

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

– Mattie Stepanek

News

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J. Renee Savickas, Editor

THE BLUEPRINT

President's Message

Summer is here and our work continues unabated! Our 2nd Quarter Board of Directors Meeting Call took place Monday, April 15; and our 3rd Quarter Board Meeting was held on July 29, 2019, and our Executive Committee, comprised of Johnny Payne, Don Lynam, Jan Marfyak, LaTanya Patton, Tom Kirk and I, has met and continues to meet monthly to handle the day-to-day operations of the Alliance. Speaking of which, although we are not formally changing our name, we are starting to use the name **“The Prostate Cancer Alliance”** to describe ourselves, which is a lot easier to say than “National Alliance of State Prostate Cancer Coalitions”. We have even reserved a domain name: “pcalliance.org”. Since some of our states are represented by different organizational forms than coalitions (for example, associations or foundations), or sometimes by people on the cusp of setting up formal coalitions, “The Prostate Cancer Alliance” name better catches that variety, and the term “Alliance” also captures the fact that the individual state organizations are independent.

On June 8 the California Prostate Cancer Coalition, together with UCSF (the Helen Diller Family Comprehensive Cancer Center), presented “The 2019 CPCC/UCSF Patient Conference on Prostate Cancer” at UCSF in San Francisco to a standing-room-only crowd. Elsewhere in this newsletter you can read about that successful Conference - which is now going to be followed by another such Conference next year, again to be a co-presentation by CPCC and UCSF. As we have asked all state prostate cancer organizations to add this quoted description to their printed materials, the California Prostate Cancer Coalition is “A Proud Participant in the National Alliance of State Prostate Cancer Coalitions”. We ask that all state prostate cancer organizations describe themselves as such Proud Participants.

On June 21 and 22 Jan Marfyak, Tom Kirk and I traveled to Phoenix, Arizona to help set up the Arizona Prostate Cancer Coalition with current Board Member Otto Sankey as its Chair. The organizational meeting was not only a success, but it was inspirational to see the amount of participation by the attendees who will also be a part of the new organization. The Board is composed of patients, 3 physicians, 2 nurses, a genetics expert and more. Welcome, Arizona Prostate Cancer Coalition!

NASPCC continues its quarterly National Conference Calls series with the next Call topic of “Fundraising for State Prostate Cancer Organizations”. The Call will take place on Thursday, August 22, at 6:00 p.m. Eastern. Communications Committee Chair Renee Savickas will be sending out Notice along with the free call-in telephone number. This National Call about successful fundraising will be led by Jan Marfyak, our NASPCC Secretary, who is also a Board Member of the Prostate Cancer Association of New Mexico.

I will be meeting with the Board of the Prostate Cancer Association of New Mexico in a few weeks, along with Jan Marfyak and Tom Kirk. We will be discussing future activities and collaboration between our National Alliance and their organization. I am happy to hold such discussions with any of the other groups as well, especially as we continue to move our organization forward and to grow it.


Our next big event will be NASPCC’s 15th Annual Meeting & Gala, which we will be holding **October 18-20, 2019 in Washington, D.C. at the Hotel Monaco**. We are calling this “**A Landmark Event in a Landmark Hotel**”. 15 years is a great start! For the first time, our Saturday evening event will be a Gala Dinner and the Sunday sessions will not conclude until 3:00 p.m. (instead of the usual noon end). Invitations have now been sent out with all of the details. Guests (other than state representative attendees) will be able to join us at the Gala for \$100 per ticket.

Elsewhere in this Newsletter are many articles and features for your reading. Please feel free to e-mail me with any questions!


