



*"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

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THE BLUE PRINT NEWSLETTER

LaTanya Patton, Editor

PRESIDENT'S MESSAGE

As we head into Fall 2018 we are excitedly preparing for our 14th Annual Meeting which will again be held at the Liaison Capitol Hill Hotel in Washington, D.C., the same location as last year. (See our Report from the 13th Annual Meeting on the www.NASPCC.org website to get a flavor of last year's Annual Meeting.) The 14th Annual Meeting is entitled "The More We Know..." and will start with a casual reception on Friday evening, October 12, 2018 following the 4th Quarter Board Meeting that afternoon. On Saturday morning, October 13 the Annual Meeting will start in earnest. There will be individual speakers such as Dr. James Gulley from NIH with an update on Immunotherapy in Prostate Cancer; as well as a speaker on the Importance of Hereditary Cancer Testing in Prostate Cancer. There will also be separate panels on topics ranging from genomic testing to advanced prostate cancer (including immunotherapy, hormonal therapy, chemotherapy and anti-androgens), to radiation therapy, targeted therapy and imaging, and presentations on bone metastases in advanced prostate cancer. The Clinical Trial results that were presented throughout 2018 will be addressed by Dr. William Berry of Duke. Saturday afternoon will conclude with elections for 2018-2019, followed by a Cocktail Reception at 6:30 p.m. honoring Dr. Alan Partin, head of the Brady Urologic Institute at Johns Hopkins. A few patients will share some of their journeys through the disease, and we will also be awarding the 2018 Outstanding State Prostate Cancer Organization Award. On Sunday morning, October 14 participants will be presented with a Panel on Emotional and Cognitive Impairment Issues in Prostate Cancer; a Panel on Best Practices; and an Introduction to Step Therapy. Guests are always welcome to attend and should contact me at mgrey@ucsd.edu for details.

Separately, NASPCC will also be conducting a Roundtable on Sunday afternoon and evening, October 14, on Bone Health Access. This should be a very interesting work around Step Therapy and Access Issues in prostate and other cancers. For details, contact mgrey@ucsd.edu. Elsewhere in this Newsletter you will see a short article on Lewis Musgrove, our former Board Member from Nevada, who recently passed away. Lew was a stalwart warrior and a gentleman, and we will miss him.

Our *Advanced Prostate Cancer Laminate* is still a work in progress but we are looking forward to its completion and to its national distribution. The *Informed Decision-Making Laminate* was recently slightly modified after the USPSTF issued its Final Recommendations for testing; the new Informed Decision-Making Laminate as well as our current Brochure for NASPCC are available to all and we have provided many copies to individuals and groups at no charge.

Our free Webinars will continue as will our free quarterly National Conference Calls. We have had two such Calls: one on April 30 on Best Practices and one on July 31 on Social Media. Our next National Conference Call will take place on September 24 and the topic will be the upcoming 14th Annual Meeting. NASPCC Advisory Committees on Advocacy, Education & Awareness, Budget, State Coalition Development, Communications, Medical Advisory, Annual Meeting and Fundraising are going strong. We look forward to a productive Fall 2018. Please let us know if you would like to be more involved in our Committees or with any aspect of NASPCC's work. Respectfully, Merel Nissenberg

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
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 COALITION CONFERENCE CALL

MARK YOUR CALENDAR – SEPTEMBER 24, 2018, 6PM CST.

TOPIC: NASPCC 14TH ANNUAL MEETING, OCTOBER 12-14, 2018

EVERYONE IS INVITED TO PARTICIPATE CALL.

CONFERENCE CALL NUMBER: 218.339.7800

ACCESS CODE: 9381332

NEWS YOU CAN USE...

Looking for Board Members

Board member Johnny Payne of South Carolina, who is Chair of the Nominating Committee for next year's slate of nominees for the Board of Directors, is currently seeking individuals who are interested in serving on the 2018-2019 Board of Directors of NASPCC. Time commitment is minimal: 3 Board Calls (in January, April and July) and attendance at the Face-to-Face Board Meeting on the afternoon before the Annual meeting takes place. No experience necessary, just an interest in the mission of NASPCC! For details, please contact Johnny Payne at johnnyrpayne@charter.net or mgrey@ucsd.edu.



