



***“Fighting Prostate  
Cancer in California since 1997!”***

**[www.prostatecalif.org](http://www.prostatecalif.org)**

***A Proud Participant in the National Alliance of  
State Prostate Cancer Coalitions***

**News**

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## **PRESIDENT’S MESSAGE**

Happy New Year to all of you and to your families and friends. My best wishes for a year of good health, first and foremost. We at the California Prostate Cancer Coalition are looking forward to a productive year in which we can continue to work on our Mission: to continue to help increase the early detection of this potentially lethal disease while working to improve the quality of life for prostate cancer patients and their families.

We also want to make sure that prostate cancer is a public health care priority for the State of California. To that end I am helping to craft the 2020-2024 Prostate Cancer Plan for the State of California and I also serve on the Advisory Committee for the California's Comprehensive Cancer Control Plan. It's important that we not fall back into a time in which men are not being offered informed discussions on testing, risk factor and other issues surrounding prostate cancer. All the while we are also learning about newly identified high-risk groups, such as fighter pilots in the military who have been exposed to very high levels of radiation due to their work.

The California IMPACT Program (IMProving Access, Counseling & Treatment for Californians with Prostate Cancer) is an important way to help underserved men with prostate cancer. CPCC was instrumental in leading the effort to pass the legislation creating the program. We now need to help educate men about how to enroll. The Program is under the operational leadership of the Department of Health Care Services. We need your help in letting people know about this great resource for underserved men. For more information go to the Impact website: <https://www.california-impact.org/pages/>

Stay tuned to hear the date for a Southern California Support Group Leaders' Workshop that will be facilitated by former CPCC Board Member Stan Rosenfeld. Our Northern California Support Group Leaders' Workshop took place on November 21, 2019 and a report appears in this Newsletter. In addition, you will be hearing more about the 2020 2nd Annual CPCC/UCSF Patient Conference on Prostate Cancer that will take place in the Bay Area on Saturday, June 6, 2020.

At our Face-to-Face Board Meeting held on November 25, 2019 in Los Angeles, the Board constructed an Action Plan for various activities to take place this year, including translating our Informed Decision-Making Laminate into Spanish for distribution and increasing our involvement with social media to get the word out on how helpful CPCC can be. You will read more about CPCC activities, goals and planned events elsewhere in this Newsletter. Our Board meets monthly by telephone, but we will hold another Face-to-Face Board Meeting on March 23, 2020 in Los Angeles again. Guests are welcome to attend.

Welcome to 2020!

***Keep up the fight against prostate cancer! -- Best regards, Merel Grey Nissenberg, President***

## **SAVE THE DATE: 2ND ANNUAL CPCC/UCSF PATIENT CONFERENCE ON PROSTATE CANCER PLANNED FOR JUNE 6, 2020**

On June 6, 2020 CPCC and UCSF will present the 2nd Annual Patient Conference on Prostate Cancer in the San Francisco Bay Area, specific location to be announced. Last year's conference was a huge success, with 370 attendees and standing room only. CPCC will be looking for volunteers to help with on-site registration, compiling conference materials, guiding attendees to their seats, and other needs. Please contact Steering Committee member, Merel Grey Nissenberg, at [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu) if you are willing to volunteer. CPCC will cover parking expenses for volunteers.

Links to the 2019 and upcoming 2020 conference are at:

- <https://twitter.com/UCSFCancer/status/1216108785367965696>
- <http://cancer.ucsf.edu/events/2020/06/06/second-annual-patient-conference-on-prostate-cancer.10058>

To view the presentations from last year's conference, go to: <https://uctv.tv/2019-prostate-cancer-conference/>. The 2019 conference videos have been viewed nearly 85,000 times.

