



A Proud Participant in the National Alliance of State Prostate Cancer Coalitions
Fighting Prostate Cancer in California since 1997

Spring 2021 Newsletter. Volume 20. Issue 3.

<https://prostatecalif.org/>

President's Message

Welcome to almost-early Spring and hopefully a path forward out of the pandemic. No matter the situation, our work in prostate cancer continues, even though we have not attended a cancer meeting in person since February 2020. Webinars and ZOOM Meetings keep us informed and engaged.

February also marks the annual ASCO GU Oncology Symposium (American Society of Clinical Oncology Genito-Urinary Oncology Meeting). This year of course the Symposium was held virtually; and elsewhere in this Newsletter you will find my REPORT FROM ASCO 2021. (It's also available at <https://naspcc.org/attachments/article/43/REPORT-FROM-2021-ASCO-GU-MEETING.docx>)

Besides the large meeting format, most of the Support Groups that CPCC networks throughout the State have been meeting via ZOOM, so that men and families in need of support do not have to go without during the pandemic.

This year the wildly successful 1st Annual CPCC/UCSF Patient Conference on Prostate Cancer will be followed up May 14-15, 2021 also in a virtual format, and soon Registration will be open on Eventbrite, being managed by the National Alliance of State Prostate Cancer Coalitions. Another stellar faculty from UCSF will present and be a major focus of breakout sessions, and we expect at least 600 attendees since no one will be required to travel in order to attend.

On a sidenote, the 2019 1st Annual Patient Conference that CPCC presented along with UCSF was videotaped, and is housed on the University of California YouTube Channel; it has been viewed over 122,000 times! View it here: <https://uctv.tv/2019-prostate-cancer-conference/>.

Elsewhere in this Newsletter you can read the current edition of our national Newsletter ("The Blue Print") published by the National Alliance of State Prostate Cancer Coalitions, in which the California Prostate Cancer Coalition is a "Proud Participant".

You will also see a Flyer for the upcoming free, 1-hour Webinar that NASPCC is presenting on March 10, 2021 at 4:00 pm PACIFIC with Dr. Ashley Ross of Northwestern Medicine, on the topic "Using Genomics to Guide Treatment After Radical Prostatectomy". The Webinars are a continuing resource for everyone, as they are stored on the www.naspcc.org site, both the slides and the recordings.

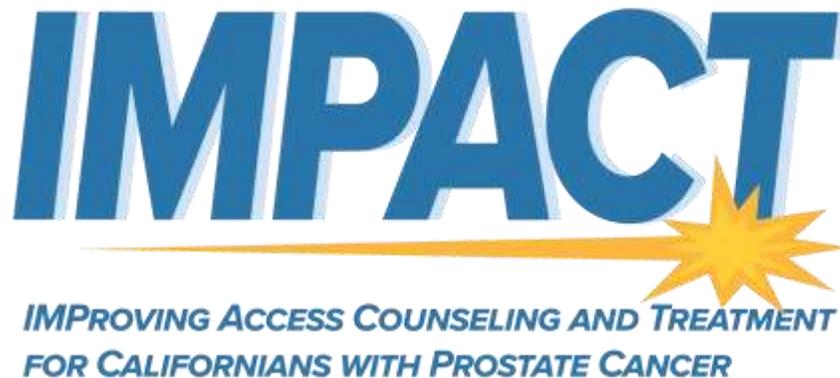
There is also a Flyer contained in this Newsletter for a free ONLINE Support Group being presented by CancerCare and co-hosted by NASPCC. And of course, there is a SAVE THE DATE card for the upcoming May 14-15 2nd Annual CPCC/UCSF Patient Conference on Prostate Cancer. Stay safe, everyone! Our fight to make prostate cancer a health care priority in the State of California continues!

Sincerely, Merel Nissenberg

Report from ASCO 2021

[Read our report from ASCO 2021!](#)

California's IMPACT Program



Kristen Williams talks about UCLA's Impact Program.

What is the IMPACT program?

