



*"Walking with a friend in the dark is better
than walking alone in the light. . .
Alone we can do so little; together we can
do so much."
- Helen Keller*

News

Volume 1, Issue 5
November 2018

THE BLUE PRINT NEWSLETTER

LaTanya Patton, Editor

PRESIDENT'S MESSAGE

It's Fall but it feels like Spring, because Spring represents new and exciting beginnings. And having just completed NASPCC's 14th Annual Meeting, with an amazing program, excellent speakers and panels, superb networking, and the election of a new 2018-2019 Board of Directors, NASPCC is indeed setting out on a new year of great accomplishments.

The 14th Annual Meeting took place October 12-14, 2018 and was held at The Liaison Capitol Hill, in Washington, D.C., in which more than 40 attendees participated, not to mention representatives of sponsors and many of the presenters. The 2017-2018 Board of Directors held its 4th Quarterly Board Meeting on Friday October 12, following which we hosted a small Reception with drinks and hors-d'oeuvres. The Annual Meeting then started in earnest at 7:00 a.m. on Saturday morning, with breakfast and panels to follow. We will be publishing a Report of the 14th Annual Meeting and the slides from all of the presenters and panelists will be available on our website, www.naspcc.org. Topics for panels and individual talks included informed Decision-Making; The Importance of Hereditary Cancer Testing in Prostate Cancer; Genomic Testing; Active Surveillance; Advanced Prostate Cancer; The Automated Bone Scan Index; Immunotherapy in Prostate Cancer; Radiation Therapy, Focal Targeted therapy and Imaging; Bone Issues in Prostate Cancer; and Clinical Trial Highlights from 2018. Dr. Eugene Kwon also presented on PET Imaging. Elections were held and a new Board elected for those openings on the Board where a Director was not finishing a second year of a 2-year term. New Directors include Harold Pharoah of Nebraska; Judy Green of Massachusetts; Renee Savickas of Colorado; and Otto Sankey of Arizona. Elsewhere in this Newsletter is a complete list of the 2018-2019 Officers and Board of Directors for NASPCC.

On Saturday evening of the Annual Meeting, NASPCC held a Cocktail Reception and Awards Ceremony, honoring Dr. Alan Partin, head of the Brady Urological Institute at Johns Hopkins Medical Institutions, for his outstanding contributions to the field of prostate cancer, including the development of the Partin Tables. Accepting his Award, Dr. Partin related how the late Dr. Don Coffey motivated him to find out why some prostate cancer is fatal and other forms of the disease do not kill the patient. He has been tireless in looking for these answers and in helping patients and their families.

An Award was presented to the Arkansas Prostate Cancer Foundation as the 2018 Most Outstanding State Prostate Cancer Organization; and an Award for Most Spirited Prostate Cancer Advocate was presented to James West of the Jim West Prostate Cancer Foundation in Florida.

Three patients: Ira Baxter of Tennessee, Gabe Rosko of New Jersey, and Dave Hulbert of Minnesota added inspirational personal words.

Sunday the Meeting continued with a short presentation by Mark Vieth on the status of the Defense Health Research Consortium and the Congressional Directed Medical Research Program (CDMRP). Then a panel was convened on Emotional Cognitive Impairment Issues in Prostate Cancer followed by a short talk on Step Therapy and why it is important to patients because of its potential impact on access to treatment. Then Best Practices for state prostate cancer organizations was the topic of a superb panel convened by Ira Baxter of the Tennessee Prostate Cancer Coalition. Tom Kirk who is the new Chair of the Steering Committee helped Committee Chairs present updates on their Committee work.

These are just some of the highlights of NASPCC's 14th Annual Meeting. We were fortunate to have staffing by Tiffany Razzo, who also serves as Secretary of the California Prostate Cancer Coalition and works at M.D. Anderson Cancer Center in Houston, Texas.

Next year the 15th Annual Meeting of NASPCC will take place October 11-13, 2019. We hope to add a Gala to the Saturday night celebration in honor of our 15th year!

Other projects of NASPCC we are working on in 2018-2019 include an Advanced Prostate Cancer Laminar, continued use of the Informed Decision-Making Laminar; more webinars; and co-partnering with CancerCare on their online Prostate Cancer Support Group led by Andrew Chesler. It's written about elsewhere in this Newsletter! We are excited to continue our efforts to help prostate cancer patients and their families. As an umbrella organization we want to filter down our efforts to the states and then all the way through to the local level. We want to lessen the suffering and burden of prostate cancer!

Respectfully submitted, Merel Nissenberg

"Elsewhere in this current Newsletter you will see a Flyer for the Online Prostate Cancer Support Group being offered by CancerCare and co-sponsored by the National Alliance of State Prostate Cancer Coalitions (NASPCC). This is an excellent opportunity to have a free clinician-run support group deliver private support group services to people who feel that they could benefit from this resource, and the Support Group runs for 15 weeks. Each person who registers receives a private ID, allowing total anonymity for him to ask questions and seek ideas 24/7. PLEASE REGISTER AND TAKE ADVANTAGE OF THIS SUPERB OPPORTUNITY!"

