



NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS

REPORT FROM THE 15TH ANNUAL MEETING & GALA

October 18, 2019 – October 20, 2019

Hotel Monaco, Washington, D.C.

“Educate, Participate, Celebrate”

The 15th Annual Meeting & Gala of the **National Alliance of State Prostate Cancer Coalitions**, also known as **The Prostate Cancer Alliance**, was held at the esteemed Hotel Monaco in Washington, D.C. on the site of the original General Post Office Building (circa 1840), from Friday, October 18, 2019 through 3:00 p.m. on Sunday, October 20, 2019.

This was a celebratory Annual Meeting, as it was a landmark year – our 15th year of helping prostate cancer patients and their families. State prostate cancer organizations – coalitions, foundations, associations and other entities - from across the entire United States, including Alaska and Hawaii, sent at least 1, sometimes 2 or 3 representatives to the 15th Annual Meeting.

The expectation as always was that at the conclusion of the Annual Meeting, all attendees would return to their respective constituencies and then disseminate throughout their states, all of the educational, scientific and practical information they’d received, thereby helping patients everywhere.

Annual Meeting Sponsors sent representatives to the 15th Annual Meeting & Gala to learn, to network and to work with state prostate cancer organizations, as well as to distribute their materials. There were a record 16 sponsors for this year's event, and NASPCC is very grateful for their support which helped us to organize and hold this stellar Annual Meeting.



The Weekend

NASPCC held its Q4 Board of Directors Meeting in the Tokyo Boardroom at the Hotel Monaco on Friday afternoon, October 18. During this Meeting the Board of Directors discussed, monitored and approved programs consistent with our Strategic Plan. As always, Board actions and decisions would be presented to the full group of Attendees at the general sessions the next day, Saturday, October 19, 2019.

The Board of Directors of NASPCC (THE PROSTATE CANCER ALLIANCE) has an important role. It determines our mission and purpose; ensures effective planning for the organization; sets the policies and procedures for NASPCC; develops and approves By-Laws; develops and approves budgets; determines and monitors NASPCC's programs and services; and serves as a link between NASPCC, its participating states and all of their constituents.



At the Friday Board Meeting, President Merel Nissenberg first reviewed the Agenda for the entire weekend of the 15th Annual Meeting & Gala. She then described many of NASPCC's accomplishments and activities during the 2018-2019 year. These included participation at the ASCO GU, AUA and ASCO Annual Meetings; participation in the AUA 2nd Annual Advocacy Summit when she and Executive Committee member Tom Kirk presented on a panel on Access Issues; the production and distribution of four Quarterly Newsletters ("The Blue Print"); Merel's participation as an Advocate for the Early Detection Research Network (EDRN) of the National Cancer Institute, and as an Advocate for the Canary PASS Trial at Stanford; the publication of NASPCC articles for Prostatepedia during the year; working on Diversity Issues with the Fred Hutchinson Cancer Center in Seattle; Merel's participation on the ASCO's Protocol-Setting Committee for Bone Health; and the continuing good work of NASPCC's 8 Advisory Committees that were originally created in July 2017 and which operate under the stewardship of Steering Committee Chair Tom Kirk. NASPCC also continues to distribute our Informed Decision-Making Laminates (<https://naspcc.org/docs/informed-decision-9-11-17.pdf>) as well as our tri-fold Brochure.

After the Secretary's Report and the Treasurer's Report were approved, Don Lynam, NASPCC Treasurer, presented the Fiscal Year 2019-2020 Budget that had been recommended by the Executive Committee for approval; the Budget was then discussed and adopted by the Board.

Board Members then heard from Steering Committee Chair Tom Kirk that the NASPCC Advisory Committees had been active this year in everything from frequent posting of medical articles to our Facebook Page; to holding national conference calls on topics such as Best Practices, and Fundraising for State Prostate Cancer organizations; to setting up new Prostate Cancer Coalitions such as the Arizona Prostate Cancer Coalition.

Our www.naspcc.org website was continually posting new articles and resources for prostate cancer patients and their families. NASPCC continues to work on an Advanced Prostate Cancer Laminar for national distribution. Additionally, NASPCC continues to co-sponsor and co-present CancerCare's Online Prostate Cancer Support Groups, 15-week sessions that are moderated by a clinical social worker and that maintain patient privacy.

And following the very successful California Prostate Cancer Coalition/UCSF Patient Conference on Prostate Cancer, NASPCC hopes to host similar Patient Conferences in partnership with academic medical centers such as Memorial Sloan-Kettering and Johns Hopkins.



