

"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 3 July 2018

THE BLUE PRINT NEWSLETTER

LaTanya Patton, Editor

PRESIDENT'S MESSAGE

The first half of 2018 has been extremely busy with my attendance at the ASCO GU (Genitourinary) Cancers Meeting in San Francisco in February; the American Urological Association Meeting in San Francisco in May; and then the ASCO (American Society of Clinical Oncology) 2018 Meeting in Chicago at the beginning of June. In between all of the Meetings there have been communications with sponsors and the planning of Webinars.

NASPCC has presented 3 Webinars so far this year: The first, on January 30, was on "Localized Prostate Cancer", with Dr. Ashley Ross as speaker. Dr. Ross has since joined our Medical Advisory Board and has attended and presented at several of our Annual Meetings. Our 2nd Webinar was held April 3 on the "AR-V7 Splice Variant and Treatment Choices in Prostate Cancer", and was sponsored by Genomic Health. Presenters were Ryan Dittamore of Epic Sciences and Deb Davison of Genomic Health. Our 3rd Webinar was held May 9 on "Genetic Testing and Genetic Counseling in Prostate Cancer" and was presented by Dr. Leonard Gomella, chair of the Consensus Panel on the topic last Fall. With the exception of the first Webinar, the slides from which are on the NASPCC Website, all the other Webinars were recorded and those recordings plus the slides are archived on the NASPCC Website.

Plans are already underway for the 14th Annual Meeting to be held at The Liaison Capitol Hill Hotel in Washington, D.C. October 12-14, 2018. We are hoping for an even bigger turnout than last year and will have some surprises in store. Awards will also once again be presented at the Saturday Night reception. Anyone who would like to attend the Annual Meeting or serve on the Annual Meeting Committee, please e-mail me at mgrey@ucsd.edu.

NASPCC is excited to announce that it is undertaking a year-long project, the Bone Health Access Initiative, sponsored by Amgen. The work will include a Roundtable on Bone Health which will be held after the Annual Meeting. Anyone who has been treated with bisphosphonates for bone metastases please contact me at the above e-mail address; we are interested in your experiences with the therapy and any side effects you may have experienced.

NASPCC was also honored to be asked by CancerCare to co-sponsor their Online Prostate Cancer Support Group which starts in June and runs for 15 weeks, and is a fully moderated group. For details, please contact me at mgrey@ucsd.edu or reach out to CancerCare directly.

A few months ago the U.S. Preventive Services Task Force finalized its Recommendations for Prostate Cancer Screening. It now advocates for informed discussions on the topic of screening between a man and his physician - but only for men 55-69. It does not support testing for men 70 and over or men younger than 55. Furthermore, the Recommendations do not have a separate age recommendation for men with a family history of prostate cancer or men of African-American descent, nor do the Recommendations even mention exposure to Agent Orange as a risk factor for the disease. On the NASPCC website is the letter I wrote to the USPSTF explaining why we cannot support their new recommendations appears on our NASPCC website. Here it is: https://naspcc.org/index.php/naspcc-responds-to-the-uspstf-final-recommendations. Elsewhere in this Newsletter you will find a link to the Report I wrote about the recently concluded ASCO 2018 Meeting. That Report will also be found on the NASPCC website. There is, as always, much that is new in prostate cancer. Our work continues!

Respectfully submitted, Merel Grey Nissenberg, President

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

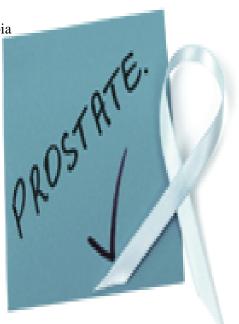
Utah

Virginia

Washington

West Virginia

Wyoming





NASPCC participated in the Advocacy Hub at the 2018 AUA Meeting in San Francisco. Tom Kirk and Merel Nissenberg represented NASPCC and were able to provide information to attendees on what NASPCC is and does to help prostate cancer patients and their families.

In the July issue of Prostatepedia, NASPCC President
Merel Nissenberg discusses Hypofractionated
Radiotherapy and whether it is ready for Prime Time.
The link to the article will be available on
www.naspcc.org or

at https://prostatepedia.blog/2018/07/02/ms-merel-nissenberg-hypofractionated-radiotherapy/

QUARTERLY COALITION CONFERENCE CALL

MARK YOUR CALENDAR – JULY 31, 2018, 6PM CST.

