

Celebrating over 30 years of supporting men and their families

PCSANM Quarterly July 2022 Volume 29, Issue 3

Issue Highlights

Information	2		
Prostate Cancer Resources	3		
Member's Personal Story	4-5		
Body Fat and PCa	5		
Low-Risk Tumors/Treatment 6			
Combined Therapy	7		
Negative MRI and AS	7		
Chairperson's Message	8		

Our website address: www.pcsanm.org Email us: pchelp@pcsanm.org

Support Group Meetings

Meetings are held at
Bear Canyon Senior Center,
4645 Pitt St. NE in Albuquerque,
from 12:30 – 3 p.m.
on the first and third Saturday
of most months.
Meetings may also be accessed
virtually.

Please call 505-254-7784 or email pchelp@pcsanm.org for information. Meeting topics and login information may be found at:

https://www.pcsanm.org/meetings/

The Story Behind Why I Support PCSANM

By Guy Dimonte, PCSANM Volunteer

When I was diagnosed with a serious case of prostate cancer (PC) in 2009, I was unprepared emotionally and factually to make the important decisions on how to proceed. I consulted a local surgeon who recommended surgery, a radiation oncologist who recommended radiation, and a medical oncologist who recommended hormone therapy. WHAT TO DO? The doctors suggested Dr. Walsh's seminal book (Guide to Surviving Prostate Cancer), which was informative, but it was not specific to me and it did not provide emotional support.

Luckily, I was introduced to a retired surgeon who had been battling cancer for 20 years. He shared his experiences, helped me develop a medical plan for myself and provided inspiration and support for battling my cancer. I also met with a local PC survivor group. They shared their experiences with different treatments and also provided support. Both were so important to me for dealing with my newfound malady and it was blind luck to have found them.

Since I was young (60 years old) and healthy otherwise, I chose to have a prostatectomy as my initial treatment with an experienced urologist. Since my PC was severe, my PSA did not become undetectable in the following months so I was given radiation to my prostate bed. This made my PSA undetectable but only for two years. Meanwhile, my surgeon friend introduced me to a urologist at the Mayo Clinic in Minnesota who treated my recurrence with PET scans to find the metastases and with various treatments.

According to the tables in Dr. Walsh's book, there was a 100% chance that I would die of PC after seven years, similar to my dad. But because of chance encounters with experienced, knowledgeable and supportive men, I was able to formulate a plan to successfully deal with my PC. It was also important to keep current on the many wonderful treatments being developed for PC and to make lifestyle changes.

Along the way, I met a board member of PCSANM at a cancer retreat in Pecos who invited me to attend their Saturday meetings. WOW. The members were supportive and knowledgeable about PC and local medical capabilities. The annual meetings are also very informative. The group provides all the tools for dealing with PC that I only stumbled upon with chance encounters. That is why I give to PCSANM financially and with my time.

PLEASE SUPPORT PCSANM!

Online: www.pcsanm.org/donate

or

By check: PCSANM 2533 Virginia St. Ste. C Albuquerque, NM 87110

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Kat Lopez
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Phil York

Prostate Cancer Support Contacts Around the State

City	Contact	Phone
Clovis	Kim Adams	(575) 769-7661
Farmington	Deb Albin	(505) 609-6089
Los Alamos	Randy Morgan	(505) 672-3486
Las Cruces	John Sarbo and Ron Childress	(915) 503-1246 (602) 312-9289
Silver City	Herb Trejo	(575) 574-0225
Santa Fe	Guy Dimonte	(505) 699-2139

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The Prostate Cancer Support Association of New Mexico, Inc. 2533 Virginia St NE, Suite C Albuquerque, NM 87110

(505) 254-7784 (505) 254-7786 Fax (800) 278-7678 (toll free in NM)

> Office and Library Hours: Monday-Thursday 10 a.m. - 2 p.m. (Subject to Change)

EMAIL pchelp@pcsanm.org

VISIT OUR WEBSITE http://www.pcsanm.org

www.Facebook.com/ ProstateCancerSupportNM

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FACEBOOK Rod Geer

> EDITOR Rod Geer

MEETINGS Gene Brooks

PROGRAM MANAGER Ann Weinberg

ZERO – The End of Prostate Cancer (PCa) Prostate Cancer Support Programs and Direct Resources for Those Impacted by Prostate Cancer

ZERO360: Comprehensive Patient Support

1-844-244-1309 (Toll-Free) zerocancer.org/zero360

Zero360 is a free, comprehensive patient support service that helps patients navigate insurance, find financial aid resources, connect with support services, and secure access to care. ZERO's experienced case managers are ready to help men and their families through their personal prostate cancer journeys.

