



“Fighting Prostate Cancer in California since 1997!”

News

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December 2017

PRESIDENT’S MESSAGE

Welcome to the December 2017 issue of the CPCC Newsletter. As we look forward to the holidays and stay mindful of our gratitude and our goals, we are gearing up for the New Year – 2018 – with renewed energy to constructively fight prostate cancer and save men’s lives. In doing so we improve the quality of life of wives and partners as well.

I represented the California Prostate Cancer Coalition in October at the National Alliance of State Prostate Cancer Coalitions’ 13th Annual Meeting, held in Washington, D.C. on Capitol Hill. The Meeting was exceptional, with speakers as varied as Dr. James Gulley of Building 10 at NIH discussing immunotherapy in prostate cancer; Dr. Michael Zaragoza, a urologist and President of the Delaware Prostate Cancer Coalition speaking on the USPSTF Tentative Guidelines for Screening in Prostate Cancer; Andrew Chesler of Cancer Care in New York talking about “Emotional Issues in Prostate Cancer: Patients and Caregivers”; and Mark Vieth, a federal advocate leading a session on the Congressionally Directed Mandated Research Program (CDMRP) in danger of losing its funding. At our Awards and Cocktail Reception, we welcomed guests such as the Chief Counsel for Senator Roy Blunt of Missouri, and the Executive Director of the Vietnam Veterans of America. I was once again elected President of NASPCC, and Tom Kirk (our CPCC Vice President) remains an “Invited Member of the Executive Committee of NASPCC”. For a look at the report of the 13th Annual Meeting, along with photos, go to: <http://tinyurl.com/y8g5wdk9>. Next year the 14th Annual Meeting will take place October 12-14, 2018.

CPCC has been invited to participate in various local, state and national events. In November, Board members Bill Doss and Beverly Nicholson “manned” a table at the ZERO 5 K Race/Walk in Sacramento and both spoke to the crowd about the value of informed, shared decision making in prostate cancer. They distributed our Informed Decision-Making Laminates, our new Brochures and special printed Blue Bags with CPCC Logo and Information. Congratulations to Bill and Beverly! In November I participated in the Prostate Cancer SPORE Quarterly Investigators Meeting at UCLA where new research was presented, some involving the Androgen Receptor and its function in treatment. I learned that UCLA will likely be applying for the upcoming renewal process of the IMPACT Program grant for underserved men in the state. Several years back CPCC was instrumental in making IMPACT a permanent program. We see real results with IMPACT, which is administered by UCLA.

In early November Bill Doss, Stan Rosenfeld, Beverly Nicholson and I held a call with Shauntay Davis from the California Department of Public Health (CDPH) Comprehensive Cancer Control Program, to talk about its prostate cancer program, especially in light of major cutbacks in their funding. The California Dialogue on Cancer (CDOC) Program is down now to one staff member. Due to these budget cuts activities have been scaled back. The CDOC Prostate Cancer Workgroup was disbanded along with several other cancer specific teams. However, I will continue to represent prostate cancer issues serving on the CDOC Executive Committee. CDPH has our Informed Decision-Making Laminates on its website and there may be a small amount of funding for prostate cancer projects for us. CDPH and the Department of Health Care Services (DHCS) have been very helpful in dissemination of our Informed Decision-Making Laminates. CDPH mailed the Informed Decision-Making Laminates to seventy health care providers throughout the State. Each provider received ten paper copies and one durable plastic copy. In addition, CDPH printed 1800 paper color copies and 130 copies on durable plastic and provided them to CPCC.

CPCC has also been asked to participate in a Proposal for PCORI (the Patient-Centered Outcomes Research Institute) which will seek patient input on a decision-making tool for men with localized prostate cancer. Tom Kirk, CPCC Vice President, and I are participating in helping construct the proposal which is being submitted to PCORI by urologist Dr. Christopher Saigal of UCLA.

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Lastly, CPCC will be holding its once-a-year Face-to-Face Board Meeting on January 10, 2018 in San Francisco. We thank Board Member Dr. Barry Chausser for his hospitality in arranging for his hospital to host the Meeting. It will be an opportunity to set goals and activities for the year and to see how we are doing as we strive to save men's lives.

You can see that there is a lot happening at CPCC. Please visit our Website www.prostatecalif.org as well as "Like" our Facebook Page: "California Prostate Cancer Coalition – CPCC". As always, we are looking for volunteers and new Board Members to help us with our CPCC activities. Reach out to me at mgrey@ucsd.edu with suggestions for our organization! Onward to a great 2018!

