



**National Alliance of State Prostate Cancer Coalitions  
14th Annual Meeting Report  
October 12, 2018 – October 14, 2018  
The Liaison Capitol Hill, Washington, D.C.**



**“THE MORE WE KNOW...”**

The 14<sup>th</sup> Annual Meeting of the National Alliance of State Prostate Cancer Coalitions was held in Washington, D.C. on Capitol Hill from October 12 through noon on October 14, 2018. As always, state prostate cancer organizations, including state coalitions, associations, foundations and other organizational entities, were represented by at least one leader, sometimes two; and invited guests also attended. Sponsors of the Annual Meeting sent representatives to participate or speak, network and share information; they were also invited to bring their materials for the tables. There were over 14 Sponsors who helped support the 14<sup>th</sup> Annual Meeting.



The Event Sponsors, NASPCC President Merel Nissenberg, Don Lynam, Treasurer and Jan Marfyak, Board Secretary; all are ready for an exciting 14<sup>th</sup> Annual Meeting!



President Merel Nissenberg and Vice President Johnny Payne and the Board Members are ready and excited too

NASPCC held its 4<sup>th</sup> Quarterly Board Meeting on Friday afternoon, October 12, at the hotel location before the formal Annual Meeting began. Several states sent new or temporary replacement representatives to this year’s Annual Meeting and several of those attendees were guests at the Q4 Board Meeting, including men and women from Delaware, Nebraska, New Hampshire, Florida, New York and Connecticut.

President Merel Nissenberg reviewed the Agenda for the 14<sup>th</sup> Annual Meeting and related many of NASPCC’s accomplishments from 2017-2018, including NASPCC’s representation at ASCO GU, ACO and AUA; her participation on behalf of NASPCC at the AUA 1<sup>st</sup> Annual Advocacy Summit in March; NASPCC’s presentation of several GoToWebinars which are now stored on the website; the production and distribution of 4 NASPCC Newsletters known as The Blueprint; and the creation and activities of 8 Advisory Committees under the stewardship of Tom Kirk, Chair of the Steering Committee.

Board members heard that together the Committees had held 32 Meetings and had been active in everything from near-daily Facebook posts of medical and scientific articles, to holding national conference calls on topics such as Best Practices and Social Media use for Coalitions, to work on an Advanced Prostate Cancer Laminar as a durable educational tool for patients across the country.

NASPCC was also honored to be asked to co-sponsor both 15-week sessions of the Online Prostate Cancer Support Group conducted by CancerCare in 2018. Merel Nissenberg also reported that at the conclusion of the Annual Meeting on Sunday afternoon, NASPCC would be holding a Bone Health Access Roundtable with a dinner to follow, covering Step Therapy as well as next steps to ensure patient access to appropriate treatment.

The Fiscal Year 2019 Budget was presented by Don Lynam, NASPCC Treasurer, discussed and adopted by the Board. Tom Kirk gave an overview of the 8 Advisory Committees, with a full report slated for the actual Annual Meeting. Discussion ensued about next year’s 15<sup>th</sup> Annual Meeting as it will be an Anniversary Year – 15 years for NASPCC!

After the Board Members signed their Conflict of Interest Disclosures, the Board Meeting was adjourned and Board Members and all Annual Meeting guests convened for a Reception at 6:30 p.m. in an adjoining Reception room at the hotel. Sponsors also attended this casual Reception, as well as Annual Meeting guests representing new states such as Arizona and Oklahoma who joined the rest of the 14<sup>th</sup> Annual Meeting attendees for this happy event.



Fellowship at the Saturday Morning October 13 Breakfast sets a great tone for all who attended from around the country.



