Prostate Cancer Support Association of New Mexico

LIFELINE

Supporting those with prostate cancer and their families since 1991

Quarterly Newsletter
April 2024
Volume 31, Issue 2

Issue Highlights

Scan to learn more about PCSANM

Support Group Meetings

Meetings are held at Bear Canyon Senior Center, 4645 Pitt St. NE in Albuquerque, from 12:30 p.m. to 2:45 p.m. on the first and third Saturday of most months.

Meeting topics and information may be found at:

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

Please call 505-254-7784 or email pchelp@pcsanm.org with questions.

Dennis's Journey from a Terminal Prostate Cancer Diagnosis to a Genetic Discovery

Promise.

Dennis was only 53 when he was diagnosed with aggressive prostate cancer. His doctor gave him 18 months to live, but he refused to give up. He tried various treatments and lifestyle changes, and eventually found a clinical trial that saved his life. Dennis also learned about his genetic risk factors through a free DNA test offered by the PROMISE Registry. PROMISE is a nationwide registry study of prostate cancer patients with inherited gene mutations. The purpose of the PROMISE registry is to learn more about the role genes play in improving treatments and outcomes for prostate cancer patients. This is Dennis' inspiring story.

The Diagnosis
In 1997, Dennis went to his primary doctor for rectal pain. He had read about a new test for prostate cancer called the PSA (prostate specific antigen). Dennis asked for a PSA test, but his doctor said he was too young. Dennis insisted, and it turned out he was right to be worried. His PSA was 197, much higher than the normal range. A biopsy confirmed that he had advanced prostate cancer that had spread to his bones. He was shocked to hear that he had only 18 months to live.

The Treatment
Dennis started intermittent hormone therapy, a new therapy at the time. He also changed his diet to a low-fat vegan/pescatarian one and exercised more. He quit his stressful job as an electrical engineer and focused on his health. These changes worked for more than a decade, until his PSA started to rise again.

The Clinical Trial
At age 63, Dennis searched for clinical trials and found one in California. He was accepted into the study and given Abiraterone daily. Abiraterone is a drug that blocks the production of testosterone, which fuels prostate cancer. After six weeks, his PSA was undetectable and has stayed that way for 15 years. Last year, his oncologist declared Dennis cured and discharged him as a patient. He has no sign of prostate cancer.

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In Memory

With deep sympathy and regret, we list these names:

Ramon Baca

Ron Christman

PCSANM *Lifeline*
A quarterly newsletter addressing issues of prostate cancer

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FACEBOOK

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The PROMISE Registry
Most recently, Dennis learned about the PROMISE Registry through a talk sponsored by Prostate Cancer Support Association of New Mexico. Dennis was especially curious about his genetics because he had been told years ago during his clinical trial that he had a "wild" gene. He wanted to know what that gene was and what it meant for his family. He enrolled in the PROMISE Registry and got his answer.

Dennis found out that he had a mutation in the CHEK2 gene, which is involved in DNA repair. This mutation increased his risk of prostate cancer and colon cancer. It also made him more sensitive to Abiraterone, which explains why he had such a good outcome. The mutation is inheritable, which means his children and grandchildren could have it too.

Dennis shared this information with his two sons and daughter. They, too, had their DNA tested. Should any have the CHEK2 mutation, they will be monitored closely for prostate and colon cancer. Further, Dennis has resumed regular colon cancer screenings, which he had stopped in his 70s as is recommended by the U.S. Preventive Services Task Force unless there are elevated colon cancer risk factors. Several large polyps were discovered during a recent colonoscopy and were removed. These precancerous lesions would not have been discovered had Dennis and his physician not been aware of his increased risk for the disease.

The Message
Today, Dennis is 80 years old, and he is doing remarkably well. He has outlived his doctor's prediction by nearly three decades. He is grateful for the clinical trial that gave him a second chance at life. And he is thankful that he now understands the role his "wild" gene plays in his health and the health of his children, grandchildren, and generations to come.

Dennis encourages other men with prostate cancer to join the PROMISE Registry and get DNA testing. He says, "If you have a chance to do it, do it! The information you get back may have a significant impact on your treatment and your outcomes and inform loved ones of their risk."

The PROMISE Registry will help researchers and physicians understand which drugs are most effective against which genetic variants. According to Dennis, "PROMISE is very easy to enroll, it is free, and the information is easy to understand with the help of a PROMISE genetic counselor."