Best regards, Merel Grey Nissenberg, President

The 20th Anniversary of the California Prostate Cancer Coalition – Our Start

In the mid-90's the California Division of the American Cancer Society was very supportive of prostate cancer, early diagnosis and types of treatment. Glen Harrington, working with the American Cancer Society's Mission Delivery, helped organize a statewide summit on Prostate Cancer in 1995 or 1996, which I attended as Co-Chair of their Prostate Cancer Task Force. While at the summit some of the attendees posed the question: what if we had a statewide prostate cancer coalition in California? Most people there said it couldn't happen because California is too big.

We said, "Watch us!" In 1997 a group of interested individuals held an organizational meeting in San Francisco at which the California Prostate Cancer Coalition was born. I was elected President, and outstanding Board Members were elected including Wes Sholes, Harry Pinchot, and Lew Musgrove. Lew lived in Las Vegas but since he had been with the group since the beginning, he was brought on board. Lew eventually became the Chairman of US TOO International and later the Nevada representative to National Alliance of State Prostate Cancer Coalitions (NASPCC). See the complete list of past CPCC Board member below.

At that first meeting we developed a Mission Statement, Goals and Objectives and began an amazing **20 years** so far, full of achievements. Everyone on the Board is a worker-bee. CPCC covers the entire State of California, from the boundary with Oregon to the boundary with Mexico. We make it work in such a large state by holding monthly conference calls and only one Face-to-Face Board Meeting every January.

Shortly after the founding of CPCC, the IMPACT Sub-Committee was formed and soon became well known throughout the halls of the Capitol in Sacramento. The Committee was instrumental in finding Senator Debra Ortiz in 2004 to introduce legislation (SB 650) to make IMPACT (Improved Access, Counseling & Treatment) a permanent program in the State, and then 104 men came off the waiting list and received treatment.

CPCC networks with all of the prostate cancer support groups in the state; runs a Northern California and a Southern California Support Group Leaders' Workshop yearly; developed the Informed Decision-Making "Laminate", a durable tool for patients and for primary care providers (www.prostatecalif.org/patient-guide); and represents California prostate cancer patients and their families from the grass roots up to the Departments of Public Health (DPH) and Department of Health Care Services (DHSC).

Along the way we have lost some of our prostate cancer warriors, the most recent being Stan Mikkelsen a few months ago. Stan was tireless in his efforts to keep the momentum going, as a Board Member, Treasurer and President of CPCC-Advocates. We are in his debt. Board Member Harry Pinchot lost his battle with prostate cancer and there is even an award named for him at the Prostate Cancer Research Institute (PCRI).

Twenty years of helping men and their families. Twenty years of fighting for the early detection of potentially lethal disease. Twenty years of informing even as-yet-undiagnosed patients. Our new CPCC brochure is something we want to share everywhere. Here is the link to the brochure: <http://prostatecalif.org/cpcc-brochure/>. Please contact CPCC if you wish to have more copies to distribute in your community.

We are a proud participant in the National Alliance of State Prostate Cancer Coalitions. **We are proud to be the California Prostate Cancer Coalition in our 20th year!**

Written by Merel Grey Nissenberg

California Prostate Cancer Coalition

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Erlinda Patterson
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Glen Harrington *
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See last page of Newsletter for list of current CPCC Board members

Focus on Prostate Cancer Treatment in California: New Imaging Tool Guides Options for Prostate Cancer Treatment

UCSF is leading the United States evaluation of a new imaging technique that is helping patients and physicians better target prostate cancer treatment. Called PSMA-PET, it is especially useful in men who have rising levels of prostate specific antigen (PSA) after initial treatment. This condition, called biochemical recurrence, is the earliest sign that the cancer may have returned. PSMA-PET is much more accurate than conventional imaging in locating small metastases, and thus may allow men to choose targeted treatments, rather than systemic therapies, for recurrent cancer. PSMA-PET can also be used to help guide decisions about initial treatment of prostate cancer.

How it works

Positron emission tomography (PET) has been used in conjunction with computed tomography (CT) for many years to image other types of cancers. A tracing agent, often a sugar molecule, is labeled with minute amounts of a short-lived radioactive element. The resulting radioisotope is then injected into the patient. An imaging study is conducted after the tracer molecules have been taken up by tumor cells. The positrons emitted by the molecules as the radioactivity decays are mapped over CT images to locate cancer metastases.

