



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

## News

Volume 3, Issue 3  
November 2020

# THE BLUEPRINT

**J. Renee Savickas, Editor**

## President's Message

Welcome to the Fall edition of THE BLUEPRINT, NASPCC's Newsletter edited by our own Renee Savickas of Colorado! As I write this, COVID-19 continues to be a major health concern for young and older, everywhere in the country. All of our meetings and conferences and many support group meetings as well, have been converted to zoom or other virtual formats. That includes the annual AUA and ASCO Meetings as well.

Yet NASPCC continues to grow and to increase its visibility and its participation in the prostate cancer community. We continue with our Webinars – the most recent was November 4 with Dr. Andrew Armstrong of Duke University Medical Center on "The PROCEED Registry and Diversity Work in Metastatic Prostate Cancer". There will be a **Webinar on December 8, 2020 ("Incontinence and Sexual Side Effects of Prostate Cancer Treatment")** with Dr. William Brant, and a **Webinar on January 11, 2021 ("Theranostics in Prostate Cancer")** with Dr. Michael Morris of Memorial Sloan-Kettering Cancer Center. Our PROSTATEPEDIA Magazine and weekly PROSTATEPEDIA DIGESTS continue to be on our [www.NASPCC.org](http://www.NASPCC.org) website and are mailed out to over 12,000 people. We plan optimistically for an in-person 16<sup>th</sup> Annual Meeting to be held **SEPTEMBER 24-26, 2021 (NEW DATES!)** in Washington, DC. We are continuing to create, produce and distribute unique Laminates on several topics. We have held a virtual Roundtable on patients' desires in terms of research topics in prostate cancer, as a follow-up to a two-part Survey sent out to all the state organizations. We have participated in the AUA's Patient Advocacy Connection Program and continue to participate as an organization in the Friends of Prostate Cancer Care Community. We have also participated in CURE Magazine's Educated Prostate Cancer Patient Summit. We are moving!

I am also sad to report the passing of Board Member Alvin Chin of Virginia from a heart attack on November 17, 2020. We will miss his enthusiasm, natural curiosity, and passion for the cause. Alvin chaired the Advocacy & Public Policy Committee and served for several years on the Budget Committee. We valued Alvin's thoughtful advice and opinions. **His passing reminds us of the need to appreciate every day.** We will honor him in September at our 16<sup>th</sup> Annual Meeting.

Let's hope that when we produce our next Newsletter, THE BLUEPRINT, we will have better news in the health arena, and also that we as a country will be improving our management and survivability of COVID-19. We of course hope for more developments in testing and in new and better treatments for prostate cancer. **In the meantime, please wear a mask and stay safe!!!**

Merel Nissenberg

**NASPCC BOD Minutes**  
**October 27, 2020**  
**By Merel Nissenberg**

The Board of Directors of NASPCC met on Tuesday, October 27, 2020 starting at 1:00 pm EASTERN. Present were: Mary Anderson, Dave Hulbert, Crissy Kantor, David Sauls, Renee Savickas, Bruce Williams, LaTanya Patton, Johnny Payne, Don Lynam, Tom Kirk and Merel Nissenberg. Absent were: Alvin Chin, Paul Kradel, Robin Leach, Harold Pharoah, Stephen Richardson, Gabe Rosko, Clarence Williamson, and Ulyses Wright. Tony Minter of South Carolina was also present as a guest.

**PRESIDENT'S REPORT:** Merel gave her President's Report, and stated that every single Meeting and Conference since the end of February has been virtual. That included ASCO, AUA, ACCR, and a few others. She stated that the Annual Meeting which had been continued from October to January is scheduled now for March 12-14, 2021 at the Hotel Monaco in Washington, DC again, and she said that she has asked for large round tables in the Ballroom instead of the usual hollow rectangle, in order to spread people out. Merel also reported on how our new PROSTATEPEDIA is so exciting, not only the Magazine (the August issue had been "flippable"), but the DIGEST which goes out every Friday. She also talked briefly about the Webinars we have been holding, which are archived on our website (both the recordings and the slides). She also mentioned that we are working on more Laminates.

**SECRETARY'S REPORT:** In Jan Marfyak's absence, Merel brought up the July Board of Directors Meeting Minutes for approval. (All Minutes had been sent to the full Board last Sunday, October 25, 2020). There were no suggestions or edits. Bruce Williams moved, LaTanya Patton seconded, and the July BOD 2020 Minutes were approved. She also then brought up the Executive Committee Minutes from August and October 2020. There were no edits or changes; LaTanya moved, Don Lynam seconded that the BOD accepted those EC Minutes (also sent out to the BOD last Sunday October 25, 2020). Motion was approved.

**TREASURER'S REPORT:** Don Lynam reported that he had sent out all of the Financials last Thursday, October 22, 2020. He stated that NASPCC had \$180,015.24 in the bank in checking and savings as of September 30, 2020, the end of our fiscal year. He said that he had also sent out the Profit & Loss Detail and Profit & Loss Summary; and that as of September 30, 2020 we had expenses for the fiscal year of \$177,662.93 and income of \$250,059.89, for a net positive income of \$72,396.96. Don further stated that NASPCC has had a "great year" and said that Merel had done a "tremendous job" of raising funds, more than \$246,000 in donations for our "banner year". He congratulated her. LaTanya moved, David Sauls seconded, that we accept Don's Treasurer's Report as submitted. Motion was approved.

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Don Lynam then introduced the **Budget for 2020-2021 (Draft 9)** that he said the BOD needed to approve now that the EC had voted to send it to the Board for their approval. He stated that we are proposing for the new fiscal year (October 1, 2020 - September 30, 2021): Total income of \$202,004 and proposed expenses of \$250,650, which would leave us with a net loss of \$48,646. He said that we have many projects, including Laminate projects; he said that we have definitely raised our profile as an organization and have raised our income and we have more recognition now.

LaTanya moved, and Crissy Kantor seconded, that we accept and approve the Budget for 2020-2021. The Motion was approved. Merel gave a brief description of some of the projects, including our agreement to create, produce and distribute a very large number of 2-sided Laminates with 10 questions, one side for patients and the flip side for physicians. We currently have 6 or 7 in process.