## **CPCC FACE-TO-FACE BOARD MEETING PLANNED FOR MARCH 23, 2020**

On **Monday, March 23, 2020** the California Prostate Cancer Coalition (CPCC) will hold its first 2020 Face-to-Face Board Meeting at the Westin LAX in the Board Room within the Daily Grill. All are welcome to attend. A light breakfast, and lunch will be served. Although Board Meetings are usually held monthly by conference call, CPCC Board members believe that these in-person meeting, held whenever possible, lead to greater efficiency and productivity.

## **PROSTATE CANCER SURVIVORS INVITED TO ATTEND MARCH 23<sup>RD</sup> ROUNDTABLE MEETING**

Prostate cancer survivors are cordially invited to apply (by e-mail) to attend a small roundtable on "Patient Preferences for Research Topics in Prostate Cancer" which will take place on **Monday, March 23, 2020** at the Westin LAX Hotel in Los Angeles, California. The Roundtable will take place from 2:30 pm - 6:00 pm in "The Boardroom" inside the Daily Grill by the hotel lobby. Dinner will be included for those who can stay after 6:00 pm so that the discussion can continue. This forum presents a wonderful and unique opportunity for patients' voices to be heard, on what patients want researchers to study. The University of Washington is planning to use the information gained to apply for a grant to pursue those patients' interests. please e-mail Merel Nissenberg ([mgrey@ucsd.edu](mailto:mgrey@ucsd.edu)) if you are interested in participating.

## **NORTHERN CALIFORNIA PROSTATE CANCER SUPPORT GROUP LEADERS' WORKSHOP HELD – SOUTHERN CALIFORNIA WORKSHOP COMING SOON**

The annual Northern California Prostate Cancer Support Group Leaders' Workshop sponsored by CPCC was held on Thursday, November 21, 2019 with fourteen men and women support group leaders in attendance. The popular workshop was expertly facilitated by Stan Rosenfeld, an 18-year Bay area support group leader. Prostate cancer support group leaders, facilitators, administrators and prospective group leaders from Northern or Central California were invited to attend.

The workshop is designed to share best practices used by leaders in their own support groups to help others become more effective group facilitators. A significant proportion of the day focused on various challenging questions and situations that arise during support group meetings, both procedural as well as technical. The speaker was James Smith MD, MS, Associate Professor and Director, Male Reproductive Health at UCSF. Among his specialties, Dr. Smith treats men with erectile dysfunction. His presentation drew praise from all attendees. A delicious and healthy continental breakfast and lunch was provided. The workshop costs including meals and parking was covered by CPCC. Feedback from the day was very positive with participants expressing their thanks for the expert facilitation to Stan and CPCC for its sponsorship. Stan Rosenfeld will be facilitating the CPCC Southern California Support Group Leaders' Workshop in the Spring/Summer of 2020. More information will be forthcoming.

## **NASPCC/ CPCC ROUNDTABLE ON ACCESS TO CARE, STEP THERAPY AND THE IMPACT PROGRAM HELD**



*Left to Right: Tiffany Razzo, Jessica Myers-Schechter, Westley Sholes, Tom Kirk, Elizabeth Helms, guest speaker, Kristin Williams, guest speaker, Steven Schultz, guest speaker, Jonathan Madeiros, guest (partially hidden), Frank Balthis, Merel Grey Nissenberg, Beverly Nicholson, and Sarah Conner, guest speaker, at the November 2019 Roundtable.*

The National Alliance of State Prostate Cancer Coalitions (NASPCC) and the California Prostate Cancer Coalition (CPCC) held a Roundtable on Access, Step Therapy and the Impact Program on November 25, 2019 at the Westin LAX Hotel in Los Angeles, California in conjunction with the CPCC Face to Face Board meeting. Attendees were privileged to hear presentations from leaders advocating for better access for patients.

