



Facing Prostate Cancer with Strength and Hope

Men Share Their Stories



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Chances are that you know someone besides yourself who has been diagnosed with prostate cancer. It is the second most common cancer in American men.¹ In recent years, we have seen an increase in the diagnosis of advanced stages of the disease and resulting mortality rates.² At the same time, we have seen advances in diagnosis and treatment that are helping the 3+ million men living with prostate cancer to achieve better outcomes.¹



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¹ American Cancer Society. Cancer Facts & Figures 2022. American Cancer Society; Atlanta, Ga. 2022

² www.cancer.net/cancer-types/prostate-cancer/statistics





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A photograph of a man and a woman embracing on a sandy beach. The man is wearing a grey t-shirt and orange shorts, and the woman is wearing a yellow long-sleeved shirt and grey pants. They are both looking up and smiling. The ocean waves are visible in the background.

FINDING YOUR WAY FORWARD

A Roadmap for Your Journey

Foreword by Daniel Canter, MD

As a practicing urologist, I am often the person who tells someone they have prostate cancer. It's hard news to deliver. But it's something that 1 in 8 men will hear at some point in their lives.¹ It is shocking for many, as it's a cancer that appears with little to no warning or symptoms. The path forward is usually filled with difficult decisions that impact both survival and quality of life. However, with the right information and care team, the path can sometimes be made a bit easier. We are making strides not only in the diagnosis and treatment of prostate cancer, but also in our willingness to talk about it more openly.

While each person's journey is unique, I have observed that there are common "stops" along the way. Each experience is not an exact blueprint for the next, but one person's lessons may help another make decisions or give comfort. That is the

point of this booklet. These men have shared their stories so that their challenges and struggles might become signposts for your journey. Their hope is that your load may be made a little lighter knowing that someone else has traveled this road before.

Following are some signposts from a doctor's point of view. I encourage you to use this as a starting point for talking with your own treatment team. This is not meant to replace the advice of your own doctor.

The Patient Knows Best

Prostate cancer, in general, is not a fast-growing form of cancer. With some cancers, people do need immediate treatment, but prostate cancer, fortunately, is not always that way. Patients usually have time to get as many opinions as they need in order to make an informed decision. The doctor's role is to give information and allow patients and partners to choose what is best for their overall health and lifestyle. Doctors may be medical experts, but these decisions will impact your life.

These men have shared their stories so that their challenges and struggles might become signposts for your journey. Their hope is that your load may be made a little lighter knowing that someone else has traveled this road before.

¹ American Cancer Society. Cancer Facts & Figures 2022. American Cancer Society; Atlanta, Ga. 2022

One thing to keep in mind when making care decisions is that in some cases “active surveillance” not treatment, may be the best option. Prostate cancer is unusual in this regard because it can be very slow to progress and there are advanced, reliable



ways to monitor its progress. Patients should not be wary if a doctor tells them that active surveillance is recommended, but it's still a good idea to confirm that it's the best choice for you.

Anyone who is newly diagnosed should educate themselves about the specifics of their case and gather information

about the testing and treatment options. Patients, their caregivers, and families, can become well informed about their situation using reputable sources such as the American Cancer Society, the National Cancer Institute, and hospital-affiliated websites. As a doctor, I appreciate when people ask me questions based on their research. Any question is a smart question when it comes to understanding your health.

Revealing the Clearer Picture

Once prostate cancer is confirmed, your doctor will likely order a full range of tests including biopsies, imaging and possibly molecular testing, to gather information about your cancer. The tests will help determine the aggressiveness, location and stage of the cancer so that all existing treatment options can be considered. You will become familiar with terms like “Gleason score” and “PSA level” which are used to help decide on the appropriate testing and treatment needed. If staging is needed, a specialist will likely conduct imaging. Depending on the patient, this can be a computed tomography (CT) scan, a bone scan, and now a prostate-specific membrane antigen positron emission tomography (PSMA PET) scan, which can be used to stage prostate cancer that is suspected to have spread outside of the prostate.

Molecular testing, genetic testing, and PSMA PET scans provide more information to add to decision-making for





potentially better outcomes. Patients should ask their providers about these resources. I am especially excited about PSMA PET because one of the main challenges in prostate cancer treatment is adequate detection and staging. A PSMA PET scan is visually easy to understand, and it is more exact because it targets PSMA, a protein that is overexpressed on cancer cells. PSMA PET scans help us do a better job of recommending the most effective and least debilitating treatment options.

