



“Fighting Prostate Cancer in California!”

www.prostatecalif.org

News

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September 2018

PRESIDENT’S MESSAGE

Welcome to the Fall 2018 Newsletter of the California Prostate Cancer Coalition (CPCC), now in our 21st year of helping patients and their families as a not-for-profit 501(c)(3) organization. Our Board is comprised of very active worker bees who accomplish so much throughout the State. Please see www.prostatecalif.org for details on our work and our resources.

Our Informed Decision-Making Tool (the “Laminate”) is now on the website of the California Department of Public Health and has been adopted by the National Alliance of State Prostate Cancer Coalitions (NASPCC) as a national project. It is co-branded with NASPCC with room for other states to add their own state prostate cancer organization logo on either side. After the United States Preventive Services Task Force (USPSTF) finalized its new Guidelines for Prostate Cancer Screening a few months ago, CPCC updated this important awareness and educational tool to make it current. We were fortunate that a few months ago the California Department of Health Care Services mailed out the Laminate (as well as copies) to a multitude of primary care providers in the State, so hopefully our message about informed decision-making is making its way to patients and to physicians.

Speaking of the USPSTF Guidelines, CPCC does not approve of the Taskforce’s final prostate cancer screening recommendations for several reasons. First, they only recommend informed discussions about testing between physicians and patients between 55 and 69, totally rejecting any testing for men 70 and over. Next, while the Guidelines mention men at high risk, they only include African-American men and men with a family history, completely failing to mention men who have been exposed to Agent Orange. Even then, the Guidelines do not set an earlier age for informed discussions and testing for these men at higher risk. As President of the National Alliance of State Prostate Cancer Coalitions, I wrote the Task Force a letter setting out our objections.

I attended various national meetings this year in Prostate Cancer, including ASCO GU (February, 2018); the AUA (May, 2018) and the general ASCO Meeting (June, 2018). I also participated in the AUA’s 1st Annual Advocacy Summit in March in Washington, D.C. and spoke about Informed Decision-Making. Attendees took home all 100 Laminates I had brought to the Summit. Reports I prepared on ASCO GU (<https://tinyurl.com/yayvcubo>) and from ASCO (<https://tinyurl.com/y7b5po92>) are on NASPCC’s website: www.naspcc.org. I also wrote an article on hypofractionated radiation therapy for an issue of Prostatepedia (<https://prostatepedia.blog/2018/07/02/ms-merel-nissenberg-hypofractionated-radiotherapy/>).

On September 17, 2018 the CPCC Board will have its first Fall Face-to-Face Meeting in Los Angeles. Normally the Board meets once a year in January convening in San Francisco. This year it was decided that a Fall Face-to-Face Board Meeting should be added on a yearly basis to better track our progress on Action Items we chose and discussed in January. We will include a report on the September Board Meeting in the next Newsletter.

Elsewhere in this Newsletter you will find details about CPCC’s Northern California Prostate Cancer Support Group Leaders’ Workshop scheduled for November and moderated, as always, by Board Member Stan Rosenfeld. You will also read about the 14th Annual Meeting of the National Alliance of State Prostate Cancer Coalitions (NASPCC) which we will be holding in Washington, D.C. on Capitol Hill. We are excited to begin months of planning for a statewide Prostate Cancer Summit which we just learned we will be co-hosting with UCSF. Stay tuned for details but we are planning the event for next Spring. It has been a very long time since we have held a California-wide (and beyond) prostate cancer meeting and we are thrilled about the opportunity.

PRESIDENT’S MESSAGE CONTINUED:

Our mission continues, and our work grows by leaps and bounds. We could use assistance with our website and we welcome volunteers to help us in our activities. We hope to always be of benefit to men and their families. Lastly, we’d like to wish our Treasurer, Earl Jones, a speedy recovery.

Respectfully submitted, Merel Grey Nissenberg

NEW EVIDENCE SHOWS THE BENEFIT OF PSA SCREENING

A recent article in the journal, Urology, investigates the question whether prostate cancer screening with prostate-specific antigen (PSA) is beneficial in reducing prostate cancer mortality. The article concludes that the answer is “yes” based on the results of this new study. A retrospective cohort study was conducted of 400,887 men under age 80, with no history of prostate cancer, who had PSA testing at Kaiser Permanente Northern California in the 5 calendar years; 1998-2002. The men were also followed up for 12-16 years. The data showed that yearly PSA screening was beneficial, reducing prostate cancer deaths by 64% for men aged 55-75 years.

