



NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS

2017-2018 ANNUAL REPORT



NASPCC Board of Directors, 13th Annual Meeting, *"Share, Learn & Lead"*, October 2017, Washington, DC

Seated left to right: Jan Marfyak, Johnny Payne, Merel Nissenberg, Don Lyman, and LaTanya Patton
Standing from left to right: Alvin Chin, Paul Kradel, Mary Anderson, Dave Hulbert, Ira Baxter, Michael Zaragoza, MD and Robert Johnson, not pictured: Patricia Green and Sanford Jeames

NASPCC PRESIDENT'S MESSAGE:

“A NEW VISION AS WE MOVE FORWARD”

Welcome to the 1st Annual Report for the National Alliance of State Prostate Cancer Coalitions! We are pleased to reflect on our past, how we started as an umbrella organization of 20+ state prostate cancer coalitions in 2004 to create a way to network, share best practices and benefit patient and families. And now – next year we will be 15!

We thank so many people who have helped us along the way, such as Lew Musgrove of Nevada, who started with us in the California Prostate Cancer Coalition; the late General Mike Rice of Michigan who helped guide us early on; former NASPCC Vice President Michael Siler of Utah who played a strong role in our advocacy training for patients; Johnny Payne of South Carolina, who was elected Vice President last year and has enthusiastically undertaken several important Committee assignments; and Jan Marfyak of New Mexico (formerly of Pennsylvania) who co-authored our idea to form NASPCC and joined me as we set up new state prostate cancer coalitions around the country. I also want to thank Tiffany Razzo, the Secretary of the California Prostate Cancer Coalition, who joined NASPCC as staff for our 13th Annual Meeting last October on Capitol Hill and is running our new quarterly Webinars. She has agreed to serve as staff again for the next Annual Meeting October 12-14, 2018 on Capitol Hill again. **Of course, this is a TEAM EFFORT.** Over our last 14 years we have always been part of a bigger, unified and focused whole. I thank each and every one of you.

BUT this is no longer business as usual. WE ARE A NEW ORGANIZATION, eyeing the future with a NEW VISION, A NEW DIRECTION. On the following pages of this Annual Report you will read about the NEW Strategic Plan that NASPCC created and approved last July, with our NEW Mission Statement and Amendments to our By-Laws; a NEW Committee Structure of Standing and Advisory Committees; a NEW Brochure; a NEW Newsletter; a NEW Webinar Series; a NEW version of our Informed Decision-Making Laminate; an updated Website and prolific Facebook Page with breaking medical and scientific news; and NEW State Prostate Cancer Coalitions on the way. These are just some of the exciting changes for NASPCC as we move forward.

I am proud to have served NASPCC as President since we started in 2004. We on the NASPCC Executive Committee and the Board of Directors take our stewardship responsibilities very seriously. All of us in NASPCC want to improve the lives of prostate cancer patients and their families across the U.S. and empower them to be better health care consumers. We also aim for the earlier detection of potentially lethal disease and for using informed decision-making in the process. Stay tuned for our NEW Advanced Prostate Cancer Laminate and other new projects this year.

And get ready for our upcoming 14th Annual Meeting which we will again hold on Capitol Hill in Washington, D.C. October 12-14, 2018. --- MEREL GREY NISSENBERG, ESQ.

NEW 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 July 2017 Board Meeting

2017-2018 ACTIVITIES/ACCOMPLISHMENTS:

Together, we...

- Conducted two 2017 Strategic Planning Workshops (one in April and the second in May) which resulted in a new NASPCC Workplan that was adopted at the July Board of Directors meeting. The Workplan contained 3 recommendations: 1) Adopt a new revised Mission Statement, 2) Take action on a list of 15 Identified Issues and 3) Keep a close eye on and closely manage the NASPCC Budget.
- Amended our By-Laws to include a *“Confidentiality and Conflict of Interest Policy Disclosure Form”* and a *“Statement of Values and Code of Ethics Policy”*, which were added at the July Board Meeting.



Executive Committee members Don Lynam, Johnny Payne, Jan Marfyak, Merel Grey Nissenberg, LaTanya Patton with Tom Kirk at the May 19, 2017 Planning Workshop

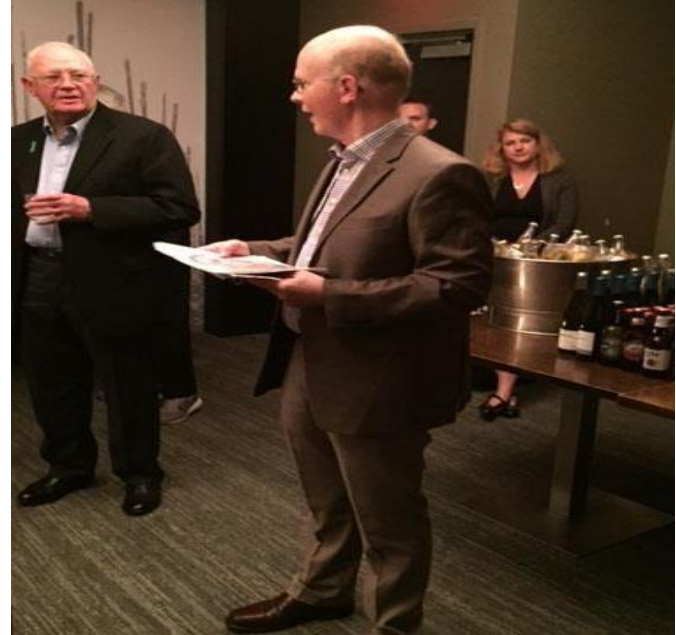
- Conducted an outstanding and well-attended **13th Annual Meeting: “SHARE, LEARN & LEAD” held in Washington, DC on October 13-15, 2017** which featured Panel Presentations on “Advanced Prostate Cancer”, “Genomics and Genomic Testing”, “Meet the States” (which showed Coalitions’ activities) and “New Products and Advances Benefiting Prostate Cancer Patients”, as well as a Special Lecture by NIH’s James Gulley, MD, PhD on “Immunotherapy in Prostate Cancer”.