NASPCC Board Members Mary Anderson, NC, LaTanya Patton, MO, Presenter Katherine Atkinson, Epic Sciences and Mike Crosby, OK, Veterans Prostate Cancer Awareness



Former NASPCC Board Member Robert Shekdar, CT, Current NASPCC Board Member Ira Baxter, TN, Presenter Shyam Natarajan, PhD, President, Avenda Health, Former NASPCC Board Member Jerry Bortman, PA, and Ted Hinderman, AZ



Peggy and Walt Dardenne, CA, NASPCC Secretary Jan Marfyak, NM, David Sauls, DE, NASPCC Vice-President Johnny Payne, SC, and NASPCC Treasurer, Don Lynam, KY (Above Left) and Presenter, William Berry, MD, Duke University with NASPCC President Merel Nissenberg (Above Right)

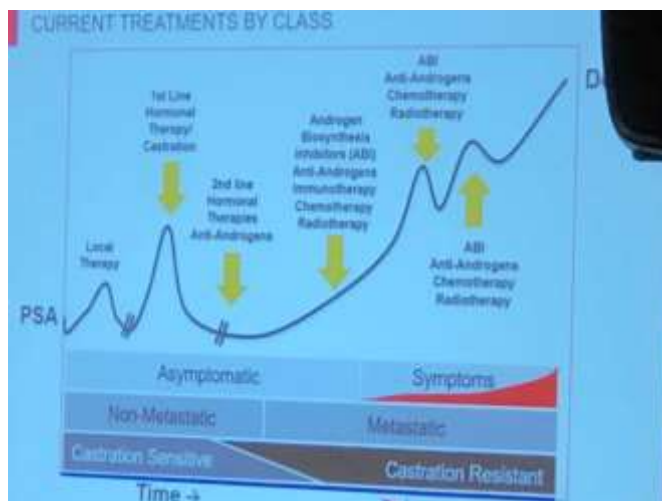
After a breakfast early on Saturday morning, October 13, the 14<sup>th</sup> Annual Meeting began in earnest. The proceedings of the 14<sup>th</sup> Annual Meeting began with a Welcome and Introduction by President Merel Nissenberg and a short discussion about Informed Decision-Making, one of the goals of NASPCC. The Informed Decision-Making Laminate that is co-branded by both NASPCC and the California Prostate Cancer Coalition (CPC) and is being distributed by NASPCC on a national basis has been updated to reflect the 2017 USPSTF Guidelines, and she discussed that tool as well as the work-in-progress of NASPCC's Advanced Prostate Cancer Laminate which is being created by Merel and Dave Hulbert of the Minnesota Prostate Cancer Coalition with the assistance of several medical and radiation oncologists.



Welcome and Introduction by President Merel Nissenberg Starts the Annual Meeting

**Scientific and Medical Discussions** began with a fascinating presentation by Robert Finch, a Certified Genetic Counselor at Myriad Genetics, on **“THE IMPORTANCE OF HEREDITARY CANCER TESTING IN PROSTATE CANCER”**, followed by **Panel Number 1** titled **“GENOMIC TESTING: WHEN AND WHY?”** with participation by Genomic Health, Myriad Genetics and Epic Sciences. The next topic addressed was **“ACTIVE SURVEILLANCE: CURRENT TRENDS AND THOUGHTS”** presented by Dr. Michael Gorin, Assistant Professor of Urology, Oncology & Radiology at Johns Hopkins University School of Medicine.

**Panel Number 2** was entitled **“ADVANCED PROSTATE CANCER: ANTI-ANDROGENS AND CHEMOTHERAPY”** and included presenters such as Nick Souders of Astellas/Pfizer and oncologist Jeanny B. Aragon-Ching, M.D., Associate Professor of Medicine, Virginia Commonwealth University and Clinical Program Director of GU Cancers at Inova Schar Cancer Institute. As always, the format of panels enabled much interaction between the attendees and the panelists and there were many questions and discussions with those on the program.



