



PRESIDENT’S MESSAGE

Welcome to CPCC’s Spring 2019 Newsletter and to an exciting calendar of events! On June 8 from 7:00 am to 5:00 pm, CPCC and UCSF will be co-presenting the CPCC/UCSF PATIENT CONFERENCE ON PROSTATE CANCER, a National Conference for Patients, Families, Caregivers, Health Care Providers and Advocates across the country, which will take place at Cole Hall on the UCSF Parnassus Medical Campus in San Francisco. We have an exciting agenda and a stellar faculty most of which is from UCSF, but which will include CPCC Board Members Dr. Joseph Scherger, Dr. Leonard Marks, and Joe Ferrara.

I attended the American Society of Clinical Oncology (ASCO) GU Meeting in San Francisco in February and heard reports on Phase II and III studies in prostate cancer. For example, the results of the Phase III Aramis Trial on a new drug, Darolutamide, demonstrated excellent benefits for patients with castrate-resistant, non-metastatic disease. If approved, this would mean there would be 3 drugs in that non-metastatic space, drugs meant to delay or even prevent metastasis. The benefit of this particular drug is that it did not cross the blood/brain barrier so there were fewer central nervous system side effects.

In March Vice President Tom Kirk and I spoke at the American Urology Association 2nd Annual Advocacy Summit in Washington, DC on the topic of Step Therapy and Fail First Insurance Coverage. We were part of a Plenary Session that dealt with regulatory burdens and challenges to patient access to appropriate treatments. CPCC has been asked to convene an Advocacy & Policy Roundtable on that topic, as well as on the topic of state programs to help patients (such as the IMPACT Program) That Roundtable will tentatively take place in early September 2019. The plan is to hold the Roundtable a day apart from the Fall Face-to-Face Board Meeting to capitalize on the presence of so many Board Members, but we will also invite non-Board Members to participate in the Roundtable.

As your President I continue to represent CPCC as a “Proud Participant in the National Alliance of State Prostate Cancer Coalitions (NASPCC)”. The Alliance is planning its 15th Annual Meeting and Gala to take place October 18-20, 2019 in Washington, D.C. Guests are always welcome. This year’s special landmark 15th Annual Meeting & Gala will be held at the Hotel Monaco, a unique and historic property.

Happy Spring and let’s re-double our efforts to save men’s lives and increase early detection of potentially lethal disease.

Best regards, Merel Grey Nissenberg, President



Prostate Cancer

**The following are some little-known interesting facts about this disease
2019**

Did you know that

- Prostate cancer is the most diagnosed cancer in American men after non-fatal skin cancer.
- In the USA, 1 out of every 9 men will be diagnosed with prostate cancer in their lifetime.
- 174,650 American men are forecast to be diagnosed with prostate cancer this year.
- 31,620 American men are forecast to die from this deadly disease this year.
- The number of prostate cancer deaths increased 7.5 % between 2018 and 2019 for American Men.
- After lung cancer, Prostate cancer is the leading cause of cancer death in American men.
- Every 17 minutes, 24/7, an American man dies from prostate cancer.
- Prostate cancer usually has no symptoms in its early stage and there are no self-tests for this disease.
- The 5-year survival rate approaches 100% if malignant prostate cancer is treated in its early stage.
- The 5-year survival rate drops to 30% if malignant prostate cancer spreads to other parts of the body.
- African American men have the highest prostate cancer incidence rates in the world.
- African American men are twice as likely to die from prostate cancer than any other ethnic group.
- More than 3 million men are living in the USA today with a history of prostate cancer.
- \$100 million Congressional research funding for prostate cancer. (CDMRP* FY 2019).
- \$130 million Congressional research funding for breast cancer. (CDMRP* FY 2019) (30% difference).
- 66 is the median age for men being diagnosed with prostate cancer.
- 62 is the median age for women being diagnosed with breast cancer.
- The Affordable Care Act provides free breast cancer screening, but not free prostate cancer screening.
- At least 42% of all newly diagnosed cancers in the USA are potentially avoidable.
- Smoking, excess body weight, physical inactivity, excess alcohol consumption, and poor nutrition are some of the leading causes of all cancers.
- Heart disease is the most common cause of all deaths in the USA followed by cancer.