Respectfully submitted,

Merel Nissenberg

NASPCC 15th Annual Meeting and Gala Information



**15TH ANNUAL
MEETING
& GALA** October 18 - 20, 2019
Washington, D.C.



“PARTICIPATE, EDUCATE, CELEBRATE”

You are cordially invited to the 15th Annual Meeting & Gala of the National Alliance of State Prostate Cancer Coalitions (“The Prostate Cancer Alliance”), October 18-20, 2019 in Washington, D.C. at the beautiful Hotel Monaco! The Board will meet on Friday, October 18 from 3:00 -5:30 pm, with a Reception at 6:30 pm to follow. Saturday the Meeting will take place from 8:00 am to 5:30 pm, followed at 6:30 pm by a Gala Dinner honoring Paul Schellhammer, M.D., and others, and also featuring Dr. James Gulley, MD, PhD of NIH in his third appearance for the Alliance. Sunday, we will convene at 8:00 a.m. and, unlike other years, the Meeting will not conclude until 3:00 pm that day. Please do not book your return until at least 5:30 pm on Sunday.

NASPCC will cover both nights’ hotel, the Friday Reception, Saturday meals, Sunday breakfast and lunch, and reasonable transportation costs up to \$550 per person. Additional Guests for the Gala are welcome to attend for \$100 per person. Guests for the work sessions on Saturday and Sunday are welcome at no charge.

We will need your RSVP by August 15, so that our discounted hotel block can be preserved. Please do not make your own hotel reservations, but do purchase your transportation no later than September 17 to obtain the best price. NASPCC would be very grateful if you or your organization will cover any of your travel expenses. Please let us know!

For more information, e-mail Merel Nissenberg at mgrey@ucsd.edu.



15TH ANNUAL MEETING GALA

October 19, 2019
Washington, D.C.



“PARTICIPATE, EDUCATE, CELEBRATE”

The National Alliance of State Prostate Cancer Coalitions – “The Prostate Cancer Alliance” - is pleased to present its 15th Annual Meeting GALA on Saturday, October 19, 2019 at 6:30 pm. Cocktails and Dinner will be provided, along with an evening of celebration, honoring Paul Schellhammer, M.D., and others, and also featuring James Gulley, MD, PhD of NIH in his third appearance at the Annual Meetings held by the Prostate Cancer Alliance.

Tickets for guests (non-state representatives) are available at \$100 per person, and additional donations are welcome. For information please contact Merel Nissenberg at mgrey@ucsd.edu.



SAVE THE DATE!

EXECUTIVE COMMITTEE

Merel Grey Nissenberg, *President*
 Johnny Payne, *Vice-President*
 Jan Marfyak, *Secretary*
 Donald R. Lynam, *Treasurer*
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The 15th Annual Meeting & Gala of the National Alliance of State Prostate Cancer Coalitions (“The Prostate Cancer Alliance”) will take place Friday, October 18, 2019 through 3:00 p.m. on Sunday, October 20, 2019!

We will be holding a “Landmark Event in a Landmark Hotel”, when we convene at the Hotel Monaco in Washington, D.C., to celebrate our 15th year, starting with a Reception that Friday evening, after the Board of Directors meets that afternoon. Saturday the Annual Meeting will begin at 8:00 a.m. and the day will conclude with a Gala Reception and Dinner honoring Paul Schellhammer, M.D. and others. Sunday the Annual Meeting re-convenes at 8:00 a.m. and will end at 3:00 p.m. for the first time.

The Gala Reception and Dinner Saturday evening will take place in the illustrious Paris Room at the Hotel Monaco.



PLEASE SAVE THE DATE FOR A WEEKEND OF EDUCATION, SHARING OF BEST PRACTICES, AND NETWORKING. JOIN US AS WE CELEBRATE OUR 15TH YEAR!

Recent Articles and Interviews by By Merel Nissenberg and Thomas Kirk

USA Today/Media Planet - Future of Personal Health

How to make well informed decisions when dealing with prostate cancer

The best patient-physician relationship involves joint decision-making by both parties based upon current, accurate, and appropriate information. Thus, in order to make the best decisions, both parties need to be well informed.

The California Prostate Cancer Coalition (CPCC) is just one of many state prostate cancer organizations participating in the National Alliance of State Prostate Cancer Coalitions (NASPCC) that has made informed decision-making part of its mission statement. In reality, this means educating both the prospective patient and the physician.

Both NASPCC and CPCC (among other state prostate cancer organizations) utilize a durable awareness and educational tool, referred to as the “Laminate,” that helps men 40 and older ask their doctor questions that will enable them to make informed decisions about whether to get tested for prostate cancer.