The IMPACT program is a state funded program funded through the Department of Healthcare Services in the State of California. It provides prostate cancer care and comprehensive case management for men who have a low income and little to no health insurance. We function a little bit like an insurance company, but we are not an insurance company. We're actually in the same sort of state department as Medi-Cal.

Which communities do you serve?

California residents. Anyone who lives in California who meets our eligibility requirements. We do all of our case management by phone so we can serve anyone across the entire state.

What are the eligibility requirements?

The eligibility requirements are just residents in California. You meet the 200% or below of the federal poverty line and you have little to no insurance. That could mean that, for example, maybe you only have emergency Medi-Cal. It might mean you only have catastrophic insurance. It might mean that you don't have any coverage at all. There's a variety of things that we cover. Even in some cases, Medi-Cal share of coverage plans, we can help cover the prostate cancer care.

What kinds of services do you offer?

We work to help empower our patients to understand the healthcare system. A lot of the men that we work with have never worked with a medical system before. It's confusing and feels very

inaccessible, particularly since about 80% of our patients are exclusively or preferentially Spanish speaking.

We work really hard to help men learn how to ask the right questions, help men learn how to do behavioral things like Kegel exercises and diet modification. It's not just about paying for prostate cancer care. We have a holistic approach to case management to leave men better than they found us.

Eventually all of our men either are stable and have no recurrences or they get some sort of other coverage. (Maybe they get Medicare because they age into it.) We want to leave them better prepared to deal with their health in the future.

We have a nurse case manager who follows up regularly with every patient. We check in on every appointment that is related to prostate cancer. We talk over what's going on, help men understand their treatment. Help them figure out what questions they would like to ask, since sometimes in that appointment your mind goes blank. We're always telling people, let's work on your list of questions. What's going through your head? And we also will provide incontinence supplies as well for our patients that need them. We offer a broad range of services.

This is prostate cancer care. What about diagnosis?

We don't actually have coverage for a prostate biopsy, which is one of the big struggles that we face. Especially right now, because biopsies have been really reduced by COVID. We have folks who are concerned they may have cancer and they find us and we try to navigate them to resources for getting biopsy, but most screening programs across the state focus on PSA. And without a verified diagnosis through biopsy, we can't actually enroll the patients. That is definitely a gap that we face.

Are there any resources for people who need a biopsy and don't have healthcare in California?

The big one is the county facilities. So we, for example, Olive View UCLA medical center in Los Angeles, as well as Harbor UCLA and USC LAC are all places where folks can get county services to get their prostate biopsy, and then we can enroll them and they can see a different provider, or stay in county depending on their preference.

If a support group leader has a member that they think may benefit, what's the process for getting him enrolled?

The patient call 1-800-409-8252. He will go through an interview to determine eligibility. We may request certain documents from as well, but we can do all of that over the phone.

Support Group Spotlight: Prostate Forum of Orange County



Neal Berke of Prostate Forum of Orange County talked with CPCC about his support group.

How did programming for Prostate Forum of Orange County change during the pandemic?

Mr. Neal Berke: We traditionally have met at the first Presbyterian Church of Fullerton. With COVID, by about June or July of last year, we were on Zoom and Zoom exclusively. Principally what we do when we're up and running to full capacity is presentations. We do 11 presentations a year by prominent MDs in the field. We draw people from UCLA, Cedar Sinai, and Prostate Oncology Specialists-- the top people in the Southern California area.

We meet once a month-- the fourth Thursday of the month--at 7:00 PM right now. Except for November when we meet the third Thursday because of Thanksgiving. We're dark in December. When we meet in person, we'll have the advanced disease sharing group meet at the church in a separate room. Anybody who's been newly diagnosed will be seen by the leader of our newly diagnosed group. At 7:00 PM those who want to stay for the presentation will stay for the presentation. Traditionally, those advanced and newly diagnosed groups are a draw to a large extent for the presentations.

Different parts of the program are important, for different people, I imagine--depending on where they are in their journey....

Neal: It depends upon where they are in their journey. Along with that, we also have a hotline that not only men can call but concerned women can call. Many times, it is the women who lead the healthcare agenda for families.