A Prostate Cancer Warrior Leaves Us

CPCC is sad to report the passing of **Lewis Musgrove**, a giant of a man and a tireless warrior in prostate cancer. Lew was one of the founding members of the California Prostate Cancer Coalition in 1997 and, although he lived in Las Vegas, we kept him on our Board of Directors for as long as we could because he was a wonderful colleague and an activist in saving men's lives and helping their families.

Lew worked with the State of Nevada in creating their Prostate Cancer Task Force and he led a vibrant UsTOO Support group in Las Vegas that I was fortunate to address at one of their meetings. Lew also became the first Nevada representative to the National Alliance of State Prostate Cancer Coalitions; he participated in the first organizational meeting of NASPCC in 2004 and served on our Board of Directors. We at CPCC and at NASPCC were always lucky to have the benefit of his wise counsel and endearing personality.

Always passionate, Lew had a favorite expression that I remember fondly. He wanted people to stay focused, otherwise, he would say, it was like "getting on your horse and riding off in all directions". Lew was vigilant in seeking and training patients and state leaders to create ways to contact federal and state representatives in order to make the needs of the prostate cancer community known. He also served as Chairman of the Board of UsTOO International.

We at CPCC and NASPCC were proud to call Lew Musgrove our own. Lew leaves behind children and a caring wife, Sue Ann. Condolence cards can be mailed to Lew Musgrove's family at: 6408 Vicuna, Las Vegas, Nevada 89146. Contributions can also be made to CPCC in Lew Musgrove's name by sending them to the CPCC Treasurer, Earl Jones, at 4581 Don Felipe Drive, Los Angeles, California 90008.

--Merel Nissenberg

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 North Carolina (PCCNC)

The PCCNC was officially formed as a 501(c)3 non-profit on March 21, 2001. Prior to this, the late Robert “Bob” J. Anderson, worked with others nationally to help secure and support the Department of Defense (DoD) Congressionally Directed Medical Research Fund (CDMRP), and on a local level Bob also worked diligently to establish state mandates for coverage of screening and to network support groups and hospitals throughout the state. This groundwork proved a critical foundation to forming a truly statewide coalition.

One point of frustration prostate cancer patients faced collectively throughout NC was the lack of attention given to prostate cancer compared to breast cancer awareness. In response to this, the PCCNC developed the Brothers & Sisters program, whereby prostate cancer awareness advocates have an active platform to partner with breast cancer awareness advocates. The program leverages key overlapping messages about prevention, early detection, and survivorship to draw compassionate analogies between the 2 cancers. The program has since expanded to engage colorectal cancer awareness advocates in this important discussion.

These foundational activities made NC a prime candidate as a pilot site for the UsToo Minority and Underserved Populations Outreach and Awareness Program. By 2006, we had further expanded our statewide network to include influential groups, most of whom through the NC Office of Minority Health and Health Disparities. During this time, PCCNC colleagues at North Carolina's 3 National Cancer Institute (NCI) Academic Research Centers held deepening discussions about shared concerns of survivors regarding who and how men were being screened for prostate cancer. By 2005, medical leadership reached consensus and, under the banner of the PCCNC, published clinical screening and early detection guidelines in a clinically usable 2-sided one page summary of what were, at the time, emerging “best practices” in respect to utilization of the prostate specific antigen (PSA) blood test and the digital rectal exam (DRE). The reversed side consisted of what were considered, at the time, “best practices” regarding follow-up for abnormal screening results. These guidelines were comprised of a compilation of “best practices” for early detection as defined by the National Comprehensive Cancer Network (NCCN) and the American Urological Association (AUA).

This effort proved a tremendous success, and for 6 years these guidelines were annually updated, produced, and disseminated through active partnership with the NC chapter of the American Academy of Family Physicians (AAFP). NCAFP members provided valuable insight regarding concerns over screening, most notably community health literacy, access to care, and overtreatment of prostate cancer. This provided justification for 2 additional PCCNC initiatives. We had been tracking and promoting low and no cost screening events throughout the state, so (1) we began informally assessing said events to better understand how they might promote or interfere with community health literacy and access to care, and (2) we developed a navigation tutorial for newly diagnosed men to assist them in better understanding diagnosis, appropriate care based on risk, and evidence-supported tests and treatments.

