



*"Unity is strength... when there  
is teamwork and collaboration,  
wonderful things can be  
achieved"*  
– **Mattie Stepanek**

## News

Volume 4, Issue 2  
June 2021

# THE BLUEPRINT

**J. Renee Savickas, Editor**

## President's Message

Welcome to the June/Summer 2021 Edition of the Blueprint, our NASPCC Newsletter! Our National Alliance continues with its action-packed activities as we navigate our way out of COVID restrictions. Plans are underway for our **16<sup>th</sup> Annual Meeting** which is scheduled to be held IN PERSON September 24-26, 2021 at the Hotel Monaco in Washington, DC. An exciting Agenda will be presented, and the plans will include a reception that Friday evening; Education and Panel Sessions all day Saturday, followed by a Dinner on Saturday night (with a speaker and the presentation of awards); and then Sunday Education Sessions ending at 3:00 pm. Please let us know if you are interested in attending as your state representative or as a guest!

Our National Alliance is still excited that we assumed responsibility for production of **PROSTATEPEDIA Magazine and the PROSTATEPEDIA DIGEST** starting last June. We had exemplary Magazine Issues in August 2020 (CHEMOTHERAPY); November 2020 (IMMUNO-ONCOLOGY); and March 2021 (TESTING); and in June of 2021 we will be publishing our Magazine on IMAGING. And the PROSTATEPEDIA DIGEST goes out every single week on Friday with the most recent articles and abstracts in prostate cancer from the preceding week or two. The subscription list that we maintain for PROSTATEPEDIA has over 12,000 people who receive both the Magazine and the weekly DIGEST, and the latter also includes Flyers for upcoming Webinars and events, and links to archived Webinars and other resources on our [www.naspcc.org](http://www.naspcc.org) website. The founding Editor, Jessica Myers-Schechter, agreed to stay on to continue as Editor and she is an essential piece of the puzzle.

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We are presenting amazing **Webinars** almost every month. This calendar year we have had Dr. Michael Morris from Sloan-Kettering; Dr. Ashley Ross from Northwestern; Dr. Jonathan Epstein of Johns Hopkins; and Dr. Saul Priceman from City of Hope. On June 10 we will be presenting Dr. Dan George from Duke on “Cabazitaxel in Metastatic Prostate Cancer”; on July 28 we will have Dr. Charles Ryan from the U. of Minnesota on “PARP Inhibition in Prostate Cancer”; and on August 2 we will have Dr. Michael Hofman from Australia on the topic of “TheraP/VISION Trial on Lutetium-PSMA”!

On June 24, 2021 NASPCC will present a half-day **Symposium on Immuno-Oncology** moderated by Dr. Saul Priceman of City of Hope. It will be held virtually, and we are expecting the hours to be 10:00 am – 3:00 pm PACIFIC. More details to follow shortly!

We love to hear what our “Proud Participants in NASPCC” State Prostate Cancer Coalitions are doing. Example: on May 14 and 15, [the California Prostate Cancer Coalition](#) together with UCSF presented (virtually) its **2<sup>nd</sup> Patient Conference on Prostate Cancer**. CPCC was so fortunate to work with the esteemed faculty from UCSF including Drs. Eric Small, Matt Cooperberg, Peter Carroll, Rahul Aggarwal, Felix Feng, Mack Roach and others. The last such Patient Conference was held in person at UCSF in June 2019 and attracted over 400 people. It was videotaped and resides on the UC Television Station (You Tube) and has been viewed over 122,000 times. [The Massachusetts Prostate Cancer Coalition](#) presented a virtual 2021 Symposium on May 14 with esteemed speakers such as Drs. Michael Carducci of Johns Hopkins and Caroline Moore of University College in London. [NASPCC welcomes news of any of your events so we can publish them in our Newsletter, on our Website, or in our weekly DIGESTS.](#)

NASPCC has just completed 3 additional **Laminates**: one on Non-Metastatic Castrate-Resistant Prostate Cancer (nmCRPC); one on Metastatic Castrate-Sensitive Prostate Cancer (mCSPC); and one on The Role of PSA Throughout the Prostate Cancer Journey. These join our already-published Laminates on Informed Decision-Making. [We have another 5 Laminates in process.](#) The Laminates Series are meant to help men and their physicians have better informed discussions and engage in better shared decision-making. Look for the links to these new resources on our Website.

So, as I always write, our work continues. We hope that life will soon return to the normalcy of pre-COVID times, and that we will continue to help prostate cancer patients and their families!

Sincerely, Merel Nissenberg

## NASPCC BOD Minutes

April 20, 2021

By Merel Nissenberg

The 2<sup>nd</sup> Quarterly Board of Directors Call of NASPCC took place Tuesday, April 20, 2021 beginning at 1:00 pm EASTERN. Present were: Merel Nissenberg, LaTanya Patton, Tony Minter, Don Lynam, Gabe Rosko, Crissy Kantor, Bruce Williams, David Sauls, Renee Savickas, Clarence Williamson. Tom Kirk was present as Chair of the Steering Committee. Tiffany Razzo was a guest and presenter.

Absent were: Robin Leach (Texas), Harold Pharoah (Nebraska), Paul Kradel (W. Va), Stephen Richardson (Utah), Jan Marfyak (New Mexico), Mary Anderson (North Carolina), and Dave Hulbert (Minnesota).

Merel Nissenberg gave the President's Report. She talked about how active NASPCC has become and about the new monthly Webinar Series and gave details. She also talked about the CPCC/UCSF 2<sup>nd</sup> Patient Conference on Prostate Cancer (May 14-15), the NCCN Webinars on Advanced Prostate Cancer (May 19 and May 21) in which she will be one of 3 presenters; about the Immuno-Oncology Symposium we will be doing for AMGEN at the end of June; about PROSTATEPEDIA (for later in the Agenda), and other activities. She also said the 16<sup>th</sup> Annual Meeting is still being planned for September 24-26 in person.

Jan Marfyak is in the hospital so Merel asked LaTanya if she would present the Secretary's Report. First, LaTanya asked if there were any corrections/edits to the January 19 Board Meeting Minutes. Hearing none, Don moved, and Crissy seconded, and Minutes were approved. Then she asked if there were any corrections or edits to the February 2, March 2, and April 6 Executive Committee Minutes. Hearing none, Renee moved, Clarence seconded to accept those EC Minutes. Motion was approved without dissent.

Tony Minter then presented the Treasury Report. He stated that as of March 30, NASPCC had a total of \$ 215,407.95 between checking and savings. He also stated that for the period of October 1 through March 30, our expenses were \$ 62,391.36, and our income was \$97,784.09, for a net income of \$ 35,392.73. Merel reported on funds that have been committed to NASPCC but not yet received. LaTanya moved, and Don seconded to approve the Treasury Report. Motion approved without dissent. Tony thanked Merel for her heroic efforts. Checks have already come in but are not yet in the Report.

La Tanya then reported on Merel's efforts with PROSTATEPEDIA and detailed the amount of effort that Merel is putting into both the PROSTATEPEDIA Magazine and the weekly PROSTATEPEDIA DIGEST. She stated that this had been discussed at the last EC Call (in April) and that the EC had approved a raise in her independent contractor fees to reflect the additional work on PROSTATEPEDIA in the amount of \$2,500, for a total monthly amount of \$7,500. LaTanya then moved that this be approved by the Board: she moved that NASPCC raise Merel's independent contractor fees by \$2,500, for a total of \$7,500. She made a motion, and Crissy seconded. Motion was approved, without dissent.