Us TOO Support Groups

zerocancer.org/supportgroups

Us TOO Support Groups offer in-person and virtual support. These groups meet regularly to provide peer support, resources, and education to empower men to make informed decisions on testing, treatment, and management of side effects. Groups are also available for special interests, including: Veterans, Black Men, Gay Men and their partners (All LGBTQIA+ welcome), Caregivers, Spanish Language, Deaf Men, and others.

Online Support Services

A variety of online support services are available to help men affected by prostate cancer and their loved ones to connect with others who are going through, or have gone through, similar situations. ZERO Connect is a Facebook-based support group for participants to share stories, ask questions, and connect. The Inspire Online Support Community (<u>ustoo.inspire.com</u>) connects patients, families, friends, and caregivers to enhance the quality of life for all those affected by prostate cancer.

Peer Support

MENtor is a peer support network at <u>zerocancer.org/mentor</u> for anyone who has received a prostate cancer diagnosis or has experienced a recurrence. ZERO's trained, volunteer MENtors represent many different prostate cancer journeys and have a wealth of insights to share based on their experiences. The ZERO Caregiver Connector Program at <u>zerocancer.org/caregiver-connector</u> matches prostate cancer caregivers with others who have been in similar situations. Both MENtor and Caregiver Connectors provide valuable one-on-one support customized to meet individual needs.

Educational Resources

zerocancer.org

Covering awareness, early detection, screening, treatment and side effects

Maintaining Physical Fitness During Hormone Therapy: A Personal Account

Lawrence Benson, PCSANM Board Member

I didn't really start to learn much about prostate cancer and its treatments until attending PCSANM's annual conference at the Sandia Prep School in November 2018 - and many of its bi-monthly meetings since then. The knowledge I keep gaining is why I find it well worth making regular contributions to this valuable and potentially life-saving organization.

Here's my story. In July 2016, at the age of 72, I got the bad news that my Prostate Specific Antigen (PSA) level had more than tripled from 3.84 in 2014 to 14.0. A subsequent biopsy revealed an aggressive cancer with a Gleason score of 9, and I was referred for external beam radiation at the UNM Comprehensive Cancer Center. In November 2016, I received the first of what has become 16 androgen deprivation therapy (ADT) injections with 11.25 mg of Trelstar, which dramatically lowered my PSA to 1.08 by January 2017. I then got a second Trelstar injection and began two months (39 sessions) of intensity modulated radiation therapy. Except for a stubborn case of proctitis (which would take another article to describe), I was feeling well after the radiation and continued my normal physical activities. I don't know what my previous testosterone levels had been, but in July 2017 it was measured at 287 ng/dL (well below the normal). For the rest of the year, I was hopeful that I might be finished with ADT to allow my testosterone to keep increasing.

By June 2018, however, my PSA had climbed to 2.40, so I began getting Trelstar injections every 6 months. This put me on a two-year roller coaster ride of rising and falling PSA and testosterone numbers. In June 2019, shortly after an Axumin PET scan revealed some suspicious activity in the prostate area, a blood test showed testosterone at 323 along with a PSA of 3.07. Placed under the care of a medical oncologist in July 2019, I began my current regimen of quarterly 22.5 mg Lupron injections. These successfully kept my PSA below 1.0 until the final three months of 2021, when it more than doubled to 1.94. That was evidence the cancer cells were becoming castrateresistant, so my oncologist began supplementing ADT with daily tablets of Nubeqa (Darolutamide), the newest androgen receptor inhibitor. This lowered my PSA to 0.74 in March and to only 0.16 by June 2022!

When I had to begin quarterly ADT injections, I knew I would have to adjust not only to "Low-T," but to living with virtually "No-T" (<07 ng/dL). Some of the common physiological side effects are losing muscle mass and bone density, gaining fat, and suffering from fatigue. I've always had a scrawny physique and was not much of an athlete. But ever since a stint in the Army, I've kept myself in pretty good aerobic condition by fast walking, jogging, cycling, and hiking in mountainous terrain (including every trail in the Sandias) and also doing simple exercises such as pullups and pushups. After learning about the value of weight-bearing exercises in my early 50s, I also began working out two or three times a week with a set of dumbbells and a weightlifting bench.

