



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

News

Volume 4, Issue 1
February 2021

THE BLUEPRINT

J. Renee Savickas, Editor

President's Message

Welcome to Spring 2021 and directing our hopes and efforts to hopefully ending the pandemic soon. The world is upside down, with no medical or scientific meetings to attend except virtually, no socializing, working with ZOOM Meeting overload. Did we really have a 2020? Our goal is not only to help men and their families, but also to keep our families and friends, and acquaintances safe in these very unusual and trying times.

The Mission of NASPCC hasn't changed, just our activities towards that goal. Besides continuing with participation in educational events in a virtual format, NASPCC has been very active with its quarterly PROSTATEPEDIA Magazine and its weekly (every Friday) PROSTATEPEDIA DIGESTS, all of which are e-mailed out to over 12,000 people on our Listserv. The upcoming March 2021 PROSTATEPEDIA Magazine Issue will be on the subject of "TESTING", and the June 2021 Issue will address the topic of "IMAGING". The Magazine is always chock-full of fascinating and teachable-moments from interviews of physicians, scientists, and patients. We are so thrilled that this amazing resource is under NASPCC's banner.

NASPCC Webinars include the most skilled practitioners and scientists in the country and are becoming legendary. From Dr. Michael Morris of Sloan-Kettering Cancer Center presenting on "PSMA Imaging" and then on "Theranostics", to Dr. Saul Priceman of the City of Hope presenting on "Immuno-Oncology and Novel Mechanisms of Action in Prostate Cancer", to Dr. Ashley Ross of Northwestern Medicine scheduled to present on March 10 with the title of "Use of Genomics to Guide Treatment Decisions after Radical Prostatectomy"; NASPCC puts on the best Webinars out there. Further, all of our Webinars (both slides and recordings) are archived on the outstanding www.naspcc.org Website.

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As we look to the future, we are planning our 16th Annual Meeting (1 year late!) which will be in-person September 24-26, 2021 at the Hotel Monaco in Washington, DC. Our work continues! ***We would love to know what your state coalitions/associations/foundations and the like are up to – how you are navigating helping men and their families through the pandemic.*** Next up for us in terms of medical education will be the ASCO GU meeting later this month in February, and the American Association of Cancer Research Annual Meeting in March.

Also, CancerCare in collaboration with NASPCC (and other organizations) will hold a free CancerCare Connect Education Workshop on “Advances in the Treatment of Metastatic Prostate Cancer” on February 23, 2021, from 1:30-2:30 pm EASTERN. And on March 10, 2021, at 7:00 pm EASTERN, NASPCC will present another in our Webinar Series with Ashley Ross, MD, PhD, on “Use of Genomics to Guide Treatment Decisions After Radical Prostatectomy”.

We keep learning and keep helping. Stay safe, everyone!

Sincerely, Merel Nissenberg

NASPCC BOD Minutes

January 19, 2021

By Merel Nissenberg

The Board of Directors of NASPCC met on Tuesday, January 19, 2021 at 1:00 pm Eastern. Present were: Merel Nissenberg, LaTanya Patton, Jan Marfyak, Tony Minter, Renee Savickas, Paul Kradel, Harold Pharoah, Bruce Williams, Mary Anderson, Dave Hulbert, Crissy Kantor, David Sauls, Robin Leach, Gabe Rosko, Clarence Williamson and Ulyses Wright. Don Lynam was only able to stay on the Call for about a half hour. Tom Kirk attended the Call as Chair of the Steering Committee. The Meeting Call started at 1:00 pm EASTERN. Absent was Stephen Richardson.

Merel Nissenberg gave her **President's Report**. She talked about how COVID has changed our lives, with virtual meetings, cancellation of in-person conferences, etc. She stated that she is optimistic that we will be able to meet in person September 24-26, 2021 to hold our long-delayed 16th Annual Meeting. She touched on PROSTATEPEDIA which she will give a full report on later in the Call. She also touched on our Webinars, which she said she would also address later in the Call.