In an effort to make PET useful in prostate cancer, many research groups have attempted to develop imaging agents that would target prostate-specific membrane antigen (PSMA), a protein that is overexpressed on prostate cancer cells. However, it was not until German researchers developed PSMA-11 and made it widely available that PSMA-PET became a powerful tool in imaging patients with the disease. To perform each study, PSMA-11 is labeled with the radioactive element gallium-68. The radioisotopes,

which have a very short half-life, are made specifically for each patient on the day of the scan.

"PSMA-PET allows us to determine the extent of prostate cancer more than any other imaging test currently available," said Peter R. Carroll, MD, MPH, professor and chair, Department of Urology. "That lets us focus our efforts on tailored treatment, whether it be to the prostate alone, regional or distant lymph nodes, or other sites."

A New Tool for Defining Treatment Options

PSMA-PET can also help guide initial treatment decisions. When the study is performed before prostatectomy, it detects up to 70 percent of lymph node metastases, as compared to 40 percent with conventional imaging. This can help men determine whether they want to add systemic therapy to their initial treatment plan.

"Molecular imaging with PSMA-PET has the potential to revolutionize our approaches for detecting and treating prostate cancer," said UCSF radiation oncologist Felix Feng, MD. "With PSMA-PET, we can now see prostate cancer, in the prostatic area, in lymph nodes, and in bones, that we could not previously detect, and this has significant ramifications for how we approach this disease clinically. I think that molecular imaging approaches like PSMA-PET will eventually become a standard of care for patients with aggressive prostate cancers."

Excerpted by Stan Rosenfeld from article by Leslie Lingaas for the University of California San Francisco Urology Dept. Used with permission

Editor's Note: The PSMA PET imaging at UCSF is available through a Phases III clinical trial entitled: Protocol No.175518 "Gallium-68 PSMA-11 PET in patients with biochemical recurrence". For men who qualify for the clinical trial the scan is free, but the participant must pay for the Gallium-68, approximately \$1500 out of pocket. One requirement to participate in the clinical trial is a PSA greater than 0.2. For more information about this clinical trial go to: <https://cancer.ucsf.edu/clinical-trials/find-a-clinical-trial> or <http://cancer.ucsf.edu/clinical-trials/>.

In addition, the following clinical trials are available at UCLA and Stanford. For more information about these trials go to: <https://www.cancer.gov/about-cancer/treatment/clinical-trials/advanced-search>, contact the clinical trials department for those institutions or discuss with your physician.

- Gallium Ga 68-labeled PSMA-11 PET / CT in Detecting Recurrent Prostate Cancer in Patients after Initial Therapy - UCLA
- 68Ga-PSMA PET / CT in Detecting Prostate Cancer Recurrence in Patients with Elevated PSA after Initial Treatment – Stanford

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- 68Ga-PSMA PET / MRI in Finding Tumors in Patients with Intermediate or High-Risk Prostate Cancer Undergoing Surgery - Stanford

Focus on California Prostate Cancer Support Groups: Us TOO Modesto Prostate Cancer Support Group

- Meets the 4th Monday of each month, 6:30 pm to 8:45 pm (no meeting in December)
- Meeting Location:
Health Education and Conference Center
1700 McHenry, Suite 60B, Modesto, CA 95350
(behind McHenry Village Shopping Center - best accessed from E. Briggsmore Avenue).
- Free, registration not required
- For more information contact: Steve Bain at email: steelroofer@yahoo.com or phone: 209-602-1215

Why was the group started?

The Modesto Chapter of Us TOO was informally started at a birthday party/BBQ for Chuck Rowland in September 1993 after his prostate cancer diagnosis. In 1997, Lewis Woodward, one of the BBQ originals, did the leg work to make the group an affiliate of Us TOO International. The first official meeting was held in October 1997. We recently celebrated our 20th Anniversary.

Who were the founding members?

Six couples composed of men who had been diagnosed with prostate cancer and their wives attended. The men exchanged stories and the women shared their experiences of living with men who had prostate cancer. Five of the original couples continued to meet irregularly for several years at the Beijing Chinese restaurant in Modesto.

How did you decide where to meet?

From the beginning Cheryl Casey, community outreach coordinator, and the staff at Memorial Medical Center's Cancer Services, provided us with a meeting room for our monthly meetings and most of our Steering Committee meetings.

Does your current location seem to work well? Challenges?

Our facilities are excellent, well suited and fitted to our needs with the latest audio/video/computer equipment. This beautiful meeting location is provided to us without charge by the Sutter Gould Medical Foundation.

Do you have any financial support?