New Board Member Robin Leach, Ph.D. (representing Texas) participated in the Board Meeting for the first time, and the Board also approved new State Representatives to the 15th Annual Meeting from Alabama; Arizona, Arkansas, Hawaii, Illinois, Wisconsin, Louisiana, Michigan, New Hampshire, New York, Oklahoma, South Carolina, Utah and West Virginia. Some of these states were new to NASPCC and others needed representation due to illness or unavailability of the approved Representative.

After the Board Members signed their Conflict of Interest Disclosures, the Board Meeting was adjourned; and at 6:30 pm Board Members, attendees and sponsors convened in the Footed Bar in the Hotel Monaco for a Welcome Reception, as guests continued to arrive from around the country to attend the landmark weekend event.

This casual Reception was a great place to meet new attendees, greet attendees from other years, and open our arms to representatives from states never before represented at the Annual Meeting.







The 15th Annual Meeting formally convened on Saturday, October 19, in the Athens Room of the Hotel Monaco. President Merel Nissenberg opened the Meeting with an Introduction and Welcome, and noted that each attendee had received a blue folder (sponsors received red folders) with various materials - but most importantly containing our “15th Annual Meeting & Gala” “Participate, Educate, Celebrate” glossy 8 ½” x 11” Brochure booklets. The Brochure booklets contained a Welcome Letter; the detailed Agenda with topics, times and presenters; a Description of NASPCC – “The Prostate Cancer Alliance”; the Educational Objective for the 15th Annual Meeting; Bios and photos of NASPCC’s Executive Committee; a list of the current Board of Directors with the state that each represents; information about NASPCC including our Mission Statement, Leadership, and Description of our reach; and a description of our Annual Meeting, which is unique to NASPCC among all national prostate cancer organizations. The Brochure also had two pages devoted to special Awards honorees: Paul Schellhammer, MD, FACS, “2019 NASPCC Honoree”; and Phil Olsen, set to receive “The

James West Spirit Award” created this year following the passing of Board Member James West of Florida.

Next, the Brochure booklet contained detailed Faculty BIOS and photos, showcasing the physicians, scientists and other professionals who would be delivering the outstanding individual and panel presentations that would comprise the Sessions over much of the next two days. Finally, on the back cover of the Annual Meeting Brochure were the logos of the 16 sponsors who helped make our 15th Annual Meeting & Gala possible. NASPCC had more sponsors than ever in 2019 and hopes to increase that number for our 2020 16th Annual Meeting.



Scientific and Medical Presentations then began with **Session I** entitled **“THE BASICS”**. First up was **“Prostate Cancer 101: the basics you need to know”** presented by Dr. Vin Laudone

of Memorial Sloan-Kettering, followed by **“Prostate Cancer Genetics 101”** with Dr. Leonard Gomella of Thomas Jefferson University in Philadelphia.



Dr. Adam Metwalli of Howard University in Washington, DC next presented **“Basics of Prostate Cancer Immunology and Immuno-therapeutics”**.



The next presentation in **“THE BASICS”** was returning presenter Dr. Ashley Ross, of U.S. Oncology in Dallas, who spoke on **“Demystifying Clinical Trials: What are they, and what should you think about when considering a trial?”**





“THE BASICS” continued with **“The ABCs of Androgen Deprivation Therapy”** presented by Dr. Jeanny Aragon-Ching of Inova Schar Cancer Institute in Fairfax, Virginia; and ended with Dr. Judd Moul of Duke University presenting on **“Prostate Cancer and African-American Men”**.

Session II, “TREATMENT OF NON-METASTATIC DISEASE BASED ON RISK ASSESSMENT” began with Dr. Vin Laudone presenting on **“Disease Location and Risk Assessment: the scientific tools available to help”** and then the ~100 attendees broke for lunch in The Paris Room, where physicians and scientists and a genomics expert took lunch seats at various round tables so that attendees could ask questions in an informal setting. Following lunch, the Annual Meeting continued with a solo presentation by Dr. Joseph Germino of Bayer who presented **“Review of the ARAMIS Data presented at ASCO”**. Then Dr. Asha Das of Progenics spoke on **“The Dawn of a New Era for Prostate Cancer Patients; The Role of PSMA and Artificial Intelligence in Diagnostics and Therapy”**.



The next two Agenda items in **Session II** were Panels: First, Dr. Vin Laudone, Dr. Judd Moul, Dr. Daniel Song of Johns Hopkins, and Dr. Gregory Gagnon of the Frederick Regional

Health System in Maryland took their seats on the dais to discuss **“Low Risk Localized PCa: Genomic Tests, Focal Treatment and Active Surveillance”**.



The Second Panel consisted of Dr. Laudone, Dr. Paul Schellhammer (our Honoree) from Urology of Virginia, and Dr. Jeff Skinner (Walter Reed Military Hospital) who discussed **“Intermediate and High-risk Disease and Multimodal therapy”**.