It was therefore fortuitous, twenty years later, that I didn't need to start from scratch in using weights to help cope with extended ADT. I did, however, increase the frequency and variety of exercises. Here's the schedule I've obsessively followed almost every day for the last several years, starting with the weightlifting.

<u>First day</u>: (1) four sets of 15 knee bends (for legs), alternating with three sets of 10-12 bench presses (for upper body), both using two 40-pound dumbbells; (2) three sets of 12-15 flyers ("wing-spreads") lying on back using two 35-pound dumbbells (for pectorals) alternating with three sets of 7-10 reverse flyers lying on my stomach using two 15-pound dumbbells (for triceps and upper back); (3) three sets of 10-12 curls using two 25-pound dumbbells (for biceps); and (4) three sets of 12 reverse lifts with each arm using a 25-pound dumbbell (for rotator cuffs), which involves lying face down on a sofa with padded armrests to brace against with head and feet.

<u>Second day</u>: Three sets of 50 pushups and three sets of 4 pullups using a chinning bar. (Disclaimer: My form might not satisfy a military drill sergeant.)

See Most, page 5

Maintaining Physical Fitness During Hormone Therapy

Lawrence Benson, PCSANM Board Member

Continued from page 4

Most evenings (while watching television): 150 crunches with hands under the small of my back to keep from bending my spine; side planks, holding my body straight for at least 60 seconds; balancing on each leg for at least 30 seconds; and 100 forward knee dips on each leg while holding 15-pound dumbbells.

Almost every morning: I hike 4 or more miles up local streets and onto trails in the Sandia Foothills wearing heavy 8-inch service boots and a 20-pound backpack. (Others might prefer a weighted vest.) In addition to helping stimulate bone density, the extra weight slows me down enough for my wife and I to walk together. Meanwhile, I get some aerobic exercise when breathing heavily on uphill segments. A few days a week I also jog up and run down a short uphill segment of a gravel road (without the backpack).

Exercising in a gym with modern equipment and personal trainers could well be more effective, but working out at home is very convenient, and using free weights does have some physiological advantages. Although I've not built any new muscle mass—which would require testosterone—I think I've been able to retain most of what I had before ADT. I still do about as many reps as in the past, which indicates that I haven't lost much upper body strength (even while continuing to age). But despite the daily walks and the weighted knee bends, I no longer have enough strength or stamina in my legs to backpack up mountain trails. And despite all the crunches, my abdomen has grown a slight paunch. As regards common medical measurements, my lipid levels have remained very favorable, my blood oxygen saturation has stayed in the upper 90s, my blood pressure is usually only slightly elevated, and my resting heartbeat is 60 per minute or less. Based on three DEXA scans since 2017, my bone density, although declining, has remained normal for my age. I feel very fortunate to still be in relatively good health.

Cancer Therapy Advisor: May 19, 2022

Higher Body Fat Linked to Higher Risk of PCa Death

Leah Lawrence

Higher total and central adiposity (excess fat in the abdomen) are associated with an increased risk of death from prostate cancer, according to research published in *BMC Medicine*. Researchers found that increases in waist-to-hip ratio, body mass index (BMI), waist circumference, and total body fat percentage were associated with increases in the risk of prostate cancer death.

To discover these associations, the researchers conducted a prospective study of patients in the UK Biobank and included data from this study in a meta-analysis. The prospective study included 218,237 patients, 661 of whom died from prostate cancer. Increases in most measures of adiposity were associated with an increased risk of prostate cancer death.

Hazard ratios (HRs) for prostate cancer death were 1.07 for every 5 kg/m² increase in BMI, 1.07 for every 0.05 increase in waist-to-hip ratio, 1.06 for every 10 cm increase in waist circumference, and 1.00 for every 5% increase in total body fat percentage.

In the meta-analysis, increases in all measures of adiposity were associated with an increased risk of prostate cancer death. The meta-analysis included 19 studies reporting on BMI. There were 19,633 prostate cancer deaths in these studies, and the HR for dying from prostate cancer was 1.10 for every 5 kg/m² increase in BMI.

There were 6 studies on waist circumference and 3181 deaths in these studies. The HR for prostate cancer death was 1.07 for every 10 cm increase in waist circumference. There were 3 studies reporting on waist-to-hip ratio and 1639 deaths in these studies. The HR for prostate cancer death was 1.06 for every 0.05 increase in waist-to-hip ratio. There were 2 studies reporting on body fat percentage and 670 deaths in these studies. The HR for prostate cancer death was 1.03 per 5% increase in total body fat percentage.

