



Informed Prostate Cancer Support Group Inc.

"A 501 C 3 CORPORATION ID # 54-2141691"



Thursday, September 14,

SEPTEMBER 2023 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

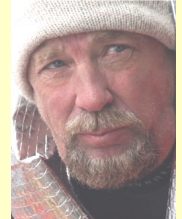
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Volume 16 Issue 09

Next Meeting Saturday, September 16, 2023 IPCSG—10:00am—Noon PDT.

- Dean Hall is a licensed clinical therapist and coach with over 30 years of experience, an author and highly sought-after speaker, a two-time cancer survivor who experienced radical remission from leukemia and lymphoma, and a two-time world record-setting extreme distance swimmer His talk is entitled "Swimming in Miracles"
- As always, spouses/partners and caregivers are welcome and encouraged to attend!
- After the meeting a light lunch will be served in the foyer outside the meeting room
- For links to further Reading: <https://ipcs.org.blogspot.com/> (includes member suggested links)
- If you have Comments, Ideas or Questions, email Newsletter@ipcs.org
- For more information, please send email to bill@ipcs.org or call Bill at (619) 591-8670 or Gene at (619) 890-8447



Prostate Cancer Round Table Speakers

August 2023 IPCSG Presentation - Summary by Bill Lewis

The first of our three member speakers sharing their personal prostate cancer journey, was David Ferraro. David joined us via Zoom from his home near Baltimore Maryland. He had a biopsy in October 2018 at age 62, that confirmed prostate cancer (PCa), with Gleason scores of 3+3 and 3+4. He was determined to cut out the prostate and move on with his life, avoiding radiation, chemo, or hormone therapy. PSMA scans were not yet available, but he was assured that the cancer was only in the prostate. After a robotic prostatectomy at Johns Hopkins in Baltimore, the pathology report showed that there was a "burst," a prostatic extension of 3 mm, and that Gleason = 9 cancer cells were found in the margin. The surgeon said he believed he had gotten it all, and that salvage radiation was not needed. Da-

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Prostate Cancer: GET THE FACTS
Other than skin cancer, prostate cancer is the most common cancer in American men.

1 in 6 
 men will be diagnosed with prostate cancer during his lifetime.



Prostate cancer can be a serious disease, but most men diagnosed with prostate cancer do not die from it. In fact, more than 2.5 million men in the United States who have been diagnosed with prostate cancer at some point are still alive today.

Organization

a 501c3 non-profit organization - all positions are performed gratis



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NEWSLETTER

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PROSTATE CANCER—2 WORDS, NOT A SENTENCE

What We Are About

Our Group offers the complete spectrum of information on prevention and treatment. We provide a forum where you can get all your questions answered in one place by men that have lived through the experience. Prostate cancer is very personal. Our goal is to make you more aware of your options before you begin a treatment that has serious side effects that were not properly explained. Impotence, incontinence, and a high rate of recurrence are very common side effects and may be for life. Men who are newly diagnosed with PCa are often overwhelmed by the frightening magnitude of their condition. Networking with our members will help identify what options are best suited for your life style.

Join the IPCSG TEAM

If you consider the IPCSG to be valuable in your cancer journey, realize that we need people to step up and HELP. Call **President Bill Lewis @ (619) 591-8670** "bill@prostatecancerhelp.info"; or **Director Gene Van Vleet @ 619-890-8447.**

From the Editor

In this issue:

Bill Lewis produced a summary of the member round table from the last meeting. For further articles see the blog at <https://ipcsbg.blogspot.com/> . Many new advanced topics are covered in articles linked in the blog for further reading. Some apparently important optimistic items of interest this month:

1. UCSD Health Breakfast of Champions— an event to help fight prostate cancer
2. Signs and Symptoms of End Stage Prostate Cancer—this is tough to read, but I can't get my oncologist to talk about it.
3. Application of next-generation imaging in biochemically recurrent prostate cancer | Prostate Cancer and Prostatic Diseases

vid was pleased.