Asking the right questions

There are 10 questions and answers, using words designed for the layman (not for the physician). The beauty of the **Laminate** is that the flip side of the durable 8 ½ x 11 tool is “Informed Decision-Making for Primary Care Providers,” those at the forefront of seeing most patients and deciding whether to test PSA, perform a digital rectal examination, and otherwise look for prostate cancer.

The same 10 questions appear on this flip side for physicians, but the answers are more medical and scientific. The patient is able to read both sides and the physician can do so as well, letting them know in advance what questions the patients will be asking them personally. The Laminate can be found here: <http://prostatecalif.org/patient-guide>.

The Laminate is about deciding whether to get tested for prostate cancer. Farther along the continuum, in order to keep patients and physicians informed to enable better shared decision-making, NASPCC is working on an Advanced Prostate Cancer Laminate, which also asks 10 questions (lay answers on one side, scientific answers to the same 10 questions on the flip side, as with the other).

These questions have to do with types of advanced prostate cancer, such as hormone-resistant and hormone-sensitive, metastatic or not. Some palliative (non-curative-intent) care may be part of the scenario, but there is also a new emphasis lately on prostate cancer that requires a different kind of treatment: treatment meant to delay or prevent metastases.

New developments as above, combined with the latest scientific research and results of clinical trials, plus genomic as well as genetic testing, help inform us about prostate cancer in ways we never imagined. We need to make that information available and share it widely with patients and physicians, so the basis of their shared decision-making is informed and appropriate. For information, visit www.prostatecalif.org and www.naspcc.org.

Merel Grey Nissenberg, Esq., President, National Alliance of State Prostate Cancer Coalitions, us.editorial@mediaplanet.com

Link to actual article: <https://www.futureofpersonalhealth.com/prostate-and-urological-health/how-to-make-well-informed-decisions-when-dealing-with-prostate-cancer/>

Prostatepedia Interview with Merel and Tom

Helping Patients Navigate the World of Clinical Trials



Ms. Merel Grey Nissenberg, a California attorney specializing in medical malpractice cases, is the President of both the American-based National Alliance of State Prostate Cancer Coalitions and the California Prostate Cancer Coalition.

Mr. Tom Kirk is the Vice-President of the California Prostate Cancer Coalition and an Invited Guest of the Executive Committee of the National Alliance of State Prostate Cancer Coalitions.

Together they form Informed Health Consulting, a group that helps patients of all kinds find clinical trials appropriate for them.

Prostatepedia spoke with them about how, why, and when patients should consider a clinical trial.

How did each of you become involved in prostate cancer advocacy?

Ms. Merel Grey Nissenberg: In one of the cancer cases I was handling in my medical malpractice law practice, the surgical oncologist recommended that I join the Prostate Cancer Task Force for the California Division of American Cancer Society (ACS). I ended up co-chairing the group the next year.

I have also handled a lot of medical malpractice cases involving prostate cancer, among other cancers—especially inexcusably late diagnoses of prostate cancer. I became an advocate for patients in that way as well.

In 1997, ACS, California Division held a statewide meeting on prostate cancer. During the conference a few of us suggested that California should have its own prostate cancer coalition. People thought it couldn't be done because the state was so big. We're now in our 22nd year!

Along the way, we started the National Alliance of State Prostate Cancer Coalitions in 2004 (www.nasppc.org) to serve as an umbrella entity over the existing and future state prostate cancer organizations around the country.

Mr. Tom Kirk: I got involved in prostate cancer in 2004 when I was recruited to be the President and CEO of Us TOO (<https://www.ustoo.org/>).

That was about the same time that the National Alliance of State Prostate Cancer Coalitions was formed, so I have known Merel and her work for many years

When I started at Us TOO, one of the strategic plan goals was to increase the amount of educational materials by 100%. For many years, educational material development remained the focus of Us TOO. Of course, we also focused on support groups and support group leader training.

I left Us TOO in 2016 and moved to California where I quickly started work with Merel and the California Prostate Cancer Coalition. I've been the Vice-President of the California Prostate Cancer Coalition for a number of years. I also became involved in the National Alliance of State Prostate Cancer Coalitions as Invited Guest of the Executive Committee, and Chair of its Steering Committee.