"Overall, we found that men with higher total and central adiposity had similarly higher risks of prostate cancer death, which may be biologically driven and/or due to differences in detection," the researchers wrote. "In either case, these findings support the benefit for men of maintaining a healthy body weight."

Medscape Medical News: May 15, 2022

Most Men With Low-Risk Prostate Tumors Now Forgoing Treatment

Howard Wolinsky

The number of men with prostate cancer who opted for active surveillance (AS) doubled nationally between 2014 and 2021, according to experts who say the dramatic increase reflects a growing understanding among both researchers and patients that low-grade prostate tumors can be safely watched for years without requiring treatment.

Roughly 60% of men eligible for AS chose that approach in 2021, up from 27% in 2014 and less than 10% in 2010, according to panel member Matthew Cooperberg, MD, MPH, of University of California San Francisco. He presented the data for a panel of the American Urological Association (AUA) today at the group's 2022 annual meeting in New Orleans.

Cooperberg attributed the hike in AS rates in the United States to the growing scientific literature and guidelines supportive of the approach, which calls for periodic assessments of low-risk tumors but no surgery, radiation, or other therapies. In Canada and parts of Europe, approximately 80%-90% of men who are eligible for AS choose that approach, experts said.

Earlier this month, the AUA and the American Society for Radiation Oncology released the <u>strongest guidelines to date</u> supporting AS for <u>low-risk patients</u>, and, for the first time, for select patients with favorable intermediate-risk prostate cancer.

In 2012, the US Preventative Services Task Force (USPSTF) recommended against screening for prostate-specific antigen (PSA), concluding that the benefits of the test did not outweigh the risks, such as overdiagnosis and overtreatment of low-risk prostate cancer. Urologists blamed the USPSTF policy for a decline in PSA screening and an uptick in the diagnosis of advanced prostate cancer.

Cooperberg said the shift served as "a bit of a wake-up call for at least a segment of the urology community that if we didn't fix the overtreatment problem, we would never retake the terms of the conversation about screening and early detection."

In 2018, following protests by urologists and patient advocates, the USPSTF revised its statements to include shared decision-making for PSA testing in men aged 55-69 years, reflecting emerging evidence of longer-term benefits and widespread adoption of active surveillance after detection of low-risk disease, he said.

Laurence Klotz, MD, the University of Toronto researcher who named and helped develop AS 30 years ago, and who was not on the AUA panel, said other factors also help to explain the growing interest in AS. These include an increasing consensus among experts on the value of the strategy, mounting public awareness of its benefits, the efforts of support and advocacy groups, and the arrival of more sophisticated imaging and biomarkers that help further refine risk.

"We're shrinking the gray zone," Klotz said. "Remaining resistance to AS is due to legitimate concerns about missing significant cancer and losing a patient to metastatic disease, and perhaps financial drivers, particularly with less invasive technologies like radiation and focal therapy."

William Catalona, MD, a panel member from Northwestern University Feinberg School of Medicine in Chicago, said the AUA's Prostate Cancer Active Surveillance Project has set a goal of 80% uptake of AS in patients with low-risk prostate cancer. Catalona, an early critic of AS, called that figure "optimal and realistic" and should happen "as soon as possible."

Catalona said the 80% benchmark matches acceptance of AS within the US Department of Veterans Affairs hospitals. However, Klotz said the American culture of treatment, which is driven at least in part by financial incentives on the part of physicians, may prevent the growth of AS above 80% in this country.

Cooperberg said financial incentives are real. "I think it's a small minority of docs that are heavily driven by the financial incentive, but it certainly exists," he told Medscape. When you look at the extreme variation of active surveillance rates, there is no question that factors like reimbursement are going to play a role."

Catalona, who through the first decade of the 2000s regularly debated Klotz about the concept of AS, said he today recommends AS when appropriate. "The variability of AS adoption among practices and physicians varies from 0% to 100%. Therefore, some are too 'tight' in recommending AS and some are 'too loose.' I do not attempt to steer [patients] into treatment unless I believe that would be their best option. Nevertheless, some opt for surveillance when I believe they are making a mistake, and some opt for treatment when I believe surveillance would have been a rational choice."

Science Daily: May 26, 2022

New Combined Therapy Extends Lives

Cedars-Sinai Medical Center

A cancer study shows hormone therapy, plus pelvic lymph node treatment, improves survival in men with prostate cancer.