After two years of undetectable PSA, there was a bio-reoccurrence of 0.2 PSA in February 2021. Still determined to avoid hormone treatment, radiation treatment or chemotherapy, David sought out immunotherapy. No good options in the US, and no insurance coverage. So he went to the Immunotherapy Institute in Tijuana for autologous immunotherapy – engineering your own T-cells to fight cancer – for 18 days. He was very pleased with the institute, but the therapy did not work for him. His PSA rose to 1.7 by December, then jumped to 3.9 in January 2022.

He looked unsuccessfully for clinical trials, then paid for a PSMA scan – not covered by insurance. This showed two pelvic area lymph nodes were cancerous. So he got 38 proton radiation treatments combined with “deep thermal therapy” (110° / 1 hour, twice a week after the radiation dose). He was to check his PSA after 3 months. It was 2.0 in mid-July, and the same 5 weeks later. He said to himself, “Now what?”

David found online the August 2022 IPCSG talk by Dr. Robert Hoffman, about methionine restriction and a new oral methionase enzyme product. Methionine is an essential amino acid that cancer is “addicted to.” Methionase helps reduce levels of methionine in the body beyond what can be achieved with a strict version of a vegan diet – including the elimination of beans, nuts and seeds.

The diet has been effective, but somewhat hard to maintain. His PSA dropped to 0.1 in January of this year, but with a less strict following of the protocol, has crept up to 1.6.

Next, Phillip Young, age 72, shared his Prostate Journey. He has no family history of any cancers. Has had good health except for controlled high blood pressure and blood clots. Urination is normal and prostate is smooth though enlarged to 51 cc (normal would be 30cc). He is an active cyclist and exercises daily.

PSA tests in 2022 and 2023 (\$20.95 PSA Test through Ulta Labs / Quest Labs available via the ipcs.org website) showed worrisome increases: 1.4-2.1 and 2.0-2.9. The NCCN & AUA guidelines recommend investigating a 1-year PSA increase of 0.35 ng/mL or greater.

Phillip first considered non-invasive tests. The miR Sentinel™ Prostate Cancer Test (urine) seemed attractive, but is not available in California. Also, the 4Kscore® Test (blood): Probability of Aggressive Prostate Cancer test was declined due to his low PSA score. He was able to get the ExoDx™ Prostate Cancer (urine) Test, which involves an easy home test collection kit. The ExoDx™ test result: 22.53 – meaning a 30% chance of PCa. A score >15.9 indicates a possibility of Gleason score > 7, high grade cancer. If the ExoDx™ test score is 16 to 19, one is advised to consider a 12-Core Biopsy. Another data point ob-

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tained was Phillip's free (unbound) PSA. In 2022 it was 41%. Since it was >25%, his cancer risk was 8%.

He plans to follow up with an ExoDx™ liquid biopsy test yearly. Another test option was the Promise - Free Germline DNA Test (saliva) for PCa Patients. See ProstateCancer-Promise.org/genetics. This provides for 29 DNA Cancer Screening Germline Tests, including BRACA1 and BRACA2 (BReast CAncer genes) which look for changes / mutations that increase the risks for breast, prostate, & other cancers. 15 of the genes screened play a role in PCa. If there are any bad genes, you get long term monitoring by Promise. Otherwise, you can opt for bi-annual PCa treatment updates, including information about new genes of concern. Phillip's test showed 0 of 30 mutated genes – so no increased risk of PCa from any mutations of concern.

An MRI scan was done. This was the currently used multiparametric MRI, using a 3 Tesla magnet, with Restriction Spectrum Imaging (RSI) software that includes a precise look at the lowest Water Diffusion Index (DWI), that can show the cancer's location. The range is 0 (BAD low water mobility) to 1800 (GOOD high water mobility / normal tissue). Phillip's lowest DWI was 1398, in the transition zone – not indicating any significant tumor. Overall, the MRI images looked good, so no 12-Core Biopsy for now. He will continue on Active Surveillance: PSA (6-months) and ExoDx™ (1-yr). He expressed gratitude for the IPCSG and the UCSD Urology Team following his journey.