Merel next brought up the Treasurer's position out of order from the Agenda. Don Lynam has been doing an amazing job with such hard work as Treasurer for several years, and he really needs to step down because of bad back problems. Merel had discussed this with the Executive Committee during their last October EC Call, and with their approval has asked Tony Minter of South Carolina to serve as Treasurer in Don's place. Tony had attended our 15<sup>th</sup> Annual Meeting last October because Johnny Payne had been unable to attend. Since that time, Tony has participated on our Budget Committee and his wife has participated on the Education & Awareness Committee. Merel asked the Board to approve the nomination of Tony Minter as Treasurer to replace Don in that position; and she also said that LaTanya had agreed to step up as Vice President (because Johnny Payne can't stay as an officer as he would be a second South Carolina representative). She also had asked Don to take over LaTanya's position as Director-at-Large so that he would be remaining on the Executive Committee. This group of suggested changes was approved by acclamation. Don will start transitioning the Treasurer's job to Tony which may take a month or so. The entire Board expressed thanks to Don for an excellent job well done!

**COMMITTEES STATUS REPORT:** Tom Kirk, Chair of the Steering Committee, reported on the status of all of the 8 Advisory Committees, and had also mailed out a Summary Report to the full Board a couple days ago. Communications Committee: Renee Savickas, chair of the Communications Committee, stated that she needs articles for the upcoming Newsletter (The Blueprint), by October 30, and hopes to get the Newsletter out by November 16. The Education & Awareness Committee has been very active, with Fran Franklin of Delaware chairing. The last call was October 14; Merel and Tom were unable to join. They have not yet seen the Minutes. Tom also stated that Tiffany Razzo and Jessica Myers-Schechter have been working hard on our weekly PROSTATEPEDIA DIGEST, and Jessica on PROSTATEPEDIA MAGAZINE, all of which is now under the NASPCC banner.

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Alvin Chin was chair the Advocacy & Public Policy Committee, and along with Merel and Tom is participating in the FoPCCC - Friends of Prostate Cancer Care Community.

Tom also stated that he and Merel had recently (September 26) participated in the virtual Educated Prostate Cancer Patient Summit put on by CURE Magazine. CURE Magazine is currently putting together a Supplement that will include material on NASPCC. Fundraising and Annual Meeting Committees are chaired by Merel, and she already reported on both. Budget Committee is chaired by Donald Lynam who Tom said had done an exceptional job - 9 drafts for the proposed 2020-2021 Budget which has now been adopted. Tom then said there had been little activity by Rob Johnson's State Coalition Development Committee and Michael Zaragoza's Medical Advisory Committee.

Merel then reiterated her description of the work we are doing with PROSTATEPEDIA MAGAZINE and the weekly PROSTATEPEDIA DIGEST. She again said there is a Distribution List of over 12,000 people, and that the Magazines and DIGESTS are on our website. She had already talked about the Annual Meeting and stated that seating will be changed to allow for social distancing.

As to Webinars, Merel mentioned the excellent webinars we have already done this year (which are archived on our website), and also stated that the next webinar is scheduled for November 4 and will be Dr. Andrew Armstrong from Duke University Medical Center presenting on "The PROCEED Registry and Diversity Work in Metastatic Prostate Cancer".

Before the Board Meeting ended, Bruce Williams (Arizona) asked if I could share with the full Board the list of all of the Laminates that we are going to be producing and distributing. Merel agreed to do that.

The Board Call ended at approximately 1:31 pm EASTERN.

Respectfully submitted, Merel Nissenberg (in secretary Jan Marfyak's absence)

# NASPCC WEBINARS

NASPCC continues to offer an outstanding Webinar Series. The Webinars are always free and offer an opportunity for live Q&A during the 1-hour time frame. This year we have already had Webinars on: Side Effects of PCa Treatment; Exosome Testing; Immunotherapy and PARP Inhibition PSMA Imaging; The PROCEED Registry and Disparities Work in Prostate Cancer; and more. Before the year's end we will also have held Webinars on Immuno-Oncology, How to Treat Side Effects of Prostate Cancer Treatment, and more.

We utilize the GoToWebinar Platform which includes 500 portals for free attendance. After each webinar, the recording of the Webinar along with the slides that were utilized are archived on our [www.naspcc.org](http://www.naspcc.org) website for utilization by anyone – we've even received requests for utilization from as far away as Canada. These Webinars are “the gift that keeps on giving”, and since we have the most stellar experts presenting, our Webinars are unique and stand out from those of any other organization. Please visit <https://naspcc.org/index.php/naspcc-webinar-series-presents-july-29-2021>.

(Upcoming NASPCC Webinars continued on next page)



NASPCC Webinar Series Presents:

**“Incontinence and Sexual Side Effects of Prostate Cancer Treatment”**

With William Brant, MD, FACS, FECSM, Urologist & Men’s Sexual Health Physician in Salt Lake City, Utah

The 1-hour Webinar will take place on

**Tuesday, December 8, 2020 at 7:00 pm – 8:00 pm Eastern.**

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



Dr. Brant attended Dartmouth College and the University of Washington, and obtained his MD at the University of California, San Diego. He completed residencies in Surgery and Urology at the University of Colorado Health Sciences Center and a fellowship in sexual medicine and surgery at UCSF. Dr. Brant’s practice is dedicated to Men’s Health, with a particular focus on sexual and erectile medicine; male urinary incontinence; penile reconstructive surgery; and prosthetic surgery. His current practice is divided between Summit Urology/Granger Medical Clinic and the Salt Lake City Veterans Affairs Medical Center.

Dr. Brant is a member of the AUA, the Sexual Medicine Society, and the Society of Urologic Prosthetic Surgeons, among others. He has authored over 100 works, including various chapters in 6 textbooks in Urology.

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NASPCC Webinar Series Presents:

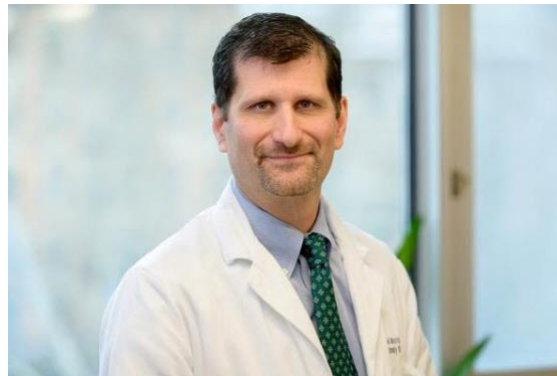
**“Theranostics in Prostate Cancer\*\*”**

With Dr. Michael Morris, Section Head of Prostate Cancer, Genitourinary Oncology Service,  
Memorial Sloan-Kettering Cancer Center in New York

The 1-hour Webinar will take place on

**Monday, January 11, 2021 from 7:00 pm – 8:00 pm Eastern.**

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



Dr. Morris is a prostate cancer specialist, clinical investigator, and the Section Head of Prostate Cancer of the Genitourinary Oncology Service at Memorial Sloan-Kettering Cancer Center. He earned his medical degree from the Mount Sinai School of Medicine in New York, and performed his internship and residency in Internal Medicine at Columbia Presbyterian Medical Center. He then completed his medical oncology fellowship at Memorial Sloan-Kettering Cancer Center, where he was the Chief Fellow as well.