Other sessions included a lunch presentation by NASPCC Board Member Michael Zaragoza, MD on “The Current Proposed USPSTF Guidelines for PSA Testing”. Attendees also heard a presentation on “Important Advances in the Diagnosis and Treatment of Prostate Cancer” by Ashley Ross, MD, PhD and “The Need for Action on the Congressional Directed Medical Research Program (CDMRP)” from Mark Vieth, from the Defense Health Research Consortium (DHRC).

Following a presentation on “The New NASPCC Workplan” by Tom Kirk, the group heard Andrew Chesler of CancerCare speak on “Emotional Issues in Prostate Cancer: Patients and Caregivers”.



Long-time Advocate Paul Sanders, representing the Washington State Prostate Cancer Coalition at the 13th Annual Meeting “Share, Learn & Lead”, offers an opinion and suggestions to other participants.



Survivors and NASPCC Board Members Rob Johnson (Wyoming) presents *“Why We Are Here”*, and Dave Hulbert (Minnesota) presents on his journey as an Advanced Prostate Cancer patient, during the October 2017 13th Annual Meeting Reception and Awards Event, as Board Member/Treasurer Don Lyman and Board Member Alvin Chin look on with guests.

- Updated the PROSTATE CANCER: *“Informed Decision-Making Laminated Tool”* designed to facilitate discussion between Primary Care Physicians and Patients, in September 2017; this is an awareness and education tool developed in collaboration with the California Prostate Cancer Coalition and featured as a perforated tear-out in PCRI’s June 2017 Newsletter.
- Produced a New, Updated NASPCC Brochure in October 2017 which outlines the Organization and lists its Executive Committee and Board Members; urges people to *“Become Informed and Aware”* (and explains the NASPCC recommendations on testing); presents information on Early and Advanced Disease as well as Treatment Approaches; lists the Participating States; explains how NASPCC reaches Prostate Cancer patients and their families; and describes the Annual Meeting.
- Re-structured NASPCC and appointed members to 8 new NASPCC Advisory Committees in November to better assure the Strategic Plan’s success (Education & Awareness, Communications, Budget, State Coalition Development, Advocacy & Public Policy, Annual Meeting, Fundraising, and Medical Advisory).
- Developed and launched the first Quarterly Electronic Newsletter, *“The Blue Print”* in January 2018.
- Launched the first in a series of Quarterly Webinars with Presenter Ashley Ross, MD, PhD in January 2018.
- 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. <https://tinyurl.com/yayvcubo>
- Sought collaboration with several State Coalitions to develop joint Education Conference events.
- Joined 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 2017-2018.
- Identified and began development of several targeted new State Coalitions.
- Began development of a new Advanced Disease Laminate tool to assist men living with Advanced Prostate Cancer.
- Began the formation of a Gala and Education Conference for the 2019 15th Year Anniversary event in 2019.
- Began planning a new *Online Prostate Cancer Support Group* in Partnership with CancerCare.
- Began writing featured quarterly articles for the Magazine *Prostatepedia*.

PLANNED PROGRAM PRIORITIES FOR 2018

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. 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 Laminate*
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 14th 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 in 2018: *Education and Celebration*
15. Website Maintenance and Design: *Anticipated re-design of the active Website*

OUR 2018 BOARD OF DIRECTORS

OFFICERS/Executive Committee Members:

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



2017-2018 Executive Committee Members Assembled During the 13th Annual Meeting October 2017

BOARD MEMBERS:

- Mary Anderson, North Carolina
- Ira Baxter, Tennessee
- Alvin Chin, Virginia
- Patricia Green, Washington, DC
- Dave Hulbert, Minnesota
- Sanford Jeames, Texas
- Robert Johnson, Wyoming, Chair of State Coalition Development Committee
- Paul Kradel, West Virginia
- Michael Zaragoza, MD, Delaware, Chair of Medical Advisory Committee

OUR 2017-2018 SPONSORS

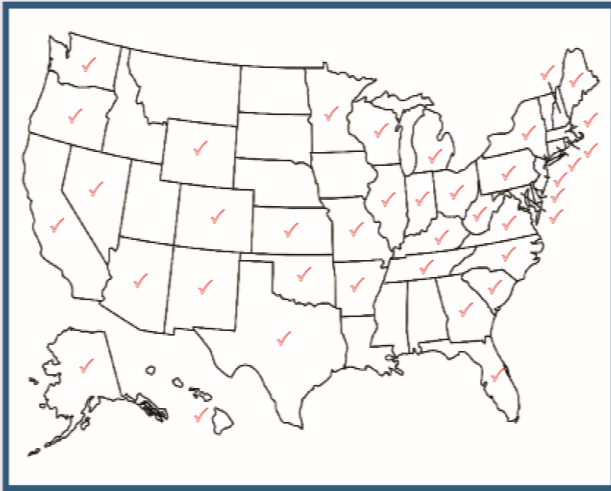
The NASPCC would like to thank the following partners for their support



NASPCC MEDICAL ADVISORY BOARD

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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.

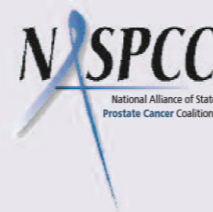
NASPCC ANNUAL MEETING

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.



NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS

- 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.naspcc.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



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Website: www.naspcc.org

October 2017

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

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