Elizabeth Helms, Director, Chronic Care Policy Alliance based in California, discussed their efforts to help patients facing problems with healthcare coverage. This group has published an outstanding booklet, "Get to Know Your Rights," which was distributed at the Roundtable. For information about the booklet go to: [www.MyPatientRights.org](http://www.MyPatientRights.org). Steven Schultz, State Director of Advocacy, Arthritis Foundation, presented the patient advocacy work done by his organization. Arthur Lurvey, MD, Medicare Contractor Medical Director at Noridian Healthcare spoke on Medicare coverage for tests and treatments. Sarah Connor, UCLA Urology

Research Manager and Kristin Williams, UCLA Program Liaison for the California IMPACT Program (Improving Access, Counseling & Treatment for Californians) updated the group about the program activities and discussed how advocates for underserved men can support the program. One of the most important ideas discussed was the “Share Your Story” program which helps to personalize access to care challenges faced by some patients. These stories can help to drive change and improve insurance coverage decisions. For more information go to: <https://mypatientrights.org/share-your-story/>

NASPCC and CPCC look forward to holding other Roundtables on these important topics in the future. This topic was chosen as an action plan action priority for NASPCC last year. Merel Nissenberg and Tom Kirk organized and led this important roundtable for NASPCC and CPCC.

## **CPCC BOARD IDENTIFIES GOALS AND SETS DIRECTION FOR 2020**

The CPCC Face to Face Board meeting was held on November 25, 2019 at the Westin LAX Hotel in Los Angeles, California. Merel Grey Nissenberg, President, led Board members through an ambitious agenda with wide-ranging discussions. The goals for 2019 were reviewed and new goals for 2020 developed.

### **2019 Goals Reviewed:**

- 1) Continue support of the IMPACT program - IMPACT's Kristen Williams and Sarah Connor provided the Board with a program update and CPCC will continue support the program.
- 2) Continue to publicize and encourage the use of the Informed Decision-Making Laminate – distributed to all attendees at the June CPCC UCSF Prostate Cancer Patient Conference.
- 3) Plan and Conduct a Statewide Patient Summit - first Patient Conference held in collaboration with UCSF in June 2019
- 4) Continue the Prostate Cancer Proclamations Project – 2019 project accomplished.
- 5) Develop the CPCC Board – new Board members added.
- 6) Conduct at least six awareness/outreach events – still under development
- 7) Improve CPCC Website - explore bids for CPCC Website hosting/maintenance – still in progress.
- 8) Develop Quarterly CPCC Newsletters – three newsletters done in 2019

### **CPCC 2020 Goals**

- 1) Hold 2<sup>nd</sup> Annual CPCC UCSF Prostate Cancer Patient Conference
- 2) Increase support group awareness in remote areas and explore how CPCC can support/develop groups in underserved areas.
- 3) Improve CPCC Website - explore bids for CPCC Website hosting/maintenance.
- 4) Explore a Spanish translation for the Informed Decision-Making Laminate.
- 5) Update the California Support Group Leaders Directory.
- 6) Plan and conduct Face to Face Planning Meeting in March 2020.
- 7) Convert CPCC newsletter to an electronic format for expanded sharing (such as Mail Chimp) - quarterly newsletter.
- 8) Create a new CPCC Twitter account.
- 9) Add content to the CPCC Linked-in page.
- 10) Continue the Prostate Cancer Proclamations Project

The 2020 goals will be reviewed during the monthly Board meetings on conference call and at the next Face to Face Board meeting on March 23, 2020.

## FOCUS ON CALIFORNIA PROSTATE CANCER SUPPORT GROUPS



The Prostate Forum of Orange County is one of largest, independent and growing prostate cancer support groups. The group's mission is to offer help and hope to men by providing prostate health information. The Prostate Forum of Orange County is an all-volunteer organization with informational materials, print and video, free to everyone. The Prostate Forum of Orange County is a member of the Us TOO Foundation International and is a 501(c)(3) organization. Among its many activities, the Prostate Forum holds monthly meetings and maintains a Helpline.