Before Us TOO, I was on staff at the National Alzheimer's Association and had an interest in advocacy.

What is Informed Health Consulting?

Ms. Nissenberg: Informed Health Consulting is our consulting group. Tom and I concentrate in three areas: we set up Patient Ambassador programs; we set up Patient and KOL Roundtables; and most importantly, we do Patient

Accrual for Clinical Trials using a direct patient model.

Informed Health Consulting (IHC) has a very unique methodology. Unlike clinical trial matching services, we work directly with the patients. We know the patients. We're involved in advocacy groups. We are embedded in and between advocacy groups.

IHC does all of its activities across different types of cancer and different disease sites.

For example, we were working for Medivation, which has since been purchased by Pfizer, on a trial that looked for women with advanced or metastatic breast cancer who had a BRCA 1 or BRCA 2 mutation. When we first talked to the company, they said, "We cannot get the last 100 patients. We have tried and tried."

Tom and I identified which patients we needed to approach. We were pretty imaginative, which is what we do. We came up with great ways to meet patients who would be really good candidates for the trial. We went to national and local breast cancer advocacy meetings. Since BRCA 1 and 2 mutations are very frequently seen in Jewish populations, we targeted Jewish university women and big Synagogues on the West Coast.

Long story short, we helped accrue the rest of the patients, the trial closed, and it was a positive trial. The drug, a PARP inhibitor, has already been approved.

It's so exciting because we can really see the fruits of our labors. Hopefully, we have helped to save lives.

You had a direct impact.

Ms. Nissenberg: IHC is unlike a clinical trial matching service that doesn't really get to know the patient until the patient or their physician contacts them. Companies don't have that personal relationship. Tom and I start out with the personal relationship.

It's been really successful. We hope that we're helping to accrue patients who can benefit from an appropriate trial.

What might some of the benefit be? Why should patients consider a clinical trial?

Mr. Kirk: Often a clinical trial is the best way to gain some access to new developing interventions.

Ms. Nissenberg: First of all, the control group is always going to receive at the very least, standard of care. It's not like you're not going to get care that hasn't already been approved or in practice. But it is an opportunity to see if there is a new therapy or intervention that can benefit patients.

If the response is really striking, they'll stop the trial midway through after the interim analysis and let patients cross over into the group that is showing great success.

A trial is an opportunity to take advantage of new therapies and new interventions that may ultimately become standard of care.

Mr. Kirk: The word you just used, interventions, is essential. Often, clinical trials develop new approaches to treating patients. It's not just access to a drug per se, but also about access to the latest care.

Frequently at a reduced cost, right? Sometimes trials cover the cost of the drug or procedure.

Ms. Nissenberg: Absolutely.

Some of the numbers people bandy about for clinical trials are not quite accurate. In an issue of the The National Cancer Institute journal that just came out this year, a study shows that the barriers to entering clinical trials are structural, cultural, or clinical for more than three-quarters of cancer patients.

Everyone says that generally 8 percent of patients enter a trial, but only 3 percent of cancer patients. However, this study says that that number is too low.

They performed a meta-analysis. Nearly 56 percent of patients did not have a trial available to them at their institution. Nearly 22 percent were deemed ineligible. [That's what they mean when they talk about structural and clinical barriers.] That low number of 2 - 3 percent is from the 1990s and early 2000s. It was largely based on enrollment in government-sponsored trials. About twice as many patients are enrolled in pharmaceutical-sponsored trials.

The authors of the NCI article believe that an estimate of 8% is likely more reflective of patient involvement in cancer clinical trials, government- or pharmaceutical-sponsored.

Still, 8% is pretty low when you think about it.

Ms. Nissenberg: Absolutely. However, the authors made an important observation: when patients are offered an available clinical trial, they choose to participate only about 50% of the time. That's shocking. I didn't realize it was that high.

Why the reluctance in the other 50 percent?

Ms. Nissenberg: I used to be in something called the Summit On

Cancer Clinical Trials. I was part of the dissemination strategy to create a piece for the NCI website to help patients learn what clinical trials are, long before they ever need or consider joining one.