CDMRP* Congressionally Directed Medical Research Programs. The above information comes from the American Cancer Society and the National Cancer Institute. It is available at www.cancer.org and www.cancer.gov
Additional prostate cancer information is also available at www.prostatecalif.org and www.ustoo.org

Many cancer research centers and advocacy groups suggest that every man consider having a prostate cancer test at age 40 to establish a baseline for future reference. Men with a family history of prostate cancer and African American men should consider having this test at age 35. The basic prostate cancer test consists of a simple blood test called a PSA (prostate-specific antigen) followed by a DRE (digital rectal exam). Both of these simple tests can be conducted in the local family doctor's office.

To obtain additional copies, or provide a comment, contact wdoss@surewest.net

file: Did you know, 2019-A

CPCC PROSTATE CANCER ADVOCACY ACTIVITIES FOR SEPTEMBER 2019: PROSTATE CANCER AWARENESS MONTH – VOLUNTEERS NEEDED

Each year many government leaders and legislative bodies around the United States recognize September as Prostate Cancer Awareness Month. Since 2005, William Doss, CPCC Board member, has spearheaded a project to increase the number of California local legislative bodies participating in this effort. Volunteers are needed to assist with this project. Bill provides volunteers with a tool kit containing all the materials and information needed to request a proclamation from local government entities. If you are interested in participating or wish to learn more, contact Bill at email: wdoss@surewest.net.

FOCUS ON PROSTATE CANCER TREATMENT AND RESEARCH IN CALIFORNIA:

Shorter Course of Radiation Therapy Effective In Treating Men With Prostate Cancer

A long-term, UCLA-led study finds that those with low- or intermediate-risk disease can safely cut treatment to 4 to 5 days that this could be a viable treatment option for men with low- and intermediate-risk prostate cancer.

A new UCLA-led study shows that men with low- or intermediate-risk prostate cancer can safely undergo higher doses of radiation over a significantly shorter period of time and still have the same, successful outcomes as from a much longer course of treatment.

This type of radiation, known as stereotactic body radiotherapy, is a form of external beam radiation therapy and reduces the duration of treatment from 45 days to four to five days. The approach has been in use since 2000, but has not yet been widely adopted because of concerns over how safe and effective this approach would be in the long term.

"Most men with low- or intermediate-risk prostate cancer undergo conventional radiation, which requires them to come in daily for treatment and takes an average of nine weeks to complete," said lead author Dr. Amar Kishan, assistant professor of radiation oncology at the David Geffen School of Medicine at UCLA and researcher at the UCLA Jonsson Comprehensive Cancer Center. "That can be very burdensome on a patient and be a huge interruption in their life. With the improvements being made to modern technology, we've found that using stereotactic body radiotherapy, which has a higher dose of radiation, can safely and effectively be done in a much shorter timeframe without additional toxicity or compromising any chance of a cure."

The UCLA research team analyzed data from 2,142 men with low- or intermediate-risk prostate cancer across multiple institutions who were treated with stereotactic body radiotherapy for prostate cancer between 2000 and 2012.

The men were followed for a median of 6.9 years. Just over half of the men had low-risk disease (53 percent), 32 percent had less aggressive intermediate-risk disease and 12 percent had a more aggressive form of intermediate-risk disease.

The recurrence rate for men with low-risk disease was 4.5 percent, the recurrence rate for the less aggressive intermediate-risk was 8.6 percent, and the recurrence rate for the more aggressive intermediate-risk group was 14.9 percent. Overall, the recurrence rate for intermediate-risk disease was 10.2 percent. These are essentially identical to rates following more conventional forms of radiation, which are about 4 percent to 5 percent for low-risk disease and 10 percent to 15 percent for intermediate-risk disease.