Jan Marfyak gave the **Secretary's Report**. He presented the full Minutes of the Board of Directors Call held on October 27, 2020 for approval by the Board. No comments or corrections were made, so LaTanya Patton moved, and Renee Savickas seconded to approve the Minutes from the Board Call of 10/27/20. Motion passed. Then there was a review of our Executive Committee Minutes from November, December, January for acceptance by the Board: Bruce Williams moved, LaTanya Patton seconded, Motion passed.

New Treasurer Tony Minter presented the Financials in his **Treasurer's Report**, which he had sent out to the Board a few days ago. These are for the period of October 1, 2020 (start of our fiscal year) to January 4, 2021. Tony reported that we have (between Checking & Savings) the following: \$ 172,575.14; P & L shows Income of \$ 31,500.59 and expenses of \$38,940.67, for a net Loss of \$ 7,440.08. Clarence asked Tony Minter to verify his e-mail address; Merel said that she has already written to John Brandt to make sure that Clarence is included in those Listserves. She said she would send the Financials to Clarence after the Call since he had not received them. Gabe Rosko then asked about the \$7,500 payments to Tom Kirk and Merel Nissenberg each for creation, design and production of two (2) Laminates. Merel explained how each Laminate is \$10,000 (each) as listed in our Sponsorship Menu; and that the \$7,500 for Tom Kirk and \$7,500 for her was for the work on both of those 2 Laminates which are for Bayer, including creation, design, meeting and working with experts, and production. She further answered his question as to whether it was pursuant to contract with NASPCC and Merel said that it was (as Independent Contractors) per contract with NASPCC. Jan Marfyak then moved, Ulyses seconded, for approval of the Treasurer's Report. Motion passed.

Website/Facebook Report: Merel reported that John Brandt, our Webmaster, continues to do an excellent job in keeping the www.naspcc.org website current. He recently posted the Webinar of January 11 with Dr. Michael Morris on Theranostics to our website (slides plus recording). He also maintains the Listserves.

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There have not been recent postings to the NASPCC Facebook Page. Merel said she will ask Tiffany Razzo, our “Staff” for NASPCC’s Webinars and Annual Meetings, who is putting together the DIGEST with Jessica Myers-Schechter after Merel send the articles and abstracts each week, if she can add those to our Facebook Page while adding them to the CPCC Facebook Page as well. Merel strongly urged everyone to check out our outstanding website at www.naspcc.org.

Committees Status Report: Tom Kirk, Chair of the Steering Committee, presented this report which he had sent out to the full Board yesterday. **Committees:** Communications: Renee has given us the new dates for the new Newsletter (The Blueprint): a February 1 deadline, distribution planned for February 8, 2021. Tom said that the last Newsletter in November was outstanding; Education & Awareness: This Committee continues to meet; its last call was January 13. Next Call is February 10, where we will discuss the Memorandum of Understanding, as well as the various State Coalitions’ websites and use of social media. The Committee continues to be chaired by Fran Franklin of the Delaware Prostate Cancer Coalition, assisted by Board Member David Sauls, and Calvin Jackson, among others. Tom then mentioned PROSTATEPEDIA and PROSTATEPEDIA DIGEST; Advocacy & Public Policy: Tom talked about Alvin Chin, the late Chair, whose In Memoriam was highlighted in the last “Blueprint”; he then said that he and Merel had attended the Michigan BIO Advocacy Forum; participated in Friends of Prostate Cancer Coalition calls; they had attended the OVAC Meeting recently, and on December 15, they had participated in a DHRC (Defense Health Research Consortium) Call; and they are planning to attend the DHRC Organizational Meeting on January 29. He stated that NASPCC has also reviewed and signed letters including opposing the Most Favored Nation pricing policy. Tom then said that Alvin Chin who passed away in October had chaired this Committee and we are looking for a new Chair; State Coalitions Development Committee: Rob Johnson Chair, still has not called a meeting of this Committee, although Merel has sent him an e-mail with the list of the current members; Fundraising: Merel continues to do a lot of work in raising funds for NASPCC. This year we are having to file a full 990 because we brought in over \$200,000 in the 2019 Fiscal Year; Annual Meeting: Merel will report on this shortly; it is still scheduled for September 24-26, 2021 in person in Washington, DC.; Medical Advisory: No activity in this Committee which is chaired by Dr. Michael Zaragoza. Budget Committee: Don Lynam headed this up before and we need to have a new Chair, although Don had said that he would help. Tom reminded the Board that the Newsletter lists who is on each Committee. He invited everyone to join or participate in any of the Committees.

