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*"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 2  
April 2018

## THE BLUE PRINT NEWSLETTER

**LaTanya Patton, Editor**

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### **PRESIDENT'S MESSAGE**

Welcome to the 2<sup>nd</sup> Quarterly Newsletter in 2018 for the National Alliance of State Prostate Cancer Coalitions! The activities we are engaging in as representatives of NASPCC continue to register off the charts in terms of reach, uniqueness and benefits for patients and their families. In February I attended the 2018 American Society of Clinical Oncology (ASCO) Genitourinary Cancers Symposium in San Francisco. This Meeting represented four solid days of presentations, lectures, symposia and meetings with companies who are working in the prostate cancer space. A lot of new information was presented that will impact prostate cancer patients for the better. I prepared a Report from 2018 ASCO GU and distributed it to our Listserve, and it is also available on our NASPCC website. The link to the Report is: <https://tinyurl.com/yayvcubo>.

In mid-February Tom Kirk on our Executive Committee and I prepared our first NASPCC Annual Report 2017-2018. Our Executive Committee accepted the Report at our February Meeting and it is being sent to our state coalitions' Listserve. The Annual Report appears on our Website at <https://tinyurl.com/yaagpmnd>. We welcome any comments on this project that was the culmination of a great deal of work.

In early March I participated as the national Patient Advocate for the Early Detection Research Network (EDRN) of the National Cancer Institute, an advocacy activity I began in 2008. Part of my EDRN duties involves the GU Cancers Collaborative Group, and I shared with them our updated Informed Decision-Making Laminate and our new NASPCC Brochures. Then on March 11-14 I participated in the American Urologic Association (AUA) 1<sup>st</sup> Annual Advocacy Summit, with 260 attendees. NASPCC's Informed Decision-Making Laminate (that NASPCC adopted as a National Initiative a few years ago) was featured during the AUA Session on Informed/Shared Decision-Making at which I answered questions following my PowerPoint presentation. All 100 Laminates I brought were taken by the attendees, along with our NASPCC Brochures. Next up in terms of Meetings are the AUA Annual Meeting in San Francisco, May 17-20, and the Annual ASCO Meeting in Chicago May 31-June 5.

Our Webinar Series for 2018 continues as well! Our next and 2<sup>nd</sup> Webinar of the Series will take place Tuesday, April 3, 2018 at 6:00 p.m. CENTRAL and will feature Ryan Dittamore of Epic Sciences and Deb Davison of Genomic Health on "[AR-V7 Splice Variant and Treatment Choices in Prostate Cancer](#)". This Webinar is supported by Genomic Health and mirrors the launch of the AR-V7 Test a few weeks ago. The results of that test are helpful for men making treatment decisions. Each Webinar has 100 portals and is free to attendees. Each Webinar is an hour of presentation with Q & A following. The Webinar will be recorded and archived on our NASPCC Website. Please contact me at [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu) to get details on how to register for the April 3, 2018 Webinar. (The Next Webinar in the series will take place May 9, 2018, will be supported by Myriad Genetics and will be on "Genetic Testing and Genetic Counseling".)

Our work continues. Please let us know how your state organization is doing and how we can help! Once again, let me say that we would like each state coalition to use the words "Proud participant in the National Alliance of State Prostate Cancer Coalitions" on its brochures, website, Facebook Page and any events. This will enhance stature and influence!

Best regards, Merel Nissenberg

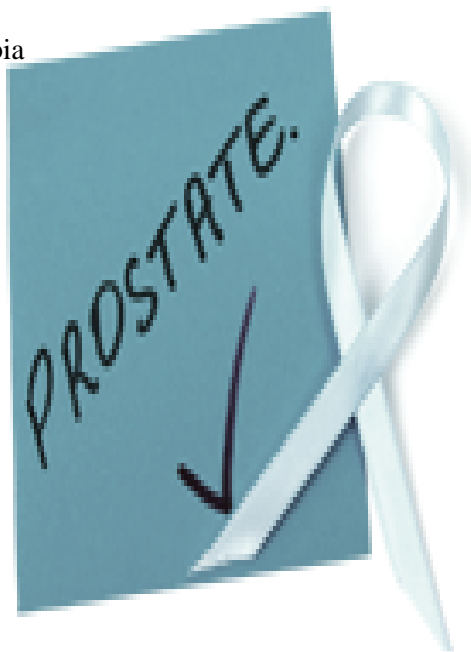
## **About NASPCC: OUR MISSION STATEMENT**