Lenny Green told how prostate cancer saved him from lung cancer. His journey began unawares a dozen years ago, when he was 50 and his father (age 87) was diagnosed with prostate cancer. He failed to recognize this alarm bell, and didn't notify his doctor, nor ask for a PSA test. Regular PSA testing was not a priority for his primary care physician back then. Between 2011 and late 2019, he did not ask for a PSA measurement, nor was it suggested. In December 2019, Lenny was concerned about fatigue, so asked his doctor if there was a testosterone supplement he could take. She said that was possible, but first wanted to check his PSA to ensure his prostate health was good. It wasn't.

Just before traveling for the holidays, he learned from his doctor that his PSA was 43 – but that it might be due to an infection. After his return, and a course of antibiotics, another dreaded phone call came, indicating his PSA was still elevated – at 38. A referral to a urologist led to a digital rectal exam. It was abnormal! So this led to a very not-fun 12-core biopsy. Every core was positive (bad news!) Two cores showed Gleason 9 and the remainder were 7's, with up to 80% involvement.

Next, determine if the cancer had metastasized, right? First, he consulted with UCSD about treatment. He was told that the cancer had not spread, and that they would keep an eye on a spot in his lower left lung lobe. He also got an MRI, which not surprisingly said “Clinically Significant Cancer Is Highly Likely To Be Present.”

At an appointment to discuss the finding, Lenny met with a Urologist, Radiation Oncolo-

gist, and Medical Oncologist to discuss their team treatment approach. Lenny decided to attack from three directions – hormone therapy, surgery and radiation. Surgery was scheduled for March 25th, 2020 – just as Covid was exploding. Still, his diagnosis qualified him to go ahead with surgery. But in early March, Dr. Rana McKay (his medical oncologist) called to indicate she was not comfortable postponing investigation of the spot on his lung. A PET scan quickly showed “Left lower lobe 3 cm mass. Causes could include infection or primary neoplasm or metastatic disease. Recommend further evaluation and/or tissue sampling.” Dr. McKay was unsatisfied with the finding. She ordered a lung biopsy.

His prostate surgery was postponed, but he did start on ADT (anti-testosterone therapy). After his lung biopsy on April 2nd, Dr. McKay called to say, “I have good and bad news for you. The good news is that your prostate cancer has not spread to your lung, but the bad news is that you have another form of primary cancer.” It was “Invasive Adenocarcinoma,” a type of non-small-cell lung cancer (NSCLC) usually found in the outer region of the lungs, that grows more slowly than other types of lung cancer. It’s more likely than other types of NSCLC to be found before it has spread.

Lenny had lung surgery in April 2020, for a left lower lobectomy, while isolated from his family for four days due to Covid restrictions. Fortunately, the cancer had not spread. After a month of recovery from the lung surgery, lab results indicated that the ADT was beginning its work as his PSA was 0.37, and his Testosterone was <0.12. Lenny humorously noted that at the same time, he found himself getting addicted to the Hallmark Channel 😊.

Prostate surgery was rescheduled for June 25, 2020. His PSA had dropped further to 0.22. Nerve preservation was not possible due to the nature of the cancer invading the nerve bundles. Lymph nodes tested positive for cancer as well. He then went on Zytiga (abiraterone) and Lupron for nearly two years.

Fatigue was the most noticeable side-effect. Nonetheless, he tried to keep active and walk. Bone density loss was also measured and is being treated by Reclast (zoledronic acid) infusions. PSA dropped to <.001, and testosterone remained <0.12.

