



National Alliance of State Prostate Cancer Coalitions

2018 ANNUAL REPORT



NASPCC Board of Directors, 14th Annual Meeting, "The More We Know...", October 2018, Washington, DC

Seated left to right: Don Lynam, Jan Marfyak, Merel Nissenberg, Johnny Payne and LaTanya Patton
Standing from left to right: Sanford Jeames, Renee Savickas, Dave Hulbert, Paul Kradel, Mary Anderson, Harold Pharoah, Judy Green, Ira Baxter, and Jim West

Not pictured: Michael Zaragoza, MD, Otto Sankey, Patricia Green, Alvin Chin, and Robert Johnson

NASPCC PRESIDENT'S MESSAGE:

"THE MORE WE KNOW..."

Welcome to the 2018 Annual Report for the National Alliance of State Prostate Cancer Coalitions! As we progress and achieve more and more of our goals, some of which are reflected in the new Strategic Plan we adopted in 2017, we realize that "the more we know", the more we discover that there is to know! This realization broadens our Mission, helps guide us, and allows us to focus on what we want to accomplish for men and their families.

We want to thank all of those selfless men and women who have given time and contributed their efforts to the cause of NASPCC, such as early state representatives Phil Olsen of Hawaii, Mary Anderson of North Carolina, and Gabe Rosko of New Jersey. Some of the first state prostate cancer coalitions to participate have changed leadership but not involvement in our cause. We again also thank Tiffany Razzo who continues to serve as staff for our Annual Meeting. A look at our current brochure shows just how many states have participated in NASPCC since we formed in 2004. We also have new states who joined us this past year, including Nebraska and Arizona. NASPCC is growing and serving prostate cancer patients and their families; and we also continue to espouse the early detection of potentially lethal prostate cancer, the types that do require early detection and early treatment choices.

New activities in 2018 included 3 Webinars, which were also recorded and stored on our NASPCC Website, along with National Conference Calls on important topics such as Best Practices and the use of Social Media for State Prostate Cancer Coalitions. Our Newsletter, The Blue Print, has been a success and is also stored on our Website. NASPCC was asked to participate in the 1st Annual Advocacy Summit held by the American Urological Association (AUA) in March 2018, and we also added value to NASPCC by attending important national meetings such as ASCO GU, AUA and the 2018 ASCO Annual Meetings. NASPCC was honored to be asked to co-sponsor the Online Prostate Cancer Support Group put on by CancerCare in New York, and two such online series took place this past year. Following our outstanding 14th Annual Meeting in Washington, D.C. October 12-14, 2018, the report from which is on the NASPCC website, NASPCC held an Invitational Roundtable on Step Therapy for medication and drug access. We contributed 4 articles to Prostatepedia for the year and, as NASPCC President I represented NASPCC as a national patient advocate for the Early Detection Research Network of the National Cancer Institute and as the Advocate for the Canary/PASS Trial out of Stanford. I also participated in the UCLA Prostate Cancer SPORE. It was a busy but a fulfilling year for our organization.

We look forward to achieving even more in 2019! Please calendar our Gala 15th Annual Meeting which will take place October 11-13, 2019 in Washington, D.C. and we suggest that you visit www.naspcc.org for more details about us and to access some of the resources that are currently in place on our website. If you have any questions about our 2018 Annual Report, please contact our Steering Committee Chair, Tom Kirk, or me.

Sincerely, MEREL GREY NISSENBERG, ESQ., President

Our 2017-2018 Revised Mission Statement

“NASPCC is a nation-wide organization 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.”

Approved at July 2017 Board Meeting

2017-2018 ACTIVITIES/ACCOMPLISHMENTS:

Together, we...

- Moved forward with the 2017 NASPCC Strategic Plan which identified 15 key Issues and was approved by the NASPCC Board in July 2017
- Created eight new Advisory Committees in November 2017 to move forward the Strategic Plan’s Workplan for FY 2017-2018 and FY 2018-2019:
 - Education and Awareness (Chaired by Johnny Payne, Co-chair Patricia Green & Chaired by Sanford Jeames in 2019), 2) Communications (Chaired by LaTanya Patton, Co-Chair Ed Haddad & Chaired by Renee Savickas in 2019), 3) Budget (Chaired by Don Lynam), 4) Advocacy & Public Policy (also Chaired by Don Lynam), 5) State Coalition Development (Chaired by Ira Baxter with Rob Johnson), 6) Annual Meeting (Chaired by Merel Nissenberg), 7) Fundraising (also Chaired by Merel Nissenberg) and 8) Medical Advisory (Chaired by Dr. Micheal Zaragoza)
- Conducted an outstanding and well-attended **14th Annual Meeting: “The More We Know...” held in Washington, DC on October 12-14, 2018** which featured Presentations and Panels on *“The Importance of Hereditary Cancer Testing in Prostate Cancer”*, *“Genomic Testing: When and Why”*, *“Active Surveillance: Current Trends and Thoughts”*, and *“Advanced Prostate Cancer: Anti-Androgens and Chemotherapy”*, all before lunch.