**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



**NASPCC has authored a quarterly article for the April issue of Prostatepedia on genetic testing and genetic counseling. The issue goes to press on April 1, 2018.**

**NASPCC will participate in the AUA Advocacy Hub at the Annual AUA Meeting in San Francisco, May 17-20, 2018.**

### **National Alliance of State Prostate Cancer Coalitions Webinar Series**

Join us for a webinar on Apr 03, 2018 at 6:00 PM CDT.

**Register now!**

Please join NASPCC for an important Webinar on a new, exciting topic! Ryan Dittamore of Epic Sciences and Deb Davison from Genomic Health will be presenting on "AR-V7 Splice Variant and Treatment Choices in Prostate Cancer".

*\*Supported by Genomic Health*

After registering, you will receive a confirmation email containing information about joining the webinar.

**REMINDER: THIS TUESDAY, APRIL 3 AT 7:00 pm Eastern is our 2<sup>nd</sup> Webinar of 2018. Please see elsewhere in this newsletter for "How To Register" OR Call Merel Nissenberg 619-518-6465**

### **QUARTERLY COALITION CONFERENCE CALL**

**MARK YOUR CALENDAR - APRIL 30, 2018, 6PM CST. EVERYONE IS INVITED TO PARTICIPATE  
CALL NUMBER FORTHCOMING.**

## NEWS YOU CAN USE...

**ADVANCED PROSTATE CANCER LAMINATE:** NASPCC is currently working on an Advanced Prostate Cancer Laminate to complement the Informed Decision-Making Laminate we are already using for men not yet tested. If you have any suggestions for distribution, content etc. please contact either Dave Hulbert at [dhulbert@mnpsc.org](mailto:dhulbert@mnpsc.org), or Merel Nissenberg at [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu). Our aim is to provide talking points for an informed discussion between a man and his physician on Advanced Prostate Cancer so that they can jointly make decisions on care and treatment. We plan on one side for the patient and the flip side for his treating physician. There will be laminated copies of the guide as well as an electronic version for downloading.

**BIG NEWS!!!** “Shhh....Too soon to announce quite yet, BUT in Mid-April, NASPCC will be seeking patients for an Online Support Group in Prostate Cancer which we will be conducting with a very well-known national Cancer organization, name to be announced...The online sessions will start mid-June, with ability to register at the appropriate time...STAY TUNED...”

### 3<sup>rd</sup> IN OUR 2018 WEBINAR SERIES

NASPCC's 3<sup>rd</sup> Webinar in their 2018 Series will be on “**Genetic Testing and Genetic Counseling**” based upon the Consensus Statement that derived from the Philadelphia Meeting on the subject last Fall...This Webinar will be supported by Myriad Genetics, and will feature fascinating and helpful material on genetic testing and on the meaning and practical effect of the involvement of certain genes such as BRCA 1 and BRCA 2. It will take place **May 9, 2018 at 7:00 p.m. Eastern**, and will be presented by Dr. Leonard Gomella who chaired the Consensus Conference on Genetic Testing last Fall. His presentation will cover the topics that make up that Consensus Statement, such as testing for BRCA 1 and 2 alterations and mutations. These genetic changes, mutations, and alterations are important not only for men with prostate cancer but also for women in their families with respect to risk of other cancers. The link to register for the May 9, 2018 Webinar is <https://tinyurl.com/ybfhp4pm> Please contact [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu) for details.

**AUA COLLABORATION:** NASPCC participated in the 1<sup>st</sup> AUA Annual Advocacy Summit in Washington, D.C. March 12-14, 2018 and contributed to a panel on the topic of Informed (Shared) Decision-Making. Merel Nissenberg presented and distributed 100 of our Informed Decision-Making Laminates to some of the 260 attendees at the Summit. The AUA has requested follow-up to see how they can collaborate with NASPCC to help patients.

### FACEBOOK PAGE

Please “LIKE” the Facebook Page for the National Alliance of State Prostate Cancer Coalitions (there are two, so make sure you “like” the correct one, the one with all the medical articles). Almost every day our Facebook Master Johnny Payne posts medical and scientific articles hot off the press, sometimes online before print! If you “LIKE” the Page, you will receive e-mails or notification on your own FB Page that we have posted something of significance for your information!

