



National Alliance of State Prostate Cancer Coalitions
13th Annual Meeting Report
October 13, 2017 – October 15, 2017
The Liaison Capitol Hill, Washington, D.C.



“SHARE, LEARN AND LEAD”

The 13th Annual Meeting of the National Alliance of State Prostate Cancer Coalitions was held in Washington, D.C. on Capitol Hill from October 13 through noon on October 15, 2017. As always, state prostate cancer organizations, including state coalitions, associations, foundations and consortia, were represented by at least one leader; and invited guests also attended. Sponsors of the Annual Meeting sent representatives to participate or to network and to share information; they were also invited to bring their materials for the tables. There were over 15 Sponsors who helped support the 13th Annual Meeting.

NASPCC held its 4th Quarterly Board Meeting the day before, on October 13, at the hotel location.

The new Workplan for NASPCC that was adopted by the full Board of Directors in July 2017 was discussed and our 3 Progress Reports on implementation were presented for consideration. Committee Reports were made and new state representatives were approved for attendance. The Fiscal Year 2018 Budget was adopted by the Board as well. Non-Board Members were invited to attend and observe the Board Meeting. An informal Meet & Greet took place later in the evening.

After a breakfast early on Saturday morning, October 14, the 13th Annual Meeting began in earnest. Every state prostate cancer organization received a Blue Packet with materials including the new NASPCC Brochure; the Informed Decision-Making Laminate co-branded with NASPCC’s logo; a Welcome Letter; a Thank You Letter to the Sponsors; Sponsor Logo sheets; Important Dates for 2017-2018; and various other papers of importance to the attendees. Sponsors received a red packet with different materials, but which included the new NASPCC Brochure and the co-branded Informed Decision-Making Laminate.

Panel Number 1 addressed **“Advanced Prostate Cancer”**. The group heard about new treatments for advanced prostate cancer, and about clinical trials that were or might be appropriate. After detailed Q & A, a second group was empaneled on the subject of **“Genomics and Genomic Testing” (Panel 2)**. The discussion and presentations included information on many of the markers being used in prostate cancer, and attendees received written materials on these tests.

In the late morning the attendees were privileged to hear a talk by James Gulley, M.D., Ph.D., Lead Prostate Cancer Researcher at Building 10 of NIH, who talked about **“Immunotherapy in Prostate Cancer”**. It was a fascinating look into new types of therapy, including the use of T-Cells. Dr. Gulley has already agreed to speak for us next year at the 14th Annual Meeting and to give us an update on what will have transpired in immunotherapy between now and then.



James Gulley, M.D., Ph.D. (NIH) and Tom Kirk

Panel 3 dealt with widespread and mission-oriented activities of state prostate cancer coalitions, five in particular (Georgia, Arkansas (P CA Foundation), New Mexico, South Carolina and California) in **“Meet the States”**, which was moderated by Tom Kirk, (former President and CEO of Us TOO International) who is now an invited member of the Executive Committee of NASPCC and Vice President of the California Prostate Cancer Coalition. The five state representatives talked about the widespread awareness and education programs and activities in their states, and expressed a willingness to help other states that need ideas on how to implement the goals of their respective Mission Statements.

Lunch included attendees, guests and sponsors; and Dr. Michael Zaragoza, President of the Delaware Prostate Cancer Coalition, presented on **“The Current Proposed USPSTF Guidelines for PSA Testing”**. When we re-convened in the Meeting Room, the full group heard from Ashley Ross, M.D., Ph.D., a Urologist/Oncologist from Dallas (formerly of Johns Hopkins), for whom this was a 5th speaking engagement for NASPCC’s Annual Meetings. His topic was **“Important Advances in the Diagnosis and Treatment of Prostate Cancer”** and discussion included genomic testing, early and advanced prostate cancer, and 2017 results of clinical trials. As always, Dr. Ross then handled a lively Q & A session on his talk.

Next, the Annual Meeting attendees heard from a Congressional Advocate in Healthcare, Mark D. Vieth, who is also the Coordinator for the Defense Health Research Consortium (DHRC), and who spoke about the urgent need to keep the **Congressional Directed Medical Research Program (“CDMRP”)** in place, as it has been in danger of being eliminated. (NASPCC has been a signatory of the letter asking that the CDMRP remain in place, and in fact joined the DHRC by vote after the Annual Meeting.)