The next Session was **“III. A SYSTEMATIC APPROACH TO SYSTEMIC THERAPY”** in which first, Dr. Philip Saylor of Harvard presented **“The optimal treatment of bone metastases”** and then a Panel consisting of Dr. Mark Markowski (of Johns Hopkins) and Dr. Paul Schellhammer elucidated on **“New and Developing Treatment Approaches for patients with localized prostate cancer”**. While attendees helped themselves to snacks at the back of the room, in lieu of a formal Break, the Agenda continued.



The last two sole presentations of the afternoon were Dr. Judd Moul presenting on **“Biochemical/PSA Recurrence of Prostate Cancer”**, and then California Prostate Cancer Coalition Board Member Dr. Joseph Scherger of Eisenhower Medical Center in California presented a riveting, practical talk entitled **“The Role of Nutrition and Lifestyle in addressing Prostate Cancer”**.



The Annual Meeting then adjourned for the day to prepare for the evening Gala celebrating NASPCC’s 15 years and presenting Special Awards!

At 6:30 p.m. on Saturday night, October 19, state representatives, Annual Meeting Sponsors and guests gathered in the magnificent Paris Room at the Hotel Monaco for **The Gala** 15-year celebration at the 15th Annual Meeting. The room, already a spectacular space from the 1840’s replete with ornate columns, carvings and a beautiful cupola, was awash with blue lights spotlighting the columns.

Guests entered the room with soft jazz playing and saw a scene of fresh blue and white floral centerpieces on the 11 dining tables, as well as high tables in an adjacent cocktail space. The Paris Room was indeed a perfect setting for such a splendid occasion.



Following Cocktail Hour at which delicious hors'-d'oeuvres were passed and a Bartender poured libations, everyone was seated at 7:30 p.m. and welcomed by President Merel Nissenberg.





The guest of honor, Dr. Paul Schellhammer, was seated at a center table and came to the podium to accept the **Outstanding Service Award** which was presented by Merel Nissenberg. Dr. Schellhammer really needed no introduction; he has been a scholar, a practicing urologist, a urologic cancer researcher, a leader among physicians, a friend to prostate cancer patients and their families as well as advocates - and is himself a prostate cancer patient. It was an honor for NASPCC to bestow this Award on Dr. Schellhammer!



Next, NASPCC Secretary Jan Marfyak presented the first-ever **James West Spirit Award** to Phillip Buck Olsen, Prostate Cancer warrior from Hawaii and an active help to patients everywhere.



The James West Award was created in honor of NASPCC Board Member Jim West of Florida who passed away in August. He was a tireless champion for early detection through his Jim West Foundation in Florida. Last year NASPCC presented Jim West with the “Most Spirited Advocate Award” and now there is an Award in his memory. NASPCC invited his daughter to attend the presentation of the Award in her father’s honor. It was a moving moment as she was able to attend to see the Award presented.



The last Award presentation was for **Most Outstanding State Prostate Cancer Organization**, which was a surprise to the winner: the Delaware Prostate Cancer Coalition, headed by Dr. Michael Zaragoza who was in attendance.

The Award was presented by Director-at-Large LaTanya Patton; and it was accepted by Dr. Zaragoza and by two additional Delaware PCC Members who were in attendance at the 15th Annual Meeting: David Sauls (who was running for the 2019-2020 Board) and Dr. Fran Franklin, who chairs NASPCC's Education & Awareness Committee.





Following dinner, the assembled guests heard from Dr. James Gulley, Lead Prostate Cancer Researcher in Building 10 of the National Institutes of Health (NIH). This was Dr. Gulley's third appearance and 3rd year of participation in NASPCC's Annual Meeting. His talk was entitled **"Update on Immunotherapy in Prostate Cancer"**, always an intriguing topic in prostate cancer. **The Gala** ended at 9:30 p.m. following Merel Nissenberg's closing remarks.



On Sunday, October 20, 2019 a full breakfast was again served from 8:00-8:45 am, during which attendees were addressed by speaker Mark Vieth from CRD Associates, who again (as he did last year) gave us a **“Current Update on the CDMRP and DOD Research Funding”**. After Q & A, attendees then moved to the Athens Room for the Sunday Sessions.



Session IV, “OPTIMIZING NASPCC: HOW CAN WE HELP STATES AND PATIENTS?” consisted of a superb Panel of leaders from various state prostate cancer organizations: Ira Baxter of Tennessee chaired the Panel, and others who served were Judy Green (Massachusetts), Dwight Thomas (Georgia), David Sauls and Fran Franklin (Delaware), and Beverlyn Eckert and Chris Collier (Arkansas).



