



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

News

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THE BLUEPRINT

J. Renee Savickas, Editor

President's Message

Welcome to the continuation of our unexpected, COVID-19 way of life! I hope you are all staying safe, taking all possible precautions and practicing social-distancing. Meanwhile our efforts to help men with prostate cancer and bring benefit to them and to their families are unflagging. The Executive Committee continues to meet on the first Tuesday of every month; the Board meets quarterly, in January, April, July and just before our Annual Meeting. Our most recent Board Meeting took place on April 21, 2020 and the next Board Meeting will take place on July 21, 2020. You will find the April Board Minutes in this Newsletter, and please remember that guests are always welcome to listen in. Also, the Roundtable that was previously scheduled for March 23 on the topic of patient preferences for prostate cancer research topics (as a follow-up to the Survey that was sent to the full NASPCC Listserv a few months back) will be re-scheduled for later this year, but will take place virtually, as a ZOOM meeting.

Many of the medical meetings which I regularly attend in my role as President of NASPCC and which populate this time of year have been postponed or transformed into virtual formats to be experienced from our laptop computers (as we work remotely). ASCO GU which was held in San Francisco in February – 4 months ago - was the last in-person scientific meeting that most of us attended! The AUA Advocacy Summit at which I have presented the past two years, and which was scheduled for this March, has been postponed until August 31-September 2 and is planned as an in-person meeting; further information will be forthcoming. The 2020 Annual AUA Meeting has been re-scheduled from May 15-18 to June 27-28, when it will be experienced as a virtual event. AACR (American Association for Cancer Research) held Part I of its Annual Meeting virtually in 2 full-day sessions April 27-28; Part II will take place June 22-24, again in a virtual format. Most of us have become ZOOM experts so that we can participate in group meetings and conduct business - (not) as usual. But it works!

Continuing, the 2020 ASCO Meeting (American Society of Clinical Oncology) was moved from Chicago, May 29-June 3, to our computers instead, when it took place virtually May 29-31. Elsewhere in this Newsletter you will see my "Report from ASCO" covering some of the important presentations that were made at this year's Annual Conference. The well-regarded Massachusetts Prostate Cancer Symposium (read about it in this issue) was converted to a virtual event and took place May 15. (Continued on page 2)

In California, the 2nd Annual California Prostate Cancer Coalition/UCSF Patient Conference on Prostate Cancer which was scheduled to take place June 6, 2020 is now postponed until next June 2021 and will be held at Mills College in Oakland, California (with a capacity of 400 people). The value of that Patient Conference as an in-person meeting bringing experts and patients together in one venue prevented us from using a virtual format.

And NASPCC's 16th Annual Meeting, previously scheduled for October 9-11, 2020 in Washington, DC, has now been formally postponed until January 29-31, 2021 to take place at the Hotel Monaco there. Our Annual Meetings are unique, comprised of a weekend of sharing of best practices, bonding, networking and participation in educational sessions, as well as presentations of awards. No virtual meeting could capture the energy produced by the in-person weekend of learning and gathering of information and materials, not to mention the time spent meeting personally with the most outstanding caliber of experts. **SO, PLEASE CALENDAR JANUARY 29-31, 2021 FOR OUR 16TH ANNUAL MEETING & DINNER!**

You will find some very valuable and interesting pieces in this Newsletter ("The Blueprint"). We have included the Board Meeting Minutes from April 21, 2020. I have shared my "Report from ASCO". Judy Green has written a piece on the Massachusetts Prostate Cancer Symposium. Tom Kirk has written about the proposed Memorandum of Understanding that all states will be asked to sign and the deadline for comments and suggested edits. There is an article about how Support Groups are continuing to assist prostate cancer patients in this time of no in-person Group Meetings.

Our CPCC Secretary, Tiffany Razzo, has written about her experience working at a major cancer center (M.D. Anderson Cancer Center in Houston, Texas) during the COVID-19 pandemic. And I have shared with you an "ad" that the California Prostate Cancer Coalition has placed in the California Family Physician magazine which is running in each of their four quarterly issues this year. In a slight of hand, it has links that take the reader (predominantly primary care providers) directly to our Informed Decision-Making Laminates at NASPCC. We hope we can thereby change non-testing practices and have more men with potentially lethal disease diagnosed when there is still chance for cure. There are other superb resources in this Newsletter.

Thank you to our Editor, Renee Savickas, for her work on "The Blueprint"!

Respectfully submitted,

Merel Nissenberg

Board of Directors Quarterly Calls and Meeting Minutes

Q2 – April 21, 2020

By Merel Nissenberg for Jan Marfyak

The Board of NASPCC meets quarterly by conference call on the first Tuesday of January, April and July, and in person the day before the Annual Meeting. Guests are always welcome to listen in on our Calls. Our last Board Call took place Tuesday, April 21, 2020 at 1:00 pm EST and here are the “Minutes”:

Board members present on the Call were: Merel Nissenberg, Johnny Payne, Don Lynam, Jan Marfyak, LaTanya Patton, Mary Anderson, Alvin Chin, Dave Hulbert, Crissy Cantor, Paul Kradel, Robin Leach, Harold Pharoah, Stephen Richardson, Gabe Rosko, Bruce Williams (newly elected), David Sauls, Renee Savickas and Clarence Williamson. Absent were: LaTanya Patton; Stephen Richardson; Ulyses Wright. Also, present: Steering Committee Chair Tom Kirk

