



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

News

Volume 3, Issue 1
March 16, 2020

THE BLUEPRINT

J. Renee Savickas, Editor

President's Message

Welcome to the Spring 2020 Newsletter – “THE BLUEPRINT”. As I write this, we are trying to keep all of our collective “heads above water” with the corona virus pandemic and with scheduled meetings and roundtables being cancelled right and left. NASPCC – a/k/a “The Prostate Cancer Alliance” - is forging ahead with its programs and state coalition development and support. Our Advisory Committees continue to meet by e-mail or conference call; for example, the Education & Awareness Committee (chaired by Dr. Fran Franklin) has already met 3 times this quarter, and was instrumental in NASPCC holding its first Webinar of 2020 which was held February 27, 2020 entitled “Side Effects of Prostate Cancer and its Treatment”, sponsored by Boston Scientific. For those who missed it, the slides and recorded Webinar will be up on our website as of Friday, March 13. Our GoToWebinar platform is in place, and we are always looking for excellent topics to present as Webinars in order to reach so many people and provide education at no cost. Our Communications Committee, with Renee Savickas as Chair and Editor of THE BLUEPRINT, is responsible for producing this outstanding Newsletter. Rob Johnson of Wyoming has just agreed to chair the State Coalition Development Committee. The Fundraising Committee which I chair just held its first Call of 2020 during which a great discussion took place on Tribute fundraisers to benefit individual states. And the list goes on.

Our Steering Committee Chair, Tom Kirk, and I attended the Annual ASCO GU (Genito-urinary) Cancers Meeting in San Francisco February 12-14. Presentations were excellent, and there was ample opportunity to meet with researchers and physicians to discuss new developments in prostate cancer. Some hot topics included best treatments for pain management, and then the new spaces in advanced prostate cancer: metastatic, castrate-sensitive; and non-metastatic, castrate-resistant prostate cancers. There have been new drugs approved for these spaces, but sequencing is not yet established, including when to add in hormonal therapy and radiation therapy, if applicable. In urology and in prostate cancer specifically, there are so many changes and so many interesting and valuable clinical trial results, that it's a true challenge for physicians to keep up with all the new information. Thus, the importance, as always, of making sure that we help educate medical consumers, especially here: prostate cancer patients and their families.

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As promised, the leadership of NASPCC has prepared a Memorandum of Understanding to be signed by each state prostate cancer organization participating in our organization. At the conclusion of last October's 15th Annual Meeting & Gala I discussed this topic with the attendees and told them that, at a minimum we would want co-branding on state activities by incorporating the following language: "A Proud Participant in the National Alliance of State Prostate Cancer Coalitions". I asked for concerns and doubts and none was received, and in fact all in attendance said they would sign such an agreement. Elsewhere in this Newsletter you will read a short article about the Memorandum of Understanding and then see the proposed Memorandum of Understanding to review. We will welcome comments on the proposed Memorandum of Understanding until August 1, 2020. We will expect all 16th Annual Meeting attendees to sign the document at the Annual Meeting which will take place October 9-11, 2020 at the Hotel Monaco in Washington, DC again. (Those not attending the Annual Meeting will sign it separately.) Any concerns about this should be sent to me via e-mail at mgrey@ucsd.edu.

The Board of Directors met by conference call on Tuesday, January 21, 2020. The Minutes from that Board Meeting appear elsewhere in this Newsletter. Our next Quarterly Board Meeting will take place via conference call on Tuesday, April 21, 2020 from 1:00 – 2:30 p.m. eastern. All are welcome to join our Call. The July Quarterly Board Call will take place Tuesday, July 21 at the same time. **And of course, our 16th Annual Meeting & Dinner will take place October 9-11, 2020 at the Hotel Monaco again, in Washington, DC.**

Wishing you all good health and avoidance of the corona virus!