Annual Meeting 2018







2018-2019 Board of Directors

The 2018-2019 Board of Directors of the National Alliance of State Prostate Cancer Coalitions (NASPCC) are:

President: Merel Nissenberg (California)

Vice President: Johnny Payne (South Carolina)

Treasurer: Donald Lynam (Kentucky)

Secretary: Jan Marfyak (New Mexico)

Board Members: Mary Anderson (North Carolina), Ira Baxter (Tennessee), Alvin Chin (Virginia), Judy Green (Massachusetts), Dave Hulbert (Minnesota), Sanford Jeames (Texas), Paul Kradel (West Virginia), LaTanya Patton (Missouri), Harold Pharoah (Nebraska), Renee Savickas (Colorado), Otto Sankey (Arizona), James West (Florida) and Michael Zaragoza, M.D. (Delaware). Tom Kirk (California) is an Invited Member of the Executive Committee and is also Chair of the newly-created Steering Committee. LaTanya Patton is the Director-at-Large and serves on the Executive Committee in that capacity.

Advisory Board

Christopher J. Logothetis, MD

University of Texas MD Anderson Cancer Center

William G. Nelson, M.D., Ph.D.

Sidney Kimmel Comprehensive Cancer Center at John Hopkins

Alan W. Partin, M.D., Ph.D.

James Buchanan Brady Urological Institute at John 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

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

Leonard Gomella, M.D.

Thomas Jefferson University Hospitals

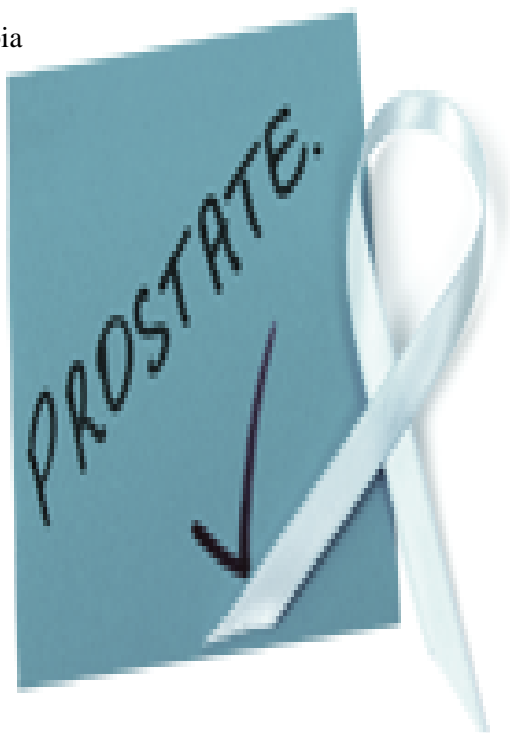
About NASPCC: OUR MISSION STATEMENT

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:

Alaska
Arizona
Arkansas
California
Colorado
Connecticut
Delaware
District of Columbia
Florida
Georgia
Hawaii
Indiana
Kansas
Kentucky
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
Wyoming



INFORMED DECISION-MAKING LAMINATE

Anyone having a prostate cancer-related event in their state or community?

Please ask us to ship you Informed Decision-Making Laminates (our excellent awareness and educational tool for informed discussions between men and their physicians), as well as our Brochures. 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!

QUARTERLY COALITIONS' CONFERENCE CALL

MARK YOUR CALENDAR – JANUARY 2019

TOPIC: TO BE DETERMINED

“ EVERYONE IS INVITED TO PARTICIPATE IN THE CALL.”

CONFERENCE CALL NUMBER: 218.339.7800

ACCESS CODE: 9381332

NEWS YOU CAN USE...

BONE HEALTH ACCESS ROUNDTABLE

Following the 14th Annual Meeting October 12-14, 2018, NASPCC conducted a separate Bone Health Access Roundtable at The Liaison Capitol Hill, Washington, D.C. on Sunday, October 14 from 1:00 p.m. – 5:00 p.m., followed by a dinner with the attendees. Present were Johnny Payne, Don Lynam, LaTanya Patton, Merel Nissenberg and Tom Kirk (all of whom are on NASPCC's Executive Committee); along with Elizabeth Franklin of Cancer Support Community; Anna Hyde from the Arthritis Foundation; Maureen Rigney from Lung Cancer Alliance; Walt Dardenne (Advanced Prostate Cancer Support Group in California); NASPCC representatives Gabe Rosko (New Jersey), Renee Savickas (Colorado), Beverly Eckert (Arkansas), Dave and Doreen Hulbert (Minnesota), and James West (Florida); Breast Cancer Advocates Vernal Branch and Valerie Fraser; Samuel Denmeade, M.D. of Johns Hopkins; Karl Sjostrand, Ph.D. of Progenics; and Linda Murakami from Amgen.