The good news is that prostate cancer is treatable and oftentimes curable. Even for men with metastatic disease, it is treatable for a long period of time. Men are living longer with prostate cancer, especially with concerted efforts underway to develop newer therapeutics and diagnostics that change the treatment landscape.

Outside of the doctor's office, educational information is often provided to newly diagnosed patients through patient support groups. Talking to other men who have been through a similar experience can be therapeutic. It may sound obvious, but it should be stressed that talking to a partner, friend or another trusted loved one is often the most impactful form of support.

A prostate cancer diagnosis can be a challenging road to navigate, but there are many resources to help map your journey that are available to empower patients and provide support. If you are newly diagnosed – get as much information as you can, be active in making decisions about your testing and treatment, take advantage of available resources, and seek support from those around you. Above all, stay hopeful. New technologies and medicines are always on the horizon.

Dr. Daniel Canter grew up in the Washington D.C. area. He graduated from New York University, cum laude, with a BFA in Film and TV Production. He later received his medical degree from George



Washington University School of Medicine, graduating as the valedictorian. He completed his residency in urology from the University of Pennsylvania. Following this, Dr. Canter pursued specialized fellowship training in urologic oncology at the Fox Chase Cancer Center.

THEIR *Stories*



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COMMUNICATION

Keith



Keith was first diagnosed with oropharyngeal cancer in 2017. He handled it in a completely different way than his prostate cancer diagnosis that followed two years later. “Most of my friends didn’t know at all [when I was first diagnosed with cancer]. I didn’t mean to keep it a secret, but I didn’t want to burden them with my problem ... because they all have their own problems.”

But talking about prostate cancer helped Keith push ahead at every stage of his journey.

“Surgery, radiation, and probably chemo is where I was headed but because of the scan, the doctor started talking surgery only with none of the bad effects of radiation. Believe me, I went through 37 rounds of radiation (for oropharyngeal cancer) and it’s brutal ... If my PSA number starts to go up from zero or one, I will be asking about getting another PSMA PET scan.”

Lesson: Ask Questions

Keith reached out to his friend who had been open about his own battle with prostate cancer when he was first diagnosed. He was worried because his doctor did not recommend treatment right away. His friend told him to seek second and third opinions, even though Keith had to travel out of state to do so. It was good advice. Both doctors disagreed with the first doctor. Keith reflects that “both looked at my biopsy report and looked at my age and my family history and said, ‘You don’t have a choice. You have an aggressive form of prostate cancer. Active surveillance is not the answer for you.’”

“I learned from my first journey with cancer, and that’s why the second time, I think I was more open and willing to talk.”



Lesson: Be Persistent

Keith quickly scheduled a prostatectomy, but due to the COVID-19 pandemic, the surgery was postponed multiple times.

While waiting for surgery, he looked for ways to improve his treatment outcome. His search led him to a study involving a new PSMA PET scan, which did indeed lead to good news.

The scan helped his doctor to confirm that Keith would not require radiation on top of surgery.



Beyond the medical advances that helped with his treatment, he points to the support he received as a key to his recovery. A main source of comfort for Keith was being surrounded by friends and family, especially his wife. In thinking about his journey, he emphasizes the importance of resources such as patient support groups for newly diagnosed men. He understands that men can have difficulty being vulnerable. He says being open about one's concerns and emotions is key for healing from prostate cancer.

Lesson: Share Your Story

Now 62, Keith continues to stay active. He plays golf, pickleball and even rides a bike 25 to 30 miles a week. He also works full-time as the Director of Facilities for a U.S. Federal Courthouse overseeing maintenance and budgetary needs. He is enjoying life.

Keith hopes more men will have courage to tell their stories – for their own sake and for the benefit of others going through the same thing.

“When you talk prostate cancer and men getting in a room as a support group and talking about it, sometimes there’s not a lot of conversations. Sometimes it takes somebody that’s willing to stand up and say, ‘This is my diagnosis. This is my journey. This is what I want to share with you.’”