Visit ProstateCancerPromise.org or call 646-449-3363 to learn more about the PROMISE Registry.

In the fight against prostate cancer, your DNA may be the most powerful tool.

PROMISE is a registry of prostate cancer patients participating in a research study to learn how genetic differences can affect patient outcomes, help family members understand their own risk of prostate cancer and other types of cancer, and guide discovery of new personalized treatments.

The PROMISE study examines the critical role of inherited genes in men with prostate cancer and their families. The research examines genes linked to the most common hereditary cancers. Patients across the country share their DNA to help build a genetic database so that every prostate cancer patient who is interested can better understand their genetic risk and potential new treatment options, as well as their family's risk for prostate cancer and other types of cancer.

Helio, HemOnc Today: January 29, 2024

Multivariable Blood Test Identifies Aggressive Prostate Cancer More Accurately than PSA

Josh Friedman

The Stockholm3 multivariable blood test demonstrated superior specificity of prostate cancer detection across a diverse population compared with PSA screening, according to findings presented at ASCO Genitourinary Cancers Symposium.

Results of Stockholm3 testing could have eliminated unnecessary biopsies of benign and low-grade tumors for 45% of men vs. data derived strictly from PSA.

"Although PSA is considered standard of care, this study confirmed previously shown associated harms of isolated PSA testing, suggesting better risk stratification is still needed in current clinical care," said Hari Thambiah Vigneswaran, MD, an attending urologist and researcher in translational epidemiology and prostate cancer at Karolinska Institutet. "Since the minority recruitment was so large in number, powered subanalysis was feasible and showed nearly identical results across all races and ethnicities," he added. "Although detection of aggressive cancer was higher in Black and African American men and lower in Asian men in the cohort, the biomarker did not require different calibration for different races and ethnicities, making the results generalizable to current clinical practice."

Background and methodology

The American Cancer Society projects prostate cancer to have nearly 300,000 diagnoses in 2024, the second most of any cancer in the U.S. However, screening for prostate cancer and determining next steps is a complicated and divisive issue. "PSA was developed in the 1990s, and it's a good test, but it's not perfect because PSA can be elevated not just from prostate cancer. It can be elevated for benign reasons," Vigneswaran said. "If you have an enlarged prostate, like [benign prostatic hyperplasia] or inflammation of the prostate, your PSA can be high. When you just look at PSA, it has a poor specificity. If it's elevated, a fairly invasive biopsy procedure can be done unnecessarily for a man who has a benign elevation of the PSA. Additionally, you have to choose a certain threshold to use for PSA, keeping in mind that it's got a poor specificity. You have to choose a threshold that's somewhat elevated so you're not doing all of these unnecessary biopsies. So you may miss some aggressive cancers."

"Stockholm3 (A3P Biomedical) incorporates several variables such as five circulating plasma proteins, including PSA, germline genetic risk and clinical factors such as age and family history," Vigneswaran said.

The multivariable blood test has been "supported by extensive clinical evidence, including 90,000 men," he added, but Vigneswaran and colleagues wanted to determine whether it could achieve non-inferior sensitivity and superior specificity in a diverse population. "When you evaluate new technology like a prostate cancer biomarker, it's important to look at how to improve specificity in a high-risk group like Black men because a lot of markers are elevated risk when it comes to Black men."

Researchers conducted a prospective trial of men who received referrals for a prostate biopsy from 2019 to 2023 at 17 different North American locations. They also used bio-banked specimens from 2008 to 2020. Study participants had no previous prostate cancer diagnosis.

Results

The cohort comprised 912 enrolled men and 1,217 with bio -banked blood (median age, 63 years; 46% white; 24% Black; 16% Asian; 14% Hispanic).

Biopsies discovered clinically significant prostate cancer in 29% of patients, grade 1 disease in 14% and benign tissue in 57%, with variation in clinically significant prostate cancer detection across all four ethnic groups (37% in Black patients; 29% in Hispanic patients; 28% in white patients; 21% in Asian patients).

Reduction of unnecessary biopsies performed due to Stockholm3 would have ranged between 42% and 53% across all four ethnic groups. "When we set it up, there was a secondary aim that we would need to recalibrate a model to fit different ethnicities and races, but in actuality we didn't have to do that," Vigneswaran said. "The area under the curve and performance was nearly exactly the same across all the races and ethnicities and overall."