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Tiffany Razzo presented an update on our Facebook Page and our Website. She reported that our latest Webinar is archived (Jonathan Epstein on April 13), and we asked John Brandt to add a link to our Facebook Page. Facebook – decrease in total page views down. 3 new Page likes in the last 30 days. Post engagement up 6% in the last 30 days, 119 people. 3 new followers, a 25% decrease. We do not have a Twitter account; she offered to do that for us. She reported on the PROSTATEPEDIA DIGEST – our FB website receives it too. Also includes all of our upcoming Webinars, interviews, ASCO GU Report are included. She encouraged to follow us on our FB Page. Renee agrees that we should have a Twitter account.

Tom Kirk as Chair of the Steering Committee then reported on the “Committees Status Update”. He said that he had sent an updated version of the report yesterday with a minor change. He then stated that the last Newsletter - The Blueprint – had done an update on the Committees. Committees: Communications: Renee gave an update on the target for the next by May 10, so articles by May 1 or 2. Education and Awareness Committee: Clarence is the new Chair, and he described what we have been doing: working diligently, discussed PROSTATEPEDIA on a regular basis, state coalition update on the MOU verbiage, they have completed a grid on who does what; State Coalitions Development Committee – up and running. Re-scheduled last meeting; next is May 11; can we do it by ZOOM; Advocacy & Public Policy: Alvin Chin had done a great job and we still need a new Chair, and in the meantime attend OVAC, the Prostate Cancer Impact Alliance, we pay attention to the DHRC (did a briefing that Tony Minter was involved with in March); we have a Dear Colleague letter we are signing onto; their focus is on Grassroots Lobby Day in May; we follow a group of e-mails and lobbyists; April 22 the Spring Public Policy Roundtable of NCCS; Fundraising and Annual Meeting; Budget: we still need a new Chair, Don and Tom will stay on the Committee; Medical Advisory Committee: Michael Z is Chair. Our newest Medical Advisory Board Member, Dr. Saul Priceman of City of Hope, will lead a Symposium for us in late June. Crissy said she is waiting to hear from the North Dakota and the Maine group. Merel said she has a call with Cheryl Cropp of Alabama next week to talk about starting up a state prostate cancer coalition there.

Merel gave a PROSTATEPEDIA update, similar to what she talked about in her President’s Report. Crissy asked if we could have a link to the PROSTATEPEDIA Magazine on our FB Page so she could share it on her social media. Tiffany put that link onto our FB Page a few minutes later and advised the group. Merel also once again detailed the upcoming Webinars on June 10 (Dr. Daniel George of Duke), July 28 (Dr. Charles Ryan) and August 2 (August 3 in Australia; Dr. Michael Hofman). She also mentioned the CPCC/UCSF 2<sup>nd</sup> Patient Conference on Prostate Cancer (May 14-15, 2021) and the NCCN Webinars on Advanced Prostate Cancer (she’s a presenter) on May 19 and May 21, and the NASPCC Symposium on Immuno-Oncology moderated by Dr. Saul Priceman on June 24. She then stated that the 16<sup>th</sup> Annual Meeting is on track for September 24-26, IN PERSON! She asked for new volunteers for the Annual Meeting Committee.

Merel said that the next Board Meeting will take place Tuesday, July 20 (the 3<sup>rd</sup> Tuesday of July) at 1:00 pm EASTERN and said that Tiffany has volunteered to let us use the M.D. Anderson ZOOM capability.

There being no other Business and no New Business, the Board of Directors Meeting Call was adjourned at 1:52 pm EASTERN.

Respectfully submitted,

Merel Nissenberg for Jan Marfyak

# NASPCC WEBINAR SERIES

The National Alliance of State Prostate Cancer Coalitions (NASPCC) a/k/a “The Alliance” prides itself on the outstanding caliber of the presenters it chooses to put on monthly Webinars.

The presenters and the Webinars that we produce are so superb that we keep them as a continuing resource for patients, their families, and health care providers, by archiving them on our Website, on [www.naspcc.org](http://www.naspcc.org). Those wishing to access the archived Webinars will be pleased to see that they can access both the slides and the recordings.  
<https://www.naspcc.org/index.php/resources/webinar-archives>.

This calendar year we have heard from:

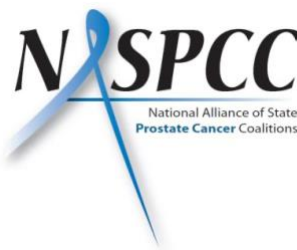
- Dr. Michael Morris of Memorial Sloan-Kettering Cancer Center on “Theranostics”
- Dr. Saul Priceman of City of Hope on “Immuno-Oncology: Novel Mechanisms of Action in Prostate Cancer”
- Dr. Ashley Ross of Northwestern on “Use of Genomics to Guide Treatment Decisions after Radical Prostatectomy”
- Dr. Jonathan Epstein of Johns Hopkins on “Critical Aspects of Prostate Cancer Pathology for Patients”.

Our next Webinars in line are:

- June 10th when Dr. Daniel George of Duke will present on “CABAZITAXEL in Metastatic Prostate Cancer and an update on the CARD Trial”
- July 28th when Dr. Charles Ryan of the University of Minnesota (formerly of UCSF) will present on “PARP Inhibition in Prostate Cancer”
- August 2nd (August 3 for the presenter who is in Australia) when Dr. Michael Hofman will present on “Thera-P/VISION Trial on Lutetium-PSMA”.

All Webinars utilize the GoToWebinar Platform, with 500 portals for attendance. You can register for any and all of these Webinars which take place at 7:00 pm EASTERN (4:00 pm PACIFIC) either on the Flyers themselves, or on the [www.naspcc.org](http://www.naspcc.org) website:  
<https://www.naspcc.org/index.php/naspcc-webinar-series-presents-july-29-2021>.

NASPCC Webinar Flyers continued on next page



NASPCC Webinar Series Presents:  
**“Cabazitaxel in Metastatic Prostate Cancer, with an Update  
on the CARD Trial”**

With Daniel George, M.D., Professor of Medicine and Surgery, Divisions of  
Medical Oncology and Urology in the Duke University School of Medicine

**Thursday, June 10, 2021 from**

**7:00 pm – 8:00 pm EASTERN**

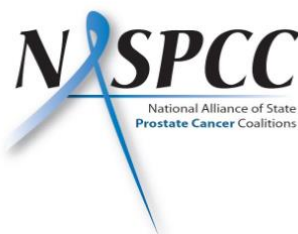
**4:00 pm – 5:00 pm PACIFIC**

To register for this event, please click [here](#) or visit the NASPCC website  
at [www.NASPCC.org](http://www.NASPCC.org)



Dr. Daniel George is Professor of Medicine and Surgery, Divisions of Medical Oncology and Urology in the Duke University School of Medicine. He also has appointments in the Duke Clinical Research Institute and the Duke Cancer Institute where he is the Director of Genitourinary (GU) Oncology disease-based group and is co-lead of the DCI Center for Prostate and Urologic Cancers. He is an internationally recognized clinical researcher and thought leader in GU Malignancies, with over 200 peer-reviewed publications. His areas of research include new drug development and biomarkers of GU Cancers with an emphasis on signal transduction pathways and cancer disparities. Dr. George is the co-PI of IRONMAN, an international multi-sponsor supported registry in advanced prostate cancer.