TOPIC: SOCIAL MEDIA

EVERYONE IS INVITED TO PARTICIPATE CALL. CONFERENCE CALL NUMBER: 218.339.7800

ACCESS CODE: 9381332

NASPCC Committee Progress Summary: June 2018

As you may recall, NASPCC created a new work plan following two Strategic Planning sessions held during April and May 2017 and a new Strategic Plan which was passed by the NASPCC Board in July 2017. In November 2017 eight Committees were formed by the Executive Committee to move forward the plan. To date, there have been fourteen committee meetings held and seven more are planned.

Major tasks/accomplishments have included a rapid increase in the number of active Facebook posts, Webpage updates and changes, three new Webinars which were conducted (in January, in April and another in May) as well as, two editions of the "Blue Print" Newsletter which were completed in January and March. A third is being prepared.

Also completed was the first State Representative Conference call held on April 30th on "Best Practices" and several articles printed in Prostatepedia, as well as a panel presentation on Informed Decision-Making at AUA's Advocacy meeting in DC which was held in March.

In process is a new Draft for an Advanced Disease Laminate, initial planning for the 15th Anniversary Gala & Education event (which was addressed in the May Executive committee meeting) as well as other State Representative Conference calls planned for July and September/October and finally acceptance of a new Bone Health Access Initiative by the Executive Committee in May (which features a Round Table meeting after the Annual Meeting).

- 1) Education & Awareness: Johnny Payne, Chair, Patricia Green, Co-Chair
 - a. First meeting 12/01/17, Second meeting 3/02/18, Third meeting Planned for 6/01/18 was moved to and held on 6/15, the Fourth is set for September 7th.
 - b. Webinar #1: 1/30/18, "Tissue Biomarkers for Localized Prostate Cancer" by Ashley Ross, MD, #2: 4/03/18, "AR-V7 Splice Variant and Treatments Choices in Prostate Cancer" by Ryan Dittamore of Epic Sciences and Deb Davison of Genomic Health, #3: "Genetic Testing and Counseling in Prostate Cancer" by Leonard Gomella, MD held on 5/09/18
 - c. Advanced Disease Laminate, first Draft in place
 - d. Prostatepedia, article submitted on Genetic Testing
 - e. AUA Informed Decision-Making Panel, 3/12-14/18 in DC
 - f. Cancer Care On-line support group target launch June
 - g. 15th Year Gala Education Celebration, initial planning draft questions and Executive Committee planning discussion on May 1st.
 - h. Bone Health Access Initiative accepted in Executive Committee discussion on May 1st and contract signed with Amgen on May 21st. Planning for a Round Table meeting is being planned after the Annual Meeting.
- 2) Communications: LaTanya Patton, Chair, Ed Haddad, Co-Chair
 - a. First meeting 1/18/18, Second meeting 2/22/18, Third meeting scheduled 3/22/18 rescheduled & held 3/29/18, Fourth committee meeting held 4/26/18 to plan first State Representative Conference call, the Fifth committee call set for 5/24 was cancelled, next call set for June 28th
 - b. First "Blue Print" Newsletter out 1/29/18, Second out 3/29/18, Third is planned for June (copy deadline 20th)
 - c. First Conference call with State Coalition Leaders held on Best Practices on April 30th, next planned in July (31st)/planned early October or late September for next, all after email inquiry email from LaTanya showed interest
- 3) Budget: Don Lynam, Chair
 - a. First meeting 3/12/18, Second held 6/11/18, Third set for August 3rd
- 4) State Coalition Development: Ira Baxter/Rob Johnson, Co-Chairs
 - a. First committee call held May 23rd and Second committee call set for June 27th.

- b. WI, TX, AZ, WY and OR have been discussed
- 5) Advocacy & Public Policy: Don Lynam, Chair
 - a. First meeting 2/05/18, Second meeting 3/12/18, Third meeting held 4/23/18, Fourth held 6/11/18 and the Fifth call set for August 3^{rd} .
 - b. Monitoring OVAC and DHRC activities (budget increase passed for prostate cancer, FY 19 now the focus) REPORT FROM ASCO 2018 cont.
- 6) Annual Meeting: Merel Grey Nissenberg, Chair
 - a. First call was held on 5/04/18 (and the same location as last year was approved), the Second call was held on 6/12/18 (and the contract has been secured) and the Third committee call is planned for July 6th.
- 7) Fundraising: Merel Grey Nissenberg, Chair
 - a. Active but no Committee meetings/calls yet, EC reports from Merel on activities
- 8) Medical Advisory: Michael Zaragoza, Chair
 - a. No Committee meetings yet
 - b. Ashley Ross appointment and acceptance, following 3/06/18 EC discussion