EMPOWERMENT

John

Having his Oregon farm suddenly in the path of wildfires as he was getting ready to retire was a wake-up call for John. He credits it with helping him to “reprioritize” his life and take control over his health. John scheduled a much-needed annual checkup while he had the benefit of employer-provided insurance. The doctor recommended a PSA test. John was surprised to learn that in 10 years his PSA

had skyrocketed to approximately 10ng/ml. A doctor took a biopsy and confirmed that there was a tumor in John’s prostate. Following additional testing, he was diagnosed with metastatic prostate cancer. He knew he had to take control. It would give him the best chance to overcome the challenges ahead.

John’s active participation in his care didn’t stop at diagnosis or even with his first round of treatment. At first, he was told that he would likely have to return for secondary treatment: androgen deprivation therapy (ADT). Even though his PSA had dropped drastically after the removal of his prostate, it had still not reached zero. As a result, John began looking up new diagnostic and treatment options. He discovered the availability and benefits of PSMA PET scans. He asked his care team about it, and they agreed to schedule one. The scan showed two “hotspots” which he and his doctor decided to treat with radiation. Reflecting on the scan, John said, “It significantly improved my understanding of the metastases, led to minimal radiation treatment and confirmed

Lesson: Make Your Own Decisions

“You deal with this, not by letting it roll over you, but through knowledge. You take an active role in understanding your condition,” says John. After educating himself about the different treatments available, John opted to go for a radical prostatectomy. He acknowledges that it may not be the best route for everyone. He felt this was the right decision because his surgeon was highly recommended. He also knew that radiation could be an option post-surgery.

“You’ve got to own your own health and when you do, you will start feeling better, feeling stronger, feeling more like you can deal with the world around you and the world within you.”



Lesson: Own It

Part of owning one's health, according to John, means digging deep for answers and searching for reliable information – which sometimes also involves more than an internet search. In his case, he cites a book, “Dr. Patrick Walsh’s Guide to Surviving Prostate Cancer,” written by a renowned physician that has become a trusted guide. He also points to the importance of making your own decisions.

“This isn’t your grandad’s prostate cancer. It isn’t even your older brother’s prostate cancer. There is so much more now than ever to effectively manage your disease. But it won’t necessarily all be laid out for you. There’s plenty of work, learning and decisions ahead.”

that hormone therapy wasn’t needed ... in my case, accurate, detailed diagnosis led to minimal, successful treatment.”

When a doctor recommends a diagnostic or treatment, ask how long the provider has been doing the procedure, ask about



your case in relation to other cases they have previously treated, ask for a detailed description of the risks involved. With a potentially overwhelming amount of information to discover, he suggests that it can also be helpful for patients to bring someone to their appointment to help with taking notes or asking questions.

Finally, John stresses the benefits of finding a reliable local support group early on. For him, his support group not only helped with the mental aspects of processing the information but the people he met there also helped him navigate finding a new doctor when he decided that his care team wasn’t the right fit.

Lesson: Control What You Can

John lives an active life with prostate cancer. He works on his farm. He has found time to continue the pursuit of his passions – hiking and singing. In his own words, his journey has helped him “realize there’s a lot of stuff that’s outside of my control and I accept that, but there are a lot of choices that I can make that will influence my health in ways that I didn’t realize.”

Many of those choices relate to what he calls the “four pillars of health” – diet, exercise, sleep and attitude. He also encourages men who are dealing with side effects after surgery to stay the course and follow the recommendations of their care team until their issues improve. He believes these choices helped with his recovery: “Physically, I’m as healthy as I ever was. I have no aches or pains I can attribute to my cancer or cancer treatment. I can do all the work I need to on the farm and have returned full strength to my daily life. Continence has recovered. My sexual function has been modestly improving. I accept where I am, and I am satisfied.”

INSPIRATION *Ira*



“They just give me joy, my daughter and my wife, my family. I’m just counting my blessings at this point.”

Married for 25 years, Ira and Sharron had supported each other through many ups and downs. When Ira learned he had prostate cancer, Sharron’s unwavering support not only provided Ira with comfort, but it also saved his life. While recovering from his prostatectomy at age 61, Ira developed a complication.

Ira learned later that he had developed blood clots in his lungs and in his legs, a rare but potentially fatal complication following surgery. Thanks to quick thinking by his wife Sharron, he was treated successfully and was released after 11 days in the ICU.