The Prostate Forum was founded by Bill Dehn and Murray Corwin in March 1992 in Fullerton CA. These men decided to organize a prostate cancer support group where men would have the freedom and support to discuss any aspect of the disease without any censorship or restrictions. The name "Prostate Forum" was chosen to reflect their vision of an "open dialogue." The Board of Directors, established in 1992, helps to set the strategic direction of the Forum and provide support and guidance.

The Prostate Forum provides a safe and caring meeting place, where prostate survivors may share their feelings, concerns and experiences, ask questions of others in similar situations and receive understanding, empathetic support. The Prostate Forum is available to support or initiate other similar groups related to the subject of the prostate, especially in the under-represented various ethnic communities.

### **Meeting Location**

The First Presbyterian Church of Fullerton  
838 N. Euclid Street  
Fullerton, CA 92832

### **Meeting Times**

4th Thursday of month

- Speakers: 7:00 PM - 8:30 PM,
- Newly Diagnosed Class: 5:00 PM - 6:45 PM except Dec.  
Recurrent/Advanced Group: 5:00 PM - 6:45 PM except Dec.

**Help Line: 1-714-459-2058**

**Email: [prostateforumoc@gmail.com](mailto:prostateforumoc@gmail.com)**

**Website: <http://www.prostateforum.org/>**

# VETERANS AND PROSTATE CANCER



**Mike Crosby USNA '83**  
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Currently there is speculation and discussion about the increase in cancer incidence among the Veteran population, specific to prostate cancer and many other cancers. While the exact causes of the increase in cancer incidence are unknown, there is a commonsense theory that exposure to various occupational hazards are the culprits. The long-term exposure to radar radiation, Agent Orange exposure, chemicals on the flight decks and flight lines, handling of depleted uranium, and combat stress are all suspected. Although it may take decades to determine the “cause,” it is important to make all personnel aware of the importance of early and consistent screening for prostate cancer and other diseases.

This past November, the Prostate Cancer Foundation and the Veterans Health Administration (VHA) Joint Precision Oncology Program released data that continues to bring attention to the significant number of prostate cancer diagnoses among the Veteran Population. Data specific to prostate cancer reveals that:

- Over 489,000 Veterans in the VHA system have prostate cancer TODAY
- Over 16,000 Veterans in the VHA system have metastatic prostate TODAY
- SEER data shows a 7% metastatic prostate cancer diagnosis rate at first detection for the general population. The VHA rate is 14% at first diagnosis, demonstrating the need to screen earlier and better.

In the past year the United States Preventative Services Task Force updated its prostate cancer screening guidelines to a slightly more aggressive position. The new recommendation needs to be better communicated to VA physicians and Veterans. While the VHA is taking steps to address this disease as well as other men’s health concerns, the members of Veterans Prostate Cancer Awareness along with the National Alliance of State Prostate Cancer Coalitions, strongly believe that a more aggressive education and awareness campaign needs to be introduced.

At Veterans Prostate Cancer, Inc. we are firm believers that the VHA can effect changes in this disease space and take a global leadership role in setting screening policy, advancing treatment options, and coordinating the research activities within the VHA and the rest the healthcare industry. With the coordination of patient advocacy organizations and military associations, the accomplishments made within the VHA should be celebrated. VPCa intends to promote the message of greater awareness and early screening throughout the entire Veteran population. We are inviting you to join us in this mission to educate every Veteran on the importance of early and consistent prostate cancer screening, proper risk stratification so the appropriate treatment can be offered and to help the VHA with its education outreach.

The Veteran population in the USA exceeds 20 million individuals. Over 9 million individuals receive healthcare from the Veterans Healthcare Administration. Within the 9 million receiving care, over 7 million are males over the age of 40. These men are right in the heart of the prostate cancer screening recommended age range. To assist with the care of Veterans, the current Administration along with Congress passed the 2018 Mission Act. One of the specific appropriations within the Act was an appropriation of \$100 Billion for the care of Veterans outside of the VHA Medical Centers. The funding was split over 6 years and is under the administration of both TriWest Healthcare Alliance and Optum, a part of the UnitedHealth Group®. This funding is available for community providers to utilize to treat Veterans. For more information please contact Mike Crosby at [mike.crosby@vetsprostate.org](mailto:mike.crosby@vetsprostate.org). or go to VPCa at <https://vetsprostate.org/>.