Who staffs the hotline?

Neal: One of our most experienced patients staff the hotline. He's had prostate cancer for a long time. He does a fantastic job. It is basically an overlay number to someone's cell phone. It's transferable. Rather than us having to be in an office and actually pick up a phone, it's an overlay. On the Hotline, men will get support, and the ability to discuss some alternatives. They might get some resources. Which doctors to talk to, which clinics to investigate.

How many calls per month do you get?

Neal: I would say two to three.

How many people do you have in the group overall?

Neal: A typical meeting will have about 20 to 30 people. It depends. Some presenters are more popular than others. And it depends on what we're competing against—a sports events, or a political debate.

But our Advanced Sharing group gets about 20 to 30 people as well. Newly diagnosed draws one or two, depending upon the night.

Along with the advanced disease and newly diagnosed groups, our presentations, and the hotline, we archive our presentations. We have quite an archive going back about 10 years to about 2010. Those archives are available on YouTube and to some extent on our own website.

If you go to www.prostateforum.org, you can find information from previous presenters on theranostics, incontinence, impotence, various radiological therapies, and prostatectomies and more. It's quite a library.

We're developing our own newsletter too. That's going to be the subject of discussion. We have a retired urologist who's practiced many years in Southern California who has an interest in bringing everybody up to date with the latest in therapies, diagnostics, and statistics. He is wonderfully qualified to do that. We're very excited about the possibility.

Have you attracted the same number of patients to your Zoom meeting as you did to your in-person meetings?

Neal: I'd say they've gone down with Zoom despite the fact that a lot of people wanted Zoom because they didn't want to travel at night or they were coming from a great distance. In some respects membership has gone down, in others we've recaptured people who live in Arizona. We had an international meeting, this past January.

We had Dr. Nat Lenzo, from Genesis Care in Australia present. It was 11 am on a Friday there, which is 7:00 PM Thursday here. We were able to swing a 16 hour time difference with someone who's a leader in theranostics. We had about 28 people. I was watching attendance through the night. It would bounce somewhere around 28 to 29 people through the night.

What's hurting us is we need to get the Advanced Sharing group up again because Advanced Sharing draws people to the presentations.

We also have a core group of men. I think this is true of probably most, if not every, support group out there. Your core group is made up of men who have had not only metastatic cancer, but have treatment resistant metastatic cancer. They want the latest and the greatest information in addition to the support.

You think that they're the ones who are driving the group?

Neal: I think that in all of these groups, your core group of patients drives things. I think the opportunities for expansion to help more men include meetings and more presentations aimed at, for example, active surveillance. Or even potency and continence, which become a topic whether or not you have prostate cancer or whether or not you've had a prostatectomy.

True.

Neal: There's a lot of concern in that area. There is also more opportunity to dispel myths that benign prostate hypoplasia does not necessarily mean that you're headed for cancer.

I would say, you're one of the more successful support groups in California. To what do you attribute that success?

Neal: Our model has been to be independent of any particular physician, hospital, treatment, or medication. That has helped. Part of our success is due to diversity of opinion.

We've also had a STEM culture going way back long before anyone talked about science, technology, engineering and medicine as a driving force. So many of our people are engineers, or they're project managers. They're used to stress, they're used to putting out a product; they're used to working long, hard hours. They're driven. Whether they've had a 3+3 Gleason or they have metastatic disease and it's a day-to-day fight against it: there's a drive there.

They're also into technology, they can understand that stuff.

Do you think that they're then just better able to communicate that to other members of the group than others?

Neal: Yes. In fact, that's going to be a topic for tomorrow's meeting: a newsletter comes out or when a presentation is done, we want to be able to explain it to people who are not familiar with medicine, much less the complexities of cancer.

It's hard to learn new things when you're in that state of fear and anxiety.

Neal: Oh, I've lived it.

Do you have any advice for support group leaders in California?

Neal: Hang in there. COVID-19 has thrown us a loop. I think that our challenge, and I've talked about it at conferences in previous years, is talking to men and women about the advantages of being in a support group.