Merel Nissenberg

NASPCC General Activities and Updates

By Merel Nissenberg and Thomas Kirk

16TH ANNUAL MEETING, OCTOBER 9-11, 2020

Plans for the 16th Annual Meeting of NASPCC (“THE PROSTATE CANCER ALLIANCE”) are underway! Following the success of last October’s NASPCC 15th Annual Meeting & Gala, we are working on details for this year’s **16th Annual Meeting & Dinner** to take place **October 9-11, 2020**. We will again be meeting at the unique and outstanding Hotel Monaco in Washington, DC. Please let us know if you have any ideas for this year’s event, including suggestions for nominees for the Outstanding Service Award which was presented to Dr. Alan Partin in 2018 and to Dr. Paul Schellhammer in 2019. We will also be awarding an individual with the Most Spirited Advocate award, as well as awarding the Most Outstanding State Prostate Cancer Organization Award. Suggestions and nominations are welcome; please send to mgrey@ucsd.edu.

1st NASPCC WEBINAR OF 2020 WAS A HIT!

On February 27, 2020, from 7:00 - 8:00pm Eastern, NASPCC (“THE PROSTATE CANCER ALLIANCE”) held its first Webinar of the year. The topic was “Side Effects of Prostate Cancer and its Treatment” and speakers were Dr. Krishnan Venkatesan, Director of Urologic Reconstruction at Washington Hospital Center, and William Goeren, Director of Clinical Programs at CancerCare in New York. The GoToWebinar Platform that NASCC uses has 100 portals for participants; we had over 100 people attempt to register, so some had to be turned away. Why register, participate and learn from the live Webinar as it happens? As a participant during the live Webinar, one can actively participate in the Questions & Answers section during the last 15 minutes of the 1-hour Webinar. At the very least, NASPCC stores the Webinar recordings and accompanying slides on its website, www.naspcc.org, but live questions cannot be asked. Stay tuned for the announcement of the next Webinar and REGISTER EARLY!!

NEW NASPCC BROCHURES

NASPCC printed new 6-panel Brochures following last year’s 15th Annual Meeting & Gala to reflect the current Board of Directors and the updated list of states that participate in NASPCC. If you need any Brochures for your organization, please contact mgrey@ucsd.edu. Remember that each of the state prostate cancer organizations participating in NASPCC is to have the following language appear on their state organizations’ Brochures and their Website: “A Proud Participant in the National Alliance of State Prostate Cancer Coalitions”! *See elsewhere in this Newsletter for a short brief on the Draft “Memorandum of Understanding” between NASPCC and each of the participating states in NASPCC, as well as the Draft itself. Following a Comment period on the Draft that expires on August 1, we will be asking every state participant to sign that Memorandum of Understanding.*

STATE COALITION DEVELOPMENT COMMITTEE

Robert Johnson of Prostate Cancer Advocates of Wyoming has accepted the Chairmanship of the State Coalition Development Committee of NASPCC, one of the eight Advisory Committees that serve the organization. The Committees are an excellent way to serve NASPCC and the national, state and local Prostate Cancer population, even if you are not the official state representative to NASPCC. For example, the Education and Awareness Committee is chaired by Dr. Fran Franklin of Delaware, who is not the official Delaware representative but is interested in serving the organization. Committee descriptions can be found on the website at <https://naspcc.org/index.php/about-naspcc/committees>.

THE QUARTERLY BOARD OF DIRECTORS MEETINGS

The first Quarterly Board of Directors Meeting for 2019-2020 was held on Tuesday, January 21 at 1:00 pm Eastern. The Board Meeting Minutes of January 21, 2020 appear elsewhere in this Newsletter for your review. Our second Quarterly Board Meeting Call will take place on Tuesday, April 21 and then the third Quarterly Board Call will take place on July 21, 2020. Each Board of Directors Call takes place from 1:00 – 2:30 pm Eastern; during the Calls the Board approves the Minutes from the preceding Board of Directors Meeting and also accepts the Executive Committee Call Minutes from the current and preceding two months. The Board of Directors is in charge of running the organization in all areas not managed or run by the Executive Committee. Guests are welcome to listen in on the Board Calls after identifying themselves as Guests. The 4th Quarter Board of Directors Meeting takes place in person on the Friday afternoon of the Annual Meeting. Please see Pages 9-11 for the minutes.