Dr. Morris has led numerous clinical trials, but he has a particular research focus on targeted therapy for prostate cancer, especially those that bridge the fields of Medical Oncology and Nuclear Medicine. In the field of therapeutics, he has focused on radio immunotherapy and other radio-conjugates, bone directed therapy, and other targeted therapies. In the field of diagnostics, he has a keen research interest in developing novel imaging technologies for metastatic prostate cancer and in developing novel imaging biomarkers. He has been a co-developer of the Prostate Cancer Working Group 2 and 3 Consensus Criteria, and novel prostate-specific imaging technologies such as FDHT PET and PSMA-directed PET imaging.

In addition, he is the Medical Director of the Department of Prostate Cancer Clinical Consortium and chairs the GU Committee of the Alliance for Oncology Trials in Oncology (formerly CALGB).

*\* **Theranostics** describes the combination of using one radioactive drug to diagnose and a second radioactive drug to deliver therapy to treat the main tumor and any metastases*

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## Recent NASPCC Webinars



NASPCC Webinar Series Presents:  
**“Immunotherapy and PARP Inhibition”**

With Dr. Judd Moul, Professor, Duke University Medical Center.

The 1-hour Webinar will take place on

**Monday, October 5, 2020 at 7:00 pm – 8:00 pm Eastern.**

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



Judd W Moul, MD, FACS is the James H Semans MD Professor of Surgery at Duke University. In 2004, after completing a 26-year U.S. Army career and retiring as full Colonel in the Medical Corps, Moul became Chief of the Division of Urologic Surgery at Duke. Serving as Chief until 2011, he established the Duke Prostate Center (DPC) and directed the development of a DPC Outcomes database that contained the records of over 10,000 prostate cancer patients.

Dr. Moul serves on the editorial boards of *American Journal of Men's Health*, *Urology* and *Prostate Cancer and Prostatic Diseases*. He serves on the Executive Committee for the American Joint Commission for Cancer (AJCC). Dr. Moul has published over 600 medical and scientific manuscripts and book chapters and has lectured at national and international meetings. He has been a visiting professor and invited guest lecturer at universities and national symposia, in addition to appearances on ABC, NBC, CNN, PBS, and other media as a prostate cancer authority. Honors and awards received have included the American Medical Association's Young Physicians Section Community Service Award, the Sir Henry Welcome Research Medal and Prize from the Association of Military Surgeons of the United States, the Gold Cystoscope Award by the American Urological Association, the Baron Dominique Jean Larrey Military Surgeon Award for Excellence, the Order of Military Medical Merit from the Surgeon General of the US Army, and the Castle Connolly National Physician of the Year award in 2009.

NASPCC is receiving support for this Webinar from:



*\*Dr. Judd Moul is not receiving any compensation for this presentation\**



NASPCC Webinar Series Presents:  
**“The PROCEED Registry and Disparities Work in Metastatic Prostate Cancer”**

With Dr. Andrew Armstrong, Professor of Medicine, Surgery, Pharmacology and Cancer Biology and Director of Research, the Duke Cancer Institute Center for Prostate and Urologic Cancers at Duke University.

The 1-hour Webinar will take place on

**Wednesday, November 4, 2020 at 7:00 pm – 8:00 pm Eastern.**

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



Dr. Andrew Armstrong is a tenured Professor of Medicine, Surgery, Pharmacology and Cancer Biology and Director of Research for the Duke Cancer Institute's Center for Prostate and Urologic Cancer. He is a medical oncologist and internationally recognized expert in experimental therapeutics and biomarker development in genitourinary cancers, particularly in prostate cancer. He trained at Duke as a biomedical engineer, received his medical degree at the University of Virginia, medicine residency training at the University of Pennsylvania, fellowship and public health clinical investigation training at Johns Hopkins and the Bloomberg School of Public Health, and joined Duke's faculty in 2006.

Dr. Armstrong has developed a number of experimental agents in prostate and renal cell cancer, including completed or ongoing trials of AR inhibitors, immunotherapies, mTOR/PI3K inhibitors, and anti-angiogenic agents, and is heavily involved in the leadership of multiple ongoing phase 1-4 treatment and biomarker trials in men with advanced prostate cancer including serving as correlative science chair within the NCI ALLIANCE Cooperative Group in the GU Committee. He has authored over 170 peer reviewed publications as well as numerous chapters, reviews, and abstracts. He leads a team of over 50 research nurses, coordinators, data managers, regulatory specialists, scientists, and investigators dedicated to discovery science in GU cancers in the laboratory and treatment science in the clinic. As an R01 funded clinical-translational investigator, he has mentored over a dozen medical oncology fellows and junior faculty, and many residents and students both in the clinical, for clinical trials, and for laboratory training.

This Webinar is sponsored by:





# Update on NASPCC Committees

By Thomas Kirk

Since our last NASPCC Board Call on Tuesday July 21st, the Committee activities have been updated at each of our Monthly Executive Committee calls (August 4th, September 1st and October 6<sup>th</sup>).

- 1) For the **Communications Committee**, Renee has completed Volume 3, Issue 2 of the **Blueprint** on June 29th. She is targeting late October/early November for the next edition.
- 2) No action has taken place on the **State Coalition Development Committee** since March.
- 3) Fran Franklin has had the **Education and Awareness Committee** active, with meetings in July and September. The most recent call was held on October 14<sup>th</sup>, Merel and I were not able to attend. No response was received on the Draft MOU by the August 1st deadline. The Committee focuses on the NASPCC webinars (the next is set for November 4<sup>th</sup> with Dr. Andrew Armstrong on the PROCEED Registry).

Merel has been active with Tiffany and Jessica Myers-Schechter with the weekly Friday Digests and the Quarterly edition of the Prostatepedia digital magazine, the latest, on Chemotherapy, was released on August 21<sup>st</sup>.

- 4) Alvin was the chair to Chair the **Advocacy and Public Policy Committee**. On August 31st Mark Veith informed us the Alliance was signed on to the latest letter of support for the CDMRP for funding. We (Merel, Alvin and I) continue to be involved in the Friends of Prostate Cancer Care (FoPCCC), including the Patient/Physician Communication Workgroup held on September 29th, of which Merel is a member. There are 4 workgroups (Governance, Patient/Physician Communication, Policy/Advocacy, and Health Equity). The last FoPCC Zoom call was held on October 22<sup>nd</sup>.