Stockholm3 had a specificity 2.91 times higher than PSA (95% CI, 2.63-3.22) and a sensitivity (0.95) nearly equal to PSA (95% CI, 0.92-0.99).

Next steps

Stockholm3 launches in the U.S. in the first quarter of 2024, Vigneswaran said, and it could be used to evaluate men with both low and high PSA scores.

"It can act as a rule-in test and a rule-out test," he said. "You check PSA first, and at 1.5 [ng/ml] then, that's your trigger to order a Stockholm3 test. If your Stockholm3 risk score is elevated, typically an MRI is performed.

See The advantage on page 5

In Memory of Jan Marfyak, Former PCSANM Board Member

Lou Reimer, Past Chairperson of PCSANM's Board of Directors

Jan Marfyak, longtime member of the Prostate Cancer Support Association of New Mexico's Board of Directors, passed away on December 9, 2023.

Jan graduated from Miami of Ohio in 1955, and after a year at NYU Law School went to Madison, Wisconsin and enrolled in a master's program in political science. Jan was employed by the State of Wisconsin in multiple positions and was highly regarded by Governor Knowles and liaised with various state police units. Jan also worked on an investigation of nursing homes in Wisconsin and as a result he had a long standing concern about their capabilities. In the early 1970s, Jan moved to Washington, DC and worked with the Department of Justice and later with the Department of Energy, retiring in the early 1990s. He moved to Gettysburg, Pennsylvania in 1994. During this part of his retirement, he used his legal assistant certificate to assist the local people with legal problems through his service at the local library. He became intimately familiar with the events during the Civil War battle fought at Gettysburg.

Jan moved to Rio Rancho in 2006. He became involved in the State Democrat Party, worked at the local library in Rio Rancho serving on the Board, and was a member of the New Deal Preservation Society for New Mexico. His membership in the New Deal preservation society was prompted by the fact that his dad, who was a professional artist and painter, worked on WPA art projects in New Mexico during the 1930s. Jan's earliest ties to New Mexico were during this time when his family lived in Roswell for a short period.

Jan started his prostate cancer journey in 1995 when he received the news that he had prostate cancer. He underwent brachytherapy at John Hopkins. While there, he met and became acquainted with some of the leading doctors treating prostate cancer, including Dr. Patrick Walsh and Alan Partin. He had intensity-modulated radiation therapy (IMRT) as a supplement to his brachytherapy. All seemed to go well for a while, but he had a bout of bladder cancer in 2014 which continued to cause problems for the rest of his life and resulted in the eventual installation of an artificial sphincter to control urination and stents to drain kidneys.

Jan will be remembered as an outspoken member of PCSANM who served several years in different positions on the Board during his tenure from October 2006 through June 2020, including serving as Board Secretary and Legislature Liaison. The latter suited him well as he was very active in politics throughout his life.

Due to Jan's legal background, he often reminded the Board of Directors when he thought the Board was treading on shaky ground. He was a believer in the use of Robert's Rules, and he often argued about the need to follow certain steps to meet the procedures in the rules. Jan often played the role of "loyal opposition" during board meetings and encouraged fellow board members to thoroughly explore all aspects of contentious issues, but once settled, he wholeheartedly participated.

In addition to Jan's activities with PCSANM, he was a founding member of the National Alliance of State Prostate Cancer Coalitions (https://naspcc.org/). This nationwide organization is comprised of state prostate cancer coalitions dedicated to saving men's lives and enhancing the quality of life of prostate cancer patients and their families, through awareness and education and the development of a public policy network.

PCSANM deeply appreciates Jan's dedication to improving the lives of those affected by prostate cancer, as well as his years of service to PCSANM and to the community. He will be missed.

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The advantage of Stockholm3....it allows you to identify those men who are at risk in the low PSA ranges, reduces some of the unnecessary diagnostic and treatment harms associated with the high PSAs, and can reduce MRI use."

Vigneswaran believes Stockholm3 can reduce the issues surrounding prostate cancer screening and streamline it for the future.

"There's been a problem for the last 20 years where we know prostate cancer kills men and we know it affects men, but we also know we shouldn't treat every prostate cancer," he said. "That's where the primary care doctors have had some hesitancy [because] they don't know what to do, and they need a little bit more guidance beyond the PSA," he added. "The advantage with Stockholm3 is that you can use it in primary care settings where you see lower PSA values. You can find those men who are at risk and not just reduce the harms of prostate cancer but also improve detection by identifying those men who are at risk ... that would otherwise be missed with conventional PSA testing."