PATIENT SURVEY UPDATE

NASPCC wants to help identify the Research Questions that are important to patients. We are working with Dr. John Gore of the University of Washington on this Survey Project that was sent out twice to the NASPCC list serve. The second Survey was sent out January 29, 2020 to all of the state prostate cancer organizations participating in NASPCC, with a shorter list of questions that were responsive to the results that were received after the first Survey. This (second) sample Survey appears elsewhere in this Newsletter. The next step is a Roundtable that Dr. Gore will be holding in California following a California Prostate Cancer Coalition Board Meeting, at which patients and their caregivers will be able to engage in a face-to-face conversation with full back-and-forth about these research questions. Eventually the results will be part of a grant project that Dr. Gore will submit for funding to conduct that research. The Roundtable had been scheduled for March 23, 2020 but has now been postponed because of the corona virus. We will let the states know when the Roundtable has been re-scheduled. Please see Page 7 for more information and a link to the survey.

SAVE THE DATE: SEPTEMBER 2020

The California Prostate Cancer Coalition (CPCC) and UCSF will put on their 2nd Annual CPCC/UCSF Conference on Prostate Cancer in September 2020, in the Bay Area. For information, please contact mgrey@ucsd.edu.

General Updates Continued...

MEMORANDUM OF UNDERSTANDING NASPCC and State Representatives

You may recall on page 6 of the last Blueprint Newsletter of December 4, 2019, we provided an article summarizing our discussion during our 15th Annual Meeting and some comments on the Memorandum of Understanding (MOU). We also stated that you would be receiving a template of an Understanding in the next few months from Dr. Fran Franklin, the Chair of our Education & Awareness Committee.

As further background, you may also recall that NASPCC leadership engaged in Strategic Planning in 2017 and passed our current plan at the July 2017 Board Meeting. In that plan, and since, there has been a focus on developing an organizational Memorandum of Understanding (MOU) to “facilitate effective state strategies”.

Fran’s committee has been active on many fronts and has recently prepared a Draft Memorandum of Understanding (MOU) to share here. In the March 11th Committee Meeting, it was agreed that we would seek comments on the Draft by August 1st. This will help all of us in preparation for action at our Annual Meeting in October.

Please direct any comments, suggestions or concerns to Tom Kirk, Chair of the NASPCC Steering Committee at tomkirk_99@yahoo.com.

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March 2020 Draft Memorandum of Understanding (MOU)

NASPCC (the Prostate Cancer Alliance) has been “reaching thousands of Prostate Cancer Patients and their Families since 2004”. The current Mission Statement was updated and accepted by the NASPCC Board of Directors in 2017: *“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 patients and their families, through awareness and education and the development of a public policy network.”*

NASPCC is organized as a 501 (c) 3 not for profit umbrella organization with governance and oversight provided by an Executive Committee (which meets monthly and a Board of Directors which meets Quarterly) which is elected by State Representatives annually at the organization’s Annual Meeting.

This “Draft” Memorandum of Understanding (MOU) was developed to guide our working relationship.

I (State Representative) agree to participate in the NASPCC on a voluntary basis which means:

1. I/we understand there are no dues or formal membership in the NASPCC, participation is voluntary.
2. I/we understand my involvement in the NASPCC means there are no restrictions on membership or involvement in other national or local prostate organizations.
3. I/we agree to attend an Annual Meeting as the representative of the State of _____.
4. I understand I have the right, privilege and responsibility as the State Representative to vote in the Annual election for the Board of Directors and Officers of NASPCC.
5. As the NASPCC raises donations from Sponsors for the Annual Meeting, I agree to submit my expenses in a timely manner following the meeting to the NASPCC Treasurer (using the NASPCC forms).
6. I /we understand that following the Annual Meeting and returning home, I/we will use what was learned to educate and increase awareness of prostate cancer either through my/our State Prostate Cancer Coalition/Organization, personally or through another designated organization.
7. I/we understand that as an active participant(s) in the NASPCC, I/we can utilize materials and resources developed by NASPCC such as the Informed Decision-Making Laminates, NASPCC brochures, the Quarterly Blueprint Newsletter and the NASPCC Facebook posts at no charge.
8. I/we agree to use the following language in my/our state outreach materials, newsletters and on our website to demonstrate involvement and commitment to NASPCC and its Mission, **“A Proud Participant in the National Alliance of State Prostate Cancer Coalitions”**.