Following a short break, **Panel 4** took place, entitled **“New Products and Advances Benefiting Patients with Prostate Cancer”**. There were fascinating presentations including one on the Cyber Knife and one on the Hydrogel Spacer for men undergoing radiation therapy for prostate cancer. Another company talked about free genetic testing it is offering at various centers in the U.S.

Elections were then held and a new Board of Directors empaneled. The 2017-2018 Officers are Merel Nissenberg, California, President; Johnny Payne, South Carolina, Vice-President; Donald Lynam, Kentucky, Treasurer; and Jan Marfyak, New Mexico, Secretary. LaTanya Patton, Missouri, was chosen again as Director-at-Large. These 5 Officers comprise the Executive Committee (along with Tom Kirk as Invited Member). The group was reminded that the Executive Committee meets monthly and the Board meets quarterly, all by conference call except for the in-person 4th Quarter Board Meeting held the day before each Annual Meeting.



The **2017-2018 Board of Directors** are the four Officers named above, along with Robert Johnson (Wyoming); Alvin Chin (Virginia); Paul Kradel (West Virginia); Mary Anderson (North Carolina); Dave Hulbert (Minnesota); Ira Baxter (Tennessee); Michael Zaragoza, M.D. (Delaware); Sanford Jeames (Texas); and LaTanya Patton (Missouri).

Saturday evening was a stellar occasion. NASPCC held a Cocktail and Awards Reception, at which two prostate cancer survivors spoke movingly about their experience. First, Robert Johnson of Wyoming spoke on “Why We Are Here”, and then Dave Hulbert of Minnesota described his journey as an advanced prostate cancer patient. Then two Awards were presented for the first time. The Georgia Prostate Cancer Coalition won a crystal award for the Most Outstanding State Prostate Cancer Coalition of 2017, and Kathy Meade of Virginia received a first-ever crystal Service Award from NASPCC. Guests included the Chief Counsel for Senator Roy Blunt (Missouri) and the Executive Director of the Vietnam Veterans of America. Wonderful drinks and food provided sustenance after a great day. Merel Nissenberg received a surprise crystal Award of Appreciation.



Robert Johnson (Wyoming) and Dave Hulbert (Minnesota) Sharing Their Stories



Frank Catroneo (Georgia) Receiving Award; Desiree Mowry, Senator Blunt's (Missouri) Chief Counsel

Sunday morning, October 15, 2017, after breakfast the attendees heard a detailed presentation by Tom Kirk on **The New Workplan** that had been adopted by the full Board on July 18, 2017. Tom Kirk also discussed the status of many of the activities envisioned by the Workplan and by the new Mission Statement that was also adopted at that same Board Meeting.

We then heard from Andrew Chesler of CancerCare in New York on **“Emotional Issues in Prostate Cancer: Patients and Caregivers”**. Andrew is the Men’s Cancer Program Coordinator at their New York office. His talk focused on a number of emotional and physical issues facing prostate cancer patients and caregivers, and was very helpful to the group in addressing a topic that often is overlooked at prostate cancer meetings.

The last major section of the 13th Annual Meeting was an **“Open Forum”**, during which various topics were discussed including Participating State Prostate Cancer Organizations; Co-Branding issues; Better Communications; State Coalition Survey Discussion; and Goals; and all Board Members signed the Conflict of Interest Statement. This was led by Merel Nissenberg, President. Following the wonderful give-and-take, general housekeeping items were handled including calendaring of all Meetings and Calls for 2017-2018. A thank you to Tiffany Razzo who served as Staff for the 13th Annual Meeting was also given to her.

“It was a great meeting!! Super informative. Thanks.”... “Thank you for hosting this fantastic conference. The presentations were fabulous. Keep up the good work!”... “Excellent program”

Next year’s 2018 14th Annual Meeting will take place October 12-14, 2018; and we are already beginning the Planning Preparations for our 15-year Anniversary Gala in October of 2019!