The article concludes by stating that yearly PSA screening is highly effective in reducing both prostate cancer mortality and all-cause mortality in men with prostate cancer. When it is combined with active surveillance to prevent overtreatment, the data lends support for PSA screening for men in good health ages 55-75.

For more detail regarding this study, go to the website: [https://www.goldjournal.net/article/](https://www.goldjournal.net/article/S0090-4295(18)30376-5/abstract)

S0090-4295(18)30376-5/abstract

---- William Doss

California Designates September 2018 as Prostate Cancer Awareness Month



Senator Ted Gaines presents Senate Concurrent Resolution 142 to William Doss, California Prostate Cancer Coalition Board member.

For the past thirteen years William Doss, CPCC Board member, has spearheaded a project on behalf of CPCC to obtain proclamations from legislative bodies throughout the State of California to recognize September as Prostate Cancer Awareness Month. Over the years this activity has generated much publicity, educating thousands of people about the prevalence of prostate cancer and the importance of early detection. Bill receives help from a cadre of devoted volunteers who approach their local county and city governments about this project. This year the California Senate Concurrent Resolution 142 was sponsored by Senator Ted Gaines at the request of Bill. If you are interested in participating in this project in the future, contact Bill at email: wdoss@surewest.net.



Senate Concurrent Resolution No. 142—Relative to Prostate Cancer Awareness Month

SCR 142, Gaines. Prostate Cancer Awareness Month. This measure would proclaim the month of September 2018 as Prostate Cancer Awareness Month in California.

WHEREAS, Prostate cancer is the most frequently diagnosed cancer in men and the second leading cause of cancer deaths in men; and

WHEREAS, The American Cancer Society estimates there will be 164,690 new cases of prostate cancer in the United States in 2018, resulting in an estimated 29,430 deaths; and

WHEREAS, It is estimated that 15,190 men in California will be diagnosed with prostate cancer this year, and it is estimated that 3,490 of these men will die from this disease; and

WHEREAS, African American men in the United States and Caribbean have the highest documented prostate cancer incidence rates in the world; and

WHEREAS, Early prostate cancer usually has no symptoms and studies suggest strong familial predisposition may be responsible for 5 to 10 percent of the disease cases; and

WHEREAS, Advanced prostate cancer commonly spreads to the bones, which can cause pain to the hips, spine, ribs, or other areas of the body; and

WHEREAS, The five-year survival rate approaches 100 percent when prostate cancer is diagnosed and treated early, but drops to 30 percent when it spreads to other parts of the body; and **WHEREAS**, Prostate cancer treatment decisions should be based on clinician recommendations and patient values and preferences; and

WHEREAS, The American Cancer Society recommends that men should have an opportunity to make an informed decision about whether or not to be tested for prostate cancer based on their personal values and preferences; now, therefore, be it

Resolved by the Senate of the State of California, the Assembly thereof concurring, That the Legislature of the State of California hereby proclaims the month of September 2018 as Prostate Cancer Awareness Month in California; and be it further

Resolved, That the Legislature joins communities across our nation to increase awareness about the importance for men to make informed decisions with their health care providers about early detection and testing for prostate cancer; and be it further

Resolved, That the Secretary of the Senate transmit copies of this resolution to the author for appropriate distribution.

A PROSTATE CANCER WARRIOR LEAVES US



CPCC is sad to report the passing of **Lewis Musgrove**, a giant of a man and a tireless warrior in prostate cancer on August 14, 2018. Lew was one of the founding members of the California Prostate Cancer Coalition in 1997. Although he lived in Las Vegas, CPCC kept Lew on our Board of Directors for as long as possible because he was a wonderful colleague and an activist in saving men's lives and helping their families.

Lew worked with the State of Nevada in creating their Prostate Cancer Task Force and he led a vibrant UsTOO Support group in Las Vegas that I was fortunate to address at one of their meetings. Lew also became the first Nevada representative to the National Alliance of State Prostate Cancer Coalitions. He participated in the first organizational meeting of NASPCC in 2004 and served on our Board of Directors. We at CPCC and at NASPCC were always lucky to have the benefit of his wise counsel and endearing personality.

Always passionate, Lew had a favorite expression that I remember fondly. He wanted people to stay focused, otherwise, he would say, it was like "getting on your horse and riding off in all directions". Lew was vigilant in seeking and training patients and state leaders to create ways to contact federal and state representatives to order to make the needs of the prostate cancer community known. He also served as Chairman of the Board of UsTOO International.