On Friday, September 25<sup>th</sup> the Prostate Cancer Research Summit was successfully held with Dr. John Gore from the University of Washington and on Saturday September 26<sup>th</sup> the Alliance was active in the virtual Educated Patient Prostate Cancer Summit conducted by CURE. Merel was a member of the Future of Prostate Cancer Panel with Drs. Alan Bryce and Patrick Koo and the Alliance had a virtual exhibit booth featuring our NASPCC materials.

- 5 and 6) Merel continues in **Fundraising** and the last meeting of the Committee had to be cancelled in April. The **Annual Meeting Committee** has not met, but Merel has been in contact with the hotel and the Annual Meeting is now moved from January 29th-31<sup>st</sup> to March 12th-14th.

- 7 and 8) Don continues as **Budget Committee** Chairman as we look for a new Treasurer. The Committee forwarded a Budget to the Executive Committee for review in its October 6<sup>th</sup> call. Don will present the Budget at the October 27<sup>th</sup> NASPCC Board call which has Actual FY 2019-2020 Income of \$250,060 and Expenses of \$177,663 for a positive Net Income of \$72,397 and a Proposed FY 2020-2021 Budget with Proposed Income of \$202,004, Proposed Expenses of \$250,650 and a negative Net Income of \$48,646. And finally, Michael Zaragoza continues to Chair the **Medical Advisory Committee** which has not met for some time.

# Prostatepedia and other NASPCC Activities

## PROSTATEPEDIA

NASPCC was so pleased to take over PROSTATEPEDIA Magazine and its weekly PROSTATEPEDIA DIGESTS starting this past June, and to be able to keep Editor Jessica Myers-Schechter on as Editor with the publication now under our NASPCC banner. The first Magazine was published in August (Chemotherapy Issue) – here is the flipping book version: <https://online.flippingbook.com/view/193912/3/> . The current November 2020 Issue (Immuno-Oncology and PARP Inhibition) can be found in flipping-book version here: <https://online.flippingbook.com/link/574072/> . PROSTATEPEDIA Magazine is now quarterly, free and also downloadable as a pdf from the NASPCC Website. Please visit our website here at <https://naspcc.org/index.php/prostatepedia-magazine>. Both the Magazine AND the weekly, (every Friday) DIGEST are mailed out to a Distribution List of over 12,000 people every Friday; each person on that list receives the DIGEST as an e-mail comprised of a list of links to the most recent articles, abstracts, events, and press releases in prostate cancer. There are half- and full-page ads allowed in the PROSTATEPEDIA Magazine, and Banner Ads allowed in each DIGEST.

The next full, flipping-book PROSTATEPEDIA Magazines are scheduled for 2021 as follows: February 2021, May 2021, August 2021 and November 2021. The DIGEST will continue to be mailed out every Friday to everyone on the Distribution List and has a highlighted spot to subscribe for free for those not yet subscribed to the List. We are thrilled with the opportunity to helm the production and distribution of these incredibly excellent resources.

## CURE MAGAZINE

### EDUCATED PROSTATE CANCER PATIENT SUMMIT

On September 26, NASPCC's Merel Nissenberg and Tom Kirk participated in CURE Magazine's EDUCATED PROSTATE CANCER SUMMIT, an all-day virtual Summit with a unique, incredibly high-tech platform provided by 6connex. This included the "Auditorium", a virtual place to listen to speakers and panels (and to participate in a panel, as Merel did); and also included an astounding virtual "Exhibit Hall" with "Exhibitor tables" for each participating organization that was able to list its 3 most important resources, and allowed for "representatives" of those organizations to have conversations or group chats with "attendees". Following the SUMMIT, CURE Magazine will be putting together a Supplement of the participating organizations. We are excited to see NASPCC included.

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## **ROUNDTABLE RESEARCH SUMMIT**

On September 25, 2020, as a follow-up to the Survey sent out to all of the State Prostate Cancer organizations participating in NASPCC, we held a virtual ROUNDTABLE RESEARCH SUMMIT. The multi-hour event covered research needs and desires of patients, a factor not often taken into account when researchers plan clinical trials and formulate questions to be answered. The Roundtable was held in cooperation with Dr. John Gore, a urologist at the University of Washington. There will be a small Advisory Board that takes on this important topic going forward, and grant applications for studying questions decided as the most important research areas will follow.

### **CAL RIPKEN, JR.**

“Fight like Cal” is an educational and awareness project of ExosomeDx, a bio-techne brand. Merel Nissenberg, President of NASPCC, was lucky enough to interview Hall of Fame Baseball Legend, Cal Ripken, Jr. about his prostate cancer journey and his desire to reach other men to enable earlier detection of potentially lethal prostate cancer. Please click on this link to see the Interview which is also present in our weekly PROSTATEPEDIA DIGEST: <https://naspcc.org/index.php/my-prostate-journey-with-cal-ripken-jr>. It was an honor to interview him!

(FoPCCC update continued on next page)

## Friends of the Prostate Cancer Care Community (FoPCCC) Update

### By Alvin Chin

The Friends of the Prostate Cancer Care Community (FoPCCC) continues to meet and develop.

Earlier this year, the American Urological Association (AUA) proposed the creation of a coalition of national organizations focused around prostate cancer to achieve objectives that are common to the prostate cancer related groups. They invited numerous organizations to participate including the NASPCC as well as other organizations such as ZERO, USToo, Malecare, PCEC, PHEN, of which we are familiar, but also, almost 30 other organizations which we have had limited working relations like Stand Up to Cancer, Triage Cancer, Society of Urologic Oncology, Society of Urologic Nurses and Associates and others. It is a diverse group with varying focus on the prostate.

The initial meeting was held online on June 23, 2020, followed by another online meeting in late August to establish four working groups: Governance, Patient/Physician Communication, Policy/Advocacy, and Health Equity. Merel as the NASPCC representative is currently participating in the Patient/Physician Communication Workgroup. Although we were previously limited to one workgroup membership per voting organization, increased participation was mentioned at the last meeting given the workload that was reported-in. That being the case, Alvin Chin volunteered to be the NASPCC Policy/Advocacy Chair and may participate in the corresponding FoPCCC workgroup.

The recent meeting on October 22, 2020, produced an approved budget of \$140,000 supported by Pfizer, Janssen, AstraZeneca and Intuitive and allowed the reporting-in of the four working groups and discussion of their identified activities. Most of the budget will be used to reimburse AUA overhead costs for staffing and planning the organization. I must note that the FoPCCC budget is relatively well funded, but not detailed enough to further analyze. The next meeting will be 3 hours long and held towards the end of December to discuss next year's budget, governance issues, guest speakers and strategic actions.