Adverse Effects of Androgen Deprivation Therapy		
What you feel	What you see	What you do not see
<ul style="list-style-type: none"> <li>• Loss of libido</li> <li>• Hot flashes</li> <li>• Fatigue</li> <li>• Lack of initiative</li> <li>• Aches and pains</li> <li>• Emotional lability</li> <li>• Cognitive changes</li> </ul>	<ul style="list-style-type: none"> <li>• Erectile dysfunction</li> <li>• Weight gain</li> <li>• Gynecomastia</li> <li>• Loss of muscle mass</li> <li>• Loss of strength</li> <li>• Decreased penis and testes size</li> <li>• Hair changes</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of bone density</li> <li>• Anemia</li> <li>• Lipid abnormalities</li> <li>• Exacerbation of: <ul style="list-style-type: none"> <li>• Hypertension</li> <li>• Diabetes</li> <li>• CV disease</li> </ul> </li> </ul>

At lunch the attendees were privileged to hear a talk on **“PSMA and THE AUTOMATED BONE-SCAN INDEX (“ABSI”) AS A PROGNOSTIC BIOMARKER”** by Karl Sjostrand, Ph.D. of Progenics Pharmaceuticals. PSMA Imaging is an up-and-coming tool for both diagnosis and prognosis, and is quickly being looked at for other purposes as well, including, potentially, treatment. The PowerPoint utilized by Dr. Sjostrand to explain and illustrate his talk was educational, fascinating, hopeful and inspiring.





Faculty Karl Sjostrand, PhD and President Merel Nissenberg with James Gulley, MD, PhD and Eugene Kwon, MD, PhD

Following lunch the attendees were privileged to once again hear from James Gulley, M.D., Ph.D., Lead Prostate Cancer Researcher in Building 10 of NIH, who presented the **“2018 UPDATE ON IMMUNOTHERAPY IN PROSTATE CANCER”**. It was a fascinating look into possible future success for immunotherapy in prostate cancer, which so far has rarely worked for a number of potential reasons. Dr. Gulley once again agreed to speak for us next year at the 15<sup>th</sup> Annual Meeting (our Gala Year) and to give us an update then on what will have transpired in immunotherapy over the next year.

**Panel 3** was entitled **“RADIATION THERAPY, FOCAL TARGETED THERAPY AND IMAGING”** and panelists were radiation oncologist Ronald Chen, M.D. of University of North Carolina, Shyam Natarajan, PhD for Targeted Therapy, and April Renzella for Radiation Therapy Tools (such as SpaceOAR).



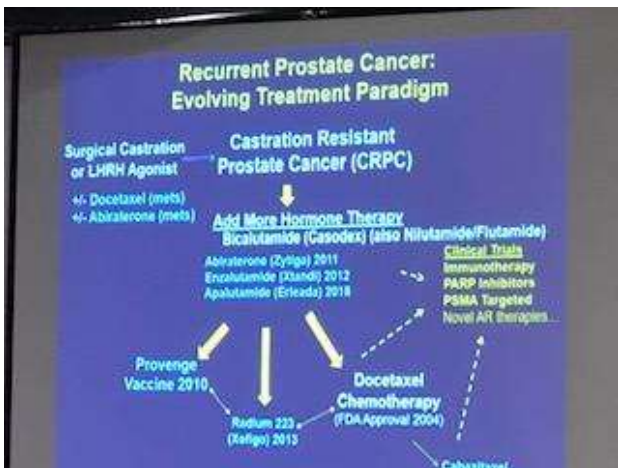
Ronald Chen, MD, Shyam Natarajan, PhD and April Renzella (not pictured) presented on Radiation Therapy, Focal Targeted Therapy and Imaging



Dave Hulbert of the Minnesota Prostate Cancer Coalition presenting Dr. Kwon with a “replica” of the Nobel Prize

Following that Panel, the attendees heard a single presentation from Eugene Kwon, M.D., Professor of Urology and Immunology at Mayo Clinic in Rochester, Minnesota, whose topic was **“PET IMAGING FOR PROSTATE CANCER MANAGEMENT: PRESENT AND FUTURE”**. The Annual Meeting attendees were thrilled not only with Dr. Kwon’s dynamic talk but by Dave Hulbert of the Minnesota Prostate Cancer Coalition presenting Dr. Kwon with a “replica” of the Nobel Prize for his pioneering work. Dr. Kwon has already indicated that he wants to speak at next year’s Annual Meeting as well.