"What is remarkable about this very large study is how favorably stereotactic body radiotherapy compares to all other forms of radiation treatments, both in terms of effectiveness and side effects," said senior author Dr.

Shorter Course of Radiation Therapy Effective In Treating Men With Prostate Cancer Continued:

Christopher King, professor of radiation oncology and scientist at the UCLA cancer center. "With such long-term follow-up data, we can now offer this approach to patients with full confidence."

Researchers have previously found that stereotactic body radiation therapy was more cost effective because of the fewer treatments involved. Other research has also suggested psychological benefits such as less regret about undergoing treatment. The current study now provides long-term data regarding the safety and clinical efficacy of this approach.

Kishan said the data show that the majority of the men followed are free of prostate cancer seven years after treatment. He added that there was no evidence that this therapy caused worse toxicity in the long term. "In fact," Kishan said, "we not only confirm that this method is both safe and effective, but we provide significant evidence that this could be a viable treatment option for men with low- and intermediate-risk prostate cancer."

The study was published 02/08/2019 in JAMA Network Open.

Source: <https://www.uclahealth.org/shorter-course-of-radiation-therapy-effective-in-treating-men-with-prostate-cancer/> Reprinted with permission.

FOCUS ON CALIFORNIA PROSTATE CANCER SUPPORT GROUPS:

Santa Cruz County Prostate Cancer Support Group

- **Meeting Date/Time:** Meets the last Wednesday of each month, 7:00 pm to 9:00 pm. Wives and partners are welcome at meetings.
- **Meeting Location:** The Bennett and Suzy Katz Cancer Resource Center, 3150 Mission Drive, Santa Cruz CA 95065
- **Website:** <http://www.scprostate.org>
- **Contacts:** Howard Waage at (831) 334-0969, Bill McDermott at (831) 423-8350, or Joe Ferrara at (831) 426-7724.

Need information about support groups in California? Go the CPCC web site to locate the nearest support group to you at <http://prostatecalif.org/>

SANTA CRUZ COUNTY PROSTATE CANCER SUPPORT GROUP: VOLUNTEERS WHO MAKE A DIFFERENCE

Mission:

The mission of the Santa Cruz County Prostate Cancer Support Group is to provide hope and support to improve the lives of those affected by prostate cancer and educate the general population on the importance of early detection.

Affiliations:

The Santa Cruz County Prostate Cancer Support Group is affiliated with the Dignity Health-Dominican Hospital Foundation and the Katz Cancer Resource Center, US Too! International and the California Prostate Cancer Coalition.

History

The Santa Cruz County Prostate Cancer Support Group (SCCPCSG) is the vision of one man, Frank Bolle. When Frank was diagnosed with advanced prostate cancer in 1991, he discovered that there were no men's support group in the Santa Cruz area. So, he organized and founded the "MEN CAN ACT" prostate cancer support group. When the group started, there were approximately 15 men who attended. Frank Bolle convened the group on a regular schedule and led the group to share experiences and information with each other. Frank passed away from his disease in April 1999.

Santa Cruz County Prostate Cancer Support Group: Volunteers Who Make A Difference Continued:

As the support group grew in membership, a Steering Committee was formed to ensure continuity with members Howard Waage, Tony Calvo, Frank Schmetz, Tim Ryan, and Doug Thorton. These men agreed to rotate the leadership of the general meetings and to meet monthly to evaluate issues such as special speakers and expenditures for educational materials. In 1999 the steering committee renamed the group the Santa Cruz County Prostate Cancer Support Group (SCCPCSG). In March 1999, the first monthly newsletter was mailed out to our membership.

The Steering Committee recognized that when a man is diagnosed with prostate cancer, it affects his entire family. Therefore, the Steering Committee and the members decided to welcome our spouses and partners to the regular meetings. Women were invited to attend the first co-ed meeting on November 26th, 2002.

The Santa Cruz County Prostate Cancer Support Group continues to grow as group of men and their partners that assist and support families in dealing with the issues of prostate cancer. The current membership is over 250 individuals.