PRESIDENT’S REPORT:

Merel Nissenberg opened the Board Meeting with a welcome and a wish that everyone has stayed safe and healthy during the quarantine. She stated that, although we are all working from home, business (and NASPCC business, in particular) still continues as usual. She stated that she and Tom Kirk had attended the ASCO GU 2020 Meeting in San Francisco, and that besides excellent scientific presentations, she had had several meetings with potential sponsors and donors for NASPCC. She stated that the Executive Committee had been meeting monthly by call and that the Board would have a chance to accept those Minutes shortly. Merel discussed that many of the usual meetings, such as AUA and ASCO, have been cancelled this year and the CPCC/UCSF Patient Conference on Prostate Cancer has been postponed until the Fall. However, she stated that she is proceeding on the optimistic assumption that by October we will be holding our 16th Annual Meeting as scheduled, October 9-11, 2020, in Washington, DC. Gabe Rosko commented that, in his opinion, we are not going to be on a normal basis for close to 2 years, until a vaccine is proven effective. He doesn’t think the Annual Meeting will happen in October. Alvin asked if we could get out of our contract if we needed to; Merel said she thought so. Gabe said that instead we could market a series of Webinars appropriately and that might work. Merel said she will never put our people in danger, and that we will re-visit this during our Q3 July 21 Board Call. Merel then stated that she also continues to scan the medical journals that arrive online every morning and she continues to send those articles to our Vice President Johnny Payne for posting on our NASPCC Facebook Page. Merel also stated that she will look into the idea of doing our July Board Call as a ZOOM Meeting, as suggested by Mary Anderson of North Carolina.

SECRETARY’S REPORT:

Secretary Jan Marfyak had to temporarily leave the Meeting so in his place Merel presented the January 21, 2020 Board Minutes that had been sent out to all Board Members, and asked for edits, corrections and a Motion to Approve. Don moved, and Harold seconded. Motion passed. Merel, in Jan’s place, next presented the three sets of Executive Committee Meeting Minutes from February, March and April for acceptance by the Board. Mary moved; Harold seconded. Motion approved to accept the EC Minutes from February, March and April 2020. (Continued on page 4)

TREASURER'S REPORT:

Don had prepared and sent out his Financial Report but stated that it is an abbreviated version since he is sheltering in place with his son in Indiana and can't get into the Quick Books properly from there. He prepared totals to share with us. We have a total of \$ 64,327.15 in checking, and \$20,887.67 in Savings, for a total of \$85,214.82. For Profit and Loss, Don stated that our total Income since October 1, 2019 has been \$121,735.82, and Expenses have been \$144,139.28, for a net loss of \$22,403.46. Don complimented Merel for raising funds. Total donations since October 1, 2019 have been \$118,000. Last year at this time we had a negative balance of almost \$76,000, so we're way ahead. Gabe asked what benefits could be available to the organization under any of the stimulus plans being utilized. He said that there are 3 COVID-19 plans that might be available. One is PPP, and he suggested that we should go online at COVID-10 SBA and see if independent contractors are covered, and if NASPCC also qualifies. Alvin asked if we have an accountant; Don said he would check with our CPA, but Merel said she would check it out first. She said that she wasn't sure it was appropriate for us; we haven't lost money and we are not being prevented from putting on any programs, but she will look into it. Harold moved, Crissy Cantor seconded, and the Treasurer's Report was approved. Merel thanked Don for his work, and many added their thank yous.

WEBSITE AND FACEBOOK:

Vice President Johnny Payne reported (and Merel added) that our illustrious Webmaster, John Brandt in Maine, continues to do a great job of maintaining our site, making corrections as needed, keeping the Listserv up to date, and adding items such as Reports, the Newsletters (The Blueprint) – including the most recent one, and announcements as needed. Johnny Payne continues to post medical and scientific articles to our Facebook Page that Merel sends him – several times a week. Johnny stated that the newest Newsletter is also on our FB page. Johnny asked that everyone ask their networks of people to LIKE our FB page.

COMMITTEE STATUS REPORT:

Tom Kirk reported that he had sent out a summary yesterday. He then mentioned that in the last three EC Calls he had done an update so it should be in those EC Minutes that were just accepted by the Board. He stated that Renee as Chair of the Communications Committee had done our Newsletter (The Blueprint) on 3/16 and it's on our Website; in the Newsletter, he said, on page 3 is a mention of the webinar of 2/27 and that it was successful, and on page 13 – there was something about committee membership. Tom stated that for the State Coalition Development Committee: he and Merel had had a 3/27 conversation with Rob Johnson (the new Chair) who will be having his first call. Tom then stated that Fran Franklin, Chair of the Education & Awareness Committee had missed the last April 8 call but that we did have a call. He then added that on p. 5-7 of the Newsletter, the Memorandum of Understanding has been posted, asking for draft responses by August 1.) Tom stated that Alvin – Chair of Advocacy and Public Policy– had tried to join last month's OVAC Call, and Tom and Merel were on the April OVAC Call yesterday. We had signed on to a letter which was mailed out on 4/14 to the leadership of the Appropriations Committees in both houses for the CDMRP-DOD Program. Tom stated that we are monitoring a few things in advocacy. Fundraising and Annual Meeting Committees – the April 16 second call of the Fundraising Committee had been cancelled. Merel stated that the reason for the cancellation was that Dick Hatin of New Hampshire had been unable to join the Call on that date, and he had been helpful for ideas for states to raise money during our first call and we needed his follow-up. Tom said that Merel has not had a Call for the Annual Meeting Committee yet but that the contract is signed. Tom stated that Don continues as Chair of the Budget Committee, and that the cycle will be starting soon. (Continued on page 5)

Tom stated that the Medical Advisory Committee continues to be chaired by Michael Zaragoza. Tom was complimented for his excellent Updates on the 8 Advisory Committees.

