



"Never doubt that a small group of thoughtful, committed people can change the world. Indeed. It is the only thing that ever has"
– Margaret Mead

News

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THE BLUEPRINT

Fran Franklin and Renee Savickas, Editors

President's Message

As Spring approaches and we transition (hopefully) out of the pandemic, we look back on what has already been an exciting year. We finally held our IN-PERSON 16th Annual Meeting on January 28-30, in Washington, DC, after 4 postponements. Nearly 60 attendees and a stellar faculty contributed to an outstanding educational weekend with continuing resources, as some state representatives participated by ZOOM and the Annual Meeting was recorded. Once the video is edited it will appear on our www.naspcc.org website. [Here](#) is the Program containing the agenda. Following the Annual Meeting, we announced the addition of two new members to our Medical Advisory Board: Jonathan Epstein, MD of Johns Hopkins, and Michael Morris, MD of Memorial Sloan Kettering. They join an illustrious group of physicians and scientists who have attached their names and efforts to NASPCC.

We continue to publish PROSTATEPEDIA Magazine (8 Issues are scheduled for 2022) as well as the weekly PROSTATEPEDIA DIGEST, which goes out every single Friday morning at 8:00 am Pacific. Both have a subscription list of over 20,000, and while most of those readers are in the U.S., we also have subscribers in the UK, parts of Western Europe, Australia, and New Zealand. As of this writing, the most recent Issue of PROSTATEPEDIA Magazine is here: <https://tinyurl.com/53c89hmk>. Many thanks, as always, to our superb Editor, Jessica Myers-Schecter, for her work on this continuing fount of information.

Our 5th Laminated resource ("The Laminate") was just produced and has begun to be distributed. This one in our Series is on "IMAGING IN PROSTATE CANCER". It is two-sided with one side for Patients and the reverse side for Physicians, and can also be downloaded as a pdf from our website here: <https://www.naspcc.org/docs/ImagingLaminate-v3.pdf> There are currently 4 more in queue and NASPCC has received requests to produce additional Laminates on new topics. Next up will be the Laminate on "IMMUNOTHERAPY IN PROSTATE CANCER".

NASPCC's Webinar Series featuring the Go-To-Webinar platform continues with outstanding presenters. On April 18th, at 7:00 pm Eastern, Dr. James Gulley of NIH who works on Immunotherapy in Prostate Cancer will present a Webinar entitled "The Path to Cure in Prostate Cancer"; then on June 7, Dr. Bruce Montgomery of the University of Washington will present a Webinar for NASPCC entitled "Prostate Cancer in Military Veterans" at 7:00 pm Eastern. Next up will be Dr. Leigh Ellis of Cedars-Sinai who will present Webinar #3 of a 6-part NASPCC series on Immuno-Oncology in Prostate Cancer. Our last Webinar was February 7 with Dr. Thomas Hope of UCSF - see report in this Newsletter.

Our work continues. Planning has begun for the 17th Annual Meeting on October 7-9 of this year! Please let me know if you are interested in serving on any of our 8 Advisory Committees!


Merel Grey Nissenberg

NASPCC WEBINAR SERIES


The National Alliance of State Prostate Cancer Coalitions (NASPCC) prides itself on the outstanding caliber of the presenters it chooses to put on our Webinars.

On February 7, 2022, NASPCC presented a Webinar with Dr. Thomas Hope of UCSF, entitled “Overview of Prostate Cancer Imaging” with an Update on Molecular Imaging. Dr. Hope is the Director of Molecular Therapy in the Department of Radiology and Biomedical Imaging at the University of California, San Francisco. An international leader in PET/MR research and the translation of new molecular imaging agents, Dr. Hope launched the highly successful PSMA prostate program at UCSF and championed the use of multiple new targeted therapies to treat patients with neuroendocrine and other tumors.


Our upcoming Webinars are:




NASPCC Webinar Series Presents:
“The Path to Cure in Prostate Cancer”
with James L. Gulley, MD, PhD
Monday, April 18, 2022
7:00 pm – 8:00 pm EASTERN / 4:00 pm – 5:00 pm PACIFIC
To register for this event, please click [here](#) or visit the NASPCC website at www.NASPCC.org



James L. Gulley, MD, PhD, is an internationally recognized expert in immunotherapy for cancer. Dr. Gulley serves within the Center for Cancer Research (CCR) of the National Cancer Institute as Chief of the Genitourinary Malignancies Branch (GMB), the Director of the Medical Oncology Service (CCR), and also Head of the Immunotherapy Section within the GMB. He has been instrumental in the clinical development of multiple immunotherapeutic agents and has led multiple first-in-human immunotherapy studies through phase 3 clinical trials.