“I thank God my wife was here. That’s the reason why I share that part because I think it’s important that

Lesson: Be Prepared

“Everything was fine. But at 2 am on the day that I’m supposed to get my catheter out, I start feeling this pain, like a cramping pain in my leg. I woke my wife up and said, this cramp is killing me. I walked to the center of the bedroom, trying to walk it out. I barely made it back to the bed when I collapsed and fell forward. All I remember was coming to with excruciating pain in my knees and hearing her talking to somebody on 911.”



folks need to have somebody with them, you know, especially when you’re recovering from surgery. That’s part of the journey.”

With an initial diagnosis of stage 4 metastatic cancer, he was facing an aggressive treatment plan. It would likely include surgery, hormone therapy and chemo. Before moving forward, he decided to seek a second opinion, which led to more diagnostic testing. Armed with the additional results of a bone biopsy and a PSMA PET scan, doctors were able to give Ira a better prognosis. The “spots” were not cancer which changed his treatment plan – since his cancer had not metastasized, he would only require a robotic prostatectomy.

Even with a less aggressive treatment plan, Ira and Sharron knew they had a lot to learn to

prepare for the road ahead. The hospital where he was diagnosed offered an educational class for couples. They jumped at the chance to attend the one-day session. Everything about Ira's condition and treatment was explained to them together. "They talked about everything from describing and defining the prostate to talking about sexual activities, incontinence or whatever, it was just a great course, especially for couples and we got really comfortable."

Lesson: Get More Information

Ira and Sharron knew more about the prostate than the average couple. Two of Ira's five brothers already had prostate cancer. Ira himself had been coping with a pre-existing prostate condition for years. With his personal and family history, Ira's doctor had also been vigilant about his yearly PSA tests. Having been delayed by COVID-19, she was anxious to get him back on schedule and for good reason. His PSA had doubled since his last test and a biopsy revealed a Gleason score of eight, indicating an aggressive form of cancer. Even more worrisome, CT scans also showed suspicious spots on his ribs, hip and back.



Ira credits his "support tribe" with getting him through it all. But it wasn't just his family that helped; he found support in unexpected places. When he shared news of his cancer more widely, he started hearing from men in his church and his college fraternity. A few had undergone the same procedure and were doing well years later. He recalls what hearing that meant to him, "I was like, wow, you know, to get that uplift, to get that, 'you're gonna be okay guy,' - it was great." Speaking to other men who have had his same surgery has also helped prepare him for the side effects.

Another unexpected source of support came from work. Ira, who teaches information operations as an Army civilian, recalls how telling his employer about his situation helped him mentally, "That was so important for me because it took some stress off. And the last thing you need when you're going through something like this is additional stress, right?"

Lesson: Gather Your Tribe

When Ira and Sharron needed backup, his family stepped up. Ira's brother attended all of the appointments he could with Ira and Sharron. This has since proved to be beneficial in helping him navigate his own prostate cancer path, as his diagnosis came shortly after Ira's surgery.

The family also provided relief to Sharron, taking turns staying with Ira while he was in the hospital, and worked together to make sure that he wouldn't be left alone when Sharron needed to leave the house or take a break.

While Ira is appreciative of the friends and family who surrounded him and the countless prayers they offered up on his behalf, the person who inspired him the most on his journey doesn't even realize his impact - he's only two years old. "I'm spending a lot of quality time with my grandson," he says smiling. "I mean, I love my family, but he gives me pure joy just being around. That's motivation."



HOPE *Scott*

For men who are first learning that they have prostate cancer, Scott suggests that they accept that it's a journey. It's more like a marathon than a sprint. And it's not easy. Living with the possibility that this might be your "last round at the rodeo" requires a certain mindset. "Cancer plays mind tricks on you, and you have to confront those mind tricks head-on."



Whatever he does is working for him. After an initial diagnosis and two recurrences, Scott's sense of humor and positive outlook remain intact.

While prostate cancer is often referred to as a "slow-growing" cancer, Scott knows that it can sneak up on you pretty fast. Now coming up on what he refers to as his "Beatles Birthday" (64), he began paying attention to his prostate health in his 50s. He wasn't shy about encouraging others to do the same. In 2011, he took a friend to a local health fair with free PSA tests and they both got tested. The results were surprising – it had only been a couple of months since he was tested at his annual exam and his number had jumped considerably. Somewhat alarmed, he followed up with his primary care doctor who sent him to a urologist. During the exam, the urologist found a tumor and a subsequent biopsy confirmed a prostate cancer diagnosis. But he remained optimistic.