REPORT FROM ASCO 2018

Submitted by Merel Nissenberg, NASPCC President

The 2018 American Society of Clinical Oncology Meeting took place in Chicago June 1-5, 2018 and I attended the entire Meeting. Unlike some past ASCO Meetings (including the ASCO Genito-Urinary Cancers Meeting ("ASCO GU") held in February of this year, there were no earth-shattering dramatic findings or clinical trial results to report. There were, however, some interesting findings and hopeful news that need further investigation and research. Additionally, we learned that Dr. Bruce Johnson, President of ASCO and a lung cancer specialist, was recently diagnosed with prostate cancer, and in his Presidential Talk during a plenary Session, he told the attendees what it was like to be a cancer patient and how it has impacted him. At that session we were also fortunate to hear from Dr. Norman Sharpless, the new head of the National Cancer Institute; and from Dr. Scott Gottlieb, new Commissioner of the FDA. Some interesting talks were "Immunotherapy Beyond the Checkpoints: CARS, trucks and More" from Dr. Carl June; "Metastatic Prostate Cancer Tumor Board: Optimizing Patient Selection and Treatment"; and an Oral Abstract Session on Prostate Cancer.

In a Phase III Trial from the Scandinavian Prostate Cancer Group (SPCG-13), findings presented showed that adjuvant chemotherapy (docetaxel) without prednisone did not improve biochemical disease-free survival in men with intermediate-risk or high-risk prostate cancer who have undergone radical radiation therapy with ADT (androgen deprivation therapy). In Arm A of the Trial men received 6 cycles of adjuvant docetaxel without continuous prednisone, and in Arm B there was only surveillance of the patients. After 5 years, there was no disease progression observed in 69% of pat8ents in Arm A and in 69.7% of patients in Arm B.

There was no difference in the primary endpoint between the Arms. In analyses, Gleason Grade looked to be the only factor predictive for progression; and a sub-group analysis there was a trend favoring docetaxel for patients with a Gleason greater than 8, but the P value was not statistically significant. Reports on the PROSPECT Trial were disappointing: there was no overall-survival benefit seen for patients with asymptomatic or minimally-symptomatic metastatic castration-resistant prostate cancer (CRPC) who

were treated with the PROSTVAC-V/F (PRO) cancer vaccine, compared with placebo. The Phase II trial had shown an 8.5 month improvement in survival (OS), but after three interim analyses of the data from the Phase III trial of PRO, the data monitoring committee recommended that the PROSPECT Trial be closed down. These results were presented by Dr. James Gulley (Building 10 at NIH) who presented at NASPCC"s 13th Annual Meeting and who is scheduled to return to give us an update on Immunotherapy in Prostate

REPORT FROM ASCO 2018 cont.

Cancer at this year's 14th Annual Meeting. While overall survival in all arms was approximately 1 year longer than anticipated, it was surmised that that was because of improved standard of care. One of the commenters suggested that we need to make prostate cancer more immunogenic to checkpoint inhibitors and vaccines so that we can see the same results with immunotherapy that we have seen with other cancers. Now at ASCO 2018 Dr. Gerhard Attard reported on the Health-related Quality-of-Life (HRQL) and pain evaluations of the men in the PROSPER Trial. Results were similar in both the enzalutamide and placebo arms. Based upon all of the results, Dr. Attard reported that along with the PROSPER results and the results from the SPARTAN Trial (using apalutamide), men in the non-metastatic, castrate-resistant space.

A very exciting area of research involves the interim results of a Phase II trial utilizing Lutetium-177-PSMA617 (LuPSMA). LuPSMA is an anti-prostate-specific-membrane antigen (PSMA) monoclonal antibody combining the precision of those antibodies with anti-tumor effects of Beta radiation. PSMA is restricted to the prostate membrane and is overexpressed 100-1000 time in prostate cancer. So the thought is that since it can be detected with RT-PCR assays in the blood it may be able to be used as a marker or micro-metastatic disease. Lutetium-177 is then used as an imaging agent. In the Phase II study, patients were given Lu-PSMA-617 four cycles at six weekly intervals. PSA response was the primary endpoint. There were high response rates (82%) with a very favorable profile of adverse events (AE). These results have now led to a current Phase III Trial, VSION, which will compare patients receiving Lu-PSMA-617 plus best supportive care alone or with a novel anti-androgen axis drug, compared to best supportive care alone. There is also now the ANZUP/PCFA TheraP trial which will compare Lu-PSMA-617 with cabazitaxel. discussion on the Phase III SPARTAN Trial took place at ASCO 2018. Dr. Matthew Smith and colleagues discussed the SPARTAN results that had been presented at ASCO GU in February 2018. In February the results showed that apalutamide decreased the risk of metastasis or death by 72% and prolonged metastasis-free survival by more than 2 years in men who had high risk but non-metastatic CRPC. The subject at ASCO 2018 presented by Dr. Smith was the time to metastasis and site of metastasis in patients with non-metastatic CRPC. He assessed the relationship between time to metastasis and the site of metastases after androgen-deprivation therapy (ADT) plus apalutamide or placebo. The patients that developed metastases were: Nodal: apalutamide 30% versus