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**NASPCC Webinar Series Presents:  
“PARP Inhibition in Prostate Cancer”**

With Dr. Charles Ryan, M.D., Director of the Hematology, Oncology, Transplant  
Division in the Dept. of Medicine at the University of Minnesota

**Wednesday, July 28, 2021 from**

**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](http://www.NASPCC.org)



Charles J Ryan, MD is the Director of the Hematology, Oncology and Transplantation Division in the Dept. of Medicine at the University of Minnesota. He also holds the B.J. Kennedy Chair in Clinical Medical Oncology. He attended the University of Wisconsin Medical School and he trained there, serving as Chief Resident, and at Memorial Sloan-Kettering. He was then on the faculty of UCSF where he served as Program Leader for Genitourinary Medical Oncology and was the Thomas Perkins Distinguished Professor in Cancer Research. Dr. Ryan is internationally recognized for his work focusing on the development of new treatments for advanced prostate cancer, as well as supportive care for men with prostate cancer. He has published over 175 articles and chapters in leading medical journals and has authored “The Virility Paradox: The Vast Influence of Testosterone on Our Bodies, Minds, and the World We Live In” released in February of 2018. Dr. Ryan is the Leader of the Advanced Prostate Cancer Cadre in the Alliance for Clinical Trials in Oncology, a national Clinical Trials group.

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NASPCC Webinar Series Presents:

**“TheraP/VISION Trial on Lutetium-PSMA”**

With Michael Hofman, MBBS, FRACP, FAANMS, FICIS, Director of the Prostate Cancer Theranostics and Imaging Center of Excellence (ProSTIC) at The Peter MacCallum Cancer Center in Melbourne, Australia

**Monday, August 2, 2021 from**

**7:00 pm – 8:00 pm EASTERN / 4:00 pm – 5:00 pm PACIFIC**

**(Tuesday, August 3, 2021 from 9:00 am – 10:00 am AEST)**

To register for this event, please click [here](#) or visit the NASPCC website at [www.NASPCC.org](http://www.NASPCC.org)



Professor Michael Hofman is a nuclear medicine physician, physician-scientist and Director of the Prostate Cancer Theranostics and Imaging Centre of Excellence (ProSTIC) at the Peter MacCallum Cancer Centre in Melbourne. He previously completed a research fellowship at Guy's & St Thomas' in London. He has broad research interest in radiopharmaceuticals for imaging and therapy (theranostics) in Oncology. This includes neuroendocrine tumours and hematologic applications; more recently he has focused on improving outcomes for men with prostate cancer. Prof Hofman has a leading academic track record for his specialty, with over 200 peer reviewed manuscripts and book chapters. He has received a number of international awards including the Society of Nuclear Medicine and Molecular Imaging (SNMMI) Image of the Year 2018 and awards for best scientific research at several international conferences. He is a frequent invited speaker at national and international meetings, and was the co-chair of the scientific committee for the 4th World Theranostic World Congress in 2016. In 2015 he was elected a fellow of the International Cancer Imaging Society, one of three Australians recognized by the society. He was a member of the oncology subcommittee of the ongoing MBS Review where he advocates for fair and equitable access to PET scanning for patients with cancer.

# NASPCC VIRTUAL SYMPOSIUM

On Friday, June 24, 2021, NASPCC is planning to present a SYMPOSIUM on “Immuno-Oncology in Prostate Cancer” from 10:00 am – 3:00 pm (PACIFIC), sponsored by AMGEN. The Symposium will be moderated by Dr. Saul Priceman of City of Hope and will include other leading lights in the field of immunotherapy – why it does and doesn’t work for prostate cancer, new ways it might work, and new mechanisms of action, including “BiTE”. Dr. Priceman presented at NASPCC’s February 1, 2021 Webinar entitled “Immuno-Oncology: Novel Mechanisms of Action in Prostate Cancer” and he is a resource in and of himself. One of the speakers and panelists will be Dr. James Gulley of the NIH, who has spoken on Immunotherapy in Prostate Cancer at the last several of NASPCC’s Annual Meetings.

The Symposium will be VIRTUAL so be sure and look for the Flyer which will be coming soon, in order to register for this great opportunity! Any questions, write Merel Nissenberg at [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu).

Dr. Saul Priceman  
City of Hope



Dr. James Gulley  
National Institute of Health



# NASPCC and NCCN WEBINAR

NASPCC President Merel Nissenberg presented at two free NCCN\* Webinars for Patients on May 19 and May 21, 2021, titled “Advanced Prostate Cancer: Know What Your Doctors Know”. The format is one urologist, one oncology nurse, and one advocate (Merel). These Webinars will likely be recorded and archived, in case you miss them.

\*The National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 31 leading cancer centers devoted to patient care, research, and education, is dedicated to improving and facilitating quality, effective, efficient, and accessible cancer care so that patients can live better lives.”



National Comprehensive  
Cancer Network®

Register: [NCCN.org/patientwebinars](https://www.nccn.org/patientwebinars)

## FREE Patient Webinar

For those with advanced prostate cancer, their caregivers, and their families

### Advanced Prostate Cancer

**Know What Your Doctors Know**



**Two chances to attend!**

**Wednesday,  
May 19, 2021**  
2:30 – 3:45 PM EDT

**Friday,  
May 21, 2021**  
11:45 AM – 1:00 PM EDT

This webinar is supported through the NCCN Foundation, by a contribution from our industry supporter AstraZeneca.

**Join experts as they discuss the best care for advanced prostate cancer. This webinar will help participants:**

- Understand advanced prostate cancer
- Compare, discuss, and select treatment options with their doctor

*Please note that this is not an accredited activity.*

**Agenda**

- Introduction
- Expert Discussion of Advanced Prostate Cancer
- Question & Answer Session

**Presenters**

- **Joshua Lang, MD**  
Vice Chair for Biomedical Research, Department of Medicine, University of Wisconsin Carbone Cancer Center
- **Jane Straus, RN, BSN**  
GU Oncology Nurse/Clinical Trials Manager, University of Wisconsin Carbone Cancer Center
- **Merel Grey**  
Patient Advocate, President of the National Alliance of State Prostate Cancer Coalitions, the California Prostate Cancer Coalition, and the Mountain Foundation for Education & Research in Lung Cancer

**Get a FREE book!**

**A free copy of the NCCN Guidelines for Patients®: Prostate Cancer – Advanced Stage, Version 2020 will be sent to the first 400 registrants to request a book.**

The NCCN Guidelines for Patients are a good starting point to learn the best health care options for a type of cancer.



### Patient Webinars Coming Soon



**Pancreatic Cancer**  
**Diffuse Large B-Cell Lymphoma**  
**Ovarian Cancer**

View other upcoming patient webinars at: [NCCN.org/patientwebinars](https://www.nccn.org/patientwebinars)

# NASPCC'S 8 Advisory Committees

By Merel Nissenberg

## **ADDITIONAL COMMITTEE MEMBERS WANTED!!**

NASPCC's Strategic Plan of 2017 led to the creation of 8 Advisory Committees, which appear below, along with the current members of each Committee. **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](mailto:mgrey@ucsd.edu).