It is worth noting that because of the pandemic, all these meetings are orchestrated by the AUA on Zoom Online. Objectives are being achieved and much credit should be given to the AUA staff for orchestrating the meetings and agenda.

***“This is the last article that Alvin wrote for us, and my last communication with him. He passed away less than a month later. We will miss him so much. Merel Nissenberg”.***

## IN MEMORIAM: ALVIN CHIN



All - I received a call from Board Member Alvin Chin's daughter telling me that Alvin had passed away last Tuesday, November 17, of a heart attack. He was only 71.

Alvin was a tireless Board Member of NASPCC, representing the Virginia Prostate Cancer Coalition. He was the Chair of our Advocacy & Public Policy Committee and served several years on our Budget Committee, always asking tough questions and guiding the Board with wisdom. He also helped to represent NASPCC with OVAC, with the Defense Health Research Consortium (DHRC), with various sponsors, and with FoPCCC (Friends of Prostate Cancer Care Community).

If you would like to send a condolence card to Alvin's wife and family, the address is: "Mrs. Naoki Chin, 6319 Capella Avenue, Burke, VA 22015". His daughter suggests that if anyone wishes to make a donation in Alvin's name, they can make a donation to NASPCC and state that it is in Alvin's memory.

If anyone has photos or stories they would like to share about Alvin, please send them to me at [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu).

We will honor Alvin Chin at our next Annual Meeting in September 2021. His passing reminds us of the importance and the beauty of cherishing every day. Merel

# Other Patient Advocacy Updates and Information



## 2020 PATIENT ADVOCACY PROGRAM REPORT

The Urology Care Foundation (UCF), the official Foundation of the AUA, is committed to advancing urology through research and education by working with researchers, healthcare professionals, patients, and caregivers to improve patients' lives. On August 31 – September 2, the UCF hosted the 2020 Patient Advocacy Connections Program (PACP). This year's event took place on a virtual platform and included participation from more than 35 patient, physician, and research advocacy organizations. AUA members, allied health professions and representatives from the pharmaceutical industry also participated in roundtable discussions.

### Highlights of 2020

The Patient Advocacy Connections Program (PACP) traditionally takes place during the American Urological Association's Annual Meeting. With the cancellation of AUA's 2020 Annual Meeting due to COVID-19, the seventh annual PACP program transitioned to align with the AUA's Annual Urology Advocacy Summit.

The newly revised virtual program remained in line with past years, as an interactive meeting platform provided participants with the opportunity to generate conversations and dialogue about key legislative issues during two roundtable discussions. Additionally, this year's program provided the opportunity for patient advocacy groups to meet with AUA Leadership in small groups to continue networking opportunities from afar. The program hosted more than 50 participants representing thirty-five urology-focused patient advocacy organizations. The main goals of the Patient Advocacy Program include:

- Providing collaboration opportunities between patient advocacy organizations and AUA members to discuss legislative priorities.
- Providing patient advocacy organizations the opportunity to network with members from the pharmaceutical industry.
- Providing interaction and dialogue about collaboration tactics that effectively promote patient advocacy legislative agendas.

### Program Participants

- |  |   |
|--|---|
| 1. Action To Cure Kidney Cancer                    | 14. Kidney Cancer Association                             |
| 2. Active Surveillance Patients International      | 15. KidneyCAN   |
| 3. AnCan   | 16. Live UTI Free   |
| 4. Association for the Bladder Exstrophy Community | 17. Malecare  |
| 5. Bladder Cancer Advocacy Network                 | 18. Multiple Sclerosis Association of America             |
| 6. Cancer ABC's                                    | 19. Multiple Sclerosis Foundation                         |
| 7. Cancer and Careers                              | 20. National Alliance of State Prostate Cancer Coalitions |
| 8. Cancer Support Community                        | 21. National Kidney Foundation                            |
| 9. Crush It For Curtis Foundation                  | 22. Oxalosis & Hyperoxaluria Foundation                   |
| 10. FORCE (Facing Our Risk of Cancer Empowerment)  | 23. Patient Empowerment Network                           |
| 11. Interstitial Cystitis Association              | 24. Prostate Health Education Network                     |
| 12. Joey's Wings Foundation                        | 25. ProstAware  |
| 13. KCCure   | 26. Resolve: The National Infertility Association         |
|  | 27. Simon Foundation For Continence                       |

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- 28. Society for Women's Health Research
- 29. Spina Bifida Association
- 30. The Max Foundation
- 31. Triage Cancer

- 32. United Spinal Association
- 33. Us TOO International
- 34. Veterans Prostate Cancer Awareness
- 35. VHL Alliance

## Patient Advocacy Roundtables

An integral component of the Patient Advocacy Connections Program experience was the development and implementation of two virtual roundtable discussions. Roundtable meeting agendas were formulated under the direction of a steering committee that included representation from five patient advocacy organizations including Association for the Bladder Exstrophy Community, KidneyCAN, RetireSafe, United Spinal, and ZERO – The End of Prostate Cancer. In close collaboration with Urology Care Foundation, the steering committee developed two interactive roundtables and a networking event that fostered opportunities for collaboration among participants and the opportunity to synergize advocacy efforts.

### *Overcoming Health Disparities and Addressing Health Equity in Healthcare: A Discussion with Pfizer*

This opening roundtable discussion featured guest speakers Beth Burnett, Director, Advocacy and Professional Relations and Jenny Ghith, MS, Director, Global Scientific Publications. The presentation highlighted key components of health equity challenges including prevention, access, and partnerships. Ms. Burnett presented information on trends in incidence of cancer by aging, challenges facing older people with cancer, and different approaches that can address age-related health disparities. This presentation launched a discussion among participants noting that a strategy addressing health disparities in older people could address additional factors in health disparities, including the LGBTQ and minority communities.

Ms. Ghith's presentation highlighted the need to break down barriers among the large amounts of medical knowledge/data, and the patient/clinician to ensure the highest levels of individualized treatment decisions and outcomes. This fostered discussion among the group regarding the need to have the patient perspective included in Medical Congresses and while creating and delivering publication plan language summaries (PLS).