ANNUAL MEETING: Merel stated that while she postponed having an Annual Meeting Committee Call, she is proceeding as planned with the October 9-11 dates. She stated that she is still fundraising for the 16th Annual Meeting. Her Letters of Request do mention contingencies – such as postponing the Annual Meeting for a month or two – but she is optimistically planning to go forward on the contracted-for dates.

NEW BUSINESS: Alvin suggested we discuss the Friends of Prostate Cancer Care Community. Merel described what this new organization is, that it has been organized by the AUA and there is also industry participation (Janssen and Pfizer), with 8 or so people who will serve as the Steering Committee, and we will identify our interests. Tom stated that we need to complete a Capabilities Statement by April 30. Dave Hulbert said that on April 15 Merel had sent out the NCCN Guidelines for Prostate Cancer during the COVID-19 pandemic, to our Listserv. Merel stated that she thought this was a good summary statement of the topic. Dave agreed, saying that changes are taking place; Merel mentioned how many clinical trials are stopped or are experiencing lower accrual. Merel also mentioned our Strategic Alliance Partnership (SAP) Program with CURE and reminded everyone that she had forwarded their first monthly Newsletter to the full Listserv. We will be able to advertise on their site for free, will be able to have Conference/Meeting coverage; and will be able to do content sharing – sharing our organization with their national audience.

NEW BUSINESS (Continued): Next Newsletter (The Blueprint) – Renee said it would be out at the end of May, so she will need articles by mid-May. Merel then asked people to write up a few paragraphs about how COVID-19 has affected them. Don stated that his support group has been holding virtual support group meetings; Merel asked Don to write something up about that experience. Merel asked that if anyone wanted their state organization to be featured, to please contact her or Renee.

There being no new other business, the **BOARD MEETING WAS ADJOURNED AT 1:55 pm EASTERN**. The next Call will be the Q3 Board Call at the same time, 1:00 pm Eastern”.

Respectfully Submitted,
Merel Nissenberg, for Secretary Jan Marfyak

REPORT FROM ASCO 2020

By Merel Nissenberg

In the last few years, advanced prostate cancer has been examined in new ways and trials designed for various subtypes of advanced disease. There is **non-metastatic but castrate-resistant prostate cancer (no longer responsive to hormonal therapy)** called **nmCRPC**; there is **metastatic but castrate-sensitive prostate cancer (still responsive to hormonal treatment)** called **mCSPC**; and of course **metastatic castrate-resistant prostate cancer, called mCRPC (cancer that has spread beyond the prostate and which is no longer responsive to hormonal therapy)**. New drug approvals have included treatments for the non-metastatic space in order to postpone or prevent metastases (nmCRPC); and some of those drugs have now been approved or await approval in the metastatic hormone-sensitive prostate cancer space. It can be confusing. Added to that are emerging treatment possibilities based on genetic alterations (such as BRCA 1/2) and on other gene repair defects, so some of the prostate cancer treatments are in a new class of drugs including, for example, PARP inhibitors. Imaging in prostate cancer is also growing as a field in which some agents are being used for diagnosis and for treatment. Even immunotherapy in prostate cancer (Sipuleucel-T or Provenge) is being examined in combination with other agents to increase efficacy. This Report can only cover a fraction of the 200+ Abstracts presented last month.

Although ASCO 2020 was held as a virtual, instead of an in-person event, there were important presentations in prostate cancer, available to online registrants, that provided data likely to affect clinical practice going forward. Some of the most significant presentations provided the updated data from the 3 major trials in **non-metastatic, castrate-resistant prostate cancer (nmCRPC)**. These are the trials that examined apalutamide, darolutamide, and enzalutamide, all of which showed OS (overall survival) benefit for the study patients. In the first clinical trial, **SPARTAN**, presented by Dr. Eric Small of the Helen Diller Family Comprehensive Cancer Center at UCSF, apalutamide (Erleada) was found to offer a survival benefit versus placebo, even after crossovers to the active agent took place. [Abstract 5516] The trial tested apalutamide versus placebo for 1207 patients with non-metastatic castrate-resistant prostate cancer who had a PSA doubling time of 10 months or less. Previous reports had shown an improvement in metastasis-free survival with apalutamide. The median follow-up now was 52 months. The median OS for the apalutamide patients was 73.9 months versus 59.9 months with placebo. Time to chemotherapy was also improved with apalutamide. There was a clear survival benefit with apalutamide, and this is true even though 80% of the patients receiving placebo eventually received therapy either at progression or with crossover to apalutamide when the study was unblinded. This means the study looked at an active agent early, versus later. The clinically relevant results reported at ASCO 2020 added to the hopeful findings reported earlier in the trial.