IN MEMORIAM for Alvin Chin: Merel reported that she, Tom Kirk, Don Lynam and LaTanya Patton attended a virtual ZOOM Memorial for Alvin on December 17. Merel presented to the assembled ZOOM group, and she has committed to do a Memorial Award in Alvin’s name at our in-person 16th Annual Meeting. She told the Board that the Burke, Virginia Volunteer Fire Dept, to which Alvin Chin had belonged, had generously donated \$250 to NASPCC in Alvin Chin’s name. Merel described all of the wonderful things that Alvin had done that few, if any, of us knew about, and said we should all be conscious of each other and supportive.

Merel presented next on our **Webinars**. She stated that we had increased our number of free portals to 500. Our last Webinar was January 11 on Theranostics, presented by Dr. Michael Morris of Sloan-Kettering. Our next Webinar is on “Immuno-Oncology and New Mechanisms of Action in Prostate Cancer,” to be presented by Dr. Saul Priceman of City of Hope. Merel is working on having Dr. Eric Klein and Dr. Jonathan Epstein do the next Webinars. She reminded everyone that all Webinars are archived on our website, both the recordings and slides.

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Merel reported on our **PROSTATEPEDIA** Magazine and our weekly PROSTATEPEDIA DIGESTS. Last Issue of the Magazine was November 2020 on “Immuno-Oncology & PARP Inhibition”. The DIGEST is e-mailed out to the large subscription list every Friday and contains links to abstracts, articles etc., and has a free subscription line to sign up. There are also Banner Ads in the DIGEST and full pages of ads in the Magazine. Next Issue: March 15 on “TESTING”. Jessica Myers-Schechter is already starting to do interviews that Merel has arranged with outstanding people. Gabe Rosko said he found the DIGEST to be confusing and suggested that we show the dates for each article in the DIGEST, because it seems like we are repeating the articles; and he also said it’s hard for him to see the print when he prints it out. He suggested it be more user-friendly. Merel said she would speak with Jessica Myers-Schechter, our Editor. Ulyses asked if people can subscribe by just going to our www.naspcc.org website. Merel said yes.

Merel reported that the **Annual Meeting** is on track for September 24-26, 2021 at the Hotel Monaco in Washington, DC. We are taking nominations for the Awards that we give out – such as the James West Spirited Advocate Award and an award for Outstanding Physician and an Award in honor of Alvin Chin.

Merel stated that the next **Board Meetings** are in April and July, on April 20, 2021 and July 20, 2021. They are always at 1:00 pm EASTERN. Mary asked when is it safe to buy our tickets, and Merel said probably not until June or July. We will add this to the April and July Board Meeting Agendas.

Bruce Williams then asked if there was any funding that resulted from the December 16 GIVING BACK Supplement to the LA Times that we had paid for. Merel said not that she can show, but that it definitely increased our visibility since it was delivered to 100,000 households. She stated that the Supplement was in magazine form and that we had a full page “advertorial” with our website, our most important activities and resources, etc. Tom then added that he agreed about increasing our visibility, and complimented Merel on her fundraising, stating that we had budgeted to raise \$152,000 last year but that Merel had raised \$250,000, and that he thought she had done a great job. Ulyses said that she was an “expert” at fundraising. Merel then added to the conversation stating that NASPCC had been participating in certain activities where we were the only invited group, such as the CURE Magazine’s Educated Prostate Cancer Patient Summit last Fall, where for prostate cancer groups it was only NASPCC and PCF. She also mentioned again that there is a limited “pot”, and all of the prostate cancer groups are going after the same “pot”, so there is a lot of competition to raise funds.