**See Attachment I for Roundtable Agenda.**



*Pictured above is the final slide from Roundtable 1 highlighting tactics needed to address and overcome obstacles associated with health disparities among minority populations.*

(Continued on next page)



## **Effective Advocacy Coordination: Collaborating with Urology Stakeholders to Improve Health Outcomes**

This panel discussion highlighted advocacy perspectives regarding how patient advocates can effectively collaborate with stakeholders within the urology community to improve health outcomes and access to care. Three panelists, representing perspectives from urology specialty organizations, research and young urologists, provided insights on experiences with addressing urologic advocacy issues. Key takeaways from these presentations included the need to increase funding for bladder health research, the benefits of joining like-minded coalitions, engagement in public advocacy events (grants/scholarship opportunities) and using social media to remain connected with urology professionals and other advocacy groups. AUA's Patient Advocacy Liaison moderated this panel and facilitated discussions with the group on ways advocates can help urologic professionals better understand and communicate with patients, be more involved in urologic research advocacy, and overall communication. **See Attachment II for Roundtable Agenda.**



Top row: (pictured left to right) is John Fortin, Panel Moderator and AUA Patient Advocacy Liaison; Kimberly Serota, AUA Patient & Research Advocacy Coordinator; Jess Bateman, AUA Patient & Research Advocacy Sr. Manager; Bottom row: (pictured left to right) is Gail Prins, PhD, AUA Research Advocacy Committee; Brook Brown, MD, MPH, AUA Bladder Health Committee; Kevin Koo, MD, former AUA Legislative Holtgrewe Scholar

## **“Advocacy Rounds” Networking Event**

Networking between clinicians and patient advocacy organizations is a main goal of the PACP. Although the program transitioned to a virtual platform, patients and physicians participated in small group discussions that produced effective conversations. The networking event utilized breakout rooms to connect patient advocacy organizations with more than 30 members of the AUA/UCF's leadership including members of the Board, Public Policy Council, Legislative Affairs Committee, Research Advocacy Committee and more. This event provided a platform for advocacy organizations and AUA members to learn more about interests and specialty areas, and further discuss potential areas for future collaborations.

Advocacy organization participants stated the following:

- “... we quickly organized ourselves and had nice conversations with the physicians. I think it was valuable for all parties.”
- “Wasn't really sure what to expect from the advocacy rounds, however, I loved them!”

(Continued on next page)

AUA members stated the following:

- *"This was time well spent. I actually think one strategy we could have moving forward would be to have such meetings set up two times per year."*
- *"Know that it was truly my delight and gratefulness to be part of that session. As always, interacting with patients to see different perspectives is enlightening."*
- *"I enjoyed participating and learned a lot about the different cancer support groups. It was a very worthwhile session and thanks for inviting me to participate."*
- *"We were all sad our time to meet was short, but I think we got a huge amount done so it was time well spent! It was a highlight of the day for me!"*

### 2020 Evaluation and Next Steps

Participant feedback was received via electronic survey that aimed to identify the strengths and weaknesses of the Virtual Patient Advocacy Connections Program. **See Attachment III for additional evaluation results.**

Key strengths of the program, as indicated on the survey include:

- *"Thank you for including me. I got a lot of useful information which will be very helpful to our organization. It was a great meeting."*
- *"I found the advocacy roundtables extremely beneficial."*
- *"Well done. Speakers were excellent. Topics were meaningful and relevant."*
- *"Thank you for a useful and most informative meeting. The presenters and participants provided stimulating forward thinking for patient advocacy."*
- *"Thanks to the AUA/UCF for putting on an excellent virtual Advocacy program. I'm looking forward to working with some of the participating groups, especially in helping them with patient accrual to clinical trials."*
- *"I thought this was a fantastic experience. I look forward to participating in more events like this!"*
- *"It was an excellent program, thank you again for including CAC in this group!"*

Some opportunities for improvement include:

- *"I wish there were more networking opportunities between the participants/different organizations"*
- *"I wish that the networking events were longer than 15 minutes and that I had more time to network with my group members before we met with the provider. Otherwise, I thought it was super valuable and look forward to the next one!"*

### THANK YOU TO OUR SPONSORS!



(Information about PARP Inhibitors next page)

## Talking to your Doctor about **PARP Inhibitors** – Which One Makes Sense for Me?

### Comparison Table for Patients & Caregivers

By Jan Manarite Cancer ABCs – Version 6 (10/26/2020)

	<b>Rubraca (rucaparib)</b>	<b>Lynparza (olaparib)</b>
<b>For mCRPC patients – with what genetic mutations?</b> (mCRPC - metastatic, castrate-resistant prostate cancer)	<b>BRCA1 or BRCA2</b> gene mutations. (Either Hereditary/Germline* - or- Tumor Tissue/Somatic*)	<b>BRCA1 or BRCA2</b> gene mutations. (Either Hereditary/Germline* - or- Tumor Tissue/Somatic*) <i>ALSO</i> – ATM, BARD1, BRIP1, CDK12, CHEK1, CHEK2, FANCL, <b>PALB2</b> , RAD51B, RAD51C, RAD51D, RAD54L <sup>1,2</sup>
<b>What type of TEST do I need for this treatment?</b>	Either Hereditary/Germline Genetic Test, or Tumor/Somatic Genomic Test. <a href="#">Foundation One's CDx BLOOD test</a> is 'Companion Diagnostic' (Somatic*) -	Either Hereditary/Germline Genetic Test, <a href="#">Myriad's BRAC CDx BLOOD test</a> is 'Companion Diagnostic' (Germline) or Tumor/Somatic Genomic Test. <a href="#">Foundation One's CDx TISSUE test</a> is 'Companion Diagnostic' (Somatic*)-
<b>What type of DOCTOR do I ask about testing for these genetic mutations?</b>	<b>Medical Oncologists</b> are usually knowledgeable in both Germline and Somatic. <b>Urologists</b> are usually knowledgeable in Germline.	<b>Medical Oncologists</b> are usually knowledgeable in both Germline and Somatic. <b>Urologists</b> are usually knowledgeable in Germline.
<b>Do patients need to have PREVIOUS treatments to qualify?</b> (for insurance to pay)	<b>Yes.</b> Zytiga (abiraterone), or Xtandi (enzalutamide), or Erleada (apalutamide), or Nubeqa (darolutamide). PLUS chemotherapy.	<b>Yes.</b> Zytiga (abiraterone) or Xtandi (enzalutamide)
<b>Do patients need to FAIL these previous treatments?</b>	<b>No.</b> They just need to have had the treatments. <sup>3</sup>	<b>Not exactly.</b> But they must have "progressed" following Zytiga or Xtandi. <sup>4</sup>
<b>Some facts about Benefit (efficacy)</b>	<a href="#">62 men with "measurable disease" in TRITON2 trial.</a> <b>44%</b> showed tumor shrinkage (tumor shrinkage by 30% or more). Responses lasted <b>1.7 mos - 2 years</b> <b>55% had PSA drop</b> by 50% or more <sup>5</sup>	<a href="#">127 men with "measurable disease" in the PROfound trial.</a> <b>33%</b> showed tumor shrinkage (vs 2% of patients on Zytiga or Xtandi). <b>Median Overall Survival was 19.1 mos</b> (vs 14.7 mos for Zytiga or Xtandi). <sup>6</sup>
<b>Some facts about Risks (side effects)</b>	Check <b>kidney &amp; liver</b> function. Nausea, fatigue, diarrhea, anemia, headache were most common side effects – talk to your Nurse about these.	Check <b>liver</b> function. <i>About 7% of patients had blood clots.</i> Nausea, fatigue, diarrhea, anemia, headache were most common side effects – talk to your Nurse about these.
<b>Percentage of Minorities in Clinical Trial</b>	Black or African American – 7% Unknown Race – 21% <sup>7</sup>	Black – 1% Asian – 29% <sup>6</sup>
<b>Type of Trial?</b>	<b>Phase 2 – no placebo, no comparison group.</b> <b>115 patients overall.</b> <sup>3</sup>	<b>Phase 3 – no placebo, but comparison group received either Zytiga or Xtandi, and was allowed to crossover* to Lynparza if cancer progressed.</b> <b>387 patients overall.</b> <sup>4</sup>
<b>FDA approval in mCRPC?</b>	Accelerated Approval - 5/15/2020 (more data and FDA review coming) or <a href="#">check to see if you qualify for TRITON3 trial here.</a>	Full FDA Approval 5/19/2020

