



*“Unity is strength... when there
is teamwork and collaboration,
wonderful things can be
achieved”*

– Mattie Stepanek

News

Volume 2, Issue 4

December 4, 2019

THE BLUEPRINT

J. Renee Savickas, Editor

President’s Message

It’s hard to believe that we are almost at the end of 2019 – a banner year for **NASPCC** (now also known as **THE PROSTATE CANCER ALLIANCE**)!

Our 15th Annual Meeting & Gala took place October 18-20, 2019 at the beautiful Hotel Monaco in Washington, DC, a Kimpton Hotel built inside the original General Post Office Building from the 1840’s. This was by far our best and most well-attended Annual Meeting yet. A stellar faculty including physicians and scientists from Memorial Sloan-Kettering, Harvard, Hopkins, Duke, Urology of Virginia and other outstanding institutions presented on many topics during the Annual Meeting weekend. Sessions included The Basics; Treatment of Non-Metastatic Disease Based on Risk Assessment; A Systematic Approach to Systemic Therapy; Optimizing NASPCC: How Can We Help States and Patients; and From the Patient’s Perspective. Sub-topics included Genetics; Immunotherapy; ADT; Prostate Cancer and African-American Men; Biochemical/PSA Recurrence; Decision-making; and Managing the Side Effects, including emotional distress and erectile dysfunction. The Gala on Saturday evening, October 19, was a special occasion and an outstanding event, during which we honored Dr. Paul Schellhammer with the Outstanding Service Award, and we presented Hawaii representative Phillip Buck Olsen with the James West Spirit Award, named after Board Member James West of Florida who passed away in August of this year. Last year James West received the “Most Spirited Advocate Award” at our Annual Meeting, and we were fortunate to have his daughter at the Gala this year who could be present for this first Award presentation named for her father.

The Report of the 15th Annual Meeting & Gala can be found on the NASPCC website at: <https://naspcc.org/docs/15thAnnualMeetingReport.pdf>. The Annual Meeting Brochure can be found at: <https://naspcc.org/attachments/article/55/Program2019Oct15qxp.pdf>. Additionally, all of the slide presentations can also be found on the Alliance website (www.naspcc.org).

Elsewhere in this Newsletter you will read about the Board of Directors for 2019-2020 including two new Annual Meeting attendees who couldn't wait to run for the Board. You will also read a description of a Roundtable on Access Issues that NASPCC will be hosting on November 25, 2019. Access to care continues to be an issue of high priority for the Advocacy & Public Policy Committee.

WE NEED EVERYONE TO SIGN UP FOR, AND BECOME ACTIVE ON, AT LEAST ONE OF OUR EIGHT ADVISORY COMMITTEES! Please let Tom Kirk, Chair of the Steering Committee, know which committees interest you.

We wish everyone Happy Holidays and send our best wishes for a healthy 2020!

Respectfully submitted,

Merel Nissenberg

Picture Gallery from 2019 Annual Meeting





NASPCC General Activities and Updates By Merel Nissenberg and Thomas Kirk

NASPCC and the California Prostate Cancer Coalition (CPCC) held a Roundtable on **ACCESS, STEP THERAPY and THE IMPACT PROGRAM** ON Monday, November 25, 2019 at the Westin LAX Hotel in Los Angeles, California. Attendees were privileged to hear presentations from leaders advocating for better access for patients, such as Liz Helms of the Chronic Care Policy Alliance based in California. That group has published an outstanding booklet, “Get to Know Your Rights” which was distributed at the Roundtable. See www.MyPatientRights.org. We also heard presentations from Steven Schultz of the Arthritis Foundation; from Dr. Art Lurvey who is a Medicare Contractor Medical Director for Noridian Healthcare, who spoke on Medicare coverage for tests and treatments; and from Sarah Connor and Kristin William of the IMPACT Program (Improved Access to Counseling & Treatment for underserved men with prostate cancer in California). One of the most important ideas that was discussed was to be able to “Share Your Story” which personalizes the access challenges for certain patients, and thereby helps drive change and better coverage decisions. NASPCC is looking forward to putting on other Roundtables to cover this important topic, which was chosen as an action priority for NASPCC last year. Merel Nissenberg and Tom Kirk organized and ran this important Roundtable for NASPCC.