Merel Nissenberg, President of NASPCC, full report from ASCO 2018 that can be read at: https://tinyurl.com/y7b5po92. The Report also appears on the NASPCC website, www.naspcc.org or https://naspcc.org/index.php/resources/reports

placebo 40%; Bone: apalutamide 57% versus placebo (52%); and Visceral: apalutamide 13% versus placebo 8%. So the SPARTAN study confirmed that apalutamide markedly decreased the risk of time to metastasis, regardless

of site.

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 Arkansas Prostate Cancer Foundation

Helping Arkansans Affected by Prostate Cancer The Mission of the Arkansas Prostate Cancer Foundation

The Arkansas Prostate Cancer Foundation (APCF) was founded in 2000 by six Little Rock business men who were diagnosed with prostate cancer and realized there was a need to help other Arkansans who were fighting the disease. *The Foundation's mission is to promote awareness, encourage timely detection, and support improved treatment of prostate cancer in Arkansas.* The Foundation's Staff, seventeen member Board of Directors, fifteen member Medical Advisory Board (comprised of urologists, prostate cancer researchers, family physicians, a radiation oncologist and a medical oncologist), and numerous volunteers around the state support this mission. The Foundation is an independent 501 (c) (3) organization, and its tax identification number is 31-1694978.

The Arkansas Central Cancer Registry (ACCR) reports that prostate cancer is the second leading cause of cancer-related death in Arkansas men. Even though the overall death rate for prostate cancer and the incidence of metastatic disease at the time of diagnosis have decreased significantly over the past two decades, the American Cancer Society (ACS) estimates a rise in mortality in 2018 to 29,430 U.S. men (280 in Arkansas). Of these more than two times as many African American men will die as Caucasian men. Furthermore, the ACS notes that other than skin cancer, prostate cancer is the most commonly diagnosed cancer in American men with an estimated 164,690 cases (1260 in Arkansas) projected to be diagnosed in 2018. *The Arkansas Prostate Cancer Foundation believes that access to information and care should be available to all men in the state especially those facing healthcare disparities.* Therefore, the Foundation attacks prostate cancer in Arkansas through an umbrella program called the Campaign Against Prostate Cancer. This umbrella program is comprised of the following services all of which are provided free of charge thanks to support from the Arkansas General Assembly, the Arkansas Department of Health, private and corporate grants and donations, plus significant in-kind support from corporate sponsors:

1. Awareness /Outreach -

Because cultural and linguistic barriers to care are a major concern in Arkansas, the Foundation recognizes that increased awareness is key to the Campaign Against Prostate Cancer because men need to know:

- the risks and symptoms of prostate cancer,
- the importance of appropriate screening for early detection including the pros and cons of the PSA test, and
- that one-on-one prostate cancer specific patient navigation (advocacy) services are offered by the Foundation to guide patients through the often daunting healthcare system.

Spotlight cont.

In addition to traditional venues such as health fairs across the state, the Foundation consistently looks for ways to reach broad sectors of uninformed men. One such initiative is the Blue Ribbon Campaign sponsored by the Foundation throughout the month of September, Prostate Cancer Awareness Month. During this campaign, the Foundation distributes blue ribbon decals (signifying prostate cancer awareness) to 11 colleges and every high school across the state. Each football player at the participating schools wears a decal on his helmet, and there are public service announcements during games and on radio broadcasts explaining the prostate cancer awareness message represented by the Blue Ribbon.

Another priority for the Foundation has been to work with its Medical Advisory Board to develop up-to-date materials for distribution to family physicians around Arkansas regarding the latest screening, diagnostic and treatment information on prostate cancer and to make the family practice community aware of Foundation services available for their patients.

In addition, the Foundation plans to host a women's event in November, 2018 to kick off a campaign to engage more women to "Join our cause and share the word" about prostate cancer. In general, men have poorer health habits than women; and most often it is women who encourage the men in their lives to pay attention to men's health issues like Prostate Cancer.