(Continued on next page)

	<b>Rubraca (rucaparib)</b>	<b>Lynparza (olaparib)</b>
Some facts about <b>CO\$T</b> (Medicare Part D)	<b>Medicare Part D:</b> 1 <sup>st</sup> month VERY expensive. HELP available through pharmacy or <a href="#">here</a> . Or (844) 779-7707 (M-F, 8am-8pm EST) .	<b>Medicare Part D:</b> 1 <sup>st</sup> month VERY expensive. HELP available through pharmacy or <a href="#">here</a> , or (800) 770-8337-3 (M-F, 8am-8pm EST)
Some facts about <b>CO\$T</b> (Private Insurance)	<b>Private Insurance</b> HELP available through pharmacy or <a href="#">here</a> . Or (844) 779-7707 (M-F, 8am-8pm EST)	<b>Private Insurance</b> HELP available through pharmacy or <a href="#">here</a> , or (800) 770-8337-3 (M-F, 8am-8pm EST)
Some facts about <b>CO\$T</b> (NO insurance)	<b>NO Insurance</b> HELP available through pharmacy or <a href="#">here</a> . Or (844) 779-7707 (M-F, 8am-8pm EST)	<b>NO Insurance</b> HELP available through pharmacy or <a href="#">here</a> , or (800) 770-8337-3 (M-F, 8am-8pm EST)
<b>Pills - Dosage?</b> <b>Administration?</b>	Pills are <a href="#">200mg, 250mg, 300mg</a> 2 x day – w or w/o food. If side effects are bad there is a “Dose-reduction” sometimes used. Talk to your medical oncologist.	Pills are <b>100 mg, 150 mg</b> <sup>4</sup> 2 x day – w or w/o food. If side effects are bad there is a “Dose-Reduction” sometimes used. Talk to your medical oncologist. <i>*Grapefruit Juice Interacts – ask pharmacist</i>
References: 1. Bryce AH, Sartor O, de Bono J. DNA Repair and Prostate Cancer: A Field Ripe for Harvest. Eur Urol (2020), <a href="https://doi.org/10.1016/j.eururo.2020.06.020">https://doi.org/10.1016/j.eururo.2020.06.020</a> 2. Foundation One CDx Label Technical - <a href="https://assets.ctfassets.net/w98cd481qyp0/41rj28gFwtxCwHQxopaEb/5031613e71b07962785e434e396b1429/P170019.S016.Label.Technical_Info.pdf">https://assets.ctfassets.net/w98cd481qyp0/41rj28gFwtxCwHQxopaEb/5031613e71b07962785e434e396b1429/P170019.S016.Label.Technical_Info.pdf</a> 3. Rubraca Highlights of Prescribing Information - <a href="https://clovisoncology.com/pdfs/RubracaUSPI.pdf">https://clovisoncology.com/pdfs/RubracaUSPI.pdf</a> 4. Lynparza Highlights of Prescribing Information - <a href="https://www.azpicentral.com/lynparza_tb/lynparza_tb.pdf#page=1">https://www.azpicentral.com/lynparza_tb/lynparza_tb.pdf#page=1</a> 5. Rubraca Patient Brochure - <a href="https://www.rubraca.com/sites/rubraca/files/2020-06/mCRPC%20Branded%20Patient%20Brochure.PP- RUCA-US-1329.pdf">https://www.rubraca.com/sites/rubraca/files/2020-06/mCRPC%20Branded%20Patient%20Brochure.PP- RUCA-US-1329.pdf</a> 6. Lynparza Patient Brochure - <a href="https://www.lynparzapr.com/content/dam/website-services/us/604-lynparza-dtc-prostate/pdf/Lynparza_Patient_Brochure.pdf">https://www.lynparzapr.com/content/dam/website-services/us/604-lynparza-dtc-prostate/pdf/Lynparza_Patient_Brochure.pdf</a> 7. Wassim A, et al., <a href="#">Rucaparib in Men With Metastatic Castration-Resistant Prostate Cancer Harboring a BRCA1 or BRCA2 Gene Alteration</a> <b>Disclaimer</b> – This document is intended to <b>help patients engage in Shared Decision-making by starting better conversations with their prostate cancer physicians.</b> It is NOT meant to be all-inclusive of Rubraca and Lynparza information. It is NOT medical advice.		

#### **\*Definitions**

**Somatic Mutation** – Acquired mutations that are the most common cause of cancer. These mutations occur from damage to genes in an individual cell during a person’s life...Somatic mutations are NOT found in every cell in the body, and they are NOT passed from parent to child. [Ref-Oncology Nursing Society](#)

**Germline Mutation** – Far less common than somatic, a germline mutation occurs in a sperm cell or an egg cell and is passed directly from parent to child...Cancer cause by germline mutations is called inherited or hereditary cancer. It accounts for 5% - 10% of ALL cancers. [Ref-Oncology Nursing Society](#)

**Crossover** - In cancer medicine, “crossover” in a clinical trial typically means that patients assigned to placebo are offered access to the investigation agent/drug at the time of cancer progression. [REF](#)

**This document is authored by Jan Manarite, and a service of Cancer ABCs.**

For questions, email [Jan@cancerabcs.org](mailto:Jan@cancerabcs.org)

See [www.cancerabcs.org](http://www.cancerabcs.org)

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## PROSTATE CANCER MARKERS

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](mailto: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](mailto:info@prostateconditions.org)

# Annual Meeting (NEW DATE) and Other Information

## **Annual Meeting:**

The 16<sup>th</sup> ANNUAL MEETING OF THE NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS HAS BEEN MOVED AGAIN FROM THE JANUARY AND MARCH DATE!