The term clinical trial itself is very foreboding. A lot of people think either of guinea pigs or they think of the boy in Pittsburgh who died after being inappropriately consented for the trial. Or they picture a green-tiled room with a big light hanging down: very stark, very cold. They feel that it's experimental. I think people worry about that. I think that's why they primarily don't join.

I think a lot of patients think of the clinical trial as a last resort. When your cancer has become so advanced that you're willing to try something experimental. That's not true obviously. Given that, at what stage along the prostate cancer journey should a man consider a clinical trial?

Mr. Kirk: Don't we always say that men should be active in their treatment? We encourage men to be very active, to be the quarterback or CEO of their own care. That would mean he should look for a trial at any stage.

Of course, we would believe the earlier stage is important because men are starting to make decisions about whether to treat or not. Approaches like active surveillance often are developed in clinical trials.

At any stage, it's important for people to explore their clinical trial options. Search early and often.

Are there many prostate cancer clinical trials available for the newly diagnosed?

Ms. Nissenberg: Just a few. Most of the trials are for advanced prostate cancer. But as you know,

advanced prostate cancer can be non-metastatic. There have been important clinical trials in this space as well. If we can delay, or maybe prevent metastases altogether, then we're going to go a long way to improving overall survival.

Do you think it's in a man's best interest to keep abreast of what kinds of clinical trials are available, even if they're not necessarily for his current disease state?

Ms. Nissenberg: That's easier said than done. There are a lot of trials out there. IHC has done a project with a group called Emerging Med. We are helping all prostate cancer groups place a clinical trial finder on their websites. These clinical trial matching finders have computer algorithms that match trials to patients.

What should a man reading this who is interested in finding a trial do?

Ms. Nissenberg: The first thing is to go to www.clinicaltrials.gov. That site lists all the NCI-approved cancer clinical trials. It doesn't list all the trials out there, but it lists most of them.

A lot of physicians either don't know about all the applicable trials or they don't really want to send their patient away to a clinical trial unless they're going to get the protocol and do it themselves.

Why?

Ms. Nissenberg: Some are disincentivized because they're going to lose a patient or lose money. That's just reality. And patients don't always qualify. Sometimes patients will come armed with information about certain trials and the physician hasn't heard of any of them.

Then, the patient could contact a company like Emerging Med and say, "This is my status. Is there a trial that you would recommend?"

Mr. Kirk: The National Alliance of State Prostate Cancer Coalitions will be offering this service on our website. We believe these matching services are important. The case management services and individual discussions with a case manager can be very helpful in removing the stress of finding the right kind of clinical trial.

Ms. Nissenberg: This is in contrast to other sites that only have a couple of sponsors' trials. They're not getting all the trials out there. They're only getting the ones that those sponsors are enrolling and that don't necessarily apply to that patient or his condition. You have to be really careful that you're looking at a completely objective, non-commercial source for clinical trial listing.

A man can look for trials from a variety of sources: online, through his doctor, through one of these clinical trial matching services and then come up with a short list of trials that he may be interested in?

Mr. Kirk: Yes.

Are there any other considerations men should keep in mind as they evaluate appropriate trials?

Ms. Nissenberg: Be realistic. See if a trial is geographically appropriate or determine if your own physician can run the protocol. Look at quality of life issues—are there known side effects that you're not going to want to deal with? But then look at the positive side too. The control arm should never be less than standard-of-care treatment. But keep in mind that if it is truly a randomized control

trial, which is the kind that we really need to set new standards of care, you're not going to be able to choose the arm of treatment. You have to be willing to go into the trial knowing that you could just get standard of care and not the new therapy or intervention. The trials are blinded; you don't know what you're getting.

Isn't it true that even men on the control group tend to do better because they're being monitored more closely?

Ms. Nissenberg: That's true. They have much better care. They've usually got an oncology nurse assigned to them. Sometimes those getting standard of care or placebo end up getting some of the benefits, especially the psychological benefits, because they think they're being treated with the new treatment. The placebo effect is very interesting.

The placebo effect can be positive.

Mr. Kirk: Right.