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9. I/we agree to join and participate in the NASPCC in at least one of the active Advisory Committees:

- a. Education and Awareness Committee
- b. State Coalition Development Committee
- c. Communications Committee
- d. Advocacy and Public Policy Committee
- e. Annual Meeting Committee
- f. Budget Committee
- g. Fundraising Committee
- h. Medical Advisory Committee

Signed (Name and Role/Title) and Dated

University of Washington Survey

Your Input Will Drive Prostate Cancer Research

Greetings and thank you to those who provided your input into the first round of the Prostate Cancer Patient Research Survey. **The University of Washington and the National Alliance of State Prostate Cancer Coalitions (NASPCC) invite you to participate in the second round survey to help drive new research for prostate cancer.** **WE WANT TO IDENTIFY THE RESEARCH QUESTIONS THAT MATTER TO YOU!!**

Prostate Cancer Patient Survey

What research questions do you wish were answered when you were (or your loved one was) going through prostate cancer diagnosis and treatment? The Prostate Cancer Patient Research Survey was developed with a mission to engage prostate cancer patients and their loved ones in the research process by identifying the most important research questions to be answered by researchers. This is a unique opportunity to have your voices heard and to have an impact on what research should be undertaken.

What has been done so far in other cancers?

Researchers at the University of Washington and the University of North Carolina developed a Bladder Cancer Patient Survey Network in 2015 to prioritize the importance of research questions for bladder cancer. The responses help researchers identify the most important questions for patients with all types of bladder cancer. Based on important input from the patient survey, researchers successfully secured an \$8.5 million grant to study the questions! With your help, we can do the same for men with prostate cancer and their loved ones: identify important research questions and partner with researchers to answer those questions. **AND NOW we have completed the first round of this survey with almost 600 responses!** Over 200 participants contributed their own research questions, which have been added back in with the most highly-ranked research questions from Round 1. When we receive your responses to Round 2, we will then send the top-ranked questions to organizations that fund prostate cancer research so they may prioritize the research that really matters to men with prostate cancer and their caregivers.

How can you help?

We are asking prostate cancer patients and their loved ones to complete this Second Round and choose the most important research questions for a specific stage of prostate cancer. Each question was chosen by patients and their loved ones (like you). If research is done on these questions and those questions answered, it will help patients make better choices about their cancer diagnosis and treatment. We will ask you to rank questions in order of importance. Your responses will remain confidential. **PLEASE SHARE THROUGHOUT ALL OF YOUR NETWORKS!**

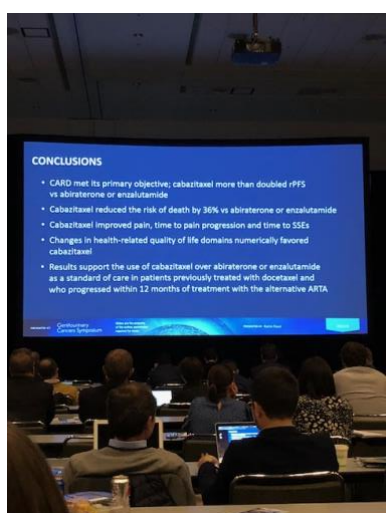
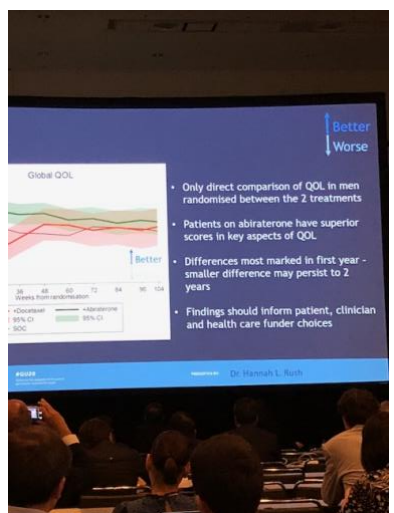
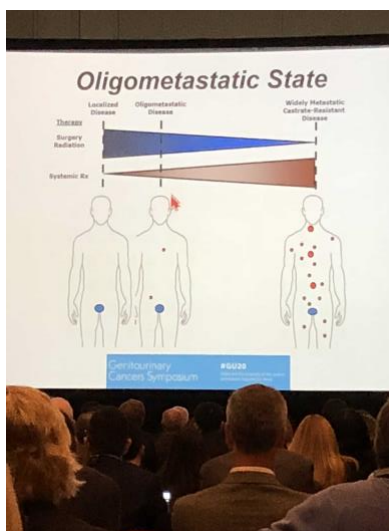
Please use this link to complete the survey, which we estimate will take **15 to 20 minutes**. <https://redcap.iths.org/surveys/?s=AT3YLFC7PL> Thank you! Merel Nissenberg, President