THE NEW DATES FOR THE 16<sup>TH</sup> ANNUAL MEETING ARE SEPTEMBER 24-26, 2021!!  
The Meeting will take place at the Hotel Monaco in Washington, DC again. It will be the 16<sup>th</sup> Annual Meeting -- 1 year late!

**PLEASE CALENDAR THE 16<sup>TH</sup> ANNUAL MEETING FOR SEPTEMBER 24-26, 2021!**

Contact Merel Nissenberg at [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu) for details.

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## **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)!

(Continued on next page)

## NASPCC Member Updates

### California Prostate Cancer Coalition

The California Prostate Cancer Coalition (CPCC) is running a quarterly ad in the California Family Physician magazine, with circulation to thousands of primary care doctors in the state. The ad has links including a link to the Informed Decision-Making Laminate that is a national priority for NASPCC. It's an outstanding way to get the message of informed decision making out to primary care physicians, a majority of whom ordinarily are not inclined to even mention prostate cancer testing to their patients.



CALIFORNIA  
**Prostate  
Cancer**  
COALITION

### **Help Your Patients Make Better Informed Decisions About Their Care**

The California Prostate Cancer Coalition, founded in 1997  
as a 501(c)(3) not-for-profit organization, is dedicated  
to saving men's lives

[www.prostatecalif.org](http://www.prostatecalif.org)  
<https://naspcc.org/docs/informed-decision-9-11-17.pdf>  
[www.naspcc.org](http://www.naspcc.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 the Arizona Prostate Cancer Coalition!



### Mission Statement

"The Arizona Prostate Cancer Coalition is an inclusive statewide organization promoting awareness, education, early detection, effective treatment and support for prostate cancer patients, their families and caregivers"

### A Busy Arizona September by Bruce Williams

The Arizona Prostate Cancer Coalition, Inc. kicked off the month with Governor Doug Ducey proclaiming September as Prostate Cancer Awareness Month: [See the Proclamation here.](#)

The Coalition also arranged for medical advisor and board member Larry Bans, MD, a Scottsdale urologist with a prostate subspecialty and focus for the past 15 years, to be interviewed by Entercom Communications Corp. and Hubbard Broadcasting, Inc. The interviews aired early in the month, with Dr. Bans covering a wide range of topics, including general prostate cancer information and the highest risk populations. He continued, discussing screenings and recommended ages, US and European data findings, USPSTF recommendations, recent years' upticks in more advanced cancers, and screenings during this coronavirus period. [You can listen to Dr. Bans interview here.](#)

Following up on Governor Ducey's Proclamation, the Arizona Capitol Times published a mid-month op-ed piece authored by Coalition leadership: [See the article here.](#)

September also saw the Coalition begin partnering with the Arizona Department of Health Services Arizona Cancer Coalition to further common objectives of early detection and prevention.

It's been a busy month for our small start-up Arizona Prostate Cancer Coalition.

*NASPCC would like to congratulate the **Arizona Prostate Cancer Coalition** for being our "Spotlight" featured Coalition of the quarter! You are doing excellent work bringing Prostate Cancer Awareness to Arizona! 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

Meryl 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

## BOARD OF DIRECTORS

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David Sauls	Delaware
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Clarence Williamson	Tennessee
Ulysses Wright	Kansas

## 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)

# 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/>

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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 and the National Alliance of State Prostate Cancer Coalitions (NASPCC) are collaborating to offer a free online support group for men diagnosed with prostate cancer. This online group provides a safe, confidential space where men can discuss the unique challenges of living with prostate cancer, while giving and receiving support, information and guidance.



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

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



## For Men: Living Well with Cancer Workshop Series

CancerCare's Men's Program is proud to present a series of virtual workshops focused on the needs of men affected by cancer – men with cancer and men who are cancer caregivers.

The workshop modules will each focus on a specific issue that are known to impact the quality of life of men who are learning to cope with cancer and treatment. The objective is to assist and support men in living with cancer with the purpose of providing resource information, health care education, as well as suggestions for improving life 'with cancer' skills.

### DATE/ TIME

This free, virtual workshop series will begin on November 23rd and will occur approximately every 6 weeks.

### DATE/ TIME

#### **Module I: Self Acupressure for Enhanced Energy and Immunity**

November 23, 2020 from 4 - 5 p.m. ET

#### **Module II: Self-Acupressure for Anxiety, Fatigue and Sleep Challenges**

December 14, 2020 from 4 - 5 p.m. ET

#### **Module III: Let's Talk About Sex: Cancer Recovery and Sexual Health**

February 8, 2021 from 4 - 5 p.m. ET

Panel Presentation by Ryan Smith, Dr Joseph Alukal and more.

#### **Module IV: Combating the Stress Response with Mindfulness Techniques**

April 12, 2021 from 4 - 5 p.m. ET

(Continued on the next page)



**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).

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## LOCATION

This workshop will be held virtually using GoToMeeting. If you are not able to use the video function, you will also be able to call into the workshop.

## FACILITATORS

Bill Goeren, LCSW-R, OSW-C, SEP is the Director of Clinical Programs at CancerCare and also coordinates the Men's Program and the LGBTQ+ Program as well as the nutrition and legal services.

Ryan Smith, M.S., Dipl. Ac. (NCCAOM)®, L.Ac., C.SMA is a licensed acupuncturist with experience interning or working at some of the world's leading health centers, including the Perlmutter Cancer Center at NYU Langone Medical Center and NewYork-Presbyterian/ Columbia University Medical Center. As the Founder and Director of 5 Point Acupuncture, he utilizes acupuncture's precision and power as part of a holistic, integrative approach to health and well-being.

Dr. Joseph Alukal, MD, New York Presbyterian/ Columbia Medical Center, Urology, Associate Professor of Urology at CUMC.

## REGISTER

Registration is limited and required for each workshop. To register or for more information about the Mens Program Living with Cancer workshops, email Bill Goeren at [wgoeren@cancercares.org](mailto:wgoeren@cancercares.org). For information about this workshop as well as other CancerCare programs and services, please call the CancerCare toll free Hopeline at 800-813-HOPE(4673).

# 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!





*(Absent: Vice President Johnny Payne)*

## **2019-2020 Board of Directors**

The 2019-2020 Board of Directors of the National Alliance of State Prostate Cancer Coalitions

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