General Updates Continued...

SAVE THE DATE!

On June 6, 2020 the California Prostate Cancer Coalition (CPCC) and UCSF will once again put on a statewide and national conference – The 2nd Annual CPCC/UCSF Patient Conference on Prostate Cancer – in the Bay Area. For information, please contact mgrey@ucsd.edu.

UPDATED BROCHURES! We have just re-printed our tri-fold NASPCC Brochures to reflect the current and newly-elected Board of Directors and the addition of more states on our map of Proud Participants in the National Alliance of State Prostate Cancer Coalitions. If you need any brochures and any Informed Decision-Making Laminates for your next event or group meeting, please send request to: mgrey@ucsd.edu. *See updated brochure in this edition.

MEMORANDUM OF UNDERSTANDING: At the 15th Annual Meeting just concluded, discussion was had on reciprocity between state prostate cancer organizations and NASPCC, our non-profit organization in which the states participate and by which they are able to attend the Annual Meeting every year with almost all costs covered. NASPCC also provides materials such as the Informed Decision-Making Laminate on request. At a bare minimum, NASPCC and individual state organizations should have some understanding about acknowledging each other and in fact have a responsibility to do so. President Merel Nissenberg asked if anyone had any objection to each state including the following on its website, brochure or other publication: “A Proud Participant in the National Alliance of State Prostate Cancer Coalitions” and all agreed that was a reasonable action to take. NASPCC is also willing to publicize activities of each state prostate cancer organization and to link to that group’s website on the NASPCC website, which should also be a mutual linking. You will be receiving a template of an Understanding in the next few months from Dr. Fran Franklin, the Chair of our Education & Awareness Committee, on this project. Please let us know if you have any concerns, by writing Merel Nissenberg at mgrey@ucsd.edu.

General Updates Continued...

By Harold Pharoah, Nebraska Prostate Cancer Coalition

General Dynamics

Program & Peer Review Management Information System Team

I am so honored to have been selected to participate on the Program & Peer Review Management Information System Team. Our team meets for 3 days in November, November 20 – 22, 2019 in Dulles, Va. We will be reviewing 29 grant applications for government grant money to be used for prostate cancer research. Our review team is made up of scientists, doctors, and prostate cancer survivors.

These grant applicants are ongoing research organizations that are studying treatments, new testing techniques, and new ways to address prostate cancer patients. Their goals are to make treatments more precise, less invasive, improve methods of diagnosing prostate cancer early, and better predict if someone is likely to be diagnosed with prostate cancer thru genetics. These are all wonderful goals and should be rewarded with the money that our government has set aside for all of these types of research and studies.

Each year better treatments, better diagnostic methods, and better ways of making things easier on men makes it all worth it. This is all due to scientists and doctors who are dedicated to improving the life of men with prostate cancer. Thanks to the US Government for allocating money to be used for prostate cancer research. When you put all of these together, we are saving more men's lives.

By Crissy Kantor, New Hampshire

Please see the link below on the 7th annual **5K Stache DASH Event** on November 17, 2019!

<https://manchesterinklink.com/nov-17-at-stark-brewing-co-stache-dash-5k-in-support-of-those-fighting-prostate-cancer/>

By Bob Shekhdar, Connecticut

Bob Shekhdar is scheduled to give a presentation to the Connecticut Prostate Cancer Education Forum at Greenwich Hospital on February 3, 2020. This will be a presentation of learnings from the NASPCC 15th Annual Meeting held in mid-October. The title is "Recent Advances in the Testing, Diagnosis and Treatment of Prostate Cancer".

Advocacy and Policy Update

By Alvin Chin

On November 20, 2019, Alvin Chin (Chair of NASPCC's Advocacy & Public Policy Committee) attended one in a series of IDEA presentations by Janssen/Johnson & Johnson, in Washington, DC. The topic was "Patient Rights: Transparency and Access", and Joanna Morales, CEO of Triage Cancer began by summarizing healthcare options and coverage, including deductibles, co-payments, co-insurance/cost share, and out-of-pocket maximums to determine relative annual costs of coverage.

