



“Fighting Prostate Cancer in California!”

www.prostatecalif.org

News

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PRESIDENT’S MESSAGE

Welcome to our Spring 2018 Newsletter! We are so grateful to our Board Member and Newsletter Editor, Beverly Nicholson, for her excellent leadership on this project. 2018 has already been an active year – starting with our Face-to-Face Board Meeting in San Francisco on January 10 – a Meeting that you’ll read about in this Newsletter. One of the most important Board actions that day was a decision to convert our Meeting Schedule from one Face-to-Face Board Meeting a year held in January, to two Face-to-Face Meetings a year instead, one in September just after we’ve started our new Fiscal Year, and the second one in April, as a monitoring and follow-up Board Meeting. Of course, we also still meet by phone every month to lead the organization forward.

In early February our Vice President, Tom Kirk and I prepared and circulated to the Board our first ever Annual Report, which covers 2017-2018. It is a microcosm of many programs and achievements during the past year, including two successful Support Group Leaders’ Workshops led by Board Member Stan Rosenfeld; a superb Prostate Cancer Proclamation project spearheaded by Board member Bill Doss; the creation of an 8-panel new CPCC Brochure led by Tom Kirk; modification and dissemination of our impressive Informed Decision-Making Laminate, including 700 sent to the Vietnam Veterans of America; and participation by CPCC in efforts and activities of other organizations, such as a Komen Race for a Cure in Breast Cancer in Sacramento. We also activated CPCC’s Facebook Page and now post medical and scientific news several articles a week.

As President I attend various meetings during the year where I represent CPCC as well as NASPCC, since CPCC is a “Proud participant in the National Alliance of State Prostate Cancer Coalitions” as the new CPCC Brochure cover reflects. I represented CPCC at the 13th Annual Meeting of NASPCC last October on Capitol Hill; and attended the ASCO GU Meeting in San Francisco. I created a Report on the scientific news coming out of that Meeting that appears on the NASPCC Website at <https://tinyurl.com/yayvcubo>

In early March I was on the AUA Advocacy Summit Panel on Informed Decision-Making, and distributed over a hundred of our Informed Decision-Making Laminates. I will also be attending the Annual AUA Meeting in May and bringing the Laminates with me as I participate in the AUA Advocacy Hub; and I will be attending the Annual ASCO Meeting in June. Please share with me any ideas or thoughts you have for me as I participate in these Meetings.

We continue to support the IMPACT Program for underserved men with prostate cancer in our state; and we enjoy a working relationship with the California Dept. of Public Health (DPH) and the California Dept. of Health Care Services (DHCS). In fact, our Informed Decision-Making Laminate appears on the website for the DPH, a feat that took a few years to accomplish. For 2018 we envision two Support Group Leaders’ Workshops; the continuation of our quarterly Newsletter; expanded outreach initiatives; quarterly webinars; and planning for a statewide prostate cancer symposium. Come along with us; join our efforts and help save men’s lives by making prostate cancer a health care priority in our State.

Best regards, Merel Grey Nissenberg, President

CPCC RESPONSE TO USPSTF RECOMMENDATIONS

On May 8, 2018 the U.S. Preventive Services Task Force issued its new Final Recommendations for Screening for Prostate Cancer:

“Based on a review of the evidence, the Task Force recommends that men aged 55 to 69 years make an individual decision about whether to be screened after a conversation with their clinician about the potential benefits and harms. For men 70 years and older, the potential benefits do not outweigh the expected harms, and these men should not be routinely screened for prostate cancer. To view the recommendation and the evidence on which it is based, please go to www.screeningforprostatecancer.org. The final recommendation statement can also be found in the May 8 online issue of JAMA.”