We know that life operates in 24-hour news cycles now, so we feel it is important to post these articles as frequently as possible each day. They are screened and read usually before dawn in Pacific Time and then Johnny Payne posts them for everyone (who has access to that Page) to read. Please take advantage of our legwork to bring you the cutting edge, newest findings and articles in prostate cancer! PLEASE “LIKE” our Facebook Page!!!

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



***SPOTLIGHT ON:***

**The South Carolina Cancer Alliance - Prostate Cancer Workgroup**

The South Carolina Cancer Alliance - Prostate Cancer Workgroup was formed on October 4th 2007 as a Subcommittee of the South Carolina Cancer Alliance. The mission of the SCCA Prostate Cancer Workgroup is to combine the efforts of researchers, educators, community leaders, healthcare providers, and partners to discover where and how educational resources can be applied to improve decision making for prostate cancer screening, diagnosis, prevention, and treatment. The Workgroup works in a spirit of partnership and collaboration with stakeholders to emphasize a systematic approach to prostate cancer education and research in South Carolina so that all men in the state can make informed decisions about screening, lifestyle modifications, and treatment.

The Prostate Cancer Workgroup is also charged with the development of the State Cancer plan for prostate cancer. The South Carolina Cancer Alliance - Prostate Cancer work group consist of approximately 50 members statewide serving as a coalition to the National Alliance of State Prostate Cancer Coalition (NASPCC)

The membership of the Workgroup includes researchers, community leaders, cancer educators, students, consultants, healthcare providers, and other partners interested in prostate cancer education and research. It is dedicated to improving the understanding of how to diagnosis and treat prostate cancer and to help patients participate in all aspects of prostate cancer research, education, prevention, and treatment. The Prostate Cancer Workgroup has a particularly strong interest in developing the knowledge base to help men make informed decisions regarding screening, diagnosis, and treatment. Acknowledging the large racial disparities in prostate cancer, the Workgroup places special emphasis on reducing the heightened burden among African American men.





## Spotlight cont.

### We strive to:

- Evaluate knowledge, perceptions, and practices about prostate cancer informed decision making among diverse populations;
- Encourage research into the epidemiology and etiology of prostate cancer in order to improve the predictive ability of screening tests and enhance primary prevention of disease;
- Advance research in prostate cancer screening decision making, e.g., using our findings to inform the content in state and national surveys;
- Collaborate with key local, state, and national partners who have interests in prostate cancer;
- Promote quality education and outreach on prostate cancer screening, prevention, and treatment;
- Work with partners to communicate community-relevant information about the state of prostate cancer screening, prevention, and treatment research;
- Contribute toward reducing prostate cancer-related health disparities through culturally sensitive research, education, and practice

Each year the Workgroup conducts an Education & Awareness initiative to improve prostate health in South Carolina. In addition to conducting education forums the project gathers feedback by surveying patients, caregivers and providers.

The findings have been published in the Journal of Cancer Education and American Journal of Men's Health and presented at national conferences.



**The South Carolina Cancer Alliance -Prostate Cancer Work Group is proud to participate in the National Alliance of State Prostate Cancer Coalitions**

### **Daniela B. Friedman, MSc, PhD**

SCCA Prostate Cancer Workgroup, Co-Chair  
Department of Health Promotion, Education, and  
Behavior & Cancer Prevention and Control Program  
Arnold School of Public Health  
University of South Carolina

### **Johnny Payne**

SCCA Prostate Cancer Workgroup, Co-Chair  
Upstate Cancer Alliance, President  
NASPCC, Vice President  
Us TOO Support Group, Leader

**2<sup>nd</sup> in our NASPCC WEBINAR SERIES!!!! Tuesday, April 3, 2018 at 6:00 p.m. Central!**  
**Testing for AR-V7 Splice Variant is an important topic for men with advanced disease, helping them to decide between treatments that are likely to work and discouraging the use of treatments not likely to be successful.**  
**REGISTER NOW – IT'S FREE and INVALUABLE!!!**  
**\*Supported by Genomic Health**

## 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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### Advisory Board

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