Panels on Transparency and Access to Care, among other topics, included many very active advocates on these access issues, such as Liz Helms (President & CEO of California Chronic Care Coalition); John Schall (CEO, Caregiver Action Network); and Stacey Worthy (Counsel, Aimed Alliance). In fact, NASPCC has worked with Stacey Worthy and Liz Helms before, as recently as November 25 of this year when Liz Helms participated in a NASPCC/CPCC Roundtable in California on Access Issues. Other panelists included Madelaine Feldman, MD (President, Coalition of State Rheumatology Organizations) and Bob Donnelly (Senior Director, Global Health Policy, J&J). Some of the speakers will likely be a resource for defining our advocacy programs as we move forward.

Report of the Janssen/Johnson & Johnson Patient Advocacy Advisory Board Meeting - Washington, DC, Dec. 7, 2019

Janssen Oncology convened its Patient Advocacy Advisory Board for a meeting Saturday, December 7, 2019 in Washington, DC and held at the Marriott Marquis. As current chair of the Advocacy and Public Policy Committee, I was asked to attend to represent NASPCC (The PCa Alliance). It was a well-attended meeting with nine representatives from PCRI, Men's Health Network (MHN), Malecare, Cancer ABC's, Prostate Conditions Education Council (PCEC), Veteran's PCa Awareness, ZERO, PHEN, and NASPCC sitting down with a professional Facilitator, six members of Janssen Oncology and three support members from the Nexus Global Group LLC.

The meeting concerned ERLEADA (apalutamide) which was initially approved by the FDA in Feb 2018 for Non-metastatic Castration-Resistant PCa (nmCRPC) but recently approved (Sept 2019) by the FDA for Metastatic Castration-Sensitive PCa (mCSPC). The focus was on topic areas which the NASPCC has been covering in recent years: accessibility, affordability, adherence (or compliance), Medicare vs commercial payer vs Medicaid, SHIPs, SPAPs, Extra Help, LIS, Utilization Management, Prior Authorization (PA), Step Therapy, Tier Placement, Formulary Exclusion, Exceptions Process, access barriers, etc. It was said during the various workshops/presentations that 2/3 of the ERLEADA drug revenues arise out of Medicare and that would suggest that we should become familiar with what Medicare/CMS does or does not do for PCa patients.

One of the Janssen leaders suggested that this may become a regular annual event and that is something that I would encourage based on my experience at this event where like-minded PCa leaders came together to discuss health and public policy issues and develop new ideas that would advance our mutual mission. Attendees may not realize it, but this was a unifying meeting as much as it was a thought provoking event.

--Alvin Chin, Chair, Advocacy and Public Policy Committee

NASPCC Committees (8) and Member Status - November 2019

All of the Alliance Board Members are now placed on Committees, at this point, we still need a **Chair for the State Coalition Development Committee.**

- **Education and Awareness Committee:** Fran Franklin, Chair
Members for 2019-2020: David Sauls, Tammie Minter, Cheryl Cropp, LaTanya Patton, Ira Baxter, Jan Marfyak, Dave Hulbert, Paul Kradel, Steve Richardson, Calvin Jackson and Clarence Williamson. Johnny Payne Chaired this Committee for the first year (2017), stayed on the Committee last year and will continue again during 2019-2020.
- **Communications Committee:** Renee Savickas, Chair
Members for 2019-2020: LaTanya Patton Chaired this Committee for the first year, served last year and will continue to serve on the Committee during 2019-2020, other members last year were Johnny Payne, Paul Kradel and Ira Baxter.
- **Budget Committee:** Don Lynam, Chair
Members for 2019-2020: Anthony Minter, Jan Marfyak, Alvin Chin, and Ullyses Wright.
- **Advocacy and Public Policy Committee:** Alvin Chin, Chair
Members for 2019-2020: Don Lynam and Tom Kirk will continue to serve, and Robert Gamage (NY) and Mike Crosby signed up.
- **State Coalition Development Committee:** **No Chair Assigned**
Members for 2019-2020: Harold Pharoah, Cheryl Cropp and Dwight Thomas signed-up. Otto Sankey and Crissy Kantor are added.
- **Annual Meeting Committee:** Merel, Chair
Members for 2019-2020: Tammie Minter, Ullyses Wright and Rob Johnson signed up. Jan Marfyak, Don Lyman, Harold Pharoah voiced interest as well. Crissy Kantor and Robin Leach are added.
- **Fundraising Committee:** Merel, Chair
Members for 2019-2020: Mary Anderson and Rob Johnson signed up and Gabe Rosko is added. Alvin Chin voiced interest as well.
- **Medical Advisory Committee:** Michael Zaragoza, Chair
Members for 2019-2020: Otto Sankey added.