- **EDUCATION & AWARENESS COMMITTEE:** Chair, Fran Franklin. Members: David Sauls, Tammie Minter, Cheryl Cropp, LaTanya Patton, Ira Baxter, Jan Marfyak, Dave Hulbert, Paul Kradel, Steve Richardson, Calvin Jackson, Clarence Williamson, and Johnny Payne.
- **COMMUNICATIONS COMMITTEE:** Chair, Renee Savickas. Members: LaTanya Patton, Paul Kradel, Ira Baxter and Johnny Payne.
- **ADVOCACY & PUBLIC POLICY COMMITTEE:** Chair, vacant since Alvin Chin passed away last November. WE NEED A NEW CHAIR. Members: Tom Kirk, Jan Marfyak, Robert Gammage.
- **STATE COALITION DEVELOPMENT COMMITTEE:** Chair, Robert Johnson. Members: Harold Pharoah, Cheryl Cropp, Dwight Thomas, Bruce Williams, Crissy Kantor.
- **BUDGET COMMITTEE:** Chair: Don Lynam, Immediate past Chair. WE NEED A NEW CHAIR. Members: Tony Minter, Don Lynam, Tom Kirk, Ulyses Wright, Jan Marfyak
- **FUNDRAISING COMMITTEE:** Chair, Merel Nissenberg. Members: Mary Anderson, Rob Johnson, Gabe Rosko.
- **ANNUAL MEETING COMMITTEE:** Chair, Merel Nissenberg. Members: Tammie Minter, Ulyses Wright, Rob Johnson, Jan Marfyak, Don Lynam, Harold Pharoah, Crissy Kantor, Robin Leach.
- **MEDICAL ADVISORY COMMITTEE:** Chair, Michael Zaragoza.

# Update on NASPCC Committees

By Thomas Kirk

Since the last NASPCC Board Call on April 20, 2021 (and the previous one on January 19, 2021), the NASPCC Committee activities have been updated at each of the Monthly Executive Committee calls (February 2<sup>nd</sup>, March 2<sup>nd</sup> and April 6<sup>th</sup>) and a summary placed in the Meeting Minutes as well.

- 1) For the **Communication's Committee**, Committee Chair and the Blueprint Newsletter Editor Renee Savickas has completed Volume 4, Issue 1 of the **Blueprint** in February and it is posted on the NASPCC website. The Committee Update (prepared for January Board Call) was also printed in the Spring/February 2021 Issue of the Blueprint on pages 9-10. The next Quarterly Blueprint issue is targeted for May.
- 2) Rob Johnson has held two meetings of the **State Coalition Development Committee** one on February 9<sup>th</sup> and the second on March 9<sup>th</sup> and finally the third for April 13<sup>th</sup> was rescheduled to May 11<sup>th</sup>. There was discussion at the March call to explore doing a virtual State start-up Zoom session.
- 3) There has been a successful transition of the leadership of the **Education and Awareness Committee** meeting. Calvin Jackson chaired the January 13<sup>th</sup> for Fran Franklin, Fran chaired the February 10<sup>th</sup> call and the new Chair, Clarence Williamson headed the March Committee call. The most recent call was held April 14<sup>th</sup> and the next call is set for May 12<sup>th</sup>. Tom has been doing Minutes for the last calls. The Committee usually keeps the NASPCC Webinars on its Agenda.

The Webinar held on January 11<sup>th</sup> on the topic of "Theranostics in Prostate Cancer" and was presented by Dr. Michael Morris Memorial Sloan-Kettering Cancer Center was well received.

The Webinar on Monday February 1<sup>st</sup> on the topic of "Immuno-Oncology: Novel Mechanisms of Action in Prostate Cancer" with Saul Priceman, PhD, Assistant Professor, Department of Hematology & Hematopoietic Cell Transplantation at City of Hope was also well-received.

The Webinar featuring Dr. Ashley Ross, Associate Professor, Northwestern Feinberg School of Medicine in Chicago, titled "Use of Genomics to Guide Decisions after Radical Prostatectomy" on March 10, 2021 was also well received.

Next, Jonathan Epstein, MD Professor of Pathology, Oncology and Urology at Johns Hopkins School of Medicine presented "Critical Aspects of Prostate Cancer Pathology for Patients" on April 13<sup>th</sup> and Dan George of Duke is set for June 10<sup>th</sup> with the title of "Cabazitaxel in Metastatic Prostate Cancer, with an Update on the CARD Trial".

Discussions are taking place for a virtual Symposium to be headed by Saul Priceman, PhD from City of Hope for June 24<sup>th</sup> titled "Immuno-Oncology: Novel Mechanisms of Action".

Two new ones are also set, the one for July will feature Dr. Charles Ryan on PARP inhibition and Dr. Michael Hoffman from Australia in August. The announcements are being placed on the NASPCC website.

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A review of the Draft MoU and the State Social Media Grid continues to be on the Committee Workplan, as well as the first two new Laminates which Merel and Tom are developing for NASPCC as Independent Contractors (nmCRPC and the Role of PSA). The Drafts of the first two new Laminates were shared with the EC on the April 6<sup>th</sup> call. As a reminder, the most recent Spring/February 2021 Blueprint also lists the topics of the Lamine Series on page 12. On April 14<sup>th</sup> through the email list, Merel announced the NCCN “Advanced Prostate Cancer: Know What Your Doctors Know” Patient Webinar set for both May 19<sup>th</sup> and May 21<sup>st</sup> (she will be a presenter). This announcement has also been placed on the NASPCC website.

Merel continues to be active with Jessica and Tiffany to roll out the next issues of Prostatepedia and the weekly Digest. The November issue Volume 6, Number 2 on Immuno-Oncology and PARP Inhibition was released on November 13<sup>th</sup> and the March issue Volume 6, Number 3 was focused on Testing and the next issue (June) will be focused on Imaging. The weekly Digest issues were sent in January, February, March and early April with minor edits made to the format (to make it easier to follow) after the January Board meeting discussion.

4) As for the **Advocacy & Public Policy Committee**, Alvin Chin, who Chaired the Advocacy and Public Policy Committee, passed away in November 2020 and we still need a volunteer to assume the committee Chair. We continued to be in the Friends of Prostate Cancer Care Community (FoPCCC), which has selected a new name, the Prostate Cancer Impact Alliance (PCIA). We attended their Zoom calls, the most recent on February 25<sup>th</sup>. We received a series of weekly emails in February and March and both of us signed onto the new PCIA on-line community they created at the end of March. Merel did use the new site to post the April 13<sup>th</sup> Jonathan Epstein webinar NASPCC is conducting. We received notice on a Briefing which PCIA is sponsoring on Most Favored Nation Status drug pricing model on April 21<sup>st</sup> which we may attend.

Mark Veith has kept us up-to-date on the DHRC and Merel and I attended the DHRC Virtual Annual Organizational Meeting call on Friday January 29<sup>th</sup> we also attended a February 17<sup>th</sup> call where we saw updated documents and were made aware of plans to contact Congressional Staffers during the week of February 15<sup>th</sup>. There was a virtual Congressional Briefing on the CDMRP on March 16<sup>th</sup> (NASPCC Treasurer Tony Minter was on the panel). We received a Draft Dear Colleague letter of support and have an April 23<sup>rd</sup> deadline for NASPCC sign-on.