Second, the final survival analysis of the **ARAMIS Trial** was also reported out at ASCO 2020 by Dr. Karim Fizazi of the Institut Gustave Roussy in Villejuif, France. [Abstract 5514]. Darolutamide (Nubeqa) showed significant overall survival (OS) over placebo along with delayed onset of cancer-related symptoms and later chemotherapy. [Abstract 5514] In this trial, 1509 patients were randomized almost 2:1 to either darolutamide twice a day or placebo, while continuing ADT. Crossover was allowed at the unblinding, and 170 patients crossed over to begin taking darolutamide. Although the median OS wasn't reached in either arm, darolutamide did reduce the risk of death by 31%. (Continued on page 7)

Key adverse events were similar in both arms, and the trial concluded that it was efficacious in both metastasis-free survival and OS.

The third Trial in the non-metastatic CRPC space with final data to report was the **PROSPER Trial**, the results of which were presented by Dr. Cora Sternberg of Weill Cornell Medicine and New York-Presbyterian Hospital in New York. The earlier results of improved metastasis-free survival had now translated into an overall survival (OS) benefit of almost 1 year in patients receiving enzalutamide (Xtandi). [Abstract 5515] The enrolled patients had non-metastatic disease, a PSA doubling time of 10 months or less, and a PSA of at least 2 ng/mL at screening, who were randomized 2:1 to enzalutamide or placebo. The median OS was 67 months with enzalutamide and 56.3 months with placebo, a 27% reduced risk of death. Grade 3 or higher adverse events were seen in 48% of the enzalutamide patients versus 27% of patients in the placebo group. Finally, it was postulated that **PROSPER** offers prospective validation of metastasis-free survival as a potential surrogate endpoint for OS in non-metastatic castrate-resistant prostate cancer.

Finally, Abstract 5561 analyzed all three trials together, and confirmed the points about safety made by Dr. Fizazi, showing that darolutamide has a favorable safety compared with apalutamide and enzalutamide. Darolutamide showed a much lower incidence of fall, dizziness, mental impairment, hypertension, fatigue and severe fatigue. Most importantly, darolutamide has significant lower blood-brain penetration - resulting, among other things, in a reduced amount of neurocognitive side effects.

Other interesting reports from ASCO 2020 included the Phase III **TITAN Trial** [Abstract 5006] which showed that for men with metastatic castrate-sensitive prostate cancer (mCSPC) (still responding to testosterone therapy), adding apalutamide to androgen deprivation therapy (ADT) improved radiographic progression-free survival (PFS) as well as overall survival (OS). This finding was the same, regardless of having had prior docetaxel. The earlier analysis had shown that TITAN had met both primary endpoints of OS and radiographic PFS. Now the final data presented here showed a 33% reduction in risk of death and a 52% decrease in the risk of disease progression, with 82% OS at 2 years in the apalutamide arm. TITAN included patients with both high- and low-volume disease. Of note, apalutamide has not yet been approved for these patients in the metastatic space who are still castrate-sensitive. **And** in the **ENZAMET Trial** [Abstract LBA2], results showed that 80% of men with metastatic castrate-sensitive prostate cancer (mCSPC) who received enzalutamide (a nonsteroidal antiandrogen) along with testosterone suppression therapy (standard of care) were alive after 3 years, compared to 72% of men who received testosterone-suppression therapy along with other nonsteroidal antiandrogens (bicalutamide, nilutamide, or flutamide). Dr. Neeraj Agarwal of the Huntsman Cancer Institute at the University of Utah reported on this data and said that the quality of life in the TITAN Trial was preserved in ENZAMET.

The Phase III **PROfound Trial** demonstrated that in metastatic castrate-resistant prostate cancer (mCRPC), men with certain genetic defects, e.g. DNA damage repair mutations such as HRR (homologous recombination repair) gene alterations, and whose disease progressed while receiving enzalutamide or abiraterone, had longer progression-free survival (PFS) and better measures of response when treated with olaparib (a PARP inhibitor) than with physician's choice of new hormonal therapy (enzalutamide or abiraterone). Notably, the olaparib patients had better health-related quality of life than the other treatment arm. This is important because these metrics come directly from patients giving us their perspective. (Continued on page 8)

And with regard to health-related quality of life, in the **ARCHES Study** men with metastatic hormone-sensitive prostate cancer who received enzalutamide in addition to androgen deprivation therapy (ADT) were able to maintain high-functioning health-related quality of life (HRQoL).

ARCHES was a Phase III trial of 1150 men; in earlier reporting it had shown that men who received enzalutamide with their ADT (as opposed to placebo) showed improved radiographic progression-free survival compared to those who only received ADT.

The **CARD Study** looked at the efficacy and safety in older patients with metastatic castrate-resistant prostate cancer (mCRPC) who received cabazitaxel versus abiraterone or enzalutamide. Significant improvement was seen in radiographic progression-free survival (PFS), progression-free survival, and overall survival (OS). The patients had all received docetaxel and progressed within 12 months on an alternative androgen-receptor-targeted-agent (ARTA): abiraterone or enzalutamide. CARD analyzed the impact of age (below 70 and 70 and older). Analysis showed that radiographic progression-free survival in the cabazitaxel arm was improved for both age groups. A higher rate of adverse events was reported in the older group for both arms. The overall survival benefit was seen even when patients had low hemoglobin, high baseline neutrophils to lymphocyte ration, and high PSA values at baseline. Multivariate analysis of the results confirmed this was a true benefit.