In the SPOTLIGHT

*In each quarterly issue of the **Blueprint**, NASPCC is proud to feature a section dedicated to a very special State Coalition or Board Member to acknowledge the wonderful services they provide in their state. This quarter we are honored to shine the SPOTLIGHT on:*

Nebraska Prostate Cancer Alliance

1437 South 190th Plaza - Omaha, Nebraska – 68130 – 402-578-3336

www.nebraskapca.org – www.cruisinforacureomaha.com



Our mission is to raise the awareness of Prostate Cancer in Nebraska and Western Iowa and to provide men over 40 with FREE PSA Tests. Over the last 9 years we have provided almost **1700 FREE PSA Tests**. 6 men have been diagnosed with Prostate Cancer, completed their treatments, and are now in remission. We provide 193 FREE PSA Tests for our 2019 Cruisin' for a Cure Omaha. There were 29 men that had elevated scores this year, They were asked to consult a Physician. We do this to raise the awareness of Prostate Cancer – Provide FREE PSA Tests so that we can catch the Prostate Cancer in its early stages.

“Early detection saves men’s lives”

2019 Cruisin' for a Cure Event



NASPCCC would like to congratulate the **Nebraska Prostate Cancer Alliance** for being our **“Spotlight”** featured Coalition of the quarter! You are doing excellent work, providing **FREE PSA testing, education, awareness opportunities** for your state! Thank you for all that you do!

NASPCCC Updated Brochure

PARTICIPATING STATES



HOW DOES NASPCCC REACH PROSTATE CANCER PATIENTS AND THEIR FAMILIES?

NASPCCC supports the development of state prostate cancer organizations, each of which is comprised of patient networks and support groups. NASPCCC 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. NASPCCC also helps equip patients and their families to actively engage in the prostate cancer cause.

NASPCCC 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. NASPCCC 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.naspc.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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Los Angeles, California 90067
Toll Free 877-NASPCCC-8 (877-627-7228)
E-mail: info@naspc.org Website: www.naspc.org

November 2019



Reaching Thousands
of Prostate Cancer Patients
and their Families
Across the U.S. Since 2004



MISSION STATEMENT

NASPCCC 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.

Please click the link below to view the entire brochure!

<https://naspc.org/attachments/article/2/8.5x11NASPCCLow.pdf>

Social Media Corner

This section of the **Blueprint** is dedicated to providing tips to help grow our Facebook page and grow your organizations page as well.



The official NASPCC Facebook page is:

<https://www.facebook.com/NASPCC/>

Here are some great Facebook tips and best practices. I have attached a link below to the Donorbox Nonprofit Blog (source)

- **Develop a Facebook Strategy**
What are you hoping to achieve? What is your Mission? What are your goals?
- **Take Care of your Profile**
Your Facebook profile represents your organization. It's very important that your profile is complete with a profile picture, a cover photo, a description, contact info and more.
- **Become a Content Geru**
Content is King! Post high-quality, relevant and compelling content that interests your target audience. You need to post frequently and consistently.
- **Share Link Posts Instead of Photos**
Facebook found the people prefer to click on links that are displayed in the link format which appears when you paste a link while drafting a post, rather than links that appear in photo captions.

<https://donorbox.org/nonprofit-blog/facebook-for-nonprofits/>

Please click the link above for more detailed information!

Please see the following information on CancerCare's Online Support Group




CANCERcare®
Help and Hope

FREE PROFESSIONAL SUPPORT SERVICES

CancerCare helps individuals, families, caregivers and the bereaved cope with the emotional and practical challenges of cancer. Our services include counseling, support groups, educational workshops, publications and financial assistance. All of our services are provided by professional oncology social workers and are offered completely free of charge. To learn more, visit www.cancercare.org.