Community Outreach and Education

The SCCPCSG members are very active in community outreach to increase awareness about prostate cancer. The Steering Committee developed a brochure for distribution at community events called "Understanding Prostate". In addition, the group maintains a free lending library with up to date books about prostate cancer, prevention, diagnosis and treatment options at the Katz Cancer Resource Center. Current literature, pamphlets and newsletters are available at each meeting.

The SCCPCSG takes advantage of unique opportunities to spread the word about prostate cancer in the community. For example, a few years ago, Howard Waage reports he and Joe Ferrara had the chance to educate about 400 boys at Palma High School. This outreach was made possible thanks to Howard's daughter, Kristen Cannon, and Howard's three grandsons who were students at the school. Howard and Joe spoke to six classes of students and teachers about prostate cancer. An age appropriate information sheet developed with the assistance of US TOO, was given to the young men with a refrigerator magnet to take home. In addition, they convinced the Palma HS and Hartnell College football teams to wear blue socks and blue ribbons on their helmets. The Palma HS varsity game was broadcast on the local KION-AM radio. The announcer and sports commentator read a message encouraging men to talk to their physicians about getting screened and to know their PSA score. That message was repeated about every 20 minutes.

Another unique and ambitious outreach program supported by SCCPCSG is the annual Songfest, the brainchild of Joe Ferrara. This event provides another opportunity to educate individuals about prostate cancer awareness and the work of the support group in a fun and festive atmosphere. See the information below.

The Santa Cruz County Prostate Cancer Support Group exemplifies what a committed group of volunteers can do when they believe in a cause. This group has certainly made a difference in educating their community about prostate cancer.

11th ANNUAL SONGFEST

Date: September 7, 2019, Time to be announced

Sponsored by: The Santa Cruz County Prostate Cancer Support Group

Featuring: Joe Ferrara, Claudio Melega, Steve Kritzer, Tammi Brown & Yuji Tojo, Rocky Pase, Rhan Wilson's All in Good Time Orchestra

Location: Kuumbwa Jazz Center, 320-2 Cedar St., Santa Cruz

Cost: Free

Thanks to Howard Waage for providing the information for this article. Edited by Beverly Nicholson.

California Prostate Cancer Coalition Information



Left to Right: William Doss, Westley Sholes, Tiffany Razzo, Beverly Nicholson, Tom Kirk, Merel Grey Nissenberg, Ericka Maldonado-Aviles, guest speaker, and Earl Jones at November 2018 Face to Face CPCC Board Meeting.

Board of Directors

Merel Grey Nissenberg, Esq, President
Thomas Kirk, Vice President
Earl H Jones Jr., Treasurer
Tiffany Razzo, Secretary
Frank Balthis
Arthur "Tony" Blain, MD, MBA, FAAFP
Barry Chauser, MD
Marc A. Dall'Era, MD
William Doss
Joe Ferrara
Arthur Lurvey, MD, FACP, FACE
Carol Marcusen, MSW, LCSW
Leonard S. Marks, MD
Beverly Nicholson, RN, CNS
Stan Rosenfeld
Joseph E. Scherger, MD, MPH
Westley Sholes, CPCC-A President
Sam Wells

Mailing Address:

6709 La Tijera Blvd, Ste 473
Los Angeles, CA 90045

Phone: (310)525-3570

Email: cpcc@prostatecalif.org

Website

Earl Jones, webmaster:
ejonesjr12@ca.rr.com

Newsletter Editor

Beverly Nicholson
beverlynicholson@comcast.net

Donate Now

Donate online at <http://prostatecalif.org/donate-now> or mail donations to:

California Prostate Cancer Coalition,
c/o Earl Jones, Treasurer
4581 Don Felipe Drive
Los Angeles, CA 90008

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.

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.



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.cancercares.org.

CONNECT WITH US

 **FACEBOOK**
www.facebook.com/cancercares

 **BLOG**
www.cancercares.org/blog

 **YOUTUBE**
www.youtube.com/cancercaresinc

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

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, LMSW
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.

