



*“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

Welcome to the 1st Quarterly Electronic Newsletter of 2018 for the National Alliance of State Prostate Cancer Coalitions. As President I am especially proud of how we are moving our organization forward. We had a banner year in 2017. Some of our activities included two Strategic Planning Workshops in LA in April and May and the creation of a Workplan for NASPCC approved by the full Board last July. We also adopted Confidentiality/Conflict of Interest and Statement of Values/Code of Ethics Policies which became part of NASPCC’s By-Laws in July, and created a new NASPCC Brochure in the Fall which was distributed at the Annual Meeting; and we began planning new activities.

Our 13th Annual Meeting was held in Washington, D.C., October 13-15, 2017, and was one of the best and most fruitful Annual Meetings we’ve held. The link to the report of the 13th Annual Meeting is: <http://tinyurl.com/y8g5wdk9>. Topics ranged from Immunotherapy, to how to have an effective State Prostate Cancer Coalition, to advanced prostate cancer, to funding for CDMRP prostate cancer research, to an update on the USPSTF Provisional Screening Guidelines of Spring 2017, to Emotional Issues in Prostate Cancer.

Following the 13th Annual Meeting and the election of new Board members, NASPCC developed a structure of new Advisory Committees and approved the appointment of Advisory Committee members. We now have the following Committees: Education & Awareness; Communications; State Coalition Development (including mentoring); Budget; Fundraising; and Annual Meeting. We also joined the Defense Health Research Consortium. This month (January) we will have our first Webinar of the year on January 30, 2018 at 6:00 p.m. Central. Our presenter will be Ashley Ross, MD, PhD, who has been an ardent supporter of NASPCC and participant in our last several Annual Meetings. Dr. Ross will be speaking on “Tissue Biomarkers for Localized Prostate Cancer” and there will be time for questions and answers. Here is the direct link <https://naspcc.org/index.php/naspcc-webinar-jan-30th>. We encourage you to participate at no cost, but if you miss the Webinar, the event will be recorded and archived on the NASPCC website (www.naspcc.org). So too, our National Initiative with the Informed Decision-Making Laminar is on track to benefit more patients; the electronic version of this durable tool is on NASPCC’s Website and we hope you will make hard plasticized copies, put your state coalition logo on them and distribute them widely to men 40 and over, and to primary care providers. It helps make men aware of prostate cancer and of their need for an informed discussion about it with one’s physician, and the tool helps guide that discussion. The link to the Laminar is: <https://tinyurl.com/yc3fvuft>.

We hope to initiate other activities in 2018, including a dedicated Website page on genomics and genomic testing; national conference calls - some educational and some with helpful topics for the state coalitions; more webinars; and working with the state prostate cancer coalitions on Brand Identity. We would like each state coalition to use the words “Proud Participant in the National Alliance of State Prostate Cancer Coalitions” on their brochures, website, Facebook Page and any materials for events they are holding. That will enhance the stature and influence of the state prostate cancer coalitions, as the national scope and effect of their work will be brought to the attention of the public and others in the prostate cancer world. In the process it will reflect the growing influence of NASPCC.

Onward for a bright, successful 2018!

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 Webinar Series



The NASPCC will host their first webinar of 2018. Our presenter will be Ashley Ross, MD, PhD, who has been an ardent supporter of NASPCC and participant in our last several Annual Meetings. Dr. Ross will be speaking on “Tissue Biomarkers for Localized Prostate Cancer” and there will be time for questions and answers.

Please register for National Alliance of State Prostate Cancer Coalitions Webinar Series on Jan 30, 2018 6:00 PM CST at:

<https://attendee.gotowebinar.com/register/6872684734559896834>

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

REMINDER: THIS TUESDAY, JANUARY 30 AT 6:00 pm Central is our 1st Webinar of 2018. Please see elsewhere in this newsletter for “How To Register” OR Call Merel Nissenberg 619-518-6465

KNOW THE FACTS...

THE BLUE PRINT: ABOUT PROSTATE CANCER

Prostate Cancer is the most commonly diagnosed non-skin cancer and the second leading cause of death in men, after lung cancer. Many people think that prostate cancer is always a harmless disease, but that is not necessarily the case. Testing for prostate cancer includes a blood test which measures Prostate-Specific Antigen, a “biomarker” of a problem in the prostate, which can be prostatitis, BPH (an enlarged prostate) or prostate cancer – clinically insignificant or (potentially or actually) aggressive disease requiring treatment.

NASPPC recommends a baseline PSA and DRE (digital rectal exam) beginning at age 40 (35 if high-risk, including African-American men, men with a certain or indeterminate family history of prostate cancer, or those with exposure to Agent Orange); and then periodically depending upon those results. A man should know and keep track of his PSA measurements and should discuss ANY CHANGE IN PSA with his doctor. Men and their physicians should have an Informed Discussion about prostate cancer and testing, and it is then the man’s choice whether to be tested depending upon his own preferences and values. This is called INFORMED or SHARED DECISION-MAKING.