Any final thoughts for men as they start to look for clinical trials or consider clinical trials, any final advice?

Mr. Kirk: Remain active. Know that your contribution is about more than just yourself. Share with others your experience of being in a clinical trial to help other men deal with their hesitancy.

One way might be to join IHC's Patient Ambassador Program. Can you talk a bit about that program?

Ms. Nissenberg: We develop groups of Patient Ambassadors. Let's say a company has a genomic test, for example. We identify a group of diverse patients—diverse in terms of geography, socioeconomics, and race.

We bring together about 15 or 16 men who have had this genomic test and want to share their experiences with other men. We bring them in for a weekend. We bring them to the company. They have a tour of the facilities. They meet everybody. They completely bond. We train them on how to go out to support groups and to civic groups like Rotary Club to talk about the test and what it meant to them.

We then maintain a call list. If a patient wants to talk to another patient who has had this test, we set up a phone call. We've had patients go to other states to talk about whatever the product is. (It could be a therapy or a test.)

Mr. Kirk: This is personal advocacy based on experience.

You mentioned genomics as one grouping but how many of these patient ambassador groups do you have?

Ms. Nissenberg: It depends. We have to be careful because we're not marketing anything for anybody. These Patient Ambassadors aren't marketing people and we're not selling a product. We're just sharing patient experiences.

Another thing Informed Health Consulting is doing are Patient Roundtables. For example, in October of last year, we had a Roundtable on bone health and access to bone-targeted therapy. Access to care is a hot-button topic.

Mr. Kirk: For not only prostate cancer, but also for breast cancer.


Ms. Nissenberg: Right. We brought in prostate, breast cancer and lung cancer patients. These were people who were dealing with bone mets, osteoporosis, or osteopenia.

We brought in physicians to talk to them and to help them with access issues.

We're going to be doing another Roundtable on step-therapy in the Fall.

The Roundtables are great because we can bring people in from anywhere in the country. We teach them. We can find out from them what they're hearing in their local communities. For example, if there is an access issue, what are they hearing? Where is their pushback? It could be on a therapy. It could be on access to different tests. It could be coverage issues.

You mentioned that these patient roundtables are not prostate cancer-specific. Is the Patient Ambassador Program also not prostate cancer-specific?

Ms. Nissenberg: Correct. We develop Patient Ambassador groups for any disease. It's the same modality. The most time-consuming and challenging parts are not the planning for the meetings or trainings. The hardest part is identifying the right patients for both programs. 

If you're interested...

...in participating in Informed Health Consulting's Patient Ambassador or Patient Roundtable programs, contact Merel at merel@informedhealthconsulting.com or Tom at tom@informedhealthconsulting.com.

Both can also be reached by calling 424-253-1169.

Updates

On June 8, 2019 the California Prostate Cancer Coalition and UCSF presented the 2019 CPCC/UCSF Patient Conference on Prostate Cancer at UCSF. More than 370 people attended with standing room only. Click here to see the video recordings from the Conference, which include all sessions except for the Meet the Professors Sessions at lunch: <https://uctv.tv/2019-prostate-cancer-conference/>." Go to www.naspcc.org to see the Flyer and the Agenda for the Conference. The link to the Conference Video is also on the website. Plans are already underway for the 2nd Annual CPCC/UCSF Patient Conference on Prostate Cancer in June 2020.

If you are interested in running for the Board of Directors of NASPCC, elections will be held at the 15th Annual Meeting & Gala October 18-20, 2019. Please contact Johnny Payne at johnnyrpayne@charter.net.

The National Alliance of State Prostate Cancer Coalitions (NASPCC) is also now known as the "Prostate Cancer Alliance". We have reserved the domain name of pcalliance.org and work will begin soon to link it to our website, www.naspcc.org.

If you are interested in joining the Annual Meeting Committee for our upcoming 15th Annual Meeting & Gala, please contact Merel Nissenberg at mgrey@ucsd.edu. We have already held 3 Calls, but planning continues on the Agenda and Speakers.

Congratulations to Otto Sankey for helping to develop the Arizona Prostate Cancer Coalition and to Rob Johnson for starting a new advocacy group in Wyoming, named, the WYOMING PROSTATE CANCER ALLIANCE! Way to go Rob! We look forward to hearing about all your activities in Wyoming!