Update from ASCO GU - San Francisco February 12-14, 2020

Merel Nissenberg, NASPCC President, and Tom Kirk, Chair of NASPCC's Steering Committee, represented NASPCC ("THE PROSTATE CANCER ALLIANCE") at the 2020 ASCO GU (Genitourinary) Cancers Meeting in San Francisco, California, February 12-14, 2020. Along with updates on Clinical trials – such as for the newly identified “spaces” in advanced prostate cancer of Metastatic Castrate-Sensitive Prostate Cancer, and non-Metastatic, Castrate-Resistant Prostate Cancer, they heard other fascinating presentations. Several scientific and medical articles have in fact already been written about some of the findings presented, and some of those appear on the Facebook Page of the National Alliance of State Prostate Cancer Coalitions, which posts them several times a week. **LIKE US ON FACEBOOK.** Merel and Tom were also able to spend time with other advocates and with some of the sponsors who generously help enable us to put on our Annual Meetings. October is not that far away, and Merel leads the Annual Meeting Committee that will put all the plans in place for the 16th Annual Meeting, so she was also busy in sponsorship meetings, along with Tom.

At the present time we are unsure as to whether the general ASCO 2020 Meeting in Chicago will be held at its scheduled time of May 29-June 2, 2020. We will keep our state organizations posted.

Photo Gallery from ASCO 2020 GU



NASPCC Board of Directors Meeting Minutes

By Jan Marfyak

JANUARY 21, 2020

Present were: Merel Nissenberg, Tom Kirk, LaTanya Patton, Mary Anderson, Alvin Chin, Dave Hulbert, Crissy Kantor, Paul Kradel, Harold Pharoah, Gabe Rosko, Otto Sankey, Renee Savickas, and Ullyses Wright. Absent: Johnny Payne, Donald Lynam, Robin Leach, Stephen Richardson, David Sauls and Clarence Williamson

PRESIDENT'S MESSAGE

Merel reported on the outstanding 15th Annual Meeting & Gala and stated that most of the speakers have already asked to speak at/accepted an invitation to speak at the 16th Annual Meeting, October 9-11, 2020. It will again be held at the Hotel Monaco. Merel signed the papers about 10 days ago, with even better rates than this past year. She stated that on the Website there are: the Annual Meeting Brochure, the Report of the 15th Annual Meeting & Gala, the new NASPCC Brochure, and photos from the weekend, along with the presentations from the Meeting proceedings. (We ordered new Brochures to make sure the Board Members are current.) Merel stated that she will re-arrange the presentations on the website because they might be out of order. She also said that she and Tom Kirk will be attending the ASCO GU Meeting next month (February 12-15, 2020) and she has already set up several meetings with sponsors and potential sponsors in her fundraising efforts. Merel told the Board that Dr. Judd Moul and Dr. Vincent Laudone had joined our Medical Advisory Board, chaired by Dr. Michael Zaragoza.

SECRETARY'S REPORT

The EC Minutes from the November 2019, December 2019 and January 2020 Calls were presented to the Board for acceptance. Harold moved, LaTanya seconded, Motion approved to accept the EC Minutes. Next the Board Minutes were presented from the last Board Meeting (which was the Face-to-Face Board Meeting the day before the 15th Annual Meeting) for approval. LaTanya moved, Harold seconded, Motion approved.

TREASURER'S REPORT

Don Lynam, Treasurer, had sent out to the Board the current Financial Report (10/1/19-1/14/20) a couple weeks ago for our review, and Merel had re-sent the Report to the full Board yesterday as well. Merel gave this Report for Don using what he had sent. Don had stated that we have a total of \$75,314.60 in assets. On the P & L (Detailed and General) he stated that we had \$78,937.43 in income, \$111,241.11 in expenses, for a net overage of \$32,303.68. Annual Meeting costs= \$86,384.14. Merel stated that we are still waiting for the \$12,000 from Boston Scientific and have received extra funds [from Bayer] that we are waiting to hear how to use them (eg, 16th Annual Meeting). Alvin commented to see the financials relative to same period last year – Merel will ask Don to send it. Paul Kradel moved, LaTanya seconded. Treasurer's Report approved.