A stunning result was seen in the Phase III **HERO Trial**, leading to relugolix soon becoming the first orally administered androgen deprivation therapy (ADDT) for advanced prostate cancer. 96.7% of patients in the study who received relugolix, an LHRH receptor antagonist, had sustained testosterone suppression to castrate levels through week 48, compared to 88% of patients in the control arm who received leuprolide acetate (lupron), an LHRH agonist and the current standard of care. Patients were randomized 2:1 to either take relugolix orally once a day or lupron through an injection every 3 months over the course of 48 weeks. Additionally, relugolix proved superior to lupron on all of the study's secondary endpoints. This included a confirmed PSA response at day 15; the probability of castration and profound castration at day 15, and follicle-stimulating hormone suppression at week 24. Not to mention, the testosterone reductions with relugolix happened very quickly; 56% of patients had testosterone suppression below 50 ng/dL after just 4 days of treatment. This compared to 0% of the lupron patients. The other major benefit occurred with respect to MACE (major adverse cardiovascular events), which occurred in only 2.9% in the relugolix group versus 6.2% in the lupron group. This is a crucial finding because death from cardiovascular events is the most common cause of death in men with prostate cancer. A testosterone recovery sub-study also yielded much better results for the relugolix group (54% of men versus 3% on lupron).

Other trial results of interest include a biomarker analysis of **KEYNOTE-199**, a trial of pembrolizumab in men with metastatic castrate-resistant prostate cancer (mCRPC) for whom docetaxel had failed. The Phase II KEYNOTE-199 demonstrated that pembrolizumab monotherapy had shown antitumor activity in those patients for whom docetaxel had failed (docetaxel-refractory). This presentation at ASCO was a look at the association between pre-selected molecular biomarkers and clinical outcomes. It was noted that tumor mutational burden and PD-L1 CPS (combined positive score for PD-L1 positive disease) were associated with a better PSA response. Unfortunately, the study had too few patients to draw any conclusions on overall survival (OS), disease control rate (DCR), and ORR. Further study was said to be warranted. (Continued on page 9)

In the accruing Phase III **TALAPRO-2 study** of talazoparib (TALA) plus enzalutamide for patients with first-line metastatic castrate-resistant prostate cancer (mCRPC), the investigators will be looking at this parp-inhibitor for prostate cancer treatment.

TALAPRO-2 will be a follow-up to **Phase II TALAPRO-1** which found that monotherapy with talazoparib appeared to have excellent antitumor activity in men with metastatic castrate-resistant prostate cancer (mCRPC) and BRCA 1/2 genetic alterations who had been pretreated with docetaxel.

There are so many combinations of therapies now being tested in prostate cancer – especially in the spaces of (1) metastatic, castrate-sensitive prostate cancer (mCSPC) and (2) non-metastatic, castrate-resistant prostate cancer (nmCRPC), along with the tentative use of drugs targeting genetic mutations and DNA alterations. Better outcomes are hopefully on the horizon.

Another topic receiving attention at ASCO 2020 was advances in Prostate-Specific Membrane-Antigen (PSMA) Imaging. Because cancers of the prostate express high levels of PSMA, it has become a logical target for developing techniques in diagnosing and treating prostate cancer. “The Evolving Role of PSMA-Based Diagnostics and Therapeutics in Prostate Cancer” was in fact a presentation in an ASCO 2020 Education Session. Worldwide there have been almost 850 studies regarding PSMA PET imaging published in the last 4 years. PSMA-PET has been incorporated into European prostate cancer guidelines in the treatment of patients with persistent PSA after radical prostatectomy, and in the imaging of patients with biochemical recurrence. However, there is little data on overall survival. Theranostics is based upon a combination of a diagnostic biomarker and a therapeutic agent and involves treatment of a target with a specific isotope. Various studies are underway. Additionally, there are several possible uses of PET imaging in advanced prostate cancer, and sometimes opportunities to combine more than one type of PET scan. In some reports, in as many as 76% of cases management of patients changed based on PSMA imaging. In just one example of a study using PSMA, the Phase III **CONDOR Trial** utilized 18-F-DCFPyL-PET CT for patients with biochemical recurrence (BCR). Results of the study found that PSMA-targeted PyL-PET/CT detected and localized occult disease in most of the patients with BCR who had had equivocal or negative imaging using conventional imaging, changing physician management in a majority of those patients.

There were also presentations on PSA and its involvement in various stages of prostate cancer and treatment, and on Circulating Tumor Cells (CTC's) and their potential in this disease.