Other sessions included a lunch presentation on *“PSMA and the Automated Bone-Scan Index (ABSI) as a Prognostic Biomarker”* and, following lunch a Special Lecture was given by NIH’s James Gulley, MD, PhD entitled *“2018 Update on Immunotherapy in Prostate Cancer”*.

There was also a Panel on *“Radiation Therapy, Focal Targeted Therapy and Imaging”*, a Presentation on *“PET Imaging for Prostate Cancer Management: Present and Future”*, and Presentations on *“Clinical Trial Highlights in Prostate Cancer from 2018”* as well as *“Advanced Prostate Cancer: Bone Issues and Metastases”*.

At our Cocktail Reception, attendees participated in a presentation to honored Guest Alan Partin, MD, PhD, Chair of the Brady Urological Institute at Johns Hopkins Medical Institutions, for Major Contributions in the field of Prostate Cancer.



Other Awards presented were Outstanding State Prostate Cancer Organization for 2018 to the Arkansas Prostate Cancer Foundation, and Most Spirited Advocate to Jim West of Florida.



The assembled Reception attendees and guests heard from patients as well, such as Ira Baxter of Tennessee, Gabe Rosko of New Jersey and Dave Hulbert of Minnesota, all of whom talked about their prostate cancer journeys and how they are strong and active advocates for others. They were truly inspiring.

Additionally, on Sunday, “*The Congressionally Directed Medical Research Program (CDMRP) Update*” from Mark Vieth, from the Defense Health Research Consortium (DHRC) was heard this year and the next Panel sessions on “*Emotional and Cognitive Impairment Issues in Prostate Cancer*” and “*What is Step Therapy and How Does it Affect Access to Treatment?*,” “*Best Practices*” and “*Committee Reports from Chairs*” brought the meeting to the last review and discussion session before the meeting adjourned.

More information can be found on our NASPCC website about the 14th Annual Meeting at <https://naspcc.org/attachments/article/43/NASPCC-Rept14AnnMeet-rev2.pdf> and plans are in place for the 15th Annual Meeting; NASPCC’s Anniversary celebration.

In 2018, NASPCC also:

- Planned and conducted a “Special Invitational Bone Health Access Roundtable”, as part of our Bone Health Access Initiative, which was held October 14th in Washington, DC with NASPCC Executive Members, Prostate Cancer Advocates, Breast Cancer Advocates, Researchers, and Advocates from the Arthritis Foundation, the Lung Cancer Alliance and the Cancer Support Community. NASPCC took a position to move forward Step Therapy Issues through its Advocacy and Public Policy Committee.
<https://www.naspcc.org/index.php/bone-health-access-roundtable>
- Developed and launched the first Quarterly Electronic Newsletter, “*The Blue Print*” in January 2018 and added four others during the year (April, July, September and November). <https://www.naspcc.org/attachments/article/41/NASPCCNewsINov18.pdf>
- Developed and authored for publication in the “Prostatepedia Magazine” articles titled “Hypofractionated Radiotherapy”, “Genetics Testing and Counseling”, “Proceedings from the 13th Annual Meeting of NASPCC”, and “Non-Metastatic Castrate Resistant Prostate Cancer”. <https://www.naspcc.org/index.php/recent-articles-from-naspcc-president-appear-in-national-journal>
- Launched the first in a series of Quarterly Webinars with Presenter Ashley Ross, MD, PhD in January 2018 entitled “Tissue Based Biomarkers for Localized Prostate Cancer” followed by Ryan Dittamore and Deb Davison on “AR-V7 Splice Variant and Treatment Choices in Prostate Cancer”, and Leonard Gomella, MD on “Genetic Testing and Genetic Counseling in Prostate Cancer” in April and May. See <https://naspcc.org/index.php/resources/webinar-archives>
- Began the review and reformatting of NASPCC literature, manuals and resources.
- Updated the NASPCC Webpage and frequently posted on the NASPCC Facebook Page with medical and scientific news and information, to increase social media participation as well as provide resources for patients and their family members.
- Attended high-profile Professional Research and Clinical Meetings such as the ASCO-GU Symposium, AUA meetings, and the ASCO Annual Meeting, etc. to share latest breaking information with patients and Alliance participants. As an example, see <https://tinyurl.com/yayvcubo> and <https://www.naspcc.org/attachments/article/43/REPORT-FROM-ASCO2018.pdf>
- Participated as an Invited Panel Presenter on Informed Decision Making in the 1st AUA Advocacy Summit in Washington, DC in March 2018
- Sought collaboration with several State Coalitions to develop joint Education Conference events.
- Jointed the Defense Health Research Consortium (DHRC), as well as continued work with One Voice Against Cancer (OVAC), and actively engaged in their advocacy

