “second-generation” ADT drug to my protocol. I was on it for four months, taking a 250mg dose daily with a high-fat meal, and not taking prednisone with it, on the advice of my doctor-friend. We just watched my blood values very closely. Perhaps the many supplements I was taking were enough to avoid needing prednisone. My PSA dropped to 0.15 in April 2018. Side effects were again very mild (except for the sexual effects), once I learned to insist that the Firmagon shots be given “deep,” not “sub-cutaneous,” and that the needle not be withdrawn for at least a minute to allow the injection to gel a bit and not leak upward.

Dr. Leibowitz really wanted me to start on chemotherapy, which had recently been shown to be helpful against early-stage metastatic prostate cancer. I was very reluctant, due to stories of damage to the immune system. He prevailed, with what I call his “kinder/gentler, effective” chemo, using Taxotere (doxetaxel), carboplatinum and Emcyt in three split doses per month. After five months, I went on his maintenance therapy, an “anti-angiogenesis cocktail,” mainly using thalidomide (yes, the same drug that caused many unfortunate effects on fetuses in the 1950’s when it was prescribed for morning sickness without adequate testing) to prevent any tumors from developing their own blood supply (needed to grow larger than two millimeters). The cocktail included both Proscar (finasteride) and Avodart (dutasteride) to prevent conversion of testosterone to the more dangerous dihydrotestosterone (DHT). Also, an immune system stimulator (Leukine – sargramostim), and repurposed drugs such as metformin, celecoxib, losartan, atorvastatin and aspirin. The chemo only caused “some” hair loss, and fatigue did not set in for four months, due to “grounding” and energy-boosting supplements I was taking, then persisted for four months. I continue taking the cocktail, except the thalidomide was eventually discontinued due to worsening peripheral neuropathy in my feet/legs and even extending to my fingers. I recently found that massage with a car buffer run at half-speed makes a big improvement, as do soft inserts (by Dr. Scholl’s) for my shoes. Contact me for details.

My PSA went down to <0.09 by Oct. 2018, then we started his High Dose Testosterone Replacement Therapy, raising my testosterone with creams to the 2000-3000 range, vs. the normal physiologic level of about 300 to 800. However, my PSA gradually rose to 17.4, so he added ethinyl estradiol, with fondaparinux (painful daily belly injections, to prevent blood clots). After a temporary drop, my PSA again rose to 12.2, so we stopped the testosterone supplementation in Oct. 2019. In June 2020, we switched from ethinyl estradiol / fondaparinux – which only kept my PSA floating under 10, to again use 250mg Zytiga (abiraterone) with food, along with Firmagon. This caused my PSA to drop to 1.2 by February 2021, so we started an ADT holiday, because Drs. Leibowitz and Eshaghian don’t like to use Zytiga more than 9 months at a time.

My PSA gradually rose to 40.6 in November 2021. Just prior, in October, I had a Pylarify (F-18 PSMA/PET) scan that showed cancer in the prostate and numerous places in my bones. I went back on Zytiga in December (again taking it with a high-fat meal, without prednisone) but delayed adding Firmagon to see the effect of Zytiga alone. My PSA dropped to 11.2 in January and 8.9 in February, but rose to 10.2 in March, suggesting that my cancer was beginning to become resistant, so I added Firmagon and the PSA gradually came down to 5.7. After three months of Firmagon, using up my on-hand supply, I switched to Orgovyx (relugolix), since it is an oral pill instead of an injection and has low side effects. I felt none. My PSA continued a slow downward slide, nearly plateauing, reaching 5.3 in July. Then I had the “bright idea” to try to get my PSA to go

up, by dropping out some of my supplements. I wanted to be declared “castrate resistant,” (defined as two successive rising PSA values while on second-generation ADT, such as I was on) to qualify for Xofigo (radium 223) treatment of my bone metastases. My PSA the next month was a “disappointingly lower” 4.4, so I gave up on trying to make it rise. Ironically, my next two PSA’s were 4.6 and 5.4. Accidental success!

Although I was now ready for Xofigo, my new urologist, Dr. Paul Dato, who could give me the six monthly treatments in San Diego instead of requiring trips to LA, convinced me that Provenge is not a practically worthless immunotherapy. Although the advanced-cancer cohort it was originally tested on only got 4 months average survival benefit, analysis of post-commercialization data has shown that men treated when their PSA was below 20 got a 13-month benefit, and those with a PSA under 5 got four years longer life. So at this writing, I just finished getting Provenge, a four-week process, and plan to follow it with Xofigo.

My nominal health is excellent, with only muscle weakness from the lack of testosterone, and some under-control peripheral neuropathy from the chemo and thalidomide treatments. I’ve never had symptoms attributable to the cancer itself! I spoke in the October 2022 IPCSG meeting about my cancer and the book I am writing about what I’ve learned over the past seven years. The recording is at https://youtu.be/VVD_aupYkRA, starting about 23 minutes in. As indicated in the video, my book chapter drafts and other helpful documents mentioned are available on request by calling me at 619-591-8670 or by emailing me at lewis.bill@gmail.com.

You can live long and well, even with aggressive prostate cancer, by being your own case manager, and by learning from IPCSG meetings!