In immunotherapy, the only agent approved in prostate cancer by the FDA to date is Sipuleucel-T (Sip-T) (Provenge). In a randomized trial presented in an abstract at ASCO 2020, 32 patients with asymptomatic, bone-predominant metastatic CRPC without any visceral metastases larger than 1.0 cm, had been randomized 1:1 to Sip-T alone or with 6 doses of Radium-223. Men in the combination arm began Sip-T between the 2nd and 3rd doses of Radium-223. The primary immunological endpoint was PA2024-specific T-cell proliferation 6 weeks after the first Sip-T infusion. Clinical endpoints were radiographic PFS, PSA response equal to or greater than a 50% decline, AlkPhos response equal to or greater than a 30% decline, and safety. Findings were that the combination of Sip-T and Radium-223 was associated with improved clinical outcomes and a higher rate of PSA responses than Sip-T alone. The data was said to suggest a synergistic effect with the combination since neither Sip-T nor Radium-223 alone was associated with reliable PSA responses, but larger randomized trials are planned.

Draft Memorandum of Understanding By Thomas Kirk

REMINDER: Please give Feedback on the Draft Memorandum of Understanding which was developed by the Education & Awareness Committee to "facilitate effective state strategies" and appeared on pages 5-7 of the last issue of the Blueprint to Tom Kirk at tomkirk_99@yahoo.com by August 1st. Your feedback will help NASPCC prepare for our 16th Annual Meeting which is now scheduled for January 29-31, 2021. 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".
9. I/we agree to join and participate in the NASPCC in at least one of the active Advisory Committees:

- Education and Awareness Committee
- State Coalition Development Committee
- Communications Committee
- Advocacy and Public Policy Committee
- Annual Meeting Committee
- Budget Committee
- Fundraising Committee
- Medical Advisory Committee

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 Ulyses 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 and Crissy Kantor.
- **Annual Meeting Committee:** Merel Nissenberg, Chair
Members for 2019-2020: Tammie Minter, Ulyses 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 Nissenberg, 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

Going Virtual: A mini case with observations on the Massachusetts Prostate Cancer Coalition (MPCC) May 15 Virtual Symposium

By Judy Green

Up until March 31, 2020, the Massachusetts Prostate Cancer Symposium planned for May 15 was intended as an in-person event. However, given the restrictions put in place because of COVID-19, the MPCC board of directors decided to make a “quick pivot” to a virtual event.

Here is how it turned out and some of what we learned:

Registration:

- More than 325 people registered and 77% attended and stayed engaged for three hours or more. (The entire event lasted three and a half hours.)
- The number of attendees was at the same level as in previous years and higher than some.
- Half of the registrants had not attended the previous year’s symposium, and some had never attended any previous symposium, largely due to having to travel or health status.

Profile of attendees:

The profile of attendees was similar to previous years, but there was a marked increase in health care providers, particularly recent graduates from nursing schools in the Commonwealth.

Presentations:

The presenters were ready, willing, and more than able to pivot with us. Here are links to their presentations and podcasts:

Massachusetts Department of Public Health:

Anita Christie, *RN MHA CPHQ*, Director of Division of Clinical Preventive Services, Bureau of Community Health and Prevention, Massachusetts Department of Public Health, kicked off the symposium with greetings from DPH and provided the following resources:

- [Go here](#) for the Shared Decision-Making Interactive Tool. Get the facts to help you talk with your doctor and make the right choice for you.
- [Go here](#) for a list of resources for individuals during Covid-19 to support survivors.
- [Go here](#) for information for prostate cancer screening.
- [Go here](#) to access the Wellness Guide for Cancer Survivors

Keynote:

Dr. Peter Pinto, *National Institutes of Health (NIH)*

- **Diagnosing and Grading Prostate Cancer**, a free video from the New England Journal of Medicine featuring our keynote speaker’s latest research findings

Individual sessions:

Glenn Bubley, MD, *Beth Israel Deaconess Medical Center*

- **Stages of Prostate Cancer: Why patients with metastatic disease are living longer than ever**
[Download Presentation](#) (Continued on page 13)

Lorelei Mucci, ScD, MPH, *Harvard School of Public Health*

- **What Is the State of Evidence behind Lifestyle and Diet for Prostate Cancer Patients**

[Download Presentation](#), [Listen to Podcast](#)

Jairam Eswara, MD., *St. Elizabeth's Medical Center*

- **Signs, Symptoms and Treatment Options for Erectile Dysfunction and Male Stress Urinary Incontinence Post Prostate Cancer**

[Download Presentation](#), [Listen to Podcast](#)

Some observations:

- The virtual program attracted new audiences and had a broader geographic reach.
- The attendees seemed very comfortable in the online format, which was Zoom, and in using the Q&A function to ask questions. Similar to in-person comments in earlier years, more time for Q&A was requested.
- Three and half hours seemed to be a good time frame; we took a 15-minute break in the middle.
- Having an MPCC moderator throughout helped put a face on the organization.
- More time has to be spent in advance of a virtual symposium to get it organized, but the actual event is less labor-intensive than an in-person event.
- Both formats have pluses and minus but going forward we are planning to continue the virtual element as we plan for another in-person event in May 2021.

If you would like further information or assistance in thinking through the elements of a virtual, but live, event, email Judy Green at judy@masspcc.org. For more information on MPCC go to www.masspcc.org

Working Inside a Cancer Hospital During COVID-19

By Tiffany Razzo, MBA

Office Manager for the Department of Genitourinary Medical Oncology at MD Anderson Cancer Center

So, what's it like to work at a Cancer Hospital during the COVID-19 outbreak? It has been an interesting experience so far. It all began on February 2nd when we received our first communication from senior leadership regarding the situation. Over the next month and a half, we would receive frequent notification from our senior leadership, letting us know the plans for operations during COVID-19.