Then **“CLINICAL TRIAL HIGHLIGHTS IN PROSTATE CANCER FROM 2018”** was addressed by William Berry, M.D. from Duke Cancer Center in North Carolina. So many new trial results were presented at the big Urology and Cancer Meetings in 2018, including the PROSPER, SPARTAN and other Clinical Trials, so Dr. Berry’s talk was timely and educational for the attendees. Dr. Berry was followed by Samuel Denmeade, M.D., Professor of Oncology and Urology at Johns Hopkins Medical Institutions, who presented on **“ADVANCED PROSTATE CANCER: BONE ISSUES AND METASTASES”**, an important topic for this Annual Meeting not only because of scarcely-mentioned bone involvement in cancer, such as osteoporosis, osteopenia and bone metastases; but because NASPCC was going to be putting on a Bone Health Access Roundtable the next afternoon on Sunday. As always, all the panelists and Presenters handled lively Q & A sessions after each panel and talk.



Elections were then held and a new Board of Directors chosen. The 2018-2019 Officers are Merel Nissenberg, California, President; Johnny Payne, South Carolina, Vice-President; Donald Lynam, Kentucky, Treasurer; and Jan Marfyak, New Mexico, Secretary. Continuing Board Members for the remaining year of their 2-year terms are: Mary Anderson of North Carolina, Ira Baxter of Tennessee, Alvin Chin of Virginia, Dave Hulbert of Minnesota, Sanford Jeames of Texas, Paul Kradel of West Virginia, LaTanya Patton of Missouri (who was chosen again as Director-at-Large), and Michael Zaragoza of Delaware. New Board Members elected for a 2-year term are: Judy Green of Massachusetts, Harold Pharoah of Nebraska, Otto Sankey of Arizona, Renee Savickas of Colorado, and Jim West of Florida. The 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 4<sup>th</sup> Quarter Board Meeting held the day before each Annual Meeting.





2018/2019 NASPCC Board of Directors and Executive Committee Members

That Saturday evening beginning at 6:30, NASPCC held a **COCKTAIL AND AWARDS RECEPTION** with food and drink and cheer, honoring **Alan Partin, M.D., Ph.D.**, Chair of the Brady Urological Institute at Johns Hopkins Medical Institutions, for Major Contributions in the field of Prostate Cancer. Dr. Partin gave a short acceptance speech detailing how he first was inspired by Dr. Don Coffey to try and unravel the puzzle of why certain prostate cancers are lethal and others are not clinically significant in term of mortality. NASPCC was thrilled to recognize such a leading light in prostate cancer – his Partin Tables alone have saved so many lives and guided treatment choices for so many.



Dr. Alan Partin, wife Vicky, President Merel Nissenberg and Tom Kirk



NASPCC 2018 Award recipient Alan W. Partin, MD, PhD

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



NASPCC Board Member, Ira Baxter, TN Prostate Cancer Coalition



Former NASPCC Board Members Gabe Rosko and wife Sheila share their Prostate Cancer Journey



NASPCC Board Members Dave Hulbert and his wife Doreen share their Prostate Cancer Experience



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



Beverly Eckert, Executive Director, Award for Outstanding State Prostate Cancer Organization  
Arkansas Prostate Cancer Foundation



NASPC New Board Member and Most Spirited Advocate, Jim West

On Sunday morning, October 14 the Annual Meeting continued with an early breakfast, at which the 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 continuing need to keep funding for the **Congressionally Directed Medical Research Program (“CDMRP”)** in place. We heard from him last year as well since this is such an important topic for prostate cancer research. He discussed what the replacement of Senator McCain and the upcoming elections may mean for the programs. NASPC is a member of the DHRC.