Fortune Well: February 10, 2024

Prostate Cancer Shouldn't Be a Death Sentence, but for Many U.S. Males, It Is

Erin Prater

Rates of America's second-deadliest cancer in men are on the rise—and they've been building exponentially for almost a decade straight.

Since 2014, U.S. diagnoses of prostate cancer—highly survivable if caught early—have risen 3% annually. Advanced-stage diagnoses have risen 5% year over year. Adding insult to injury, Black men are being diagnosed with late stages of the condition at two to three times the rate of white men, and are also around 2.5 times more likely to die of it, experts say. It's a reality that has experts like American Cancer Society CEO Karen Knudsen "ringing the alarm bell across the country."

The deaths and disparities are tragic enough. What's even more tragic: that tens of thousands of U.S. men die each year of a condition that, when detected early, has nearly a 100% survival rate. One major driver, according to experts: confusion surrounding screening guidelines issued by a medical task force in 2012—despite the fact that the controversial recommendations were revised several years later.

As Knudsen points out, "The second leading cause of cancer death for men is a very survivable cancer." U.S. prostate cancer statistics are "telling us something," she says: "We're not finding it early enough."

It's a topic that's made headlines again as of late, after a February 5 announcement that King Charles III is being treated for an unspecified form of cancer detected during treatment for a benign prostate condition.

The reason behind the rise

In the early 1990s, the U.S. Food and Drug Administration approved a test called prostate-specific antigen, or PSA. The simple blood draw detects a protein produced by cells in the prostate gland, with a rise often signaling prostate cancer. After the approval, prostate cancer diagnosis rates began to rise swiftly.

PSA levels, however, aren't just elevated by prostate cancer. Benign factors like infection or stimulation from riding a bike or vigorous sexual activity can also cause a rise, according to Dr. Bilal Siddiqui, an oncologist with the MD Anderson Cancer Center at the University of Texas.

Inevitably, elevated PSA levels sometimes resulted in unnecessary biopsies and treatments—and, along with them, undesirable side effects like incontinence, anxiety, and erectile dysfunction in some. Concerned that the blood test was doing more harm than good, in 2012, the U.S. Preventive Services Taskforce changed its guidelines to recommend against the use of it for prostate cancer screening.

Two years later, prostate cancer diagnosis rates began a steady ascent. "Sometimes when you throw the baby out with the bathwater, you have unintended consequences," said Dr. William Oh—an oncologist and professor at the Icahn School of Medicine at Mount Sinai in New York, and chief medical officer of the Prostate Cancer Foundation.

The 2012 recommendation—or reverse recommendation, of sorts—"created confusion in the minds of men, but also primary care providers," Knudsen says. The task force updated its recommendation again in 2018—to state that men should discuss screening with their doctor, weighing the risk and benefits—but the damage was done.

More than a decade after the initial recommendation, advances in imaging have reduced unnecessary biopsies, Knudsen says. And prostate cancer screening is safe and easy, with "no inherent harm." Anymore, there's no reason *not* to initiate a conversation about it with one's doctor, she adds—especially for men 50 and older, and those with a family history of prostate cancer or known genetic risk. "No one should wait to get a prostate screening until they are symptomatic," she says. "It's simple and a platform for an important discussion with one's physician."

Active surveillance an option for many patients

Not all prostate cancers are the same, experts say—and that's good news for a good deal of men with the condition. Many prostate cancer patients have "relatively low grade disease" that hasn't spread beyond the prostate itself, and treatment may simply involve active surveillance, Knudsen says.

Men who catch their prostate cancer early are unlikely to die from it, statistics show. In fact, studies have found that up to 50% of men autopsied died *with*

Fortune Well: February 10, 2024

Prostate Cancer Shouldn't Be a Death Sentence, but for Many U.S. Males, It Is

Erin Prater

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prostate cancer, but not from the condition—signaling that, "to a certain extent," some cellular changes along the spectrum of prostate cancer "may indeed be a normal part of the aging process," Siddiqui says.

"There are prostate cancers that will never be lethal in a man's lifetime," Oh advises. "As you get older, some men—many men—will have small amounts of prostate cancer in their prostate. The goal is not to treat if they don't need treatment. It's very important to separate these men and do active surveillance."