There being no other business, the Board of Directors Meeting adjourned at 1:58 pm EASTERN.

Respectfully submitted,
Merel Nissenberg
for Secretary Jan Marfyak

NASPCC WEBINAR SERIES

NASPCC WEBINAR SERIES

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 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>.

On January 11, 2021, Dr. Michael Morris of Memorial Sloan-Kettering Cancer Center, presented NASPCC's Webinar on “Theranostics”. Dr. Morris' presentation was an excellent follow-up to his November 2020 presentation on “PSMA Imaging in Prostate Cancer”, explaining in understandable terms the novel imaging modality recently approved in prostate cancer. “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.”

On February 1, 2021, Dr. Saul Priceman from the City of Hope continued our outstanding NASPCC Webinar Series with a presentation on “Immuno-Oncology and Novel Mechanisms of Action”. What is a very complicated subject became understandable and fascinating with Dr. Priceman's explanations and his superb slides. Both the recording and slides are available on our NASPCC Website at: <https://naspcc.org/index.php/naspcc-webinar-archives>.

NEXT WEBINAR, MARCH 10, 2021

NASPCC is continuing its Webinar Series of Excellence with the next free, 1-hour Webinar scheduled for **Wednesday, March 10, 2021 at 7:00 pm EASTERN (4:00 pm PACIFIC)**. The Presenter will be **Ashley Ross, MD, PhD.**, Associate Professor at Northwestern Feinberg School of Medicine in Chicago. Dr. Ross has been a frequent presenter for NASPCC at our Annual Meetings and has also already presented a Webinar for NASPCC. The topic for March 10 will be **“USE OF GENOMICS TO GUIDE TREATMENT DECISIONS AFTER RADICAL PROSTATECTOMY”**. Dr. Ross' clinical research and clinical efforts center on the development, testing and implementation of novel diagnostics and therapeutics. He is an old friend of NASPCC and sits on our Medical Advisory Board. You will find a Flyer for the March 10 Webinar elsewhere in this Newsletter, and you can also go to our website www.naspcc.org for registration details.

(NASPCC Webinars Continued on the next page)



NASPCC Webinar Series Presents:
**“Use of Genomics to Guide Treatment Decisions after
Radical Prostatectomy”**

With Ashley Ross, MD, PhD, Associate Professor, Northwestern Feinberg School
of Medicine

Wednesday, March 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



Dr. Ross is an Associate Professor of Urology at the Northwestern Feinberg School of Medicine. His research and clinical efforts focus on the development, testing and implementation of novel diagnostics and therapeutics with a goal of reducing the suffering from prostate cancer. Prior to joining the Feinberg School of Medicine, Dr. Ross served as director of the Johns Hopkins Urology Prostate Cancer Program, the executive medical director of the Mary Crowley Cancer Research Center, and an associate chair of the US Oncology Genitourinary Research Committee.

As with all NASPCC Webinars, these Webinars are archived on our website, www.naspcc.org and include both the recordings and the slides. These are superb, durable resources available for free, for everyone.

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.

- **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 January 19, 2021 (and the previous one on October 27, 2020), the NASPCC Committee activities have been updated at each of the Monthly Executive Committee calls (November 10th, December 1st, January 5th and February 2nd). We want to Thank everyone who is involved in the work of the Committees and urge others to join us. It really is rewarding!

1) For the **Communication's Committee**, Committee Chair and The Blueprint Newsletter Editor Renee Savickas has completed Volume 3, Issue 3 of the **Blueprint** in November and it is posted on the NASPCC website. This Committee Update is prepared for February 2021 Issue of the Blueprint.

2) Rob Johnson has called a meeting of the **State Coalition Development Committee** on Tuesday February 9th.