Here are a couple of pictures from the Arizona meeting!



Policy Activities by Alvin Chin

On Wednesday, July 17, 2019, Johnson & Johnson, through its Janssen Pharmaceutical affiliate, convened the **"Non-Medical Switching Conference: Implications for Patients and Healthcare Providers"** at the Capital Hilton in Washington, D.C. NASPCC was represented by Alvin Chin of the Virginia Prostate Cancer Coalition (VPCC). The conference brought together a variety of interested consumer advocacy groups and others to listen to panels discuss the adverse impact of changing medical drugs imposed by insurance companies and PBMs to save money and lower costs that ultimately and allegedly increase their profits while driving up costs to consumers and lowering quality of life and treatment to patients. The various panels included medical doctors, practicing pharmacists, social workers, and consumer advocates who have been involved in the fight against Non-Medical Switching (NMS). The panels' issues were the prevalence of NMS, the impact of NMS on patients, employer and patient perspectives on NMS, and the legislative policy implications and a path forward from what appears to be an adverse impact on patients created by insurers and PBMs interested in protecting their bottom line. (A pharmacy benefit manager (PBM) "is a third-party administrator of prescription drug programs for commercial health plans, self-insured employer plans, Medicare Part D plans, the Federal Employees Health Benefits Program, and state government employee plans" (Wikipedia) or what were previously known as middlemen in drug distribution.)

One of the conclusions at the end of the conference was that if action is to be taken, it will have to be led by consumer advocacy groups. Action may have to be taken at the state level and ultimately the federal level for patient to reclaim their right to certain ongoing therapies and avoid the arbitrary change to lower cost drugs and therapies that may be less effective though they may save money for the insurers and the PBMs.

The potential impact on prostate cancer was mentioned by at least one presenter and this will be followed so we can keep apprised of what may be a developing practice that may adversely affect our constituents. It was not that long ago when prostate cancer patients were adversely affected by the selection of a low cost generic ADT that appeared less effective than a mainstream brand drug being widely used.

In the SPOTLIGHT

*In each quarterly issue of the **Blueprint**, NASPCC is proud to feature a section dedicated to a very special state coalition to acknowledge the wonderful services they provide in their state. This quarter we are honored to shine the SPOTLIGHT on:*



PCEC is a national organization committed to men's health, based in Centennial, Colorado. Founded in 1989, the Council is comprised of a consortium of leading physicians, health educators, scientists and prostate cancer advocates. As the founder and coordinator of the national Prostate Cancer Awareness Month program, PCEC has screened millions of men across the nation for prostate health issues and has become one of the largest and most successful prostate health assessment projects in the world. PCEC works with academic medical centers, hospitals, urology clinics, churches, fire departments, public health departments and other groups providing FREE prostate health assessments, men's health testing and education events annually.

PCEC is not only the national leader in providing prostate health assessments for men; we are also the national leader in increasing awareness and education on prostate disease. Our national SET the Pace Event series features many diverse activities, including; Run/Walks, Beer Festivals and Golf Tournaments. Our Education Programs include; Patient and Caregiver Education, Health Conferences, Medical Professional Education with CME accredited programs.

Mission Statement

As a leading innovative organization, saving and improving the lives of men and their loved ones, we SET the PACE in early detection, research, education and awareness for prostate cancer and all prostate conditions.

Vision Statement

- Prevent the negative impact on prostate disease
- Challenge men to take charge of their health
- Educate men and their families
- Commit to advancing research

First and Second Quarter Events include:

- Men's Health Event- Minneapolis with Pints for Prostates and MNPCC
- Men's Health Event – Durham with Pints for Prostates
- 2 Golf Tournaments in Colorado
- 2 Father's Fest Men's Health Events with Pints for Prostates