The new USPSTF Recommendations are contrary to CPCC’s Guidelines which emphasize the early detection of potentially lethal prostate cancer and stress the importance of Informed Decision-Making for all men 40 and over. CPCC’s Informed Decision-Making Laminates can be found here: <http://prostatecalif.org/patient-guide>. In addition, we do not advocate for a cut-off of testing for men 70 and over, as does the USPSTF. There are many men in that age group in good health, active and with more than a 10-year life expectancy. Lastly, the new Recommendations do not include an earlier age for testing for men they acknowledge are at high risk (African-American men and men with a family history of prostate cancer). Also, the USPSTF does not even mention the group of men who have been exposed to Agent Orange (who are at high risk for a diagnosis of prostate cancer). CPCC believes that the new USPSTF Recommendations are a step, but only a step, in the right direction, at least as far as men 55-69 are concerned (who now have a “C” Recommendation rather than a “D”).

STATUS ON CPCC INFORMED DECISION LAMINATES

CPCC’s Informed Decision-Making Laminates is everywhere! It will appear in the next issue of the California Dialogue on Cancer (CDOC) Newsletter as part of the “Resources” block. The Laminates was a big hit with the urologists at the AUA 1st Annual Advocacy Summit in Washington, D.C. in March, at which Merel Nissenberg presented on the topic of Shared Decision-Making in

Prostate Cancer. The link to the current Laminates is <http://prostatecalif.org/patient-guide>.

FOCUS ON CALIFORNIA PROSTATE CANCER SUPPORT GROUPS:

Silicon Valley Prostate Cancer Education and Support Group

- **Meets the 1st Thursday of each month, 5:00 pm to 6:45 pm (no meeting in July)**
- **Meeting Location:**
El Camino Hospital
2500 Grant Road, Mountain View, CA 94040
Conference Room E/F
(Ground floor, next to cafeteria in the new building).
- **Website: PCaSupportGroup.org,**
- **Phone: 800-216-5556**

The Silicon Valley Prostate Cancer Education and Support Group, an Us TOO support group, was formed about twenty years ago. Ted Chamberlain facilitated this group for more than 15 years. Following Ted, Frank Weiss facilitated this group for 5 years until December 2017.

Rupen Sheth is the current facilitator for this group. Rupen is a co-founder of a cloud solutions company in Silicon Valley and has been in the high-tech industry for 28 years. Rupen was diagnosed with prostate cancer in April 2016, and went through HDR Brachytherapy, IMRT, and ADT in 2016-2017. Rupen has also been responsible for setting up the website in order to help others get access to relevant information about the local support groups and references that can help them in their PCa journey. We average about 35 attendees per meeting with a few new attendees in each meeting that gets an opportunity to talk about their situation and try to get information or answers to some of their questions. Attendees are from all over the San Francisco Bay Area, and sometimes from other locations.

The goal of the support group is to educate others, invite guest speakers, provide a forum and meeting place to share information and experiences, and to help each other have a good quality of life as part of their PCa journey. The meetings are open to all, and anyone is welcome to attend. Attendees are encouraged to bring their spouse, partner, family member, or friend to the meeting since they are usually very stressed. They

provide helpful moral support, a second set of ears, and are often active participants in the discussions.

The group has a core of regular attendees who are very experienced and knowledgeable survivors of prostate cancer. They have consulted with many of the leading prostate cancer physicians and received a wide range of therapies. Some of these core attendees, Dean Andrus, Don Bradley, George Cleveland, Walt D'Ardenne, Jim McCoy, Ron Miller, Roger Schaaf, Rupen Sheth, and Phil Steward, are members of the group's steering committee.

We are not medical professionals and cannot give medical advice. We share experiences, opinions, and provide emotional support. Each attendee is unique and our objective is to help each one develop the best action plan for him. Attendees are asked to check with their doctor before implementing anything the group might suggest.