The study also shows that patients with prostate cancer who didn't receive androgen deprivation therapy -- and who did not receive pelvic lymph node radiation -- had a five-year survival of 70%. "We can now confirm that pelvic lymph node treatment used together with androgen deprivation therapy, or even used as a stand-alone treatment option, greatly improves outcomes in patients with postoperative prostate cancer," said Howard Sandler, MD, chair of the Department of Radiation Oncology at Cedars-Sinai Cancer and senior author of the study. "These findings are an encouraging step forward, both for the medical community and for the patients and their loved ones seeking curative treatment options."

The international, Phase III clinical trial that served as the basis of *The Lancet* study, enrolled 1,716 patients between March 31, 2008, and March 30, 2015. Enrollees were separated into three groups.

Group one received salvage prostate bed radiotherapy -- a standard radiation targeted to the area in which the prostate used to exist before its surgical removal. These patients had a median five-year survival of 71%.

The second group received the standard radiation treatment, in combination with androgen deprivation therapy. They had a median five-year survival of 81%.

The third group received salvage prostate bed radiotherapy, androgen deprivation therapy *and* pelvic lymph node radiation. These patients had a five-year freedom from progression of just over 87%.

"The combined treatment approach proved to be the most beneficial approach," said Sandler, also the Ronald H. Bloom Family Chair in Cancer Therapeutics and professor of Radiation Oncology at Cedars-Sinai. Many men diagnosed with prostate cancer will undergo a prostatectomy -- the surgical removal of the prostate. After surgery, a man's PSA level should be near zero. However, some men start to see their PSA levels rise several years after surgery. This is typically an indication that radiation therapy is needed. Sandler says men with postoperative prostate cancer can have excellent outcomes, especially if radiation is given early -- when PSA levels are at their lowest -- and in combination with proven therapies, as suggested in this new research.

Renal and Urology News: May 15, 2022

Negative MRI in Active Surveillance Often Predicts Stable Prostate Cancer

Natasha Persaud

For men on prostate cancer active surveillance (AS), negative results on multiparametric magnetic resonance imaging (mpMRI) often predicts stable disease, according to investigators presenting at the American Urological Association's 2022 annual meeting in New Orleans, Louisiana. Cases with high PSA density (PSAD) are an exception.

At the Cleveland Clinic AS program, 466 patients underwent a median of 4 prostate mpMRIs over 3.4 years; 120 (25.7%) had at least 1 surveillance mpMRI showing no distinct lesions in the prostate. Of these patients, 73 patients underwent a subsequent biopsy.

Among the 95 prostate biopsies performed in this group, 34.7% displayed tumors of equal-grade to the previous pathology and 49.5% showed lower-grade tumors, Jacob Enders, BS, a medical student at Cleveland Clinic Lerner College of Medicine of Case Western Reserve School of Medicine in Ohio, reported. Only 10.5% of biopsies (in 9 of the 73 patients who underwent biopsy) showed upgrading to clinically significant prostate cancer of Gleason grade group 2 or higher.

In a multivariate logistic regression model, higher PSAD predicted upgrading to Gleason grade group 2 or higher prostate cancer at biopsy. Each 0.10 ng/mL/cc increment in PSAD was significantly associated with 4.2-fold increased odds of clinically significant prostate cancer, Enders reported.

"Patients with a negative mpMRI were more likely to be upgraded to [clinically significant prostate cancer] with increasing PSA density," Enders and colleagues wrote in a study abstract. "Thus, patients with a negative mpMRI, especially in the setting of a low PSA density, may be able to defer biopsy given the low likelihood for disease upgrading."



PCSANM *Lifeline* Newsletter Celebrating over 30 years of supporting men and their families

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A Message from the Chairperson July 2022

Why do you contribute with dollars or time to non-profit service organizations like our support group? Several reasons probably. Perhaps simply because you've been asked. Maybe you like what an organization does and want to see it flourish. Or you're looking for some tax deductions. For some years, I've been a financial and time contributor to PCSANM for a simple reason: Personal connections that were immediately available to me when diagnosed some years ago made a tremendous difference for the better in my subsequent journey. This support group, a 501(c)(3) organization, was born more than 30 years ago, which makes it one of the longest continuously operating such support groups in the country. With your help today, it can continue with its mission to provide men and their families in New Mexico with the most current information about prostate cancer detection and treatment, and to provide emotional support following diagnosis, during treatment, and beyond.

Rod Geer

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Chairperson of the Board, PCSANM