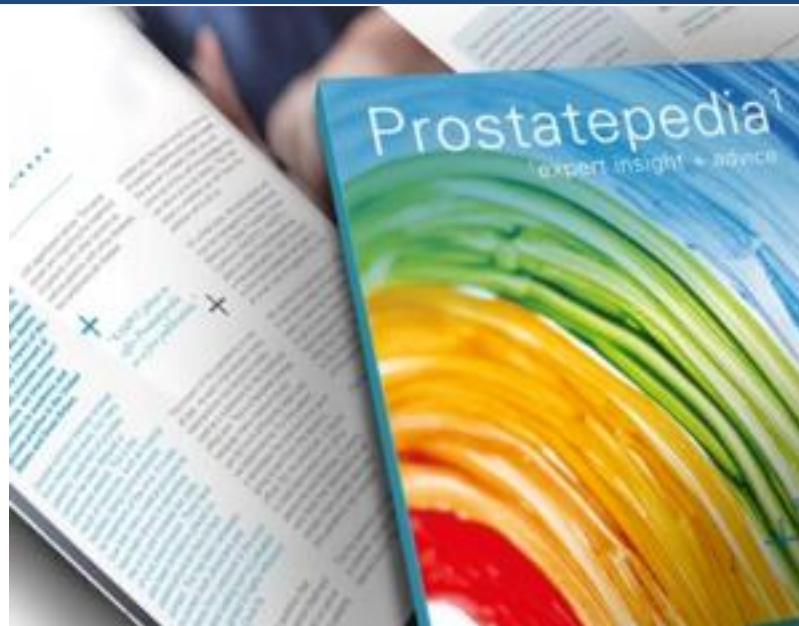
Merel and I also attended the February 8<sup>th</sup> and the March 15<sup>th</sup> OVAC calls. The OVAC Mini-Lobby Days were March 10<sup>th</sup> and their Grass Roots Lobby Days is targeted for May 12<sup>th</sup>. Merel and I were not able to stay on the April 12<sup>th</sup> OVAC call but will get the Minutes.

Public Policy/Advocacy areas we are following: 1) Friends of Cancer Research sent us the link to their April 9<sup>th</sup> Virtual Meeting they are doing with ASCO which features Ed Kim, Physician-in-Chief, City of Hope, Ned Sharpless, Director of NCI and Janet Woodcock Acting FDA Commissioner, 2) Aimed Alliance last sent the Volume 3, Issue 3 Monthly Update on April 1<sup>st</sup> and 3) NCCS sent their Health Care Roundup March 19<sup>th</sup> Newsletter which announced their April 22<sup>nd</sup> Spring Cancer Policy Roundtable (which Merel and I plan to attend) and in an April 1<sup>st</sup> email announced that the Stovall Award Nominations are open with a May 17th deadline.

5 and 6) Merel continues to head the **Fundraising Committee** and for the **Annual Meeting Committee**, she has been in contact with the Hotel Monaco staff for the September 24-26, 2021 date.

7 and 8) Don Lynam assured us that he will help with the **Budget Committee** when the Committee becomes active, but we will need a new Chairman to replace him. And finally, Michael Zaragoza continues to Chair the **Medical Advisory Committee** and Merel recently heard from Dr. Saul Priceman that he accepted the invitation to serve on the NASPCC Medical Advisory Committee.

# Prostatepedia and Prostatepedia Digest



In June of 2020, NASPCC assumed responsibility for PROSTATEPEDIA Magazine (which now is published quarterly) and the weekly PROSTATEPEDIA DIGEST (which comes out every Friday). The Magazine is in the “Flipping Book” format, so the pages click when they turn over themselves. Each Issue is comprised of several interviews with physicians and scientists and a few interviews with patients. They are also archived on the [www.naspcc.org](http://www.naspcc.org) website and can be downloaded for free as a pdf.

The Weekly PROSTATEPEDIA DIGEST always has a link to the most recent PROSTATEPEDIA Magazine and also has a link to subscribe for free. We currently have a subscription mailing list of over 12,000 people. The weekly DIGEST is unique as it contains links to abstracts and curated articles that have been published or e-printed in the week or so before that week’s DIGEST. There are also recurring resources that appear towards the bottom of each DIGEST, such as a REPORT FROM ASCO GU 2021, or an interview with Cal Ripken, Jr. on exosome testing. There are also announcements and flyers for upcoming events, such as NASPCC Webinars. And at the top of each DIGEST there may be Banner Ads from sponsoring companies or biotechs.

NASPCC is fortunate that Jessica Myers-Schechter, the founding Editor and Publisher of PROSTATEPEDIA, agreed to continue as Editor and in fact she still conducts the interviews, which are then transcribed. After review by interviewees, our designer in London puts the Magazine together, and it is then again reviewed by Jessica and others. Jessica started PROSTATEPEDIA with her father, the well-known Dr. Snuffy Myers, a medical oncologist and prostate cancer patient, who continues to write an Introduction for each Issue.

The quarterly Magazine and the weekly DIGEST are outstanding resources, and we are proud that they are now both under the NASPCC umbrella.

## NASPCC LAMINATE SERIES

The National Alliance of State Prostate Cancer Coalitions (The Prostate Cancer Alliance) has an **Informed Decision-Making Laminate** on its website, [www.naspcc.org](http://www.naspcc.org), and continues to make these available in bulk for state prostate cancer organizations holding awareness and educational events. This Laminate is both an awareness and an educational tool and can be found directly at: <https://naspcc.org/docs/informed-decision-09-11-17.pdf>.

We are in process of creating an entire Laminate Series, including (as of press time) the following topics:

1. Advanced Prostate Cancer
2. The Role of PSA Throughout the Prostate Cancer Journey
3. Non-Metastatic Castrate-Resistant Prostate Cancer
4. Metastatic Castrate-Sensitive Prostate Cancer
5. Immuno-Oncology in Prostate Cancer
6. Pain Management in Advanced Prostate Cancer
7. Testing in Prostate Cancer
8. Bone Health in Prostate Cancer
9. Imaging in Prostate Cancer

As with the Informed Decision-Making Laminate, one side of the durable resource is for Patients, with 10 Questions and Answers; the flip side (literally) is for Physicians, with the same 10 Questions but with more scientific answers and references. We think these durable educational tools are productive and welcomed by as-yet-diagnosed patients; by current patients and their families; and by health care providers. They are indeed a unique resource.

# The 16<sup>th</sup> Annual Meeting

NASPCC is thrilled to announce that our plans for an IN-PERSON 16<sup>th</sup> Annual Meeting are still in place!! We are scheduled to hold the **16<sup>th</sup> Annual Meeting September 24-26 at the Hotel Monaco in Washington, DC**, beginning the evening of the 24<sup>th</sup>, and ending at 3:00 pm on that Sunday the 26<sup>th</sup>.

START PLANNING YOUR TRANSPORTATION and make sure you calendar these important dates! We will have an outstanding Agenda, superb presenters and panelists, great educational materials, an inspiring awards ceremony at the Saturday evening Dinner, and a critical sharing of best practices. WRITE Merel Nissenberg at [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu) for further details!



---

## Nominations Are Open:

We welcome nominations for the following Awards to be presented at the 16<sup>th</sup> Annual Meeting:

The categories are:

- JAMES WEST SPIRIT AWARD
- OUTSTANDING STATE PROSTATE CANCER ORGANIZATION
- OUTSTANDING SERVICE IN PROSTATE CANCER FOR A PHYSICIAN

Please send your suggestions to Merel at: [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu)!

# NASPCC Member Updates

## “You Tube link to the Conference will be available soon”



UCSF Helen Diller Family  
Comprehensive  
Cancer Center

### **REGISTER HERE**

#### **THE 2<sup>ND</sup> PATIENT CONFERENCE ON PROSTATE CANCER**

#### **PRESENTED BY CPCC AND UCSF**

**To Be Held Virtually Friday, May 14<sup>th</sup> and Saturday, May 15<sup>th</sup>**

The California Prostate Cancer Coalition (CPCC) and the Helen Diller Family Comprehensive Cancer Center of UCSF proudly present “The 2<sup>nd</sup> Patient Conference on Prostate Cancer” to be held virtually on Friday, May 14, 2021 from 1:00 pm to 5:00 pm PST, and Saturday, May 15, 2021 from 9:00 am to 1:00 pm PST.