Then Tom Kirk, Chair of the Steering Committee which oversees the eight Advisory Committees, gave a report on each Committee or called upon the Chairs of those Committees to do so; and he mentioned that in everyone’s folder there was a sign-up sheet to gather names of those individuals wishing to serve on Committees. Merel reminded the attendees that Board Members are also required to serve on at least one Committee.

Following **Session IV, Elections for 2019-2020** were held. Of those positions that were open (with 2-year terms expiring), Merel Nissenberg was re-elected President and Don Lynam was re-elected Treasurer. Half of the 2018-2019 Board had expiring terms. The new Board Members elected or re-elected included Paul Kradel (West Virginia), LaTanya Patton (Missouri), David Sauls (Delaware), Alvin Chin (Virginia), Mary Anderson (North Carolina), Dave Hulbert (Minnesota), and Ulysses Wright (Kansas), as well as first-time attendees Crissy Kantor (New Hampshire) and Stephen Richardson (Utah).

Johnny Payne (South Carolina) and Jan Marfyak (New Mexico) remain as Vice President, and Secretary, respectively. Harold Pharoah (Nebraska), Gabe Rosko (New Jersey), Otto Sankey (Arizona), and Renee Savickas (Colorado) still have a year remaining in their terms; and Robin Leach (Texas) had already been approved to fill the Board Seat of Jim West (Florida), who passed away in August.

Tom Kirk remains an Invited Member of the Executive Committee and Chair of the NASPCC Steering Committee. LaTanya Patton of Missouri was once again chosen by the Directors to be the Director-At-Large and thus serve on the Executive Committee.



Session V, “FROM THE PATIENT’S PERSPECTIVE”, began with a Panel entitled **“How to Approach Decision-Making: Medical and Patient Perspectives”**, and Panelists were Dr. Paul Schellhammer, Dr. Michael Zaragoza, Gabe Rosko, Dave Hulbert and Phil Olsen. Both approaches, as physician and patient, were important for the attendees to hear.



Then, frequent NASPCC presenter Dr. Ashley Ross, Dr. Paul Schellhammer and Dr. Gregory Gagnon served on a Panel entitled **“Optimizing Care in the Community Setting”**, a crucial topic since NASPCC is highly cognizant of the fact that most patients in the country do not receive their care at an academic medical center but those patients still need state-of-the-art care.



Following Lunch in the Paris Room, the attendees then re-convened back in the Athens Room for the conclusory presentations of **Session V**. A topic of great interest to all attendees was **“Managing the Side Effects of Prostate Cancer and its Treatment: Emotional Distress, Intimacy Issues, Erectile Dysfunction and Incontinence”** presented by both Bill Goeren, MSW, from CancerCare, and Dr. Krishnan Venkatesan, of Washington Hospital Center. The topic was so well-received that both presenters agreed to do a Webinar in 2020 for NASPCC on the same topic.

The last item on the Agenda was **“Attendees’ Round Table: Discussion and Questions from the Floor”** in which all attendees were invited to participate. A lively and fruitful discussion took place on a myriad of topics - from veterans issues, to vitamin supplements, to asking for PSA tests, to Access Issues, to a suggestion that states work with their State Comprehensive Cancer Plans; and there were many compliments on what attendees said was an outstanding Annual Meeting. Merel Nissenberg then conducted the **“Wrap Up; Calendaring and Conclusions”**.

Dates for 2019-2020 were calendared and expense reimbursement forms explained. Merel Nissenberg thanked our Staff Tiffany Razzo and her husband George for their work on the Annual Meeting; George Razzo took photos of the full 2019-2020 Board (with absent Johnny Payne to be added in at a later date). The 15th Annual Meeting & Gala weekend was adjourned at 3:00 p.m. on Sunday, October 20, 2019.

Next year our 16th Annual Meeting will take place October 9-11, 2020.

Feedback received about the 15th Annual Meeting has been overwhelmingly positive, and NASPCC will continue moving the organization forward and serving as a unique umbrella organization for state prostate cancer organizations across the country, whereby educational and other take home messages are distributed and disseminated throughout each state, down to the local level, with individuals deriving significant benefit.

COMMENTS

“This was my first conference to attend and I came away very impressed with all aspects - program topics, quality of the speakers, fellow attendee interest and engagement, and tremendous commitment on the part of leadership to impart as much current quality information as possible...Thank you for a highly informative meeting.”

“Thank you for an amazing, informative weekend! Keep up the good work”

“Excellent and well-organized meeting. Very much worth the time and effort to attend. Thank you!”

“Everything was outstanding! Connecting with like-minded passionate people that share the same mission and purpose as I do. All the information, the amazing speakers shared was priceless. So grateful!”



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