2. Prostate Health Resource Center –

The Foundation's Resource Center houses hundreds of books, pamphlets, brochures, and other materials that are distributed free of charge to any healthcare provider or person involved in the battle against prostate cancer. These resource materials are available in either Spanish or English and are tailored to individual literacy levels. In 2017 the Foundation distributed 12,683 educational books and brochures to health care providers and the public at large.

3. Education and Screening –

Free education and education/screening events are coordinated and hosted at numerous locations around the state in collaboration with local partners at workplaces, community health centers, hospitals, clinics, churches and health fairs; 65 events were sponsored in 2017. Because it is critical that men make informed decisions about whether or not to be screened for prostate cancer, APCF focuses on a description of prostate cancer risks and symptoms as well as an explanation in plain language of the benefits and risks of detection, diagnosis and treatment of the disease.

When prostate cancer screenings are a component of an event sponsored by the Foundation, all participating men are asked to provide information that helps the Foundation identify individual risk factors and the prostate cancer health literacy of each participant. Within 2-4 weeks of the education/screening event, each man receives an explanation of his results and a recommendation for follow up if needed. Follow up with an urologist is recommended if a man has an abnormality detected on the DRE (if offered) or because a PSA score is of concern pursuant to the 2017 Early Detection Guidelines for Prostate Cancer established by the National Comprehensive Cancer Network (www.NCCN.org). In 2017, the Foundation provided free screenings to 2,579 men and provided prostate health awareness and education for 62,230 people at 65 events throughout the state.

4. Patient Navigation (Advocacy) Program -

Any man receiving a letter recommending follow up with an urologist because of a suspicious finding or any man who contacts the Foundation for help is followed by the Foundation's Patient Navigator (Advocate). The Navigator works one-on-one with patients and often their family members to explain the nature of suspicious results and to encourage and help secure follow up with a physician. If a man is diagnosed with prostate cancer, the Patient Navigator continues to assist with decisional, emotional and logistical support as well as identification and securing of needed resources throughout the treatment and recovery period. The Foundation focuses on not only preserving life, but also preserving quality of life. In 2017, the Foundation's Patient Navigator provided one-on-one prostate cancer specific support to 492 men through over 2,168 contacts.

5. Peer Network - Prostate Cancer Support Groups

The Foundation provides a Peer Network of support groups for any patient, caregiver, family member or friend who is dealing with prostate cancer. The Peer Network support groups meet routinely in five locations (Little Rock, Ft. Smith, Springdale, Conway, and Jonesboro). These meetings provide a confidential environment where participants can talk freely about questions and concerns related to prostate cancer detection, diagnosis, treatment and recovery. Additionally, one-on-one support is offered through the Foundation's Survivor - Mentor Program.

For questions or additional information about the services of the Arkansas Prostate Cancer Foundation, please call 501-379-8027 or visit the Foundation's website www.arprostatecancer.org.





Relay 2010 Event (above)

Honda III (below)

Pea Ridge Football Game (above)

Brenda (below)









COALTIONS NEWS (CONT.)...



Save the Date, Save a Life! August 4th, 2018

The National African American Male Wellness Walk Initiative (AAWALK) was established in 2004 to combat the alarming numbers of African American men dying prematurely to preventable diseases.

Be Inspired...

On **Saturday, August 4th 2018 at RFK Stadium** men, women and children will come together at the annual National African American Male Wellness Initiative 5k walk/run to raise awareness in the area of health disparities among African American men.



National Center for Urban Solutions | 202.489.0560 | jross@aawalk.org | www.aawalk.org

COALTION NEWS (CONT.)...



The Prostate Cancer Coalition of Tennessee has been working on a new approach for their area to provide information to the community. They are starting what is being called "The Barbershop Initiative". They targeted one shop for now to spend a couple hours on Saturdays to just hang out with the clients and talk about any aspect of prostate cancer they want. Their Chief Medical Officer and Ira Baxter are doing the talk. Dr. Kelvin Moses is the Chief Medical Officer and he will handle the medical side. Ira Baxter will discuss prostate cancer from the survivor side. The goal is to increase awareness and education about the disease. They also are looking to get more men involved with our coalition as well as get more men tested. For more information contact:

Ira Baxter, MBA, PMP | PMO Director, 310 Great Circle Road, Suite 4 West, Nashville, TN 37243; Phone: (615) 507-6610 Mobile: (615) 330-9684;

Email: <u>Ira.Baxter@tn.gov</u>



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

Board of Directors

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

Executive Committee

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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