We at CPCC and NASPCC were proud to call Lew Musgrove our own. Lew leaves behind children and a caring wife, Sue Ann. Condolence cards can be mailed to Lew Musgrove's family at: 6408 Vicuna, Las Vegas, Nevada 89146. Contributions can also be made to CPCC in Lew Musgrove's name by sending them to the CPCC Treasurer, Earl Jones, at 4581 Don Felipe Drive, Los Angeles, California 90008.

--Merel Nissenberg

NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS (NASPCC) PLANS ANNUAL MEETING

NASPCC is preparing for their 14th Annual Meeting in Washington, D.C. to be held October 12 – 14, 2018. The 14th Annual Meeting is entitled "The More We Know." There will be individual speakers such as Dr. James Gulley from NIH with an update on Immunotherapy in Prostate Cancer; as well as a speaker on the Importance of Hereditary Cancer Testing in Prostate Cancer. In addition, there will be separate panels on a variety of important topics. Alan Partin, head of the Brady Urologic Institute at Johns Hopkins will be honored. NASPCC will also be awarding the 2018 Outstanding State Prostate Cancer Organization Award. For more information go to <https://www.naspcc.org/>.

NORTHERN CALIFORNIA PROSTATE CANCER SUPPORT GROUP LEADERS' WORKSHOP PLANNED

The annual Northern California Prostate Cancer Support Group Leaders' Workshop sponsored by CPCC will be held on Monday, November 28, 2018 in San Francisco. As always, this popular all-day workshop will be facilitated by CPCC Board Member Stan Rosenfeld. For additional information, please contact Stan Rosenfeld at vegstan2@ix.netcom.com. Plans for the next Southern California workshop will be announced later this year.

FOCUS ON CALIFORNIA PROSTATE CANCER SUPPORT GROUPS

Santa Cruz County Prostate Cancer Support Group

- Meets the last Wednesday of each month from 7:00 pm to 9:00 pm
- Meeting Location: The Bennett and Suzy Katz Cancer Resource Center, 3150 Mission Drive, first floor, Santa Cruz CA 95065
- Phone: The Bennett and Suzy Katz Cancer Resource Center at (831) 462-7770.
- email: scprostate1992@gmail.com
- Web site: <http://scprostate.org>
- For comments or questions of a more urgent nature send an email to scprostate1992@gmail.com

HISTORY

The Santa Cruz County Prostate Cancer Support Group (SCCPCSG) was the vision of one man, Frank Bolle. When Frank was diagnosed with advanced prostate cancer in 1991, he faced a difficult challenge in uncovering the most appropriate treatments available. Upon finding minimal sources of information about prostate cancer, Frank formed and led the "MENCANACT" support group in 1992 to share information and experiences about this disease among its members. Frank unfortunately passed away from his disease in 1999, however his legacy lives on. Since its humble beginnings several milestones have been achieved. A steering committee was formed to ensure the ongoing continuity of the support group. The original members were Howard Waage, Tony Calvo, Frank Schmetz, Tim Ryan, and Doug Thorton. The group was renamed to "Santa Cruz County Prostate Cancer Support Group" (SCCPCSG). The group's Constitution and By-Laws were established and ratified. The first monthly newsletter was mailed out to the membership which later evolved into an email newsletter.

Spouses and partners were invited to attend the meetings. When a man is diagnosed with prostate cancer, it affects the entire family and we believe that his family should be part of the support group. With over 300 members, the support group continues to grow in assisting and supporting families in dealing with the issues of prostate cancer. Participation in a support group can greatly ease the burden of isolation through the journey to health and emotional well-being. The average meeting attendance is 25 members.

LIBRARY

The Santa Cruz County Prostate Cancer Support Group maintains up to date books about prostate cancer, prevention, diagnosis and treatment options for anyone interested in researching information about this disease. Our library is located at the Katz Cancer Resource Center located at 3150 Mission Drive, Santa Cruz, CA. We also provide current literature, pamphlets and newsletters available at each meeting.

AFFILIATIONS

The Santa Cruz County Prostate Cancer Support Group is affiliated with the organizations listed below. A special thanks goes to Dominican Hospital and the Katz Cancer Resource Center for the use of their facilities.

- Dominican Hospital Foundation
- Katz Cancer Resource Center
- California Prostate Cancer Coalition
- US Too International
- Palo Alto Medical Foundation

STAN ROSENFELD, CPCC BOARD MEMBER, SERVES AS PATIENT REPRESENTATIVE ON THE NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN) PROSTATE CANCER PANEL

NCCN is one of the most, if not *the* most respected medical organizations in the world. Physicians choose medical treatments and insurers decide to pay for treatments based on NCCN recommendations. NCCN is an alliance of leading cancer centers devoted to patient care, research, and education. See article below for more information.