UPCOMING EVENT:

The group is scheduled to participate in the **5th Annual Cancer Survivor's Day** event hosted by the El Camino Hospital Cancer Center on **Saturday June 2, 2018 from 12:00PM to 4:00 PM at El Camino Hospital on the ground floor of the main hospital located at 2500 Grant Road, Mountain View, CA 94040.** This is the Cancer Center department largest hospital event in the celebration for those surviving, an inspiration for those recently diagnosed, and a gathering of support for all those affected by cancer in our community. Join us to connect with others and learn ways to improve your quality of life. Activities include inspiring keynote and clinical speakers, community resource tables, art displays, and food.

The two sister support groups listed on our joint web page are oriented towards attendees newly diagnosed, undergoing treatment, recurrence, advanced, or just wanting to stay educated. They are:

- **Silicon Valley Advanced Prostate Cancer Support Group** facilitated by Walt D'Ardenne meets the first Thursday of each month from 5:00 PM to 6:45 PM (except January and July) in Conference Rooms A/B of El Camino Hospital Mountain View, and
- **San Jose Prostate Cancer Support Group** facilitated by Mike Culcasi meets the second Tuesday of each month from 12:30 PM to 2:30 PM in Conference Room 3 of El Camino Hospital Los Gatos.

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

SPOTLIGHT ON DR. CHARLES J. RYAN

After many years heading up Urologic Medical Oncology at UCSF, Dr. Ryan is moving to the University of Minnesota Medical School as the new Director of the Hematology, Oncology and Transplantation Division in the Department of Medicine. He will also serve as Associate Director for Clinical Research in the Masonic Cancer Center and will hold the B.J. Kennedy Chair in Clinical Medical Oncology.

On February 27th, 2018 the Marin Prostate Cancer Information and Support Group awarded Dr. Ryan our physician award for his invaluable service to the prostate cancer community with the following presentation text:

Most people needing treatment for their illness look for the best medical skills in a doctor, but often must compromise when it comes to "bedside manner". No compromise is necessary with Dr. Charles Ryan

Many men in our support group report how much time Dr. Ryan is willing to spend with them, answering all their questions, and making sure they understand their options.

Dr. Ryan is a kind, sympathetic, compassionate, and caring doctor.

These skills for physicians working with more advanced cases of prostate cancer, are especially essential.

Dr. Ryan is world famous for his research and knowledge of advanced prostate cancer.

Dr. Ryan keeps up on all the leading-edge technologies and techniques and makes sure that his patients are aware of the most current advances, not just in treatment, but life style including exercise and diet.

And Dr. Ryan has just written and published an excellent book on testosterone, titled *The Virility Paradox, The Vast Influence of Testosterone on Our Bodies, Minds, and the World We Live In.*

Dr. Ryan is one outstanding physician!

And now we are losing Dr. Ryan to The University of Minnesota Medical School as the new Director of the Hematology, Oncology and Transplantation Division in the Department of Medicine. He will also serve as Associate Director for Clinical Research in the Masonic

Cancer Center and will hold the B.J. Kennedy Chair in Clinical Medical Oncology. Our tremendous loss is their phenomenal gain. Congratulations Chuck!

It is one thing, and wonderful, when a doctor receives recognition from his colleagues. But when his patients also acknowledge and honor him you know that he is an extraordinary person!

SO...

The Marin Prostate Cancer Information and Support Group is delighted to award Dr. Charles J. Ryan our 2017 physician award In Recognition for His Invaluable Contributions to the Prostate Cancer Community.

Dr. Ryan has published a very informative book which could just as well be titled Everything You Wanted to Know about Testosterone. But is in fact titled The Virility Paradox: The Vast Influence of Testosterone on Our Bodies, Minds, and the World We Live In

Testosterone propels our drive for exploration and risk, for competition and creation, and even our survival. The effects of testosterone permeate the traditions, philosophy, and literature of every known culture - without it, the world would be a drastically different place. It also has a role in humanity's darker side, contributing to violence, hubris, poverty, crime, and selfishness. Recent revelations of the science of testosterone show that high levels will deplete compassion and generosity, and even reduce the affection we show our children.