NASPCC Webinar Series Presents:
“Prostate Cancer in Military Veterans”
with Bruce Montgomery, MD
Tuesday, June 7, 2022
7:00 pm – 8:00 pm EASTERN / 4:00 pm – 5:00 pm PACIFIC
To register for this event, please click [here](#) or visit the NASPCC website at www.NASPCC.org



Dr. Bruce Montgomery is Clinical Director of Genitourinary Oncology at the Seattle Cancer Care Alliance and Professor in the Medical Oncology Division of the University of Washington. He is also an Affiliate Member in the Clinical Research Division of the Fred Hutchinson Cancer Research Center. Dr. Montgomery helps lead the Precision Oncology Program for Cancer of the Prostate Network, a Veterans Affairs/PCF Collaboration. He will speak on Prostate Cancer in Military Veterans, a topic of continuing and growing interest especially with the newer considerations of carcinogenic exposures for certain veterans.

- To register for **The Path to Cure in Prostate Cancer** on April 18, 2022, please click [here](#):
- To register for **Prostate Cancer in Military Veterans** on June 7, 2022, please click [here](#):

Here are the links to the recorded Webinars and slides <https://tinyurl.com/mr2n2864> and <https://tinyurl.com/2p93b35h>; and here is the link to all of the NASPCC Webinar archives: <https://tinyurl.com/mr3a7374>

NASPCC'S 8 Advisory Committees

By Merel Nissenberg

If you are interested in joining any of the Committees, please let us know! You do NOT need to be your state's representative to NASPCC. Please e-mail Merel Nissenberg at: mgrey@ucsd.edu.

- **EDUCATION & AWARENESS:** Chair, Clarence Williamson. Members: Beth Bridges, David Sauls, Cheryl Cropp, Paul Kradel, Calvin Jackson, Tammie Minter/Bolton, LaTanya Patton, Jan Marfyak and Dave Hulbert.
- **COMMUNICATIONS:** Chair, Fran Franklin. Members: Renee Savickas, Cara Clements, Paul Kradel, Mary Anderson, and Rob Johnson.
- **ADVOCACY & PUBLIC POLICY:** Chair needed. Members: Bruce Williams and Steve Hentzen.
- **STATE COALITION DEVELOPMENT:** Chair and Co-Chair Dave Hulbert and Chris Collier. Members: Darrell Wilson, Dwight Thomas, Bruce Williams, Cheryl Cropp and Crissy Kantor.
- **BUDGET:** Chair: Anthony Minter. Members: Ronnell Showell, Don Lynam, Tom Kirk, Jan Marfyak and Ulyses Wright.
- **FUNDRAISING:** Chair, Merel Nissenberg. Members: Rob Johnson.
- **ANNUAL MEETING:** Chair, Merel Nissenberg. Members: LaTayna Patton, Tammie Minter/Bolton, Jan Marfyak, Don Lynam, Crissy Cantor and Robin Leach.
- **MEDICAL ADVISORY:** Chair, Michael Zaragoza. Members: Jonathan Epstein, MD, and Michael Morris, MD Leonard Gomella, MD, Vincent Laudone, MD, Christopher Logothetis, MD, Judd Moul, MD, Willian Nelson, MD, PhD, Alan Partin, MD, PhD, Kenneth Pienta, MD, Saul Priceman, PhD, Mach Roach III, MD, Ashley Ross, MD, PhD, Peter Scardino, MD, and Paul Shellhammer, MD.

Prostatepedia and Prostatepedia Digest



In June of 2020 when NASPCC took over publication of PROSTATEPEDIA Magazine and its weekly DIGEST, we had no idea that we would so quickly expand coverage and readership and become even more committed to making PROSTATEPEDIA the gold standard for men and their families looking for solid, objective, and up-to-date information about prostate cancer. We already have more than 20,000 subscribers.

Our goals for 2022 include 8 PROSTATEPEDIA Magazines (2 are Supplements) on: Radiation Therapy; Theranostics; ADT and Anti-Androgens; Testing; Genetics, Genomics, and Prostate Cancer; Chemotherapy & Immunotherapy; Imaging; and Side Effects of Treatment. The Magazine is archived on our www.naspcc.org website, and downloadable as a PDF. Each Magazine Issue has interviews with physicians, scientists, and patients. Patients willing to be interviewed on any of these topics, please contact mgrey@ucsd.edu.

NASPCC LAMINATE SERIES

The National Alliance of State Prostate Cancer Coalitions (The Prostate Cancer Alliance) has created, produced, and now distributes a Series of Laminates (2-sided laminated durable resources, with one side for patients and the flip side for Physicians), on various topics in prostate cancer. The Laminates are in a question-and-answer format on both sides and are designed to improve informed discussions between physician and patient to lead to better shared decision-making.

The Laminates are online at www.naspcc.org and are available for reprinting as PDF's. Here are the specific links: <https://naspcc.org/docs/informed-decision-9-11-17.pdf> for Informed Decision-Making; and <https://www.naspcc.org/index.php/new-laminated-resources> for the other topics. Besides distribution, upon request NASPCC will also send the actual Laminates in bulk for awareness and educational events, as well as to physicians and clinics.