# California Prostate Cancer Coalition Information



From the CPCC November 25, 2019 Board Meeting from left to right Board Members: Frank Balthis, CPCC President Merel Grey Nissenberg, Beverly Nicholson, CPCC Secretary Tiffany Razzo, and Jessica Myers-Schechter. Not pictured Arthur Lurvey, MD and CPCC Vice President Thomas Kirk. Pictured at right: Board member Westley Sholes.

## Board of Directors

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Sam Wells

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## Donate Now

Donate online at <http://prostatecalif.org/donate-now> or mail donations to:  
California Prostate Cancer Coalition,  
c/o Tom Kirk, Treasurer  
2220 Ave of the Stars, #1101,  
Los Angeles, California 90067.

*CPCC is a 501(c) (3) not-for-profit public benefits corporation (EIN 94-3349907). For information concerning gifts in trusts or stock transfers call (310) 525-3570 or email [cpcc@prostatecalif.org](mailto:cpcc@prostatecalif.org).*

*CPCC is a 501(c) (3) organization and, as such all contributions you make to CPCC are tax-deductible. Since we are an all-volunteer organization, we need financial resources to keep up our work including making essential information on prostate cancer available to men and families in California, holding annual support group leader's workshops, publishing a newsletter, maintaining our website, sponsoring educational conferences, and other related programs. Please help us continue to work for you! Thank you.*



NASPCC Webinar Series Presents:

**“Managing the Side Effects of Prostate Cancer and its Treatment:  
Emotional Distress, Intimacy Issues, Erectile Dysfunction and Incontinence”**

With Dr. Krishnan Venkatesan, MD, Washington Hospital Center, and William Goeren, MSW, of CancerCare, New York. The Webinar will take place on **Thursday, February 27, 2020 at 6:00 pm Eastern.**



**Krishnan Venkatesan, MD**  
**Director of Urologic Reconstruction**  
**Washington Hospital Center**

A native of Detroit, Krishnan completed his undergraduate studies at Columbia University in the City of New York before returning home for medical school at Wayne State University.

He stayed on at Wayne State for his residency in Urology, which he completed in 2010. He then undertook a fellowship in Genitourinary Reconstruction at the Institute of Urology at University College London and went on to Pune, India to pursue further training in complex urethral reconstruction at the Kulkarni EndoSurgery Institute.

Krishnan then moved to Washington, DC to become the Director of Urologic Reconstruction at MedStar Washington Hospital Center, a 900-bed urban tertiary care and trauma center. He is an Associate Professor in the Georgetown University Department of Urology and participates actively in resident training. Over his 7 years in Washington, he has developed the Reconstructive Unit into a referral center for complex genitourinary reconstruction and prosthetics throughout the Mid-Atlantic Region. He has had his work presented at the regional, national and international level, and has co-authored a number of publications in the urologic reconstruction subspecialty.



**Bill Goeren, MSW, OSW-C, LCSW-R**  
**Clinical Program Director**  
**CancerCare**

Bill Goren is the Director of Clinical Programs at CancerCare. Prior to his work at CancerCare, William was the Director of Mental Health for the AIDS Healthcare Foundation in Los Angeles, and, in 1994, opened the first Gilda’s Club in New York City. He is the co-author of the chapter “Unique Issues Confronting Gay, Lesbian, and Bisexual Individuals Diagnosed with Cancer” for the Oxford University Press *Handbook of Oncology Social Work* and the author of the chapter “Social Work, HIV Disease, and Palliative Care” for the *Oxford Textbook of Palliative Social Work*.

This Webinar is Sponsored by:



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