3) Calvin Jackson chaired the **Education and Awareness Committee** meeting for Fran Franklin on Wednesday January 13th. Tom Kirk prepared the Minutes from the January 13th call again and the next call is set for Wednesday February 10th. Potential Agenda items include a review of the Draft MoU and the survey Grid on the State Representatives' Social Media sites. The Committee usually keeps the NASPCC Webinars on its Agenda. The Webinar held on January 11th on the topic of "Theranostics in Prostate Cancer" and was presented by Dr. Michael Morris Memorial Sloan-Kettering Cancer Center was well received. The most recent Webinar on Monday February 1st 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 next Webinar featuring Dr. Ashley Ross, Associate Professor, Northwestern Feinberg School of Medicine in Chicago, is titled "Use of Genomics to Guide Decisions after Radical Prostatectomy" and is set for March 10, 2021.

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 13th. The next issue is targeted for March on Testing. The most recent weekly Digest issues were sent on January 22nd, January 29th and February 5th with minor edits to make the Digest content more manageable based on comments made during the January 19th NASPCC Board Meeting call.

4) As for the **Advocacy & Public Policy Committee**, Alvin Chin, who Chaired the Advocacy and Public Policy Committee, passed away suddenly on November 17th. His family held a Virtual Memorial on December 17th and many people attended. We will need a volunteer to assume the committee Chair.

Merel and I represented NASPCC at the virtual Patient Advocacy Forum sponsored by MIBio on December 14th. We continued to be involved in the Friends of Prostate Cancer Care Community (FoPCCC), the latest call was held on December 15th.

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Merel and I held a follow-up call with their staff on Wednesday January 13th and have received a series of new weekly emails/Newsletters from their staff, the most recent one received on February 3rd. They are attempting to highlight events of participating organizations. They recently shared two new names for the group developed with their Steering Committee on February 8th and have sought a vote.

Mark Veith has kept us up-to-date on the DHRP and Merel and I were on the December 15th call with the new program head, Col. Sara Goldman and key staff. Merel and I also attended the DHRC Virtual Annual Organizational Meeting call on Friday January 29th. Mark is targeting visits for Staff Committee Clerks during the week of February 15th.

NASPCC also signed onto several letters on issues such as United Health Care's (UHC) Accumulator Adjustment Medical Program Provider Protocol and Most Favored Status (MFS) initiative by Medicare.

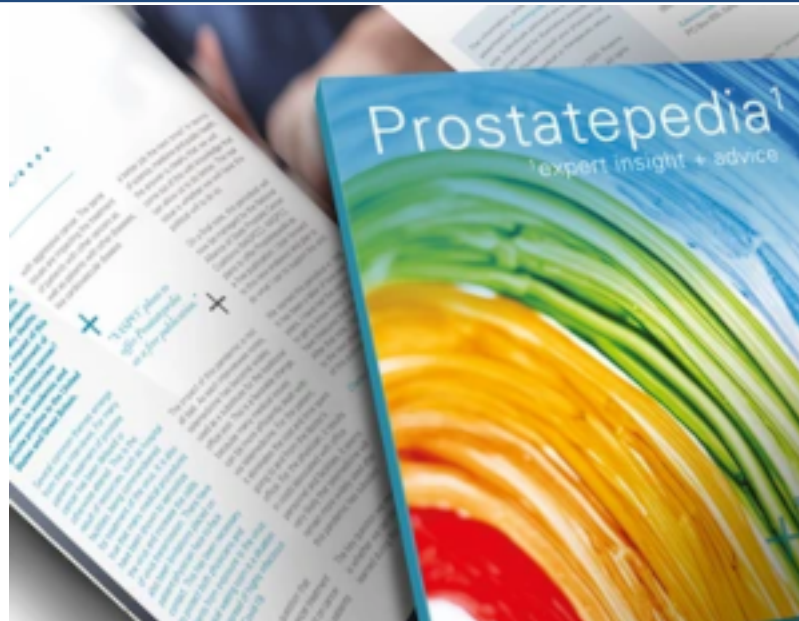
Merel and I also attended the January 11th OVAC call which featured a Presentation by NCI Director Dr. Sharpless. He will also appear on the February 11th Friends of Cancer Research Virtual meeting on "Shaping the Future of Immunotherapies and Cell Therapies". Merel and I also attended the OVAC call today, February 8th as well and heard an update on DC activities. The OVAC Mini-Lobby Days are targeted for March 10th.