After breakfast, the sessions continued. Following a recap by Merel Nissenberg of Saturday’s Annual Meeting sessions including the exciting panels and presentations in which all participated and listened as well as, the Reception, and the elections for 2018-2019, **Panel 4, entitled “EMOTIONAL AND COGNITIVE IMPAIRMENT ISSUES IN PROSTATE CANCER”**, took place. This panel was moderated by Andrew Chesler of CancerCare, and other panelists were Ronald Chen, M.D. and William Berry, M.D., both of whom had been panelists the day before on different topics.



William Berry, MD, Andrew Chesler, LMSW, CancerCare, and Ronald Chen, MD

Then in preparation for NASPCC’s Advocacy & Public Policy Committee considering whether to become active on this issue, the attendees heard next from Elizabeth Franklin of Cancer Support Community on **“WHAT IS STEP THERAPY AND HOW DOES IT AFFECT ACCESS TO TREATMENT?”** Many present were unfamiliar with insurance companies making coverage and access decisions based upon “fail first” policies, so the talk was particularly enlightening.



Elizabeth Franklin, LGSW, ACSW, Cancer Support Community’s Cancer Policy Institute Director presents on Step Therapy in Bone Health Access

**“BEST PRACTICES”** with participating state prostate cancer organizations and attendees on the cusp of new coalitions was the next topic and the panel of 4 state prostate cancer coalition representatives was led by Ira Baxter of the Tennessee Prostate Cancer Coalition. All attendees participated in the discussion. Along with Ira, the state panelists were Beverlyn Eckert of Arkansas, Judy Green of Massachusetts and Johnny Payne of South Carolina.



Ira Baxter of the Tennessee Prostate Cancer Coalition and panelists Beverlyn Eckert of Arkansas, Judy Green of Massachusetts and Johnny Payne of South Carolina



Lastly, Tom Kirk, Chair of the Steering Committee, called upon others in the Meeting Room to present **“COMMITTEE REPORTS FROM CHAIRS”**, which included the following Committees: Education & Awareness, Communications, Advocacy & Public Policy, State Coalition Development, Medical Advisory, Budget and Fundraising. Committee chairs included Johnny Payne, LaTanya Patton, Ira Baxter/Rob Johnson, Michael Zaragoza, Don Lynam and Merel Nissenberg.

The conclusion of the 14<sup>th</sup> Annual Meeting included Housekeeping and Farewell, a calendaring of 2018-2019 important dates, including the dates of the Board and Executive Committee Calls, and expense reimbursement. Merel Nissenberg provided final comments, and the Meeting was adjourned at 11:55 a.m., at which point the new Board of Directors for 2018-2019 was called to order and put into place. Box lunches were then distributed and those about to participate in the Bone Health Access Roundtable stayed for the afternoon and evening.



Former NASPCC Board Member Gabe Rosko thanking President Merel Nissenberg

Comments received were strongly positive and glowing, and the group looks forward to our Gala Year, next year, our 15<sup>th</sup> Annual Meeting which will take place October 11-13, 2019.

- ***“I just want to thank you for the outstanding ORGANIZATION & PLANNING job done by your team! I am still excited and honored to have attended your annual meeting. I learned so much In such a short period of time. To be in the company of GIANTS in the Prostate Cancer business is a dream come true for me!”***
- ***“It was an absolute pleasure attending the NASPCC meeting last weekend in D.C. I met so many wonderful people who are passionate about educating prostate cancer patients, like myself, and it would not be possible without all the work that you do! Thank you for allowing me to attend...”***
- ***“I wish you all the best with the important work that you do...”***
- ***“All Great”***
- ***“Very Organized”***
- ***“Congratulations on a Successful Weekend”***
- ***“Thanks again for an incredible event in DC. You are a Master at getting people involved and supporting the cause.”***
- ***“Thanks for all that you do.”***