A stellar faculty including Eric Small, MD; Peter Carroll, MD, MPH; June Chan, ScD; Matt Cooperberg, MD, MPH; Felix Feng, MD; Mack Roach III, MD; Stacey Kenfield, ScD; Rahul Aggarwal, MD; Hala Borno, MD; Thomas Hope, MD and many others will present during the 2-day Conference. The second day will include breakout sessions. Conference topics will include:

- The Basics
- Genetics and Genomics
- Immunology
- Clinical Trials
- ABC's of ADT
- Low-Risk Disease and Active Surveillance
- Treatment of Metastatic and Non-Metastatic Disease
- Systemic Therapy
- Prostate Cancer and African-American Men
- Imaging
- Diet & Exercise
- Managing Side Effects, Access to Care, and Intimacy and Sexual Function

Effective Shared Decision-Making requires that the patient and his doctor be INFORMED in order to make the best decisions. This Conference will help patients to think about their care, discuss their case with their own doctors and others, and join in effective informed decision-making. Ample time will be provided for the attendees to ask questions. This is an outstanding opportunity to hear from leading experts in prostate cancer. Early Registration is encouraged.

The cost for the Conference, including electronic materials for each attendee is: **\$20.00 per person\***. For additional information, please contact Merel Grey Nissenberg at [mgrey@health.ucsf.edu](mailto:mgrey@health.ucsf.edu).

\*We rely on these fees to support CPCC and this program. However, if this fee represents a financial hardship, waivers are available\*

### **REGISTER HERE**

Continued on next page



## 2021 UCSF / CPCC Patient Conference on Prostate Cancer (Working Agenda)

### Friday, May 14, 1:00-5:00PM

#### Conference Welcome

#### Session 1 (1:10-1:45): Introduction to Prostate Cancer

Prostate Cancer Epidemiology, Screening and Diagnosis: Matthew Cooperberg, MD, MPH

Race, Racism and Prostate Cancer Disparities: Mack Roach III, MD

An Introduction to Clinical Trials: Rahul Aggarwal, MD

#### Session 2 (1:50-4:30): Localized Prostate Cancer

Risk Stratification: Felix Feng, MD

Treatment Approaches

Active Surveillance: Matthew Cooperberg, MD, MPH / Peter Carroll, MD, MPH

Surgery: Matthew Cooperberg, MD, MPH / Peter Carroll, MD, MPH

Radiation: Mack Roach III, MD

Androgen Deprivation Therapy: Eric Small, MD

Panel Discussion: Localized Prostate Cancer Cases and Decision Making (Stan Rosenfeld, Moderator)

#### Session 3 (4:30-5:00): Prostate Cancer and Lifestyle

Diet and Exercise as Part of Your Prostate Cancer Treatment Plan:

June Chan, ScD and Stacey Kenfield, ScD

### Saturday, May 15, 9:00AM-12:45PM

#### Session 4: PSA Recurrent Prostate Cancer

PSA Recurrence, Risk Assessment: Mack Roach III, MD

PSMA PET and Functional Imaging: Thomas Hope, MD

Oligometastatic Disease - Metastasis-Directed Therapy and SBRT: Felix Feng, MD

Systemic Therapy Options for "PSA Only" Disease: Rahul Aggarwal, MD

Panel Discussion: Recurrent Prostate Cancer Cases

#### Session 5 (11:00-12:00): Advanced Prostate Cancer

Untreated Metastatic Prostate Cancer: Rahul Agarwal, MD

ADT Resistant Non-Metastatic Prostate Cancer (nmCRPC): Eric Small, MD

ADT Resistant Metastatic Prostate Cancer (mCRPC): Conventional Therapy: Hala Borno, MD

Investigational Therapy: Eric Small, MD

#### Session 6 (12:05-12:45): Meet-the-Faculty Breakout Discussions

Conference attendees may drop in to any or all.

- ☐ Hala Borno, MD: Advanced Disease, Clinical Trials
- ☐ June Chan, ScD: Diet and Exercise
- ☐ Peter Carroll, MD, MPH: Early Stage Disease
- ☐ Matthew Cooperberg, MD, MPH: Early Stage Disease, Genomic Testing
- ☐ Thomas Hope, MD: Imaging
- ☐ Stacey Kenfield, ScD: Diet and Exercise
- ☐ Michael Rabow, MD: Symptom Management (Physical and Emotional) for Patients and Caregivers
- ☐ Stan Rosenfeld: Patient Peer Support, Personal Decision Making
- ☐ Mack Roach III, MD: Early Stage Disease
- ☐ Alan Shindel, MD, MAS: Sexual Function
- ☐ Eric Small, MD: Advanced Disease, Drug Development Trials, Genomic Testing

# REGISTER HERE

# Save The Date



1999 Avenue of the Stars., Suite 1100  
Los Angeles, CA 90067

877-NASPCC-8  
(877-627-7228)

[www.naspcc.org](http://www.naspcc.org)

## EXECUTIVE COMMITTEE

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Eastern Virginia Medical School

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University of Texas Health Science  
Center at San Antonio

June 5, 2021

## **SAVE THE DATE!**

### **EXCITING IMMUNO-ONCOLOGY SYMPOSIUM**

Watch for our Registration Flyer next week announcing an exciting  
**SYMPOSIUM on IMMUNO-ONCOLOGY IN PROSTATE CANCER**  
to be presented by the National Alliance of State Prostate Cancer Coalitions  
on Thursday, **June 24, 2021 from 10:00 am to 2:30 p m PDT (1:00 pm to 5:30 pm EDT)!**

#### Faculty will include:

- \* Saul Priceman, PhD, City of Hope who will moderate;
- \* Rahul Aggarwal, MD, of UCSF
- \* Charles Drake, MD, PhD, of New York-Presbyterian/Columbia
- \* Lawrence Fong, MD, of UCSF
- \* James Gulley, MD, PhD, of the NIH
- \* John Lee, MD, PhD, of the Fred Hutchinson Cancer Center,

#### Seattle

- \* Vivek Narayan, MD, MS, of the University of Pennsylvania
- \* Sumit Subudhi, MD, PhD, of M.D. Anderson Cancer, Houston

In the works are topics covering the landscape of immunotherapy  
options in prostate cancer; novel mechanisms of action; BiTE antibodies;  
Car-T Cell Therapy; the use of pembrolizumab in advanced prostate cancer,  
and future perspectives.

### **REGISTRATION FLYER COMING SOON!**

# Prostate Cancer Marker Information

Prostate Conditions Education Council (PCEC) has an excellent resource on prostate cancer markers, genomic tests and genetic testing! To access this informative and interactive tool, please visit: [www.ProstateMarkers.org](http://www.ProstateMarkers.org). PCEC also has this piece available as a handout. Please email [Renee.Savickas@prostateconditions.org](mailto:Renee.Savickas@prostateconditions.org) if you are interested in placing an order for Prostate Cancer Marker cards. All PCEC educational materials are FREE of charge.

**Prostate Cancer MARKERS**

Prostate cancer markers, genomic tests and genetic testing are making an impact on the world of prostate cancer by helping to individualize patient care in early detection, diagnosis and treatment choices for prostate cancer.