I think a lot of men are just going with whatever the doctor tells them. I think they don't realize they have options that could enhance their quality of life as well as keep the cancer at bay. We've got to push screening. It's particularly important for men who have prostate cancer in their family. It's particularly important for black men.

Prostatepedia Magazine + Digest



The National Alliance of State Prostate Cancer Coalitions took over publication of the outstanding PROSTATEPEDIA Magazine and PROSTATEPEDIA weekly DIGEST last June, 2020.

Since then we have published two quarterly PROSTATEPEDIA Magazine Issues: the August 2020 Issue on “CHEMOTHERAPY IN PROSTATE CANCER” can be viewed at <https://online.flippingbook.com/view/193912/3/> and then the November 2020 Issue on the topic of “IMMUNO-ONCOLOGY & PARP INHIBITION” is at <https://online.flippingbook.com/view/542030/>.

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

Besides the Magazine, we publish a weekly (every Friday) PROSTATEPEDIA DIGEST comprised of links to the most current articles and abstracts and press releases in prostate cancer, and including a link to subscribe for free and a link to the most recent PROSTATEPEDIA Magazine Issue. Additionally, the Magazine Issues are archived on the www.naspc.org website. See <https://www.naspc.org/index.php/prostatepedia-magazine>

NASPC has a current subscription mailing list of over 12,000 people for both the Magazine and the weekly DIGEST; a subscription is now free. Visit our website to subscribe at no cost which will mean you will receive PROSTATEPEDIA Magazine as well as the weekly DIGEST.

CPCC/UCSF Patient Conference May 14-15



UCSF Cole Hall, 2019 1st Annual Prostate Cancer Patient Conference, going Virtual in 2021

THE 2ND ANNUAL CPCC/UCSF PATIENT CONFERENCE ON PROSTATE CANCER will take place virtually May 14 and May 15, 2021. The upcoming Patient Conference will again enjoy an outstanding faculty primarily from UCSF, and is being co-sponsored by both the California Prostate Cancer Coalition and the Helen Diller Family Comprehensive Cancer Center at UCSF. The Conference is an outstanding opportunity to learn from the experts and to then interact in small breakout groups part of the second day of the Conference.

Registration will be required and will be available shortly on Eventbrite, and early registration will be encouraged in order to be included in those small breakouts, as we are expecting several hundred people for the full Conference and only a limited number of people can be included in small breakouts with the faculty.

Since it will be a virtual format, we expect that many people from around the country will take advantage of this incredible learning opportunity. And we have a strong tradition to uphold: The video from the 1st Annual CPCC/UCSF Patient Conference is on the UC YouTube Channel and has been viewed over 122,000 times! You can view it here: <https://uctv.tv/2019-prostate-cancer-conference/> . Contact Merel Nissenberg at mgrey@health.ucsd.edu or Tom Kirk at tomkirk_99@yahoo.com.

FDA Approval of PSMA Scan for New or Recurrent Patients

by CPCC Board Member, Keri Gogfolin



CPCC celebrates the recent FDA approval of the Gallium 68 PSMA-11 PET scan. This diagnostic scan adds to the repertoire of sensitive imaging technologies available to patients with rising PSA levels who suspect recurrence of their prostate cancer and want to know whether it has spread.

Significantly, it is also the first such scan FDA has approved for newly diagnosed patients who have not yet chosen initial treatment and are similarly at risk for metastases. Axumin and C-11 choline scans remain FDA approved for recurrent patients only. With PSMA PET, new patients now have a chance to use sensitive imaging information to guide their treatment decisions, too.

PSMA scans are noted for their diagnostic use, yet also play a role in therapeutics (or theranostics) when paired with an anti-cancer agent such as Lu-177. This FDA approval is for the diagnostic scan, and involves injecting the radioactive tracer Ga-68 for imaging purposes

Two sites have been approved by FDA to provide this scan: University of California, San Francisco (UCSF) and University of California, Los Angeles (UCLA). CPCC recommends you consult your treating physician if interested.