- Prostate Cancer Update – Beaver Creek and Scottsdale
- AUA19-Chicago
- Summit DC
- VFW Convention-Orlando – Men’s Health Testing
- Multiple Health Fairs-National
- Multiple Church Events with Men’s Health Testing
- 100 Black Men Health and Wellness Health fair and Men’s Health Testing and Education event in Dallas
- Partner with GPCC on several PSA and Men’s Health Testing events in Georgia including; At-risk First Responder event
- 10 Spring Prostate Health Assessment Events at Hospitals and Academic Medical Centers around the nation
- 4 Patient and Caregiver Education Events-National
- 4 Patient Education Webinars
- Partner with PHEN on 1 PSA Testing Event in Tampa
- SUNA Nurse Education Event

Our REACH:

PCEC has over **13,500** followers on Facebook and Twitter, with strong engagement from patients, survivors, caregivers and medical professionals.

In the first half of the year, our websites www.prostateconditions.org and www.prostatemarkers.org has had over **290,000 views**.

PCEC would be proud to partner with your organization to help reach the men and their loved ones in your community! We have many great resources available to you and your coalition, including; the PCEC website with our new companion site on Prostate MARKERS- www.prostatemarkers.org, updated and WIRB approved screening questionnaires and educational materials; flyer templates and guidelines for hosting a screening. Please contact us at **1-800-4Prost8** or visit us at: www.prosteconditions.org, to learn how we can help make your event a success.

*NASPPC would like to congratulate the **Prostate Conditions Education Council** for being our “**Spotlight**” featured Coalition of the quarter! You are doing excellent work, providing prostate health assessment events, education, and awareness across the nation! Thank you for all that you do!*

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.
- **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.

<https://donorbox.org/nonprofit-blog/facebook-for-nonprofits/>

Please click the link above for more detailed information!

We would like to give a very Special *"Thank You"* to Johnny Payne of South Carolina for doing an amazing job managing our NASPCC Facebook page!



Other Events

PCRI 2019 Prostate Cancer Patient Conference
September 6-8, 2019
Los Angeles Airport Marriott

Join hundreds of other prostate cancer patients and their families on September 6-8th for the 2019 Prostate Cancer Patient Conference and get face to face with prostate cancer experts in every field.

For more information, visit: www.pcri.org



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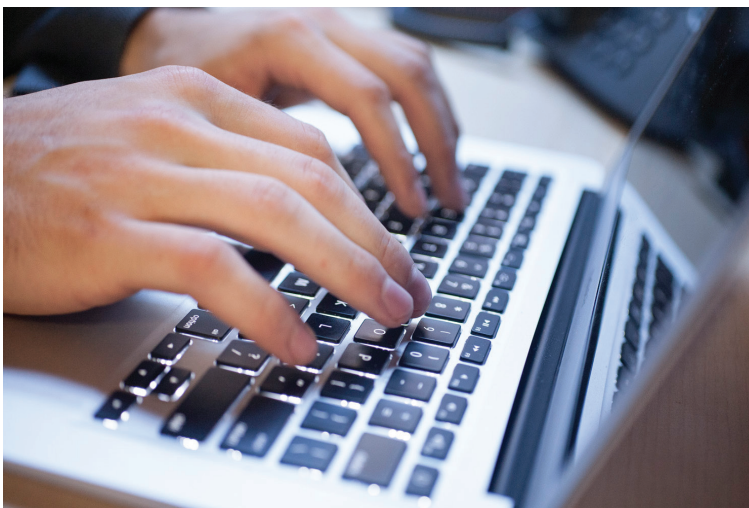
www.youtube.com/cancercaresinc



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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.

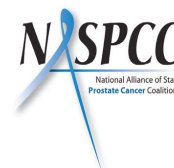
MODERATOR

Andrew Chelser, MSW, LCSW

Men's Cancers Program Coordinator, CancerCare

TO JOIN THIS SUPPORT GROUP, PLEASE VISIT

www.cancercares.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:

- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Indiana
- Kansas
- Kentucky
- 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
- Tennessee
- Utah
- Virginia
- Washington
- West Virginia
- 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!

Next National Coalition Quarterly Call:

August 22, 2019 @ 4pm MT (Mountain)

Topic: Funding Idea's
Dial-In: 1-218-339-7800
Access 9381332#



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The 2018-2019 Board of Directors of the National Alliance of State Prostate Cancer Coalitions

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