On February 2nd, communication was sent out to the workforce, informing us that MD Anderson was closely monitoring the COVID-19 and following directions that were coming down from the Federal Government. MD Anderson was activating their command center whose responsibility would be to monitor changes in the situation and to provide advice to the senior leadership. The workforce was to continue hand hygiene, and employees who felt ill were asked to stay home. Work-related travel to China was put on hold, and all individuals traveling back from China were asked to self-isolate and contact employee health. For patients, clinic teams would start screening all patients and asking them if they had recently traveled to China.

On March 5th, we received communication that our command center was moving from level one watch to level two watch. The command center was expanding previous measures for the workforce and visitors. The workforce was asked to limit the number of individuals in meetings to no more than 15 people, encouraging everyone to utilize virtual platforms like WebEx and Zoom to conduct meetings. The patient screening questionnaire now included all international travel as well as travel from Florida and California.

On March 12th, we decided to let our teams begin working remotely and dismissed the staff at noon. By 2 pm, 99% of the workforce had disappeared, only leaving the management team in the office to close the day and lock up. I have been working at home since then, and it looks to be at least another 60 days before I will be back in the office.

Since then, I have been back to the office a handful of times to work each time feeling like I am walking into a scene from a horror movie. All administrative offices and research buildings have been cut off from any patient care areas. Entry points for employees have been set up, and everyone entering needs to go through a screening and is provided with a hospital-grade surgical mask. Temporary walls have been erected, keeping patients and employees away from one another. Some clinical spaces have been converted into COVID-19 floors, and our Cancer Prevention Center has been turned into a COVID-19 testing center. Research Facilities have been closed since then, and at this time, no experiments or testing can be conducted. Labs that process protocol specimens have also been closed, and some have been converted into COVID-19 lab testing sites.

As we adjust to this new normal, our goal continues to focus on patient care, but understand that the safety of the workforce and the patients are primary. We do not know how or when we will return to normal, but we continue to operate and work towards our goals of making Cancer History!

Exciting News

NASPCC and PROSTATEPEDIA JOIN FORCES! NASPCC is excited to take over the publishing of PROSTATEPEDIA edited by Jessica Meyers-Schechter, member of the Board of the California Prostate Cancer Coalition and daughter of prostate cancer warrior, Dr. Snuffy Myers! The publication will be free, published quarterly and will be available to download from our website, beginning with the August issue. Please see below for the announcement from Jessica!

“Many of you have been with us since we started publishing in June 1996 and have remained loyal friends as my father, Dr. Snuffy Myers, opened and then closed the American Institute For Diseases of the Prostate clinic.

Today, we’re delighted to announce to our Prostatepedia family another transition for the Myers family.

This partnership will allow us to reach even more patients here in the United States, as well as continue to extend our reach into patient communities in Canada, Europe, India, Australia and New Zealand.

For the first year, we’ll continue to send you email announcements when an issue is published on the NASPCC website. In each of those email announcements there will be an option to sign up with them on your own so that you’ll continue to receive notifications in 2021 and beyond. Be sure to sign up!

Jessica Myers-Schechter, Publisher”

About Prostatepedia:

Rivanna Health Publication’s Prostatepedia features informal conversations with doctors, patients, and activists about prostate cancer.

Each month we tackle a different topic facing prostate cancer patients today, from how imaging has impacted treatment to dealing with erectile dysfunction after radiation or surgery to the evolving field of immunotherapy.

NASPCC will be creating a Distribution List for emailing issues of Prostatepedia beginning with the August 2020 issue. Write mgrey@health.ucsd.edu to add your name and email address to the List.

NASPCC Hosted Webinars and other Information

Annual Meeting:

The 16th ANNUAL MEETING OF THE NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS HAS BEEN MOVED FROM ITS NORMAL OCTOBER DATE. IT WILL NOW TAKE PLACE ON **JANUARY 29-31, 2021, AGAIN AT THE HOTEL MONACO IN WASHINGTON DC.** Contact Merel Nissenberg at mgrey@ucsd.edu for details.

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 FOR A PHYSICIAN

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

Next BOD Call:

Tuesday, July 21, 2020 at 1:00pm EST
1-800-977-8002
Participant Access 34483254#

(Continued on page 17)

“Exosome Testing and Liquid Biopsies-Risk Assessment for High Grade Prostate Cancer with a Non-Invasive Urine Test: Home or Office Testing”

On Wednesday, July 29, 2020, from 7:00-8:00 pm Eastern, NASPCC will be presenting a 1-hour Webinar on "Exosome Testing and Liquid Biopsies: Home and Office" with Dr. Judd Moul of Duke University Medical Center. There will be time for Q & A at the end of Dr. Moul's presentation. This free GoToWebinar event has limited ace. To register, please click the **click here** link in the flyer on page 18.