Years ago, I was honored to be asked to join the NCCN Prostate Cancer Panel. The panel includes physicians who are nationally recognized experts in prostate cancer treatment. We meet by phone throughout the year and once a year in person. At these meetings we review the latest research related to treatments for prostate cancer. If there is sufficient evidence, changes are made to the guidelines and new treatments are included in the “NCCN Guidelines® for Prostate Cancer.” I am asked to represent the patient perspective in our decisions on what to include in our recommendations. I also work on the patient version of these guidelines which is available to educate patients about their options.

The meetings are very interesting with a lot of back and forth discussions between the members. Submissions are made by pharmaceuticals and other companies who ask for their products to be included in the NCCN guidelines. Some products are reviewed positively, others are not. Once we approve changes to the guidelines all decisions are kept confidential as to not influence stock prices of companies impacted by the NCCN decision.

I have met many new physicians through this panel and we continue to communicate throughout the year. I feel that I make an important contribution in my role as a patient representative and plan to continue as a member of the panel.

----- Stan Rosenfeld



Your best resource in the fight against cancer. ®

What is NCCN?

The National Comprehensive Cancer Network (NCCN), a not-for-profit alliance of leading cancer centers devoted to patient care, research, and education, is dedicated to improving the quality, effectiveness, and efficiency of cancer care so that patients can live better lives.

What we do

The core resources made available by NCCN are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). These guidelines are the recognized standard for clinical policy in oncology and are the most comprehensive and most frequently updated clinical practice guidelines available in any area of medicine. Covering 97 percent of all patients with cancer and updated on a continual basis, the NCCN Guidelines® are developed through and explicit review of evidence (clinical trials, existing treatment protocol, etc.) integrated with expert medical judgment and recommendations by panels that are made up of representatives from the 27 NCCN Member Institutions.

How we help patients

NCCN aims to provide people with cancer and the general public with state-of-the-art cancer treatment information in easy-to-understand language. The NCCN Guidelines for Patients®, translations of the NCCN clinical guidelines, help patients with cancer talk with their physicians about the best treatment options for their disease.

The NCCN professional and patient guidelines may be accessed and downloaded on the web site.

For physician guidelines go to: https://www.nccn.org/professionals/physician_gls/pdf/prostate.pdf

For NCCN Patient Guidelines go to:

<https://www.nccn.org/patients/guidelines/prostate/index.html>

Reference: <https://www.nccn.org>

***** FREE CONCERT *****

Santa Cruz County Prostate Cancer Support Group

Presents Our

10th Annual Songfest

for

Prostate Cancer Awareness

Saturday, September 22nd

5:00 – 8:00 p.m.

Doors open at 4:30 p.m.

Kuumbwa Jazz Center

320-2 Cedar Street, Santa Cruz, CA

www.kuumbwajazz.org



SANTA CRUZ COUNTY
PROSTATE CANCER SUPPORT GROUP

seprostate.org



CALIFORNIA
Prostate
Cancer
COALITION



Joe Ferrara



Tammi Brown & Yuji Tojo



Vince Tuzzi



Steve Kritzer



Rocky Pase & Carol Thorson



Kylan deGhetaldi

Take home our free informational pamphlet "UNDERSTANDING PROSTATE CANCER" available in both ENGLISH & SPANISH and the INFORMED DECISION-MAKING LAMINATE courtesy of the CPCC.

Representatives from these organizations will be in attendance to answer questions about men's health.



The Katz Cancer Resource Center



NOURISH
mind body spirit

Salud Para La Gente

Working Together for a Healthy Community



Event sponsored by the Santa Cruz County Prostate Cancer Support Group. For more information call (831) 426-0158.

CALIFORNIA PROSTATE CANCER COALITION INFORMATION



(Left to Right: Earl Jones, Dottie Ferrara, Joe Ferrara, Dr. Barry Chausser, Merel Grey Nissenberg, Stan Rosenfeld, Bill Doss, Beverly Nicholson, and Tom Kirk at the Annual Board of Directors Face to Face Meeting)

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Donate Now - Mail Donations to:

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

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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 leaders workshops, publishing a quarterly newsletter, maintaining our website, sponsoring educational conferences, and other related programs. Please help us continue to work for you!
Thank you.