He was able to enroll in a clinical trial for a PSMA PET scan which found his cancer had spread outside of his prostate. This led his care team to recommend treatment with Stereotactic



Lesson: Do Your Homework

Scott sprang into action – joining a local support group and doing research on his options. Based on what he learned, and considering the side effects, he elected to be treated with brachytherapy. The treatment worked for a number of years. Then almost a decade later, his PSA started to creep up again. He decided to go on the offensive and started researching new advances.

"Once you have prostate cancer, there's no looking back and I think it's important to stay present in the moment as well as to be hopeful about the future."

Lesson: Look Ahead

“The thing about cancer,” explains Scott, “You’re always waiting for the next great thing – be it in the diagnostic tools or the treatments. And looking to be treated one way that will hopefully help stave off having to be treated in the near future. And if you do need to be treated in the future, there will be something, a new development.” Accepting that the unknown can be good is often a challenge in itself.

Body Radiotherapy (SBRT). This time his PSA dropped for a few years until starting to rise again. Doctors informed him that a CT scan of his pelvic area and abdomen, as well as a bone scan, showed nothing of concern. Knowing from experience that a rising PSA was nothing to ignore, he rolled up his sleeves and started researching options and working with his doctors to figure out why his PSA was changing.

This time, the “next thing” was a PSMA PET scan with a newer radioactive tracer than the one his doctor used previously. He learned about it in his support group. It had just been approved by the FDA. He called the company



directly to find out where he could go to get it and was relieved to find it was being offered at his treatment center. The PSMA PET scan located the cancer and showed that it was confined to the prostate, which was critical in helping Scott’s oncologist decide on a treatment plan.

“The prostate is in such a tricky area, it’s in a very bad “neighborhood” and so much can be affected by any treatment. After talking to the radiation oncologist, based on my previous treatment, it became clear that surrounding tissue was at risk. We needed to find another option.” With the input of his care team, he decided on cryosurgery and is hoping it will be successful.

His wife, Lynn, was his “rock,” providing comfort and advocating for him during his journey. He also relied on a group of people he had never met before who have since become friends.

Lesson: Ask Questions

Scott admits he couldn’t have done it without his wife, Lynn. Lynn is a medical professional who knew what questions to ask during appointments and spoke up for him when he was anxious or nervous.

“I think a lot of men with prostate cancer need to accept that they aren’t alone. People are on the journey with them. Cancer affects not just the patient. It affects everybody around them.”

Accepting that you need help from strangers can be an important part of the cancer journey. One of Scott’s core sources of information has been his prostate cancer support group, a place where he could ask questions and get valuable insights. Along with Lynn, these two main sources of support have played an instrumental role in the questions he asked his medical professionals, the options he sought and where he is now. Still, Scott emphasizes that even when you get the answers from trusted friends, the only opinion that matters is yours. It’s up to you to choose what’s best for you.

GRATITUDE *Tom*

Tom, 81, of Rhode Island, admits that the amount of information available on prostate cancer and its treatment can be daunting to review. But he sees it as a positive and says that we're lucky to live in a time with so much data available to us. He guesses that he has spent "over a thousand hours" studying the subject since he was diagnosed in 2018. He still finds there is always more to learn. He reasons that



this wealth of information highlights the need to find a well-informed doctor. He was grateful for his physician's help in pointing out which options are safest and most advanced, as that helped him to take an active role in decision making on testing and treatment, which he encourages others to do as well.

Tom asked for opinions from three different doctors regarding treatment when his high PSA score of 13 ng/ml jumped to an even higher score of approximately 17 ng/ml in a short period of time. Scans and a biopsy confirmed the aggressiveness of his cancer. All agreed that he undergo radiation treatment as a first step.

Now on oral chemotherapy, which leaves him feeling fatigued, his spirits remain high as he reflects on his care team and their expertise treating advanced prostate cancer. Going into these appointments, Tom's mission is clear: "My goal is to cure my cancer, or at least push it back a few years." He reflects that radiation has come a long way in terms of its potential precision. He points out that it's a good idea

Lesson: Seek the Facts

Aside from selecting an experienced doctor who pushes you to be active in testing and treatment decisions, he also suggests people take their health into their own hands by knowing which questions to ask. According to him, the most important thing for newly diagnosed patients to know is their Gleason score, which they should discuss with their doctor along with next steps and other concerns they may have. If time with a doctor is limited, Tom suggests, "Speak to a nurse or someone who's knowledgeable and can explain to you what's going on."