Public Policy/Advocacy areas we are following: 1) NCCS sent the January 15th Health Care Roundup which covered COVID-19 Updates and other future NCCS agenda issues, 2) Aimed Alliance sent the Volume 2, Issue 12 update on December 31st and the Volume 3, Issue 1 sent on January 30th.

5 and 6) Merel continues to head the **Fundraising Committee**, no recent meetings held, but she shared she has a copy of the LA Times impressive magazine-like Giving issue during the Board meeting call which featured information on NASPCC. 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. We have been working with Don, Tony Minter and AJ Sharpe from Hicks & Associates to review the Draft of the NASPCC Federal and CA State Tax Forms for FY 2019-2020 which are due mid-February. The Federal 990 will be sent electronically and Don and Tony will sign the CA forms, cut checks and get mailed. Tony Minter has replaced Johnny Payne as the South Carolina State Representative and has replaced Don as the NASPCC Treasurer. Don moved to serve as Director-at-Large on the Executive Committee and LaTanya has moved to Vice-Chairman of NASPCC, replacing Johnny Payne. 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



The National Alliance of State Prostate Cancer Coalitions took over publication of the outstanding PROSTATEPEDIA Magazine and PROSTATEPEDIA weekly DIGEST last June 2020. Since then we have published two quarterly PROSTATEPEDIA Magazine Issues: the August 2020 Issue on “CHEMOTHERAPY IN PROSTATE CANCER” can be viewed at <https://online.flippingbook.com/view/193912/3/> and then the November 2020 Issue on the topic of “IMMUNO-ONCOLOGY & PARP INHIBITION” is at <https://online.flippingbook.com/view/542030/>.

Our next PROSTATEPEDIA Magazine Issue will be the March 2021 Issue on “TESTING”. We will actually publish more than just quarterly this year since there are so many important topics we would like to cover. We are fortunate that the previous Editor, Jessica Myers-Schecter, has stayed on as Editor for us, and she continues to do an exemplary job of interviewing physicians, scientists and patients and putting the Magazine Issues together.

Besides the Magazine, we publish a weekly (every Friday) PROSTATEPEDIA DIGEST comprised of links to the most current articles and abstracts and press releases in prostate cancer and including a link to subscribe for free and a link to the most recent PROSTATEPEDIA Magazine Issue. Additionally, the Magazine Issues are archived on the www.naspcc.org website. See <https://www.naspcc.org/index.php/prostatepedia-magazine>. NASPCC has a current subscription mailing list of over 12,000 people for both the Magazine and the weekly DIGEST; a subscription is now free. Visit our website to subscribe at no cost which will mean you will receive PROSTATEPEDIA Magazine as well as the weekly DIGESTS.

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, 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-9-11-17.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 in 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 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 16th Annual Meeting

NASPCC's 16th ANNUAL MEETING, a time-honored tradition of a Fall weekend of education and sharing-of-best-practices and which brings together representatives from 46 states and state prostate cancer organizations, as well as industry, has been re-scheduled because of the pandemic. **The new date (fingers crossed) is now September 24-26, 2021 and will take place IN-PERSON at the Hotel Monaco in Washington, DC.** For further information, please contact Merel Nissenberg at mgrey@health.ucsd.edu. PLEASE CALENDAR THE DATES!



Nominations Are Open:

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

The categories are:


- JAMES WEST SPIRIT AWARD
- OUTSTANDING STATE PROSTATE CANCER ORGANIZATION
- OUTSTANDING SERVICE IN PROSTATE CANCER BY A PHYSICIAN
- AWARD IN HONOR OF ALVIN CHIN

Please send your suggestions to Merel at: mgrey@ucsd.edu!