Radiation was received in 27 doses in November – December 2020. The full bladder preparation for each treatment was the worst part. A PSMA scan in March 2022 came back clear.

This year, his PSA has remained undetectable, with testosterone rising slightly, but still <3. He gets lung CT scans every 90 days, and each is anxiety producing.

The video is available on YouTube at <https://youtu.be/cj7FWzLTGAM>

Items of Interest

UCSD Health Breakfast of Champions— an event to help fight prostate cancer

Christopher J. Kane, MD, dean of Clinical Affairs at UC San Diego School of Medicine, cordially invites you to attend the 10th Anniversary Breakfast with Champions event benefiting prostate cancer research in the Department of Urology and Moores Cancer Center at UC San Diego Health.

Thursday, September 21, 2023 8 –10 a.m. at the La Jolla Country Club 7301 High Avenue La Jolla, California

Together, we will celebrate our patients, highlight our clinical and research programs, and hear from Pro Football Hall of Famer Mike Haynes about his NFL career and prostate cancer advocacy. [Register Here](https://one.bidpal.net/breakfast2023/welcome) <https://one.bidpal.net/breakfast2023/welcome>

Signs and Symptoms of End Stage Prostate Cancer

This may be tough to take, but my oncologist wont talk about it

[healthline.com](https://www.healthline.com)

In your final months of life with prostate cancer, symptoms are likely to be more frequent and more severe. Symptoms like fatigue, shortness of breath, and loss of appetite may emerge in the final days or weeks.

Early screening for prostate cancer means that doctors find most cases early, leading to a high survival rate. Advances in treatment have also helped improve these rates over the last 20 years.

Even so, the American Cancer Society expects about [34,700 people](#) to die from prostate cancer in 2023. And despite the high survival rate, it's still the second leading cause of cancer death in people assigned male at birth in the United States.

Death from prostate cancer is more likely if you have [advanced prostate cancer](#), meaning it has spread to other areas in your body. At this point, there's usually no path to curing your cancer. Treatment will focus on slowing its growth or managing symptoms.

When measures to treat the cancer fail, you may start to experience more severe symptoms. At this point, a medical team may suggest focusing on supporting your quality of life for your remaining time. Here are some symptoms showing that your prostate cancer may be in its final stages.

A [2018 study](#) found that people within 6 months of dying from prostate cancer experience many of the same [symptoms](#) as other people with the disease, but with greater frequency and severity.

In your final weeks, some symptoms become more prevalent. As you get nearer to the end of life, you may notice the following:

Pain

You may have experienced pain as a symptom of advanced prostate cancer. People often experience pain in the groin, hips, or back. This can be due to the tumor pressing on a nerve or cancer that has spread to your bones.

Groin pain may also be due to excess lymph in your lymph nodes. When cancer spreads to your lymph nodes, they can't drain as easily.

Pain, even in the final stages, is usually manageable with medication.

Fatigue

You're likely to feel excessive tiredness when you are dying. This may mean sleeping for long periods, feeling drowsy when awake, and even drifting in and out of consciousness.

Loss of appetite

Your body's metabolism slows down in your final weeks of life. This reduces its need for sustenance, causing many people not to feel the need to eat or drink.

You may also experience trouble swallowing, which can cause you to eat and drink less.

Confusion

You may have trouble recognizing the people around you or understanding your surroundings. You might answer

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questions very slowly or stop responding to others entirely. This could be due to drowsiness or the medications you're taking.

It may be helpful for loved ones to introduce themselves each time they enter the room or start talking.

Restlessness

Many people experience [terminal restlessness](#), which can present as feeling agitated, anxious, or distressed. You may even experience [delirium](#) or [hallucinations](#).

A care team can provide medication to help with these symptoms. A calm environment can also help.

Changes in urination or bowel movements

Changes in metabolism combined with reduced food and drink intake means you'll also experience changes in your waste functions. These could include:

[constipation](#)

[reduced urine output](#)

[dark urine](#)

loss of [bladder](#) or [bowel](#) control

Talk with a medical professional or care team if you feel constipated. They can provide you with [laxatives](#) or a [suppository](#) if you have difficulty with bowel movements.

