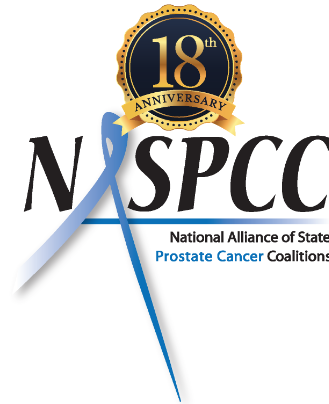


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President's Message

December 2023

It's hard to believe that the calendar year 2023 is almost over. There is so much work to do to help educate about prostate cancer and be of benefit to men and their families!

On October 6-8 we held our 18th Annual Meeting in Washington, DC, and it was one of our best yet – we had stellar faculty from Memorial Sloan Kettering, Cornell, Dana Farber, Johns Hopkins, Duke, University of Pennsylvania, City of Hope, Case Western Reserve, and University of Washington/The Fred Hutchinson Cancer Center for a weekend of education, networking, and sharing of best practices. New to the Agenda were a Panel with former PROSTATEPEDIA Magazine interviewees to reprise and update their interviews; a Panel on Side Effects from Prostate Cancer Diagnosis and Treatment with patients AND their wives; and a Panel with adult children of prostate cancer patients. Currently we have resources from the 18th Annual Meeting on the www.naspcc.org website at <https://www.naspcc.org/index.php/18th-annual-meeting>.

PROSTATEPEDIA Magazine is in full swing. We published 6 Issues of the Magazine (distributed, and now archived on our website) including a Special Issue on 'BLACK MEN AND PROSTATE CANCER', and of course our PROSTATEPEDIA DIGEST is published every single Friday of the year at 8:00 am Pacific with 28 links to abstracts and articles. NASPCC has over 20,000 subscribers to PROSTATEPEDIA and is considered the "gold standard" in prostate cancer education. We also presented several Webinars which are archived on our website as well, including November 28's Webinar on 'SEXUAL SIDE EFFECTS' with Dr. John Mulhall, and an August Webinar on "SECOND GENERATION ANTI-ANDROGENS" with Dr. Andrew Armstrong. NASPCC uses the GoToWebinar platform with 500 portals. Please see "[WEBINAR ARCHIVES](#)"

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Our Laminare production continues. We have 6 Laminates completed (which are on our website) with 5 more in queue, including "BONE HEALTH" and "GENETICS AND PROSTATE CANCER". NASPCC is also starting an "ACCESS BARRIERS Initiative" opposing Step Therapy, whereby some insurance carriers are obligating patients to use less expensive, but not necessarily appropriate, drugs, in order to cut costs. We will be convening two Roundtables and initiating a letter-writing campaign on the topic.

NASPCC is about to start our 20th year: 2024!! We are thrilled to be the premier national prostate cancer organization in the country. Let's keep up the great work!

Sincerely,
Merel Nissenberg

IN LOVING MEMORY



JAN MARFYAK
(May 13, 1933-December 8, 2023)

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prostate cancer patient advocates, individuals who were invited to discuss how we could be of help to a national prostate cancer group. That was the weekend that I met Jan Marfyak. I was representing the California Prostate Cancer Coalition as its President, and Jan Marfyak, a prostate cancer survivor, was there as Co-Chair of the Pennsylvania Prostate Cancer Coalition. We became fast friends, especially as we discussed the idea of bringing many state prostate cancer organizations together into a national umbrella organization of state prostate cancer entities and creating critical mass. We wanted to develop, mentor, and give visibility to state prostate groups across the United States. That idea became reality in September 2004 when we held the inaugural meeting of the National Alliance of State Prostate Cancer Coalitions in Los Angeles, with 24 states represented. That was how we started "The Alliance". Later Jan became the representative from New Mexico.

In just a few weeks NASPCC will be celebrating its 20th year! We now have 46 participating states and we have become the premier national prostate cancer non-profit organization, with unique programs and activities: an Annual Meeting; the bi-monthly PROSTATEPEDIA Magazine and weekly PROSTATEPEDIA DIGEST; and our 2-sided Laminates for Patients AND Physicians, serving as durable resources, along with outstanding Webinars. Along the way Jan and I traveled around the country to set up state prostate cancer coalitions, met up at meetings, visited each other, shared personal milestones and losses; and became close and special friends. We were bonded.