On the heels of these initiatives and activities, in 2011 the National Institutes of Health (NIH) held a conference in attempt to provide a consensus report of use of active surveillance to manage prostate cancer. Shortly thereafter, in 2012 the United States Preventive Services Task Force (USPSTF) released guidelines that actively discouraged screening to promote the early detection of prostate cancer. Notably, all of these efforts were seeking to solve different dimensions of the same problem. That problem being, “how do we find potentially lethal cancers early enough to provide potentially life-saving care, while sparing individuals with low-risk cancers the burden of non-life saving but quality of life impacting “over” treatment?.”

Sadly, the USPSTF response crippled the more compassionate and reasonable efforts of the NIH and many state coalition activities. The USPSTF has since reconsidered their guidelines, and our efforts today reflect lessons learned from the past. Specifically, the importance of engaging all interested and concerned parties, be they public health professionals, physicians and other clinical care givers, and especially patients, survivors, and their loved ones.

Our 2 primary focus areas for collaboration are (1) men’s health screening, and (2) lay-health navigation.

Men’s Health Screening targets men in their 40s and above to help them better understand cardiovascular and cancer risk as defined by the Centers for Disease Control and Prevention (CDC). These low and no cost screening events provide baseline assessments to help men understand their personal risk(s) and individual guidance for follow-up. There are 3 phases to each event: (1) baseline awareness and education men’s health engagement events; (2) clinical screening event day; and (3) in person 1 on 1 face to face follow-up appointment whereby results are personally reviewed and empowering information is provided in respect to personally appropriate preventive measures to consider, locally available primary care clinical resources, and referral to a specialist if appropriate.

Lay-health Navigation is a collaborative effort with American College of Surgeons (ACoS) accredited Commission on Cancer (CoC) accredited community cancer centers. These centers prioritize localized availability of multidisciplinary and holistic community care. Navigators are trained to educate patients about NCCN treatment guidelines (gold standard “best practices” accepted by most community cancer centers), and to familiarize them with other resources, such as multidisciplinary treatment consultation and other locally available ancillary services.

Over the years, we have also produces a series of public service announcements and participated in the support of various legislative initiatives including the creation of a prostate cancer awareness license plate. While valuable, we’ve come to realize that addressing the depth and breadth of the issues we face as stated above is essential to truly addressing the challenges related to prostate cancer in our state.



www.pccnc.org



Pictured: (left to right) Robert "Bob" J. Anderson (Father of Mary Anderson), Leroy S. Darkes, MD (PCCNC board member, doctor of internal medicine, and son of a prostate cancer survivor), and Michael Taylor, PhD (son of a man lost to prostate cancer, and past organizer of Feet for the Fight Prostate Cancer Awareness run).



NCAFP is a picture of the 2009 plenary session at the NC Academy of Family Physicians.



FIGHT PROSTATE CANCER

Know your Score

GOLF OUTING

September 27th, 2018



Stevens Point, Wisconsin • 18 hole – 4 person scramble
Registration opens at 8:00AM • 10:00AM Shotgun start
Continental breakfast, lunch and social hour (appetizers)


**Expand your knowledge of prostate screening
services right here in Central Wisconsin.
We encourage you to know your PSA score!**

"PSA testing is currently a man's best defense against dying of potentially lethal prostate cancer and against developing metastatic prostate cancer. Individuals have a fundamental right to choose whether or not they want to know if they have prostate cancer, prior to becoming symptomatic."

- Wisconsin Prostate Cancer Coalition



**Event Chairman: Dave Marie,
Board Certified Physician Assistant**

Sponsorship opportunities contact:
D.Marie@theurologyclinic.org 
715-295-9942

National Alliance of State Prostate Cancer Coalitions



Seated left to right: Jan Marfyak, Johnny Payne, Merel Nissenberg, Don Lyman, and LaTanya Patton
Standing from left to right: Alvin Chin, Paul Kradel, Mary Anderson, Dave Hulbert, Ira Baxter, Michael Zaragoza and Robert Johnson **not pictured:** Patricia Green and Sanford Jeames

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Merel Grey Nissenberg, President
Johnny Payne, Vice President
Jan Marfyak, Secretary
Donald Lynam, Treasurer

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Merel Grey Nissenberg, President
Johnny Payne, Vice President
Jan Marfyak, Secretary
Donald Lynam, Treasurer
LaTanya Patton, Director at Large.
Tom Kirk, Invited Member

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