NASPCC Member Updates

California Prostate Cancer Coalition

THE 2ND ANNUAL CPCC/UCSF PATIENT CONFERENCE ON PROSTATE CANCER will take place virtually May 14 and May 15, 2021. The upcoming Patient Conference will again enjoy an outstanding faculty primarily from UCSF and is being co-sponsored by both the California Prostate Cancer Coalition and the Helen Diller Family Comprehensive Cancer Center at UCSF. The Conference is an outstanding opportunity to learn from the experts and to then interact in small breakout groups part of the second day of the Conference. Registration will be required and will be available shortly on Eventbrite, and early registration will be encouraged in order to be included in those small breakouts, as we are expecting several hundred people for the full Conference and only a limited number of people can be included in small breakouts with the faculty. Since it will be a virtual format, we expect that many people from around the country will take advantage of this incredible learning opportunity. And we have a strong tradition to uphold: The video from the 1st Annual CPCC/UCSF Patient Conference is on the UC YouTube Channel and has been viewed over 122,000 times! You can view it here: <https://uctv.tv/2019-prostate-cancer-conference/> . Contact Merel Nissenberg at mgrey@health.ucsd.edu or Tom Kirk at tomkirk_99@yahoo.com.



CALIFORNIA
Prostate
Cancer
COALITION

SAVE THE DATE
SAVE THE DATE
SAVE THE DATE

UCSF Helen Diller Family
Comprehensive
Cancer Center

The California Prostate Cancer Coalition (CPCC) and
The UCSF Helen Diller Family Comprehensive Cancer Center Present

THE 2ND ANNUAL CPCC/UCSF PATIENT CONFERENCE ON PROSTATE CANCER:

**“USING CURRENT AND CUTTING-EDGE INFORMATION
TO HELP MAKE INFORMED DECISIONS”**

MAY 14-15, 2021 (Virtual)

For Patients, Families, Caregivers, Health Care Providers and
all those interested in information and tools
to make informed decisions in prostate cancer.

FEATURING AN OUTSTANDING PANEL OF EXPERTS

For Information, e-mail: mgrey@health.ucsd.edu or tomkirk_99@yahoo.com

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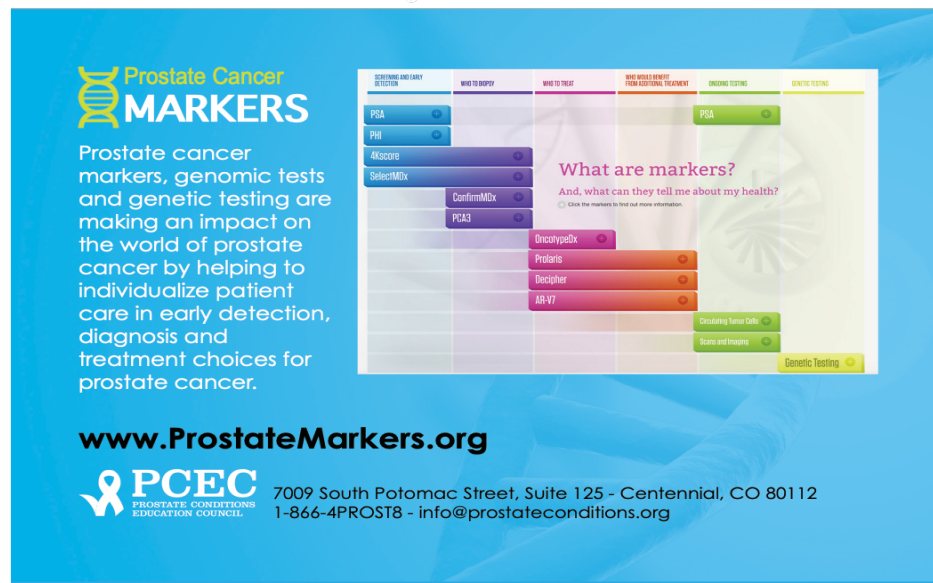
KUDOS TO DR. MICHAEL ZARAGOZA



Dr. Michael Zaragoza, President of the Delaware Prostate Cancer Coalition - “A Proud Participant in the National Alliance of State Prostate Cancer Coalitions” - was honored as a Top Doctor in ***Delaware Today*** published in October 2020. Accompanying the list was this: “Each of the doctors recognized are dedicated and committed to the practice of medicine and providing safe, exceptional care for their patients in their specialty. We applaud them...” Congratulations, Michael, a caring, exceptional urologist!