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WEBSITE AND FACEBOOK

In Johnny's absence, Merel reported that John Brandt has been posting items on our website constantly. He added the photos from the 15th Annual Meeting & Gala, as well as the Annual Meeting Brochure, the Report of the 15th Annual Meeting & Gala, the new NASPCC Brochure, and the new Blueprint, edited by Renee Savickas. Merel reported that she is sending Johnny articles for posting on our Facebook page as she receives those that she thinks should be posted. This past week she sent him several, for example. Merel once again urged every Board Member to visit the NASPCC FB page and LIKE it and also to LIKE all of the articles that Johnny posts there. With increasing numbers of visits and Likes we will be able to raise more funds and to help educate more people.

COMMITTEES' STATUS REPORT

Tom Kirk reported that the Education and Awareness Committee will be meeting on 2/12. Fran Franklin (Chair) is looking at Webinars and a MOU. Dave Hulbert stated that he will be speaking with Dr. Kwon within the hour to set up a new webinar date to replace the one originally set for yesterday. Advocacy Committee report: Alvin Chin said the Committee Call was held 12/19. He attended the Annual OVAC Meeting, and there were a few other prostate cancer groups there as well (out of the ordinary). The full group hammered out a budget with a "pretty good" amount – all were happy. "PCa has been doing well over the last few years, as has everybody else". Mini-Lobby will be coming up in March and the Grass Roots lobby coming in May which he'll try to attend. Should we have a representation there? They do have a scholarship available. They mentioned a Congressional Briefing in the Fall after Congress recesses. He talked about the DHRC that watches over the CDMRP; the Advocacy Committee will have a meeting call to create a strategy next week – January 29.

Communications Committee: Tom complimented Renee on the current Blueprint; Renee stated the next one will go out the end of February, so she asked for all content to her by 2/14. She also said that the next National Conference Call is scheduled for February 6. Date changed to 2/27 and we will present "Report from the 2020 ASCO GU Meeting". Merel reported that she will be calling for a meeting of her Fundraising Committee in late February, and her Annual Meeting Committee in March. She reported on the contract for the Hotel Monaco and the details for that Meeting. Merel reported on the State Coalition Development Committee; we still need a Chair, and the next states needing guidance in forming their coalitions are Texas, Alabama, Illinois, Wisconsin. Merel then reported on the 2nd Annual CPCC/UCSF Patient Conference on Prostate Cancer scheduled for June 6, 2020. She also stated that a piece on veterans' issues written by Mike Crosby from Oklahoma, and now in California (an issue in which Don had and Jan had expressed a strong interest on the last EC Call), would be included in the upcoming CPCC Newsletter.

Tom Kirk reported that Don Lynam continues to chair the Budget Committee, and Dr. Michael Zaragoza the Medical Advisory Committee. Merel reminded everyone that Michael had asked Dr. Judd Moul of Duke and Dr. Vin Laudone of Sloan-Kettering to join the Medical Advisory Committee and they had accepted.

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Gabe Rosko then suggested a national fundraising effort in which the states participate, getting a piece of the funds. Local level people would be marketing and selling and asking for contributions. Alvin disagreed with this idea, saying fundraising should be done locally first. Merel suggested that we take this up on our Fundraising Committee Call. Crissy Cantor reported that their NHPCC has been successful with their Elton John Show – this year will be a tour around NH, and it has been a tremendous fundraiser. Their President, Dick Hatin, said they will offer it to another state. Crissy agreed to sit in on the Fundraising Committee Call to share this. We then went back and discussed the Treasurer's Report and Don confirmed the numbers we had already discussed and approved.

It was stated that the next Board Call will be Tuesday, April 21, 2020 followed by the July 21, 2020. All Board Calls are at 1:00 pm Eastern.

Meeting adjourned 1:40 p.m. Eastern.