Changes in breathing

You're more likely to experience [shortness of breath](#) in your final days and weeks. This could be due to the cancer, loss of muscle strength, or your body needing less oxygen.

A care team can provide [opioids](#) or other medications to help with this symptom. They may also be able to provide [oxygen therapy](#). Family members can assist by helping you sit up and aiming a cool fan at your face.

Death rattle

Fluid may build up in the back of the throat because you are too weak to clear it. This can cause a distinctive gurgling sound known as a "[death rattle](#)."

A death rattle doesn't cause discomfort but can be distressing for your loved ones to hear. It usually indicates that death is imminent. Your loved ones can help by repositioning you or limiting your fluid intake.

Skin changes

Your hands and feet may be cool to the touch. They may even turn blue. This is due to changes in blood flow to the extremities.

A nonelectric blanket might help keep your hands and feet warm.

Death from prostate cancer usually occurs if the cancer spreads (metastasizes) to other parts of your body. Metastases in these other parts of your body can impair their function, leading to death.

Some sites of [prostate cancer metastasis](#) [Trusted Source](#) that can lead to death include:

bones

lymph nodes

lung

liver

[brain](#) [Trusted Source](#)

Key statistic

According to a 2021 study, about [1 in 6](#) [Trusted Source](#) deaths of people with metastatic prostate cancer are due to noncancer causes, like heart disease, stroke, or chronic obstructive pulmonary disease (COPD).

HEALTHLINE NEWSLETTER

Get our weekly Cancer Care email

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Learn about emerging research, nutrition, prevention, chemo, and more — to support you through your cancer care journey.

If you have prostate cancer, your outlook depends mostly on how soon doctors can diagnose it. But in some people, the type of prostate cancer may be a more aggressive or may be less likely to be caught before it spreads. These types include:

- ductal adenocarcinoma
- squamous cell carcinoma
- small cell prostate cancer

The median age of death from prostate cancer in the United States is 80 years old.

African Americans

African Americans are twice as likely to die from prostate cancer than people from other racial groups. They tend to develop prostate cancer earlier in life. They also often develop more aggressive forms that are already advanced at time of diagnosis.

But inequalities in access to care may be the most significant factor for this disparity. A 2020 study found that when access to care was equal, the mortality rate was actually slightly lower for African Americans.

About 1 in 41 people assigned male at birth in the United States will die of prostate cancer. Despite having a high survival rate if caught early, prostate cancer can be terminal for some people. About two-thirds of those who die from prostate cancer are over 75, and more than one-third are Black.

Symptoms like fatigue, loss of appetite, and shortness of breath may indicate that you are nearing the end of your journey with prostate cancer. This can be a difficult time for you and your loved ones. Care options are available to help manage your symptoms and provide some comfort in your final days.

Application of next-generation imaging in biochemically recurrent prostate cancer | Prostate Cancer and Prostatic Diseases

[nature.com](https://www.nature.com)

Abstract

Background

Biochemical recurrence (BCR) following primary interventional treatment occurs in approximately one-third of patients with prostate cancer (PCa). Next-generation imaging (NGI) can identify local and metastatic recurrence with greater sensitivity than conventional imaging, potentially allowing for more effective interventions. This narrative review examines the current clinical evidence on the utility of NGI for patients with BCR.

Methods

A search of PubMed was conducted to identify relevant publications on NGI applied to BCR. Given other relevant recent reviews on the topic, this review focused on papers published between January 2018 to May 2023.