Dr. Denmeade presented on bone involvement in cancer and the need to use Bone Targeting Agents (BTA's), and Dr. Sjostrand demonstrated accurate bone health imaging for use by clinicians through the Automated Bone Scan Index. Elizabeth Franklin and Anna Hyde both talked to the Roundtable participants about Step Therapy and why we should care, as the insurance rule which is being utilized by certain private insurance companies and which will be applied to Medicare Advantage patients starting January 1, 2019 is likely to interfere with access to prescribed treatments for cancer patients. There was discussion about the 10 new states that have passed legislation on step therapy and patient protections, and the need to make sure that those laws are in fact implemented.

Don Lynam, Chair of NASPCC's Advocacy Committee, agreed that we want to make Step Therapy a priority issue for our organization and hopefully lead the prostate cancer community in this effort, as well as to join state and federal activities geared for that purpose. We will also explore a meeting with Representative Ruiz of California who sponsored federal legislation on Step Therapy that needs to be reintroduced in the new Congress. NASPCC will join efforts by multiple foundations and advocacy organizations in the Step Therapy efforts that they have made and continue to make.



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

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, LMSW
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.



Every issue of The Blue Print, NASPCC's Electronic Newsletter, will feature an article high lighting one of NASPCC's participating state prostate cancer coalitions.



SPOTLIGHT ON:

The Prostate Cancer Coalition of Tennessee (PCCTN)

PCCTN was founded several years ago by prostate cancer survivor Dan McCollum and over the past three years has seen substantial growth due to the addition of three more passionate prostate advocates. These three advocates were looking for a way to make a difference in Nashville in the way men were dealing with prostate cancer. They came across Dan who was known in the area as a person who wanted to change the impact the disease was having on men across the state of Tennessee. Dan laid the foundation for a viable organization by forming an alliance with the NASPCC and establishing its 501 (c) (3) certification.

Since the three joined Dan, they helped take PCCTN to the next level. The coalition now has its own website: www.pcctn.org, trade mark logo, and business card. They developed their own vision and mission statement as well as developed other strategic initiatives. Their mission is to empower men and their families to handle the challenges of prostate cancer through increased awareness, education, and support.

Dan is still on board as the President. Prostate cancer survivor Ira Baxter is the Executive Director, Urologist Dr. Kelvin Moses is the Chief Medical Advisor, and cancer researcher Dr. Flora Ukoli is the Director of Community Outreach. The group now has eight other men that have become the corner stone of a thriving organization.

Since awareness, education, and support are the central focus of the coalition's strategy, they started a men's support group that meets at a neutral location once a month. Ira and Dan still talk about the days when only the two of them would be at the meeting and would comment on how they never knew who might come through the door so they stayed the course until they finally got their first member, Joshua Wiley. The group has a regular following now and developed a creative flyer to pass out as well as they advertise the meeting on a local radio community calendar.

Over the past the three years, the coalition developed partnerships with the Vanderbilt Ingram Cancer Center, Meharry Medical Center, Tennessee State University, American Cancer Society, Pfizer Pharmaceutical Company, Biden Cancer Initiative, Vanderbilt Medical Center, and other local businesses. These partnerships led to a meeting with former Vice President Joe Biden, speaking engagements, several health fairs, barbershop talks, awareness and education campaigns, church events, a wellness award, a newspaper article, and two magazine articles.

The past two years the coalition partnered with TSU in September at their John Merritt Football Classic to do an awareness and education campaign for Prostate Cancer Awareness Month. They gave out education material, spoke to men and woman about the prostate cancer, some of the PCCTN team were featured at half time, the football players wore the blue survivor ribbon, and the coach did a short awareness video that was shown at

different times during the game. This year the coalition was able to speak to the people from their custom designed tent they had made.

Tennessee coalition supports the NASPCC and is fortunate to have representation that works on the NASPCC Board of Directors. They frequently use their materials and find the laminates as well as the pocket size tri-folds very useful at health fairs and other education function. They make note of their partnership on their prostate cancer support group meeting marketing piece and participated in the recently held 14th Annual NASPCC Conference. They also reference the partnership on their webpage.

The future looks bright for the Tennessee Coalition. PCCTN just finished working with Meharry Medical Center to educate the community on the importance of participating in cancer research. They are preparing for their next event which is participating in Vanderbilt University's Relay for Life in November. They are starting to plan for a major prostate screening program, adding a board of directors, growing the current coalition base, working with Pfizer Pharmaceuticals on state cancer policy initiatives, and developing an awareness marketing campaign. Ultimately, PCCTN envisions a world free of prostate cancer.



TSU Football Game





Dr. Chen & PCCTN



2018 Prostate Cancer Awareness Month
Celebration with Victory Church



Our Mission

The Prostate Cancer Coalition of Tennessee's mission is to empower men and their families to handle the challenges of prostate cancer through increased awareness, education, and support.

Our Vision

The Prostate Cancer Coalition of Tennessee desires to become the information and support hub for anyone touched by prostate cancer within the state of Tennessee. Ultimately, PCCTN envisions a world free of prostate cancer.

Contact Us:

4502 Charlotte Ave.
P.O. Box 90564
Nashville, TN 37209-9988.
Phone: 615-330-9684
Email: info@pcctn.org