More information: <https://www.fda.gov/news-events/press-announcements/fda-approves-first-psma-targeted-pet-imaging-drug-men-prostate-cancer>

March 10th Webinar: Genomic Testing After Radical Prostatectomy

NASPCC is continuing its Webinar Series of Excellence with the next free, 1-hour Webinar scheduled for Wednesday, March 10, 2021 at 7:00 pm EASTERN (4:00 pm PACIFIC).

The Presenter will be Ashley Ross, MD, PhD, Associate Professor, Northwestern Feinberg School of Medicine in Chicago. Dr. Ross has been a frequent presenter for NASPCC at our Annual Meetings and has also done a Webinar for us as well. The topic for March 10 will be “USE OF GENOMICS TO GUIDE TREATMENT DECISIONS AFTER RADICAL PROSTATECTOMY”.

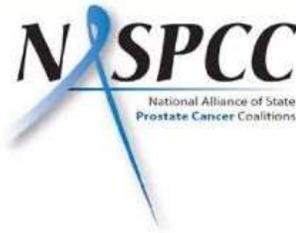


Dr. Ross is an Associate Professor of Urology at the Northwestern Feinberg School of Medicine. His research and clinical efforts focus on the development, testing and implementation of novel diagnostics and therapeutics with a goal of reducing the suffering from prostate cancer. Prior to joining the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

Dr. Ross' clinical research and clinical efforts center on the development, testing and implementation of novel diagnostics and therapeutics. He is an old friend of NASPCC and sits on our Medical Advisory Board.

**Wednesday, March 10, 2021
7 pm – 8 pm EST/4 pm – 5 pm PST**

[Register](#)



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

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

**Wednesday, March 10, 2021 from
7:00 pm – 8:00 pm EASTERN
4:00 pm – 5:00 pm PACIFIC**

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



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

NASPCC LAMINATE SERIES

The National Alliance of State Prostate Cancer Coalitions (The Prostate Cancer Alliance) has an Informed Decision-Making Laminate on its www.nasppc.org website, and continues to make these available in bulk for state prostate cancer organizations holding awareness and educational events.

We are in process of creating an entire Laminate Series, including (as of press time) the following topics: Advanced Prostate Cancer; The Role of PSA in the Prostate Cancer Journey; Non-Metastatic Castrate-Resistant Prostate Cancer; Metastatic Castrate-Sensitive Prostate Cancer; Immuno-Oncology; Pain Management in Prostate Cancer; Testing; Bone Health; and Imaging. As with the Informed Decision-Making Laminate, one side of the durable resource is for Patients, with 10 Questions and Answers; the flip side (literally) is for Physicians, with the same 10 Questions but with more scientific answers and references.

We think these durable educational tools are productive and welcomed by as-yet-diagnosed patients; by current patients and their families; and by health care providers. They are indeed a unique resource.

NASPCC Newsletter

[Read the Blue Print, the newsletter of the NASPCC.](#)



**SAVE THE DATE
SAVE THE DATE
SAVE THE DATE**

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

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

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Prostate Cancer Online Support Group

CancerCare is offering a 15-week online support group for people diagnosed with prostate cancer who are currently receiving treatment. This group is co-sponsored by the National Alliance of State Prostate Cancer Coalitions (NASPCC). In this group led by an oncology social worker, patients give support to each other and share resources and information.

OUR GROUP:

- Reduces feelings of loneliness, anxiety and distress
- Helps you learn new ways of coping
- Increases feelings of hope and empowerment
- Provides you with practical information about treatment and resources
- Helps you communicate better with your medical team and loved ones

TO JOIN THIS SUPPORT GROUP, PLEASE VISIT

cancercares.org/support_groups/126-prostate_cancer_patient_support_group to complete our online registration process. Internet access is required. After joining this password-protected group, you can read and post messages 24 hours a day, 7 days a week.

At this time, CancerCare's online support groups are only available to people residing within the United States (including Puerto Rico and U.S. territories).



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Please help us continue to work for you!
Thank you.