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. PCEC also has this piece available as a handout. Please email 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!

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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:

Prostate Cancer Advocates of Wyoming



The Prostate Cancer Advocates of Wyoming was founded in 2019 by Prostate Cancer Survivor, Rob Johnson, after recognizing the need for prostate cancer awareness, education and patient support in Cheyenne and throughout the state of Wyoming. They attend health fairs across Wyoming, local cancer conferences, national advocacy summits and educational conferences. They offer monthly online support groups for men with all stages of the disease; provide FREE tool kits with information on diet and help for spouses and caregivers. The group also started a unique form of support through their **TREATMENT BUDDY** program, where they match up patients who have the same stage of prostate cancer to share their experiences.

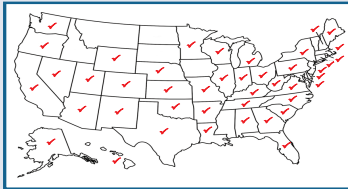
Prostate Cancer Advocates of Wyoming likes to think outside the box to reach men with their important messaging on of early detection, informed decision making and prostate cancer support by hosting and attending various types of activities, including: Car Shows, Parades, Beer Events and more!

To learn more about the Prostate Cancer Advocates of Wyoming, please visit their FACEBOOK page at: [Prostate Cancer Advocates of Wyoming](#)

*NASPCC would like to congratulate the **Prostate Cancer Advocates of Wyoming** for being our “Spotlight” featured Coalition of the quarter! You are doing excellent work bringing Prostate Cancer Awareness, Education and Support of Wyoming! Thank you for all that you do!*

NASPCC Brochure

PARTICIPATING STATES



HOW DOES NASPCC REACH PROSTATE CANCER PATIENTS AND THEIR FAMILIES?

NASPCC supports the development of state prostate cancer organizations, each of which is comprised of patient networks and support groups. NASPCC 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. NASPCC also helps equip patients and their families to actively engage in the prostate cancer cause.

NASPCC 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. NASPCC 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
- 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.nasppcc.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



NASPCC, 1999 Avenue of the Stars, Suite 1100
Los Angeles, California 90067
Toll Free 877-NASPCC-8 (877-627-7228)
E-mail: info@nasppcc.org Website: www.nasppcc.org

November 2019



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



MISSION STATEMENT

NASPCC 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

NASPCC 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.

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CONTACT NASPCC TO:

- Become a member of NASPCC
- Send a donation to NASPCC, 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?

NASPCC 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-NASPCC-8 (877-627-7228)
E-mail: info@nasppcc.org
Website: www.nasppcc.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/>

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 Connect Education Workshop

On Tuesday, February 23, 2021, CancerCare in collaboration with the National Alliance of State Prostate Cancer Coalitions and other organizations, will present “Advances in the Treatment of Metastatic Prostate Cancer” from 1:30 pm - 2:30 pm EASTERN. Faculty includes Dr. Susan Slovin and Dr. Sean McBride, both of Memorial Sloan-Kettering Cancer Center. Registration can be done by calling 1-800-813-HOPE (4673) or by registering online at www.cancercare.org/connect. You can also visit the website here for more information: https://www.cancercare.org/connect_workshops/864-advances_in_the_treatment_of_metastatic_prostate_cancer_2021-02-23.

NASPCC is also proud to co-host the CancerCare Online Support Group in Prostate Cancer. The Workshop Agenda covers a myriad of topics including Advances in Treatment, Clinical Trials, Side Effects, Quality of Life, COVID-19, Bone Metastases, Precision Medicine, and many other timely and important topics. These are recurring 15-week sessions moderated by a professional. Please see <https://naspcc.org/index.php/resources/prostate-cancer-patient-online-support-group>.

(Continued on next page)



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.

CONNECT WITH US



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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 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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