Such patients stand in contrast to men with a family history of the disease and/or those who have genetic risk factors, who often face more aggressive disease. While famous for fueling breast and ovarian cancers thanks to the advocacy of movie star Angelina Jolie, harmful mutations on the genes BRCA1 and BRCA2 can also confer a higher risk of prostate cancer, experts say. Those with such mutations on BRCA1 have an estimated 30% risk of developing prostate cancer during their lifetimes, according to a 2022 article in the *Journal of the National Cancer Institute.* That risk rises to 60% among carriers of BRCA2 mutations.

Options for treating high-risk, predisposed patients include radiation and surgery—and such patients must be treated "as aggressively as possible," Oh says. People tend to think of prostate cancer as one condition, and it's simply not true, Oh contends. As Knudsen says, cancer as a whole is more than 200 different diseases, and even prostate cancer cases can be divided into groups, or categorized on a spectrum.

A young patient with an "aggressive-looking" prostate cancer, whose father had the condition and who carries a BRCA2 mutation, is an entirely different patient from "an 80-year-old man who happens to have a biopsy and shows a very low grade, slow-growing" prostate cancer," Oh advises. "Those two men couldn't be more different," and their treatment should be vastly different too, he adds.

What to look for, and when to act

Symptoms of prostate cancer can vary widely, and some patients don't show symptoms at all, according to the U.S. Centers for Disease Control and Prevention. Some may experience:

- Difficulty beginning to urinate
- Weak urine flow, or interrupted flow
- Frequent urination
- Trouble fully emptying bladder
- Pain or burning while urinating
- Blood or semen in urine
- Back, hip, and/or pelvis pain that doesn't go away
- Painful ejaculation

Patients diagnosed in early stages of the condition can have a "high expectation of cure," Knudsen says, and "can continue to have a wonderful quality of life." In fact, the five-year survival rate for prostate cancer detected early is almost 100%, Siddiqui says. The outlook for late-diagnosed patients, however, is not nearly as rosy. There is no "durable cure" for such cancer, Knudsen points out. The five-year survival rate for advanced prostate cancer is only 31%, according to Siddiqui.

When it comes to prostate cancer prevention, "What's good for your heart is good for your prostate," Oh advises. He encourages men to pack their diets full of leafy green veggies and colorful fruits, and to limit dairy and barbecued meat, which are associated with a higher risk of prostate cancer and aggressive prostate cancer. "Exercise is also associated with a favorable outcome," he adds.

And when it comes to detection? Once men are in their 40s—or earlier if they're Black, have a family history of cancer, or carry a genetic mutation associated with prostate cancer—Oh recommends they talk to their primary care provider or urologist about screening. The conversation should occur every year or two.

"Doctors are very busy and have different feelings about everything, actually—especially in the area of cancer screening," he says. "Unfortunately, cancer screening is more controversial than it should be. Guidelines change quite often, and differ from one organization to another. It makes it harder for the average person to know what to do."

If you don't feel heard when talking to your doctor, get a second opinion, he recommends. Adds Oh: "Early detection of a bad disease is always better."

Prostate Cancer Support Association of New Mexico

PCSANM *Lifeline* Newsletter
Celebrating 33 years of supporting men and their families

Prostate Cancer Support Association of New Mexico, Inc.
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A Message from the Chairperson

April 2024

Happy spring to everyone! Change is happening all around us, and within PCSANM is no exception. I am pleased to announce the addition of two new members, Steve Tannenbaum and David Naquin, to our board of directors.

In June of 2016, Steve was diagnosed with prostate cancer. Despite his initial shock, he realized immediately that he needed additional information and support from others coping with the disease. He sought out PCSANM, learned that he is not alone, and felt inspired to become involved in contributing to the efforts of the association's outreach committee. His commitment to helping others continues to deepen with his decision to join our board.

In 2018, David had his first PSA test. By the summer of 2020, his PSA had risen enough that he decided to act. A fusion biopsy revealed Gleason 7 prostate cancer, and he underwent surgery in November of 2020. Since then, his PSA has remained undetectable. He has contributed to the efforts of the outreach committee since 2020 and looks forward to becoming more active with the association. He and his wife have lived in Albuquerque since 1990 and are retired.

PCSANM deeply appreciates both new board members, and we look forward to supporting even more New Mexicans than ever before as a result of their guidance, participation, and dedication.

Rod Geer
Chairperson of the Board, PCSANM