Award Nominations

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

The categories are:

- Outstanding Service in Prostate Cancer for a Physician
 - Most Spirited Advocate
- Outstanding State Prostate Cancer Organization
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Please send your suggestions to Merel at: mgrey@ucsd.edu!

NASPCC Committees (8) and Member Status

All of the Alliance Board Members are now placed on Committees. Here are the 8 Advisory Committees:

- **Education and Awareness Committee:** Fran Franklin, Chair
Members for 2019-2020: David Sauls, Tammie Minter, Cheryl Cropp, LaTanya Patton, Ira Baxter, Jan Marfyak, Dave Hulbert, Paul Kradel, Steve Richardson, Calvin Jackson and Clarence Williamson. Johnny Payne Chaired this Committee for the first year (2017), stayed on the Committee last year and will continue again during 2019-2020.
- **Communications Committee:** Renee Savickas, Chair
Members for 2019-2020: LaTanya Patton Chaired this Committee for the first year, served last year and will continue to serve on the Committee during 2019-2020, other members last year were Johnny Payne, Paul Kradel and Ira Baxter.
- **Budget Committee:** Don Lynam, Chair
Members for 2019-2020: Anthony Minter, Jan Marfyak, Alvin Chin, and Ullyses Wright.
- **Advocacy and Public Policy Committee:** Alvin Chin, Chair
Members for 2019-2020: Don Lynam and Tom Kirk will continue to serve, and Robert Gamage (NY) and Mike Crosby signed up.
- **State Coalition Development Committee:** Rob Johnson, Chair
Members for 2019-2020: Harold Pharoah, Cheryl Cropp, Dwight Thomas, Otto Sankey and Crissy Kantor.
- **Annual Meeting Committee:** Merel, Chair
Members for 2019-2020: Tammie Minter, Ullyses Wright and Rob Johnson signed up. Jan Marfyak, Don Lyman, Harold Pharoah voiced interest as well. Crissy Kantor and Robin Leach are added.
- **Fundraising Committee:** Merel, Chair
Members for 2019-2020: Mary Anderson and Rob Johnson signed up and Gabe Rosko is added. Alvin Chin voiced interest as well.
- **Medical Advisory Committee:** Michael Zaragoza, Chair
Members for 2019-2020: Otto Sankey added.

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:



Crissy Kantor - Chill Spa, Chill Cares

Crissy Kantor is the Founder/Director of both Chill Spa and Chill Cares. Crissy is a long-standing member of the Board of Directors of NH Prostate Cancer Coalition (NHPCC) and the newest member of the NASPCC, which further echoes her commitment to raising awareness and finding a cure for Prostate Cancer.

Crissy's passion and commitment for raising awareness for Prostate Cancer began over 20 years ago when her father, Jeff was first diagnosed. In 2015, Jeff lost his courageous battle but not without a fight! Crissy shares her Dad's inspirational story of positivity, kindness, generosity, endless optimism and never giving up attitude to give hope to others battling cancer.

With the creation of a non-profit foundation, Chill Cares, Crissy's goal is to carry on his legacy of raising awareness for the blue ribbon with the same passion as her father! Since its' inception in 2015, the Foundation has raised and donated \$38,000 to local cancer patients and \$40,000 to Prostate cancer research! The group is small but mighty! Chill Cares team is focused and committed to making a difference in the Granite State. Earlier in 2015, the Norris Cotton Cancer Center was proud to establish the Jeffrey S. Kantor Fund for Prostate Cancer Research in Jeff's honor, through the generosity of his friends and family with the NHPCC. Jeff Kantor was the driving force behind the ski race event which for many years provided NHPCC with all its seed money. Jeff wanted his commitment to Prostate Cancer awareness to carry on well after his passing and knew that recruiting Dick Hatin to lead the way in taking NHPCC to the next level, was the only answer. Dick and his wife Anne took on this challenge. Later becoming President of NHPCC and his wife Anne, as Treasurer.

Through the first five years from the launch of the entertainment fundraiser at the Palace theatre, NHPCC raised and contributed \$65,000 towards research in honor of Jeff. Dick and Anne also launched a necktie collecting campaign, where each person who has battled or is battling Prostate Cancer is encouraged to donate a necktie which is a symbol of his personal story and represents his family. We exhibit these ties at numerous events around our state.