**www.ProstateMarkers.org**

**PCEC**  
PROSTATE CONDITIONS EDUCATION COUNCIL

7009 South Potomac Street, Suite 125 - Centennial, CO 80112  
1-866-4PROST8 - info@prostateconditions.org

## Types of Markers & Tests

- Screening and Early Detection
- Who To Biopsy
- Who To Treat
- Who Would Benefit From Additional Treatment
- Ongoing Testing
- Genetic Testing

Prostate Conditions Education Council is very proud to be leading the nation in personalized medicine with prostate cancer awareness and making these markers and tests accessible to all men!

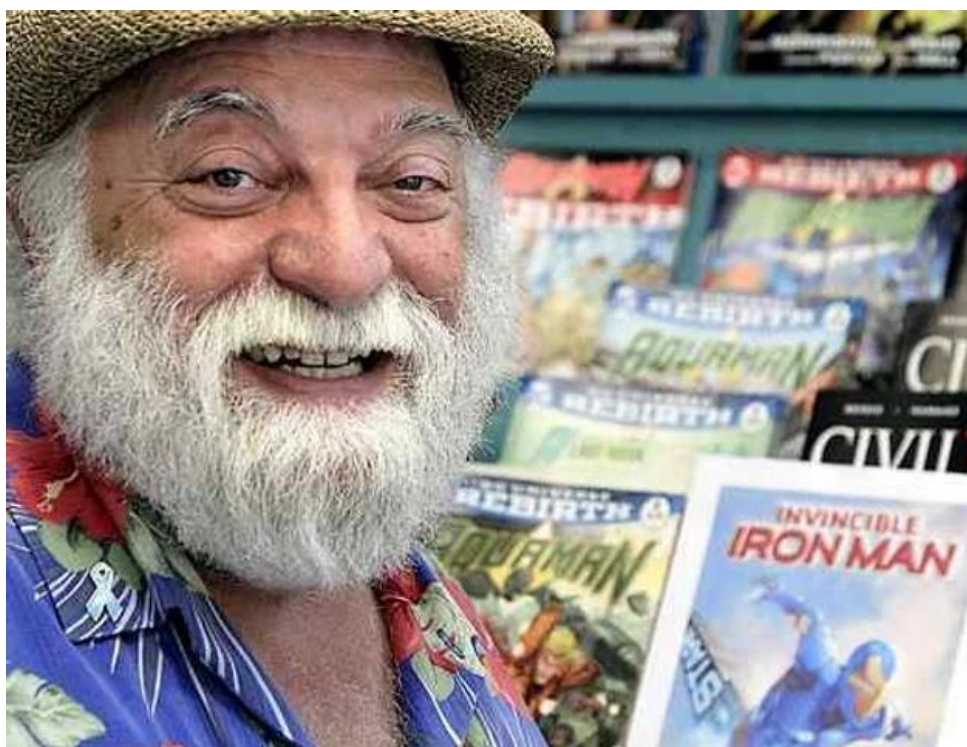
**PCEC**  
PROSTATE CONDITIONS EDUCATION COUNCIL

**www.ProstateMarkers.org**  
7009 South Potomac Street, Suite 125 - Centennial, CO 80112  
1-866-4PROST8 - info@prostateconditions.org

## 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 Board Member to acknowledge the wonderful services they provide in their state. This quarter we are honored to shine the SPOTLIGHT on:

### Joe Ferrara, Santa Cruz, California



He's called the "Cape Crusader" in California! Fifteen-year prostate cancer survivor, Joe Ferrara is a Superhero when it comes to his passion about spreading awareness on Prostate Cancer and Joe is raising the bar for awareness in unique and exciting ways!

Joe is the owner of **Atlantis Fantasyworld**, an amazing comic bookstore in Santa Cruz, CA. Atlantis Fantasyworld is an International Award Winner! Joe has combined his love for Comic Books and his passion for prostate cancer awareness. A few years after Joe's prostate cancer diagnosis and successful treatment, Joe saw the need to share his knowledge of prostate cancer to men and their loved ones on what he had learned and lived about prostate cancer. Joe is very active in the local prostate cancer community and serves on the board of the Santa Cruz County Prostate Cancer Support Group and the California Prostate Cancer Coalition in LA as well.

Joe used his connections within the Comic-book industry and worked with Marvel Comics and the American Cancer Society to launch a local, national and international campaign of awareness for Prostate Cancer.

Continued on next page

Marvel released five comic book covers in a blue banner at the bottom with important messaging. Along with these special editions bringing awareness to prostate cancer, Joe also held events at his Comic bookstore and handed out pamphlets and information about the disease. Marvel's reach with this amazing campaign of this comic book distribution, was over 150 thousand copies worldwide. Working with Marvel Comics, this offered the opportunity to reach a younger demographic to start planting the seed, so they are informed when they are old enough to start the conversation with their doctor.

Not only does Joe use his Comic-Book store as a platform for bringing awareness to Prostate Cancer, but he also uses his musical talent as well! Joe is a singer and plays the guitar too! Joe plays local gigs on a regular basis and once did a 12-hour singing marathon to raise awareness by singing 185 songs!

Joe also leads local in person support group meetings that are open to patients and their loved ones. They also offer Zoom Support Group Meetings as well. The support group hosts a meeting once a month.

Way to go Joe! Thank you for the amazing work you are doing providing interesting new ways to spread the awareness of Prostate Cancer!

To learn more about the Santa Cruz County Support Group or the California Prostate Cancer Coalition, please visit their websites: [www.scprostate.org](http://www.scprostate.org) and <http://www.prostatecalif.org/>

*NASPCC would like to congratulate Joe Ferrara of the Santa Cruz County Prostate Cancer Support Group and the California Prostate Cancer Coalition for being our "Spotlight" featured Advocate of the quarter! You are doing excellent work bringing Prostate Cancer Awareness, Education and Support in California! Thank you for all that you do!*

# NASPPC Brochure

## PARTICIPATING STATES



## HOW DOES NASPPC REACH PROSTATE CANCER PATIENTS AND THEIR FAMILIES?

NASPPC supports the development of state prostate cancer organizations, each of which is comprised of patient networks and support groups. NASPPC through its Annual Meeting, webinars, and other activities shares prostate cancer information with all of its participating state prostate cancer organizations, and this educational material is then disseminated to patients and their families, demonstrating the breadth and depth of our reach. NASPPC also helps equip patients and their families to actively engage in the prostate cancer cause.

## NASPPC ANNUAL MEETING

The Annual Meeting pulls together leaders in the rapidly developing field of prostate cancer—patients and families, researchers, practitioners, and people interested in the disease—who want to **share, learn and lead**. Industry helps support the Annual Meeting. The patient community is unique and the contemporary overview in the Take Home Messages from the Annual Meeting allows them to become empowered to do things locally. NASPPC creates support and a forum to enrich and rejuvenate these individuals and state organizations.



## NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS

- We are a 501(c)(3) not-for-profit umbrella organization with an extensive national outreach through state prostate cancer organizations and individuals
- We advocate for Informed Decision-Making in prostate cancer, and we disseminate information relating to the disease, including a durable, laminated awareness and education tool for patients and primary care providers. [www.prostatecalif.org/patient-guide](http://www.prostatecalif.org/patient-guide)
- We hold an Annual Meeting to enhance education and share best practices across the U.S.
- We conduct quarterly Webinars and moderate National Conference Calls
- We actively provide, through our participating organizations: support groups, educational forums, workshops, prostate cancer information, and awareness and educational activities
- We maintain a Website [www.nasppc.org](http://www.nasppc.org) and an active Facebook Page ("National Alliance of State Prostate Cancer Coalitions")
- We advocate for the highest quality of life for prostate cancer patients and their families
- We maintain an in-depth Education and Best Practices Guide utilized by state organizations to ensure quality outreach
- We have an Advisory Board comprised of influential and respected physicians, scientists and researchers



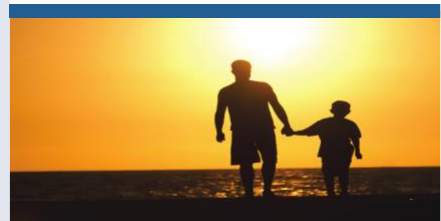
NASPPC, 1999 Avenue of the Stars, Suite 1100  
Los Angeles, California 90067  
Toll Free 877-NASPPC-8 (877-627-7228)

E-mail: [info@nasppc.org](mailto:info@nasppc.org) Website: [www.nasppc.org](http://www.nasppc.org)

November 2019



Reaching Thousands  
of Prostate Cancer Patients  
and their Families  
Across the U.S. Since 2004



## MISSION STATEMENT

NASPPC is a nation-wide organization comprised of state prostate cancer 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.

## BECOMING INFORMED AND AWARE

More and more of us are learning more and more about cancer, but even with rapid changes in oncology, much remains unknown. Although prostate cancer is a common cancer, many people do not know about it. Some people are more at risk than others. Every man should have a discussion with his doctor about prostate cancer risk and testing. After that discussion, the decision to be tested is then up to the man based upon his own values and preferences. This is called **INFORMED OR SHARED DECISION-MAKING**. We have adopted a 2-sided useful tool on Informed Decision-Making to take to your doctor's office to help you with the discussion. Here is the link: [www.prostatecalif.org/patient-guide](http://www.prostatecalif.org/patient-guide)

NASPPC recommends a baseline PSA and DRE beginning at 40 (at 35 if high risk, including African-American men or men with a certain or indeterminate family history of prostate cancer), and then periodically depending on those results. You should know and keep track of all your PSA measurements and ANY CHANGE IN PSA should be discussed with your doctor.



## EARLY STAGE AND ADVANCED DISEASE

In early stage prostate cancer the disease is still inside of the prostate and has not spread beyond the gland. This is the most treatable stage. In advanced prostate cancer, the disease has spread outside of the prostate to adjacent areas, or has spread to non-adjacent areas through metastasis (where the disease has traveled by blood or lymph nodes away from the prostate and has formed new tumors elsewhere in the body). The goal is to diagnose prostate cancer in its early stages. **The earlier 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 is nearly 100%.**



## TREATMENT FOR PROSTATE CANCER

In early stage prostate cancer, Active Surveillance, Surgery, and Radiation Therapy are the standard choices for treatment. Active Surveillance is gaining in popularity for clinically insignificant prostate cancer since it helps avoid overtreatment. For advanced prostate cancer, treatment choices include Hormone Therapy, Chemotherapy, Immunotherapy and Radiation Therapy. Most treatments for prostate cancer involve a risk of side effects. Clinical trials may be an option.

## EXECUTIVE COMMITTEE

Merel Grey Nissenberg, Esq., President	California
Johnny Payne, Vice-President	South Carolina
Donald Lynam, Treasurer	Kentucky
Jan Marfyak, Secretary	New Mexico
LaTanya Patton, Director-at-Large	Missouri
Thomas Kirk, Invited Member, Executive Committee	California

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## CONTACT NASPPC TO:

- Become a member of NASPPC
- Send a donation to NASPPC, a 501(c)(3) not-for-profit charitable organization
- Contact your state coalition
- Organize a state coalition

## WANT TO ESTABLISH A COALITION IN YOUR STATE?

NASPPC has educational materials and skilled leaders to help you establish a coalition.

## CONTACT:

National Alliance of  
State Prostate Cancer Coalitions  
1999 Avenue of the Stars, Suite 1100  
Los Angeles, California 90067  
Toll Free 877-NASPPC-8 (877-627-7228)  
E-mail: [info@nasppc.org](mailto:info@nasppc.org)  
Website: [www.nasppc.org](http://www.nasppc.org)

*\*The late Otto Sankey has been replaced on the Board by D. Bruce Williams of Arizona\**

# Social Media Corner

This section of the **Blueprint** is dedicated to providing 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!***



# CANCERCARE Prostate Cancer Online Support Group



**CANCERCare®**  
Help and Hope

## FREE PROFESSIONAL SUPPORT SERVICES

CancerCare helps individuals, families, caregivers and the bereaved cope with the emotional and practical challenges of cancer. Our services include case management, counseling, support groups, educational workshops, publications and financial assistance. All of our services are provided by master's-prepared oncology social workers and are offered completely free of charge. To learn more, visit [www.cancercares.org](http://www.cancercares.org).

## CONNECT WITH US



**FACEBOOK**  
[www.facebook.com/CancerCare](http://www.facebook.com/CancerCare)



**BLOG**  
[www.cancercares.org/blog](http://www.cancercares.org/blog)



**YOUTUBE**  
[www.youtube.com/cancercaresinc](http://www.youtube.com/cancercaresinc)

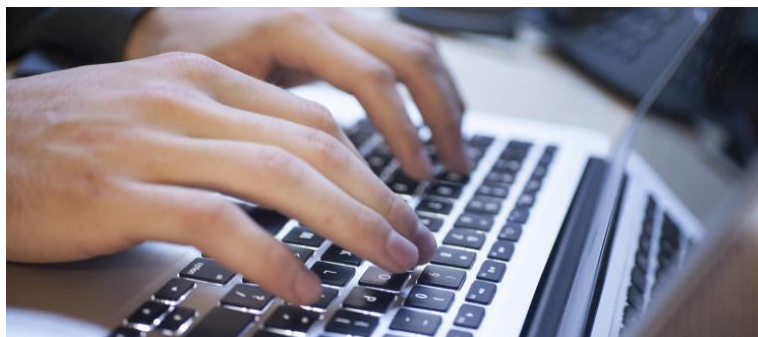


**TWITTER**  
[@CancerCare](https://twitter.com/CancerCare)



**INSTAGRAM**  
[@CancerCareUS](https://www.instagram.com/CancerCareUS)

**CancerCare® National Office**  
275 Seventh Avenue  
New York, NY 10001  
800-813-HOPE (4673)



## Prostate Cancer Online Support Group

CancerCare is offering a 15-week online support group for people diagnosed with prostate cancer who are currently receiving treatment. This group is co-sponsored by the National Alliance of State Prostate Cancer Coalitions (NASPCC). In this group led by an oncology social worker, patients give support to each other and share resources and information.

### OUR GROUP:

- Reduces feelings of loneliness, anxiety and distress
- Helps you learn new ways of coping
- Increases feelings of hope and empowerment
- Provides you with practical information about treatment and resources
- Helps you communicate better with your medical team and loved ones

**TO JOIN THIS SUPPORT GROUP, PLEASE VISIT [cancercares.org/support\\_groups/126-prostate\\_cancer\\_patient\\_support\\_group](http://cancercares.org/support_groups/126-prostate_cancer_patient_support_group) to complete our online registration process.** Internet access is required. After joining this password-protected group, you can read and post messages 24 hours a day, 7 days a week.

At this time, CancerCare's online support groups are only available to people residing within the United States (including Puerto Rico and U.S. territories).



# 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
- 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 and or Brochures.

## 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. NASPCC also has brochures as well.

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!



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The 2021 Board of Directors of the National Alliance of State Prostate Cancer Coalitions

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