Topics already completed include:

- Informed Decision-Making
- The Role of PSA Throughout the Prostate Cancer Journey
- Non-Metastatic Castrate-Resistant Prostate Cancer
- Metastatic Castrate-Sensitive Prostate Cancer
- Imaging in Prostate Cancer

In queue are “Testing”, “Immunotherapy”, “Bone Health”, and “Pain Management in Advanced Prostate Cancer”. Other suggested topics are welcome.

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!

Important Links

**NASPCC Webinar
Series Monthly
webinars with leaders
in the Prostate Cancer
field**

[CLICK HERE](#)

**NCCN Annual 2022
Conference**

[CLICK HERE](#)

**PCEC Prostate Cancer
Markers interactive tool**

[CLICK HERE](#)

**NASPCC Member
Updates**

[CLICK HERE](#)

**NIH National Cancer
Institute Treatment
Clinical Trials for
Prostate Cancer**

[CLICK HERE](#)

**CancerCare Prostate
Cancer Support Group
Online**

[CLICK HERE](#)

**Latest updates from
PROSTATEPEDIA
Magazine**

[CLICK HERE](#)

**NASPCC 16th Annual
Meeting- Proceedings**

[CLICK HERE](#)

**NASPCC Brochures
Laminated Resources**

[CLICK HERE](#)

**NASPCC Legislative
News Update: March
2022**

[CLICK HERE](#)

In the SPOTLIGHT

In each quarterly issue of THE BLUEPRINT, NASPCC is proud to feature a section dedicated to a very special State Coalition or Member to acknowledge the wonderful services they provide in their state. This quarter we are honored to shine the SPOTLIGHT on:

The Prostate Network in Kansas City, KS!



Prostate Network's mission is to support survivors and enable men to educate the public on importance of early detection to help save men's lives.

We invite all prostate cancer survivors, their partners and those helping in the fight to join us!

Recent and current activities include:

Hybrid support group meetings 1st Wednesday – monthly 6:30pm CT

- In person meetings at Gilda's Club – 21 West 43rd, Kansas City, MO
- Simultaneously in our Zoom Room

This month's group meeting will feature **Dr. Saul Priceman, Ph.D., discussing the Basics of Prostate Cancer Immuno-oncology and Immuno-therapeutics!*

Health Fair Saturday, March 5, 2022 was a total success! Click [here](#) for photos!

Podcast – Prostate Cancer: Surviving Together

Available on your favorite podcast app or directly from these sources:

[Apple Podcasts](#) • [Google Play](#) • [Stitcher](#) • [TuneIn](#) • [iHeartRadio](#) • [Spotify](#)

*Stay tuned, we have more exciting event planned for 2022!

NASPCC would like to congratulate the Prostate Network for being our "Spotlight" featured group of the quarter! You are doing excellent work bringing Prostate Cancer Awareness, Education and Support in Kansas! Thank you for all that you do!

Social Media Corner

This section of the **Blueprint** provides tips to help grow our Facebook page and grow your organizations page as well.



The official NASPCC Facebook page is:

<https://www.facebook.com/NASPCC/>

Here are some great Facebook tips and best practices. I have attached a link below to the Donorbox Nonprofit Blog (source)

Develop a Facebook Strategy

What are you hoping to achieve? What is your Mission? What are your goals?

Take Care of your Profile

Your Facebook profile represents your organization. It's very important that your profile is complete with a profile picture, a cover photo, a description, contact info and more.

Become a Content Guru

Content is King! Post high-quality, relevant, and compelling content that interests your target audience.

- You need to post frequently and consistently.
- Change up your post types.
- Sometimes share links to your blog posts and share your donation page.
- Post your event results and share "thank-you" posts appreciating your donors.
- Ask for engagement. Don't be afraid to post things like "Like if..." or "Fill in the blank. I volunteer because...". Simple additions like these can help increase your reach and engagement.
- Post visual content such as Photos, GIFs, Quote images and short videos.
- Use Infographics and Emoticons! Posts with Emoticons get a 57% higher like rate! 😊

Share Link Posts Instead of Photos

Facebook found the people prefer to click on links that are displayed in the link format which appears when you paste a link while drafting a post, rather than links that appear in photo captions. Occasionally post photos and videos that bring to life your programs and services.

<https://donorbox.org/nonprofit-blog/facebook-for-nonprofits/>

Please click the link above for more detailed information!

Please LIKE and SHARE the NASPCC Facebook posts on your organizations Facebook page!



About NASPCC and our Mission Statement

The 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:

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Kansas
- Kentucky
- Louisiana
- 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
- Wisconsin
- Wyoming

Educational Tools

Having a prostate cancer related event in your community? Just ask! We will be happy to ship some Informed Decision-Making Laminates or Laminates on 4 other topics.

The Laminate

Prostate Cancer: Informed Decision-Making for Men over 40 and Primary Care Physicians.

This is NASPCC's excellent awareness and educational tool for INFORMED DISCUSSIONS between men and their physicians.

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!



2022 Board of Directors

The 2022 Board of Directors of the National Alliance of State Prostate Cancer Coalitions

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Secretary: Jan Marfyak

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