Additional outreach:

- Provide literature to local libraries around New Hampshire;
- contribute support to other local non-profit partners;
- appear on local community access shows and radio shows;
- co-sponsor (Chill Cares and NHPCC) a series of concerts at the Palace Theater
 - o This enables us to reach over 25,000 patrons per year with our message, and mission.
 - o This initiative has led to gaining public policy support, heightened public awareness and even garnered additional financial support.

Highlights of Upcoming New Hampshire Events include:

- September 26, 2020 – 4th Annual Giddy **Up for Prostate Cancer** - “Take your health by the reins” presented by Chill Cares*
- October 2020 – 3rd Annual “**Elton John Tribute Show**” will be expanded to a multi-city event, to ensure the message resonates throughout the Granite State. This event is presented by NHPCC*
- November 15, 2020 – 8th Annual “**Stache Dash**” 5K race to support Prostate Cancer presented by Chill Cares*, Kim Cronin & Crissy Kantor co-directors & founders of the first prostate cancer road race in NH, both lost their dads to prostate cancer

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*Both NHPCC and Chill Cares Boards jointly support each other’s events.

Our organizations success is a direct reflection of the work, vision and community spirit of deeply dedicated board members & volunteers.

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Photo Gallery from Chill Cares and NHPCC



Figure 1 Jeff Kantor and Crissy



Figure 2 Giddy Up for Prostate Cancer Event 2019



Figure 3 Crissy, Caitlin Plumpton, President of CC, her daughters, Violet & Noury, youngest prostate cancer activists!



Figure 4 Stache Dash - Crissy, Mayor-Joyce Craig and Anne Marie Hafeman



Figure 5 Cupcake Fundraiser



Figure 6 Giddy Up for Prostate Cancer 2019



Figure 7 Elton John Tribute Concert



Figure 4 NHPCC Board Members with the Governor of NH with the newly signed "Proclamation"

NASPC would like to congratulate the **Chill Cares and The New Hampshire Prostate Cancer Coalition** for being our **"Spotlight"** featured Coalition of the quarter! You are doing excellent work, providing help to local cancer patients, prostate cancer research, education and awareness in your state! Thank you for all that you do!

NASPPC Updated 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.

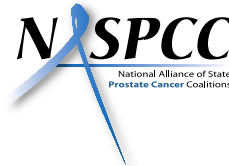
NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS

- 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
- 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 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 Website: 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

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.

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CONTACT NASPPC TO:

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

WANT TO ESTABLISH A COALITION IN YOUR STATE?

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

CONTACT:

National Alliance of
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1999 Avenue of the Stars, Suite 1100
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E-mail: info@nasppc.org
Website: 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/>

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 Geru**
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.
- **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 see the following information on CancerCare's Online Support Group



CANCERCare®
Help and Hope

FREE PROFESSIONAL SUPPORT SERVICES

CancerCare helps individuals, families, caregivers and the bereaved cope with the emotional and practical challenges of cancer. Our services include counseling, support groups, educational workshops, publications and financial assistance. All of our services are provided by professional oncology social workers and are offered completely free of charge. To learn more, visit www.cancercare.org.

CONNECT WITH US

 **FACEBOOK**
www.facebook.com/cancercare

 **BLOG**
www.cancercare.org/blog

 **YOUTUBE**
www.youtube.com/cancercareinc

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

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



Prostate Cancer Online Support Group

CancerCare and the National Alliance of State Prostate Cancer Coalitions (NASPCC) are offering a free 15-week 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. This online support group will not offer medical advice and there will be no medical professional leading the group.

MODERATOR

William Goeren, LCSW-R, ACSW, OSW-C, SEP
Director of Clinical Programs, CancerCare

TO JOIN THIS SUPPORT GROUP, PLEASE VISIT

www.cancercare.org/support_groups/126 to complete our online registration process. Internet access is required.



About NASPCC and Mission Statement

National Alliance of State Prostate Cancer Coalitions (NASPCC) is a nation-wide organization comprised of state coalitions dedicated to saving men's lives and enhancing the quality of life of prostate cancer patients and their families, through awareness and education and the development of a public policy network.

State Coalitions

The following states have participated in NASPCC:

- 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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Vice President: Johnny Payne (SC)

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