(Stan Rosenfeld presenting Dr. Ryan with an award recognizing his work with Marin Prostate Cancer Support Group)

CPCPC PARTICIPATES IN THE FIRST EVER AUA ADVOCACY SUMMIT

NASPCC participated in the 1st AUA Annual Advocacy Summit on the topic of Informed (Shared) Decision-Making. Merel Nissenberg presented and distributed 100

of our Informed Decision-Making Laminates to some of the 260 attendees at the Summit. The AUA has requested follow-up to see how they can collaborate with NASPCC to help patients.

NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS WEBINAR SERIES



(Ryan Dittamore and Deb Davidson)

Our April 3, 2018 NASPCC's 2nd-in-series Webinar was presented by Ryan Dittamore of Epic Sciences and Deb Davison of Genomic Health on the topic of "AR-V7 Splice Variant and Treatment Choices in Prostate Cancer". Registration was free, and using the GoToWebinar platform, there were 100 portals for attendees to participate.



(Dr. Leonard Gomella)

Our May 9, 2018 3rd-in-series Webinar took place May 9, 2018 and was presented by Dr. Leonard Gomella on the topic of "Genetic Testing and Genetic Counseling". His presentation covered the topics that make up the Consensus Statement from Philadelphia in the Fall of 2017 on Genetic Testing in Prostate Cancer, such as for BRCA 1 and 2 alterations and mutations. These changes are important for men with prostate cancer but also for women in their families with respect to risk of other cancers.

Both Webinars are archived on the NASPCC.org Website.

Any questions on future Webinars, contact mgrey@ucsd.edu.

CALIFORNIA PROSTATE CANCER COALITION PARTICIPATES IN COMMUNITY EVENT

“Members of the California Prostate Cancer Coalition (CPCC) residing in the Greater Sacramento area are preparing for the annual Komen breast cancer “Race for the Cure” 5k walk/run event. This annual cancer awareness event is conducted each year at the Sacramento Cal Expo fairgrounds for both Northern and Central California residents. This year’s Komen event is scheduled for Saturday, May 12th. Event day registration is from 7:30 to 8:45 a.m. Once again this year, CPCC will have our prostate cancer information table at this event. During this event, we talk with event attendees and distribute information material on prostate cancer topics. Some of the most popular material we distribute includes our Coalition 8-section brochure in both the full size and the size for a woman’s purse. The other popular document we distribute is our “Prostate Cancer Decision Guide”, which we affectionately refer to as the “laminare”. Event participants enjoy carrying these documents in a CPCC blue tote bag we provide. We will repeat our prostate cancer outreach project in November when we have our CPCC information table at the Sacramento Zero 5k walk/run event.



(CPCC Table at Komen “Race for Cure”)

PROSTATEPEDIA

“Hypofractionated Radiation Therapy for Prostate Cancer”: Watch for an article by CPCC and NASPCC President Merel Grey Nissenberg on this important topic, in the upcoming Prostatepedia

PROSTATE CANCER RESOURCES

Please visit the website of the National Alliance of State Prostate Cancer Coalitions (NASPCC) for information, articles, and links to reports. Webinar recordings and slides, and other sources of information. Visit www.naspcc.org

SEPTEMBER PROSTATE CANCER PROCLAMATIONS

Look soon for information on the Proclamations Project header by CPCC Board Member Bill Doss. The Proclamations will take place in September which is “Prostate Cancer Awareness Month”. For more information, please contact Bill Doss at wdoss@surewest.net

NORTHERN AND SOUTHERN CALIFORNIA SUPPORT GROUP LEADERS’ WORKSHOPS

Look soon for information on the Northern and Southern California Support Group Leaders’ Workshop facilitated by CPCC Board Member Stan Rosenfeld. For additional information, please contact Stan Rosenfeld at vegstan2@ix.netcom.com

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)

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Donate Now

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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.