“PSMA Imaging”

On Thursday, October 1, 2020, from 7:00-8:00 pm Eastern, NASPCC will be presenting a 1-hour Webinar on PSMA Imaging, an important developing topic, for new and recurrent disease. Our speaker will be Dr. Michael Morris from Memorial Sloan-Kettering Cancer Center in New York. **REGISTRATION DETAILS FOR BOTH WEBINARS WILL BE SENT OUT SOON!**

SUPPORT GROUP MEETINGS DURING COVID-19

Since prostate cancer support groups have not been able to meet in person during the COVID-19 pandemic, men have had to look to other formats for support services. Besides the 15-week Online Prostate Cancer Support Group run by CancerCare that is co-sponsored by NASPCC, many groups have taken to ZOOM and other virtual meeting platforms to keep active in providing these services. The California Prostate Cancer Coalition sent out a survey to all of the prostate cancer support groups in the state to see what formats the groups are using during COVID-19. A majority of the groups reported using ZOOM meetings and a few reported that they are only utilizing e-mail exchanges between group leaders and patients wanting to participate in the support group benefits. ZOOM appears to be a viable option for some groups in other states as well. NASPCC would like to hear from you with details of your support group “meetings” during this COVID time. (Continued on page 18)

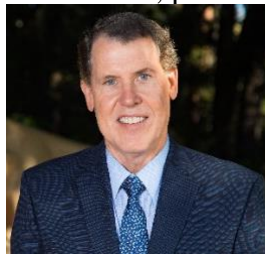


NASPCC Webinar Series Presents:

“Exosome Testing and Liquid Biopsies – Risk Assessment for High-Grade Prostate Cancer: Home or Office Testing”

With Dr. Judd Moul, Professor, Duke University Medical Center. The Webinar will take place on **Wednesday, July 29, 2020 at 7:00 pm – 8:00 pm Eastern.**

To register for this event, please click [here](#)



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

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

This Webinar is sponsored by:



PROSTATE CANCER MARKERS

Prostate Conditions Education Council (PCEC) has an excellent resource on prostate cancer markers, genomic tests and genetic testing! To access this informative and interactive tool, please visit: www.ProstateMarkers.org. 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!

PCEC
PROSTATE CONDITIONS EDUCATION COUNCIL

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

(Continued on Page 20)

California Prostate Cancer Coalition

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



CALIFORNIA
**Prostate
Cancer**
COALITION

Help Your Patients Make Better Informed Decisions About Their Care

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

www.prostatecalif.org
<https://naspcc.org/docs/informed-decision-9-11-17.pdf>
www.naspcc.org

In the SPOTLIGHT

By Bruce Williams and Authorized by Debbie Sankey

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 our beloved member, Mr. Otto Sankey, PhD., representing Arizona, who sadly passed away this past spring.



In Memoriam Otto Francis Sankey, Ph.D.

We lost a fine man, world renowned physicist, and fierce prostate cancer warrior on Saturday, March 21, 2020. My friend Otto passed peacefully at home that morning, with Debbie, his loving wife of 45 years, and their daughters Stephanie and Holly at his side. Otto earned a Doctorate from the Washington University at St. Louis in 1979, and in 1982 began teaching all levels of physics at Arizona State University. He was honored as a Regents Professor in 2008 and retired in 2011.

Otto was diagnosed with Stage IV prostate cancer two years later, with what he conversationally described as innumerable lesions. Otto understood the need to, and quickly became his own best advocate; a role he vigorously encouraged other warriors to take on in waging their own battles. Otto's brilliance attacked his challenge at a biophysics molecular level and enabled him to take an unusually active role in his treatment, participating in many clinical trials. Otto started a very active Us TOO support, education, and advocacy group in 2014, and launched the Arizona Prostate Cancer Coalition, Inc. in June 2019.

Another world-famous physicist and one of Otto's closest friends, Dr. David Drabold, characterized Otto as "A man of integrity, utterly reliable, always ready to help... I have never known a man more alive and integrated successfully into life... 'The Glory of God is Intelligence' and Otto exemplified this."

Dr. Otto F. Sankey was loved, admired, and tremendously respected by all of his Arizona Coalition friends and colleagues, and he is sorely missed.

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.

EXECUTIVE COMMITTEE

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Johnny Payne, Vice-President	South Carolina
Donald Lynam, Treasurer	Kentucky
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Thomas Kirk, Invited Member, Executive Committee	California

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CONTACT NASPPC TO:

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

WANT TO ESTABLISH A COALITION IN YOUR STATE?

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

CONTACT:

National Alliance of
State Prostate Cancer Coalitions
1999 Avenue of the Stars, Suite 1100
Los Angeles, California 90067
Toll Free 877-NASPPC-8 (877-627-7228)
E-mail: info@nasppc.org
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 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 remember what V.P. Johnny Payne said: "Please LIKE and SHARE the NASPCC Facebook posts on your organizations Facebook page!"



CancerCare and the National Alliance of State Prostate Cancer Coalitions (NASPCC) are collaborating to offer a free 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 (Updated)

Stephen Homsey, LCSW

CancerCare Oncology Social Worker

TO JOIN THIS SUPPORT GROUP, PLEASE VISIT

www.cancercare.org. Go to Support Groups and then to Online Support Groups to complete our online registration process. Internet access is required.


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
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www.youtube.com/cancercareinc
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[@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 our 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)

Treasurer: Donald Lynam (KY)

Secretary: Jan Marfyak (NM)

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*University of Texas Health Science Center at
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