CONNECT WITH US

 **FACEBOOK**
www.facebook.com/cancercare

 **BLOG**
www.cancercare.org/blog

 **YOUTUBE**
www.youtube.com/cancercareinc

 **TWITTER**
[@cancercare](https://twitter.com/cancercare)

CancerCare® National Office
275 Seventh Avenue
New York, NY 10001
800-813-HOPE (4673)



Prostate Cancer Online Support Group

CancerCare and the National Alliance of State Prostate Cancer Coalitions (NASPCC) are offering a free 15-week online support group for men diagnosed with prostate cancer.

This online group provides a safe, confidential space where men can discuss the unique challenges of living with prostate cancer, while giving and receiving support, information and guidance. This online support group will not offer medical advice and there will be no medical professional leading the group.

MODERATOR

Andrew Chelser, MSW, LCSW
Men's Cancers Program Coordinator, CancerCare

TO JOIN THIS SUPPORT GROUP, PLEASE VISIT

www.cancercare.org/support_groups/126 to complete our online registration process. Internet access is required.



IN LOVING MEMORY



In August of this year, NASPCC lost a wonderful human being, Board Member and prostate cancer warrior. James West of St. Petersburg, Florida passed away on August 7. Through his Jim West Prostate Cancer Foundation, he selflessly promoted the early detection of potentially lethal disease and helped arrange for testing for men who knew little of the disease. Jim was a vocal and passionate advocate at every Annual Meeting held by NASPCC and we welcomed his dedication to the cause. At our 14th Annual Meeting in October 2018, we presented Jim with the “Most Spirited Advocate Award”, the first time that Award was ever given. This year, following his passing, NASPCC created the “James West Spirit Award” in his honor and Secretary Jan Marfyak of New Mexico presented it to fellow prostate cancer warrior Phillip Buck Olsen, of Hawaii, at the Saturday evening Gala on October 19, 2019. James West’s daughter Daphne Blount was invited to attend and was there to see the presentation in her father’s name and honor. We will miss Jim very much.

About NASPCC and Mission Statement

National Alliance of State Prostate Cancer Coalitions (NASPCC) is a nation-wide organization comprised of state 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.

State Coalitions

The following states have participated in NASPCC:

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Illinois
- Indiana
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Missouri
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- Ohio
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- Tennessee
- Utah
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming

Educational Tools

Having a prostate cancer related event in your community? Just ask! We will be happy to ship some Informed Decision-Making Laminates and or Brochures.

The Laminate

Prostate Cancer: Informed Decision-Making for Men over 40 and Primary Care Physicians. This is NASPCC's excellent awareness and educational tool for INFORMED DISCUSSIONS between men and their physicians. NASPCC also has brochures as well.

We will send these to you for distribution at **NO COST** and they are a reminder that your state is a proud participant in NASPCC!

Next National Coalition Quarterly Call:

February 6, 2020 @ 4pm MT (Mountain)

Dial-In: 1-218-339-7800

Access 9381332#



*(Pictured above is the newly elected 2019-2020 Board, *some members not pictured)*

2019-2020 Board of Directors

The 2019-2020 Board of Directors of the National Alliance of State Prostate Cancer Coalitions

Executive Committee

President: Merel Grey Nissenberg (CA)

Vice President: Johnny Payne (SC)

Treasurer: Donald Lynam (KY)

Secretary: Jan Marfyak (NM)

Director at Large: LaTanya Patton

Invited Member: Tom Kirk

Board Members: Mary Anderson (NC); Alvin Chin (VA); Dave Hulbert (MN); Crissy Kantor, (NH); Paul Kradel (WV); Robin Leach (TX); Harold Pharoah (NE); Stephen Richardson (UT); Gabe Rosko (NJ); Otto Sankey (AZ); David Sauls (DE); Renee Savickas (CO); and Clarence Williamson (TN)

Advisory Board

Leonard G. Gomella, M.D., F.A.C.S.
*Kimmel Cancer Center Network
Jefferson University Hospitals*

Vincent Laudone, M.D.
Memorial Sloan-Kettering Cancer Center

Christopher J. Logothetis, M.D.
M.D. Anderson Cancer Center

Judd Moul, M.D.
Duke University

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*

Ashley Ross, M.D., Ph.D.
Texas Urology Specialists, Dallas, TX

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*