Many people don't know Jan's personal history and his background. Jan grew up as an only child in New York. He loved people, plain and simple. He helped so many people over the years, usually without any credit, starting years before I even met him. He had such a warm heart and was a loving colleague. Jan adored cats; treasured and was loyal to friends everywhere; and always went out of his way to assist people. Jan was also an incredible raconteur of stories - from his days at Northfield Mt. Hermon Prep School, to the University of Wisconsin (his Badgers), to his days in Wisconsin government; his devotion to the Green Bay Packers; to his time working for the U.S. Government in Washington, DC, some of which was for the Dept. of Energy with Hazel O'Leary; to his travel; to living in Pennsylvania and then in Albuquerque (Rio Rancho); to his work with cataloguing his father's paintings from the New Deal; and to his visits with friends around the U.S. He worked hard for the Prostate Cancer Association of New Mexico in educating and advising men. Jan and I shared and laughed about his stories over and over, and I knew the details of them all. I cherished our friendship.

I spoke to Jan and texted with him frequently. We would say "I love you" at the end of every conversation. Jan was so proud of NASPCC and what he helped create. I am so very thankful that last year at our 17th Annual Meeting we created the Jan Marfyak Leadership Award which he presented, and we will continue to honor him each year. We have lost a wonderful human being.

By Merel Nissenberg, President

NASPCC WEBINAR SERIES

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NOVEMBER 28, 2023

SEXUAL SIDE EFFECTS: PROSTATE CANER

www.naspcc.org



John P. Mulhall, MD, MSc, FECSM, FACS,
FRCSI
Memorial Sloan Kettering Cancer Center

Dr. Mulhall, a native of Dublin, Ireland, is a Board-Certified urologist and a microsurgeon and is the Director of the Male Sexual and Reproductive Medicine Program at Memorial Sloan Kettering in New York City. He is also an Adjunct Professor of Urology at Weill Cornell Medical College. His clinical research interests include predictors of post-prostatectomy erectile function recovery, pelvic radiation-associated ED, the development of novel instruments for evaluating sexual function, and the design and conduct of drug trials in sexual medicine.



NASPCC ANNUAL MEETING 2023



NASPCC held its 18th Annual Meeting at the Fairmont Hotel in Washington, DC from October 6-8, 2023. A superb faculty traveled to the Meeting to present on many topics in prostate cancer; they arrived from Memorial Sloan Kettering, Cornell, Dana Farber, Johns Hopkins, University of Pennsylvania, Duke, City of Hope, Case Western, and the University of Washington/Fred Hutch in Seattle. The Agenda included topics such as Prostate Cancer Genetics; Localized Disease; PSA Recurrent Disease; Advanced Prostate Cancer; Precision Medicine; Immuno-Oncology; Novel Therapies in Metastatic Prostate Cancer; and Personal Needs.

New this year was a PROSTATEPEDIA Panel reprising several interviews from the Magazine last year; a Panel with 3 Prostate Cancer survivors and two of their wives; and a Panel with Children of Prostate Cancer Patients. Bruce Smith, President of the Arizona Prostate Cancer Coalition, presented on their "Every Man Needs a Prostate Cancer Plan" for sharing with other states. Honorees for 2023 were Dr. Andrew Armstrong of Duke and Dr. Michael Morris of Memorial Sloan Kettering; other awards went to Renee Savickas with the James West Spirit Award and to Dr. Michael Zaragoza with the Jan Marfyak Leadership Award. A new Board of Directors was selected for 2 year terms. We are looking forward to next year's 19th Annual Meeting which will celebrate our banner 20th year!

For details about the 18th Annual Meeting, please see <https://www.naspcc.org/index.php/18th-annual-meeting>.



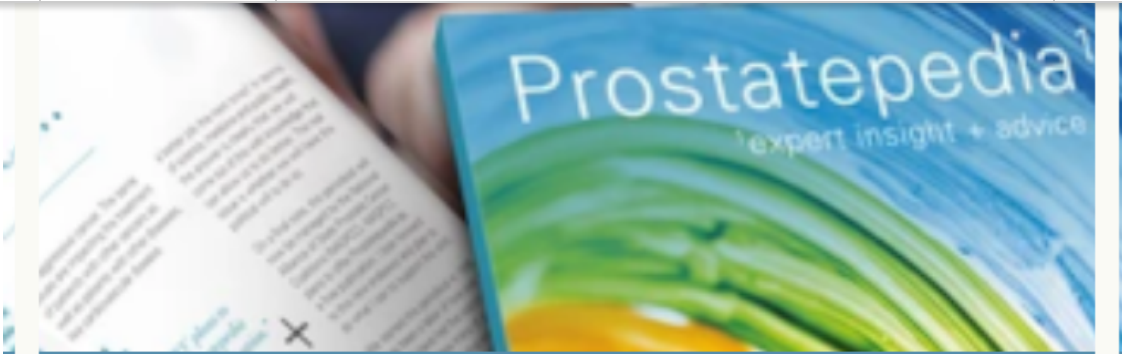
**NEW WEBSITE
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Stay tuned for NASPCC's new and improved website coming soon...