- efforts during 2018.
- Began the formation of a Gala and Education Conference for the 15th Year Anniversary event in 2019.
- Conducted a new 15-week *Online Prostate Cancer Support Group* in partnership with CancerCare and started a second Fall session. <https://www.naspcc.org/index.php/prostate-cancer-patient-support-group>
- Developed and shared a Response to the USPSTF on their Final Recommendations on Prostate Cancer Screening in May 2018. <https://www.naspcc.org/index.php/letter-from-naspcc-to-the-united-states-preventive-services-task-force>
- Identified and began development of several new State Prostate Cancer Coalitions.
- Began development of a new Advanced Disease Laminated tool to assist men living with Advanced Prostate Cancer.
- Showed continued participation by President Merel Nissenberg as the Advocate for the Canary/PASS Trial in Active Surveillance at Stanford University.
- Showed continued participation by President Merel Nissenberg in the Early Detection Research Network (EDRN) of the National Cancer Institute (NCI), as a National Patient Advocate across Cancers including Prostate Cancer.

PLANNED PROGRAM PRIORITIES FOR 2019

1. Webinars: *Quarterly sessions which will be recorded and archived on our Website*
2. Dedicated Website Pages: *New Tabs on NASPCC Website, companion materials & Facebook reminders*
3. National Conference Calls: *Up to 75 participants, presented by Sponsor*
4. Clinical Trial Finder: *Credit for new Sponsoring Trial Finder Page*
5. Patient Surveys: *Work with State Organizations to conduct surveys*
6. NASPCC/State Prostate Cancer Symposium: *Sponsor State Education Sessions*
7. "Awareness, Education & Testing" Events: *Continue to develop such sessions in States*
8. Laminated Resource Tool: *Develop a how-to for States to implement use of the Laminated*
9. Pamphlets and Educational Materials: *New materials are being planned*
10. State Advocacy Action Network Development: *Preparation for in-place action*
11. National Quarterly Electronic Newsletter: *Highlighting State Coalition Activities*
12. The 15th Annual Meeting in Washington, DC: *Committee in place, planning started*
13. Regional Meetings: *A microcosm of the Annual Meeting*
14. NASPCC 2019 Anniversary Gala Planning *Education and Celebration*
15. Website Maintenance and Design: *Anticipated re-design of the active Website*

OUR 2018-2019 BOARD OF DIRECTORS

Executive Committee Members:

- Merel Grey Nissenberg, Esq., California, President and Chair of Fundraising Committee and Annual Meeting Committee
- Johnny Payne, South Carolina, Vice President
- Donald Lynam, Kentucky, Treasurer and Chair of Advocacy & Public Policy Committee and Budget Committee
- Jan Marfyak, New Mexico, Secretary
- LaTanya Patton, Missouri, Director-at-Large
- Thomas Kirk, California, Invited Member of Executive Committee



2018-2019 Executive Committee Members Assembled
During the 14th Annual Meeting October 2018, Not present, Jan Marfyak

BOARD MEMBERS:

- Mary Anderson, North Carolina
- Ira Baxter, Tennessee, Chair of State Coalition Development Committee
- Alvin Chin, Virginia
- Judy Green, Massachusetts
- Dave Hulbert, Minnesota
- Sanford Jeames, Texas, Chair of Education & Awareness Committee
- Paul Kradel, West Virginia
- Harold Pharoah, Nebraska
- Gabe Rosko, New Jersey (Elected in 2019)
- Otto Sankey, Arizona
- Renee Savickas, Colorado, Chair of Communications Committee
- Jim West, Florida
- Michael Zaragoza, MD, Delaware, Chair of Medical Advisory Committee

OUR 2018 SPONSORS

The NASPCC would like to thank the following partners for their support



NASPCC MEDICAL ADVISORY BOARD

As always, our esteemed Medical Advisory Board continued to participate and add strength and substance to our activities. During 2018 we added Leonard Gomella, M.D. and Ashley Ross, M.D., Ph.D., to our Advisory Board.