There are many new molecular, genetic and genomic tests to further refine PSA results, and these new tests can help a man make a decision regarding further testing and/or treatment for prostate cancer if it is recommended. These tests include PHI, 4K, Oncotype Dx Prostate; Decipher; Confirm MDx; SelectMDx and others.

THE BLUE PRINT: EARLY STAGE AND ADVANCED DISEASE

In early stage prostate cancer the disease is well confined to the prostate gland itself and has not spread outside its borders. It is at this stage that prostate cancer is the most treatable. In locally advanced prostate cancer, the disease has just begun to spread outside of the gland or involves areas just outside of the prostate. In advanced prostate cancer, the disease has spread outside of the prostate gland to other areas, or has spread to non-adjacent areas through metastasis, which means that the prostate cancer has traveled away from the prostate by way of the bloodstream or the lymph nodes and has formed new tumors elsewhere in the body.

The goal is always to diagnose prostate cancer in its early stages. For some men no treatment (or delayed treatment) will be appropriate, if they have minimal disease that is not clinically significant. This is called active Surveillance. For others their prostate cancer requires timely and appropriate treatment. But always, knowledge is power; while knowing one has prostate cancer does not necessarily mean that treatment is warranted, that knowledge is a data point for men and their physicians to consider and watch. The earlier that prostate cancer is detected, the more options a man has for treatment and almost always the better the outcome. If found early, the 5-year survival rate for early stage disease is almost 100%.

NASPPC is dedicated to the early detection of potentially lethal prostate cancer and to the use of informed decision-making in the process. Please refer to our Informed Decision-Making Laminate, a durable laminated awareness and educational tool for patients and primary care providers. www.prostatecalif.org/patient-guide. This “laminate” helps educate patients and physicians and serves as a guide for having that informed discussion.

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 California Prostate Cancer Coalition (CPCC)

The California Prostate Cancer Coalition (www.prostatecalif.org) was organized as a 501(c)(3) non-profit in 1997, and it continues to thrive as an active statewide coalition. NASPCC President Merel G. Nissenberg has been President of the California Prostate Cancer Coalition since its inception. CPCC is dedicated to saving men's lives by making prostate cancer a key public health priority in California. CPCC advocates for the early detection of potentially lethal prostate cancer and the use of informed decision-making in the process. CPCC helped spearhead California's IMPACT Program, managed by UCLA, which still provides access to healthcare and counseling for underserved men with prostate cancer in the state. In fact, a CPCC Sub-Committee was able to obtain sponsorship of legislation in Sacramento that made the IMPACT program a permanent one, and many men have benefitted from its services.

With 17 Board Members, CPCC provides education, awareness and outreach activities in both Northern and Southern California. In 2015 CPCC produced an Informed Decision-Making Laminate (<http://prostatecalif.org/patient-guide>) which has now been adopted by NASPCC as a national initiative, and it was updated in the Spring of 2017. CPCC was thrilled when the California Department of Public Health, which administers the Comprehensive Cancer Control Plan for the state, agreed to place the Informed Decision-Making Laminate on its website last year.



Spotlight cont.

Thousands have been distributed to patients and primary care providers, including 700 delivered last summer to the Vietnam Veterans of America whose members have a heightened risk of prostate cancer.

Last year CPCC re-designed its brochure into an 8-panel product which gives information on prostate cancer, informed decision-making, awareness and education, and CPCC itself. The brochure is available on the CPCC Website and with this link: <http://prostatecalif.org/cpcc-brochure/>.



Managing a statewide prostate cancer coalition for a state as large as California might have been a problem, but CPCC does so effectively by holding monthly Board telephone calls to run the organization, and it now has two Face-to-Face Board Meetings a year. Cooperation among the Board Members is paramount towards helping to achieve the goals of the California Prostate Cancer Coalition, and it is proud to be celebrating its 20th year.

For many years, CPCC has conducted two Support Group Leaders' Workshops, in both Northern and Southern California; and has conducted an Annual Prostate Cancer Proclamation Project for Prostate Cancer Awareness Month every September for the last 15 years. It maintains a Website and a Facebook Page; and CPCC through one of its Board Members led a Comic Book Prostate Cancer Awareness Campaign this past year. The CPCC Newsletter was re-initiated in June 2017 and issues were published in September and December 2017 as well. These are available on the CPCC Website (www.prostatecalif.org).

CPCC is proud to participate in the National Alliance of State Prostate Cancer Coalitions!

**Our March WEBINAR (date TBD)
will feature
Ryan Dittamore from Epic Sciences in
San Diego
on "CTC's (Circulating Tumor Cells)
and AR-V7" for choosing treatment!**

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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