Results

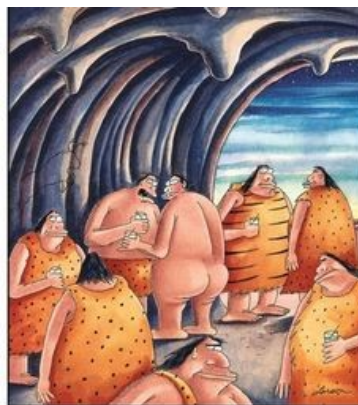
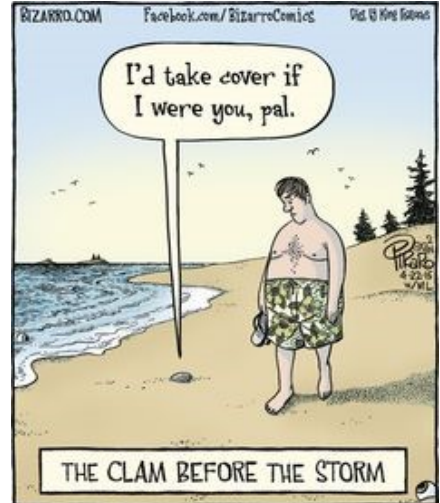
NGI technologies, including positron emission tomography (PET) radiotracers and multiparametric magnetic resonance imaging, have demonstrated increased sensitivity and selectivity for diagnosing BCR at prostate-specific antigen (PSA) concentrations <2.0 ng/ml. Detection rates range between 46% and 50%, with decreasing PSA levels for choline (1–3 ng/ml), fluciclovine (0.5–1 ng/ml), and prostate-specific membrane antigen (0.2–0.49 ng/ml) PET radiotracers. Expert working groups and European and US medical societies recommend NGI for patients with BCR.

Conclusions

Available data support the improved detection performance and selectivity of NGI modalities versus conven-

tional imaging techniques; however, limited clinical evidence exists demonstrating the application of NGI to treatment decision-making and its impact on patient outcomes. The emergence of NGI and displacement of conventional imaging may require a reexamination of the current definitions of BCR, altering our understanding of early recurrence. Redefining the BCR disease state by formalizing the role

On the Lighter Side



"A word of advice, Durk: It's the Mesolithic. We've domesticated the dog, we're using stone tools, and no one's *naked* anymore."

Today, I just want to thank God for the gift of life. No request, no complaints, just thankful to be alive.

NETWORKING

Please help us in our outreach efforts. Our speakers bureau consisting of Gene Van Vleet and Bill Lewis is available to speak to organizations of which you might be a member. Contact Gene 619-890-8447 or gene@ipcsg.org or Bill 619-591-8670 (bill@prostatecancerhelp.info) to coordinate.

Member John Tassi is the webmaster of our website and welcomes any suggestions to make our website simple and easy to navigate. Check out the Personal Experiences page and send us your story. Go to: <https://ipcsg.org/personal-experience>

FINANCES

We want to thank those of you who have made special donations to IPCSG. Remember that your gifts are tax deductible because we are a 501(c)(3) non-profit organization.

We again are reminding our members and friends to consider giving a large financial contribution to the IPCSG. This can include estate giving as well as giving in memory of a loved one. You can also have a distribution from your IRA made to our account. We need your support. We will, in turn, make contributions from our group to Prostate Cancer researchers and other groups as appropriate for a non-profit organization. Our group ID number is 54-2141691. Corporate donors are welcome!



Directions to Sanford-Burnham-Prebys Auditorium 10905 Road to the Cure, San Diego, CA 92121

- Take I-5 (north or south) to the Genesee exit (west).
- Follow Genesee up the hill, staying right.
- Genesee rounds right onto North Torrey Pines Road.
- **Do not turn into the Sanford-Burnham-Prebys Medical Discovery Institute or Fishman Auditorium**
- Turn right on Science Park Road. Watch for our sign here.
- Turn Left on Torreyana Road. Watch for our sign here.
- Turn Right on Road to the Cure (formerly Altman Row). Watch for our sign here.

DIRECTIONS TO MEETINGS