Christopher J. Logothetis, M.D., *University of Texas MD Anderson Cancer Center*

William G. Nelson, M.D., Ph.D., *Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins*

Alan W. Partin, M.D., Ph.D., *James Buchanan Brady Urological Institute at Johns Hopkins*

Kenneth J. Pienta, M.D., *University of Michigan Comprehensive Cancer Center*

Mack Roach III, M.D., *University of California San Francisco Comprehensive Cancer Center*

Peter T. Scardino, M.D., *Memorial Sloan-Kettering Cancer Center*

Paul F. Schellhammer, M.D., *The Virginia Prostate Center, Eastern Virginia Medical School*

Ian M. Thompson, M.D., *University of Texas Health Science Center at San Antonio*

Ashley Ross, M.D., Ph.D., *Mary Crowley Cancer Research, Dallas, TX, US Oncology*

Leonard G. Gomella, M.D., *Kimmel Cancer Center, Jefferson Medical College*

PARTICIPATING STATES



HOW DOES NASPCC REACH PROSTATE CANCER PATIENTS AND THEIR FAMILIES?

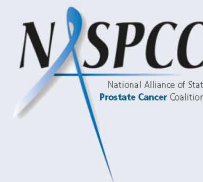
NASPCC supports the development of state prostate cancer organizations, each of which is comprised of patient networks and support groups. NASPCC through its Annual Meeting, webinars, and other activities shares prostate cancer information with all of its participating state prostate cancer organizations, and this educational material is then disseminated to patients and their families, demonstrating the breadth and depth of our reach. NASPCC also helps equip patients and their families to actively engage in the prostate cancer cause.

NASPCC ANNUAL MEETING

The Annual Meeting pulls together leaders in the rapidly developing field of prostate cancer—patients and families, researchers, practitioners, and people interested in the disease—who want to **share, learn and lead**. Industry helps support the Annual Meeting. The patient community is unique and the contemporary overview in the Take Home Messages from the Annual Meeting allows them to become empowered to do things locally. NASPCC creates support and a forum to enrich and rejuvenate these individuals and state organizations.



- We are a 501(c)(3) not-for-profit umbrella organization with an extensive national outreach through state prostate cancer organizations and individuals
- We advocate for Informed Decision-Making in prostate cancer, and we disseminate information relating to the disease, including a durable, laminated awareness and education tool for patients and primary care providers. www.prostatecalif.org/patient-guide
- We hold an Annual Meeting to enhance education and share best practices across the U.S.
- We conduct quarterly Webinars and moderate National Conference Calls
- We actively provide, through our participating organizations: support groups, educational forums, workshops, prostate cancer information, and awareness and educational activities
- We maintain a Website www.nasppcc.org and an active Facebook Page (“National Alliance of State Prostate Cancer Coalitions”)
- We advocate for the highest quality of life for prostate cancer patients and their families
- We maintain an in-depth Education and Best Practices Guide utilized by state organizations to ensure quality outreach
- We have an Advisory Board comprised of influential and respected physicians, scientists and researchers



NASPCC, 1999 Avenue of the Stars, Suite 1100
Los Angeles, California 90067
Toll Free 877-NASPCC-8 (877-627-7228)

E-mail: info@nasppcc.org

Website: www.nasppcc.org

January 2019

BECOMING INFORMED AND AWARE

More and more of us are learning more and more about cancer, but even with rapid changes in oncology, much remains unknown. Although prostate cancer is a common cancer, many people do not know about it. Some people are more at risk than others.

Every man should have a discussion with his doctor about prostate cancer risk and testing.

After that discussion, the decision to be tested is then up to the man based upon his own values and preferences. This is called INFORMED OR SHARED DECISION-MAKING. We have adopted a 2-sided useful tool on Informed Decision-Making to take to your doctor's office to help you with the discussion. Here is the link: www.prostatecalif.org/patient-guide

NASPCC recommends a baseline PSA and DRE beginning at 40 (at 35 if high risk, including African-American men or men with a certain or indeterminate family history of prostate cancer), and then periodically depending on those results. You should know and keep track of all your PSA measurements and ANY CHANGE IN PSA should be discussed with your doctor.

CONTACT NASPCC

- *Become a member of NASPCC*
- *Send a donation to NASPCC, a 501(c)(3) not-for-profit charitable organization*
- *Contact your state coalition*
- *Organize a state coalition*

WANT TO ESTABLISH A COALITION IN YOUR STATE?

**NASPCC has educational materials and skilled leaders
to help you establish a coalition.**

National Alliance of State Prostate Cancer Coalitions

1999 Avenue of the Stars, Suite 1100

Los Angeles, California 90067

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