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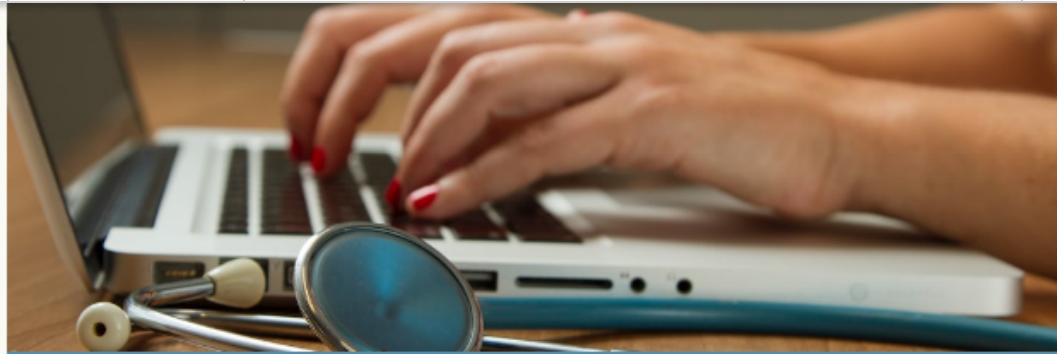
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Prostatepedia

Prostatepedia features informal conversations with doctors, patients, and activists about prostate cancer. Each month they tackle a different topic facing prostate cancer patients today—from how imaging has impacted treatment to dealing with erectile dysfunction after radiation or surgery to the evolving field of immunotherapy.

[Learn More](#)



NEW LAMINATED RESOURCES

NASPPC has published a series of free durable double-sided informative resources for patients and for physicians. Please feel free to read, download, print and share these PDFs. Informed Decision Making (PDF), Immunotherapy in Prostate Cancer (PDF), Imaging in Prostate Cancer (PDF) Prostate-Specific Antigen (PSA) and Prostate Cancer (PDF) Non-Metastatic Castrate-Resistant Prostate Cancer (nmCRPC) (PDF) Metastatic Castrate-Sensitive Prostate Cancer (mCSPC)

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Tips for Health During the Holiday Season



The holiday season is a wonderful time of year. However, it can also be a stressful time of year. There are various holiday traditions decorating holiday

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experiencing medical treatment, or the side effects related to medical treatment or experiencing their first Holiday without a loved one. As a result, at this time of year we often find ourselves in a sea of emotions. This time of year can drain our precious energy and impact our immune system either positively or negatively. Here are several tips to help manage the Holiday Season in a joyous, immune supportive, healthy manner:

- Be present in the moment – be mindful of the joys that surround you every day and give yourself permission to feel your own emotions.
- It is okay to say NO to some of the requests that come your way. Remember to use this time to relax and focus on your own needs. Create boundaries to keep yourself from getting overwhelmed.
- If you feel lonely call a friend or family member to maintain that connection. Think of the things that make you feel good and do them.
- Remember you don't have to celebrate or socialize at all if you are not feeling up to it.
- Eat well, get enough sleep, and go for a walk. Physical activity improves our mood.
- Reach out for support if you are struggling during the season. Reach out to community resources such as, hotlines, caregivers, religious or social organizations and support groups.
- And, most of all TAKE CARE of YOU!!!

SPOTLIGHT

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Ulysses Wright

Long time friend and NASPCC state leader of Kansas, has been elected to the Board at WaterOne in Johnson County, Kansas. He is the first person of color to be elected. Ulysses was elected to serve on a seven (7) member governing board for WaterOne, an independent public utility. WaterOne has been proudly serving the Johnson County, Kansas area since 1957. Every day, 480,000 customers rely on WaterOne to provide fresh, clean water on demand. Congratulations, Ulysses!

NASPCC Brochure



**Reaching Thousands
of Prostate Cancer Patients
and their Families
Across the U.S. Since 2004**



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