*"I've been so well treated by
all the technicians and doctors
and the staff and everybody,
they seem to exude love and
joy and everything."*

to consider undesirable and long-lasting side effects from treatments, such as radical prostatectomy, before making a treatment decision.

Tom admits that there have been highs and lows during his journey. Particularly when he considers his limited control over what the future holds. Among other things, he worries about the emotional impact of his condition on his wife, Cindy, but has found that writing about his feelings has been a therapeutic release for him. He says that one of the biggest positives to have come out of all of this is his increased empathy for himself and others.

Lesson: Ask About Testing and Treatment Options

One tool that was a game-changer in Tom's treatment was a PSMA PET scan, which Tom experienced twice. His second PSMA PET scan showed that his cancer had doubled in size. He feels fortunate for this discovery, as it gave his oncologist the necessary information to change his treatment accordingly.



For additional support in the face of his diagnosis, he is seeing a psychiatrist and psychologist. Tom is grateful for the support groups that he found online as he has learned from the experiences of others in similar situations and been able to share his insights in return. He emphasizes the importance of speaking up and voicing your thoughts when you're living with cancer.

He feels that prostate cancer can be especially challenging to talk about because of the stigma surrounding it. "People talk about breast cancer all the time, but a lot of people don't really share about prostate cancer." Tom has found that his gratitude and give-back mentality are helpful to him as well. He reflects, "If I use my knowledge to help other people, that's really good for me."

Lesson: Prioritize Mental Health

Though Tom's energy level limits his participation in his old hobbies, he has found new ways to fill his time. He maintains his spirited outlook on life. Tom served in the Air Force before working as a programmer for 50 years, enjoying hiking, backpacking and kayaking in his free time. He has less energy for those things now but has found that in addition to spending more time with his wife, Cindy, he loves reading and writing.

Lesson: Find Meaning in Your Journey

Tom is grateful for those around him, especially Cindy and his care team, and treasures the bonds he has created on his journey. Something he did when backpacking, as well. He compares his care team to the people he met visiting Newfoundland over the course of many years, whom he describes as friendly, family-oriented, and happy, and has always aspired to attain a similar attitude. He appreciates that his care team inspires him in a similar way.

Resources

For more information about living with cancer, ask your care team for referrals to local support groups or seek information from the following patient-centered organizations.



Veterans Prostate
Cancer Awareness

Veterans Prostate Cancer Awareness

veteransprostatecancer.org

888-899-VPcA (1-888-899-8722)

info@VeteransProstateCancer.org



Prostate Cancer
Foundation

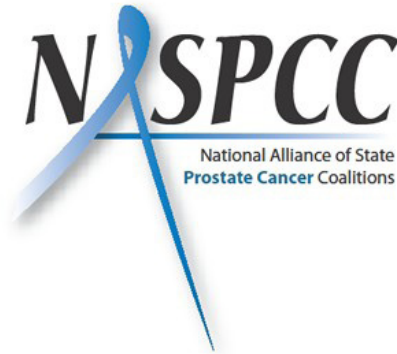
Curing Together.

Prostate Cancer Foundation

pcf.org

1-800-757-CURE (1-800-757-2873)

info@pcf.org



National Alliance of State Prostate Cancer Coalitions

naspcc.org

424-253-1168

info@naspcc.org

Resources



THE END OF PROSTATE **CANCER**

ZERO - The End of Prostate Cancer

zerocancer.org

1-844-244-1309

info@zerocancer.org



**Prostate Health
Education Network**

Prostate Health Education Network

prostatehealthd.org

1-617-481-4020

rapcancer@prostatehealthd.org

Urology Care
FOUNDATION™
*The Official Foundation of the
American Urological Association*

Urology Care Foundation

urologyhealth.org

1-800-828-7866

info@UrologyCareFoundation.org

For more information about PSMA PET
scans for prostate cancer, contact
Lantheus Customer Support at:
1-800-964-0446
(Hours M-F 8:30 am-8:00 pm ET)
or email:
cspyl@lantheus.com

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