We do not request or require dues and members are welcome without regards to donations. We do have a "sputnik" (donation receptacle) at the back of the room and welcome donations. We are blessed with support from Sutter Gould Medical Foundation for the facilities and have access to their medical library and medical research librarian. However, we do not receive financial support from them, any medical center or doctors.

How do you deal with expenses for running the group?

Expenses are generally nominal. Most monthly meeting announcements are sent via email. The few announcements sent by mail have postage subsidized by the American Cancer Society. We have historically participated in the ACS Relay for Life.

Who does the group serve? What geographical area? Who attends? Average attendance? Do wives or other female support persons attend the meeting?

Members have come from as far as 50 miles away. In recent years, the average attendance is 30 men and women. From the beginning spouses, other female support persons and family members were strongly encouraged to attend, and most men do in fact come with their partners.

How do you publicize the group? How do most men hear about the group? Are you affiliated with US TOO or a medical center? Do physicians or other medical professionals refer men to the group?

We are an affiliated chapter with Us TOO International. We occasionally get referrals from physicians or other medical professionals, but most new men find us by word of mouth, personal referrals, and newspaper meeting notices.

How is group governed (lay volunteers, prostate cancer survivors, committee structure, etc.)?

The group has always been governed by its "lay" volunteers/members. The Steering Committee is comprised of members with an interest in serving the leadership of the chapter. Only the leader is elected from/by the Steering Committee members. The original Steering Committee consisted of Lewis Woodward, Chuck Rowland, Thom Olson, Dean Jennison, and Steve Coleman. Past Steering Committee Leaders are: Lew Woodward, Chuck Rowland, Thom Olson, Jim Sharp, John Snelling, Ken Willmarth, and currently Steve Bain. Other positions and duties are met by volunteers, usually members of the Steering Committee. Dean Jennison, while more comfortable out of the limelight, was indispensable to the leadership team from 1993 until his passing in 2015. The current longest serving in these volunteer positions is LeRoy Gambrell as chapter treasurer.

What is the format of the meetings? (speakers, general discussion, etc.) Who leads the discussion?

The original founders decided that the meeting format would be an informational speaker, followed by separate discussion groups for men and women, followed by refreshments. The meetings and the men's discussion groups are usually led by the leader of the Steering Committee. This format remains typical. Occasionally there is a doctor's panel or another presentation. Historically an annual pot luck is held in the place of one meeting. There is no general meeting in December as the 4th Monday fall close to Christmas.

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In addition to providing support to men with prostate cancer, does the group participate in any prostate cancer awareness activities?

The group seeks opportunities to participate in prostate cancer awareness activities and community outreach. We are normally represented in the annual Healthy Aging Forum and Relay for Life. In honor/acknowledgement of his on-going good work with our chapter, this year our own Chuck Rowland was Grand Marshal at the Amgen Bike Race Stage 2, which began in downtown Modesto. ***Do the group leaders feel that the goals of the group are being accomplished? Any lessons for other groups to learn?***

Our goals are simple: to help men diagnosed with or treated for Prostate Cancer, and their families, lead healthy, productive lives, physically, mentally, and spiritually by offering fellowship, shared counseling and discussions pertaining to updated medical options and to promote a positive mental outlook. We are meeting these goals for those who find us. Our challenge is to extend our reach.

Any other information that you would like to share about your group?

We are in process of creating a video tape of our September 2017 doctor panel that will play on local public access TV, and will be available to any group upon request. We hope this video will expand our participation.

-Thanks to Darrell Wilson for providing the information for this article.

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



IMProving Access, Counseling & Treatment for Californians with Prostate Cancer

The California Prostate Cancer Coalition is a strong advocate for the IMPACT Program and played a vital role in its development as noted in past newsletter articles. CPCC Board members recently held a conference call with the IMPACT Program Administrator, Dieu Le, to receive an update on the status of the IMPACT Program. Ms. Le reviewed the current program and assured Board members that the mission and the services provided by the IMPACT Program remain unchanged. She noted that the program continues to serve men with no insurance as well as men who are underinsured. She urged us to encourage men with less than optimal insurance to call IMPACT to find out if they qualify for assistance. The IMPACT staff will help guide men to available resources even if they do not meet the eligibility requirements for the IMPACT

Program. Brochures in English and in Spanish are available for distribution by contacting IMPACT. The staff welcomes assistance from community groups to help publicize the program.

IMPACT is funded by the California Department of Health Care Services under the direction of Dr. Mark S. Litwin from the UCLA Department of Urology.

Here is a summary of the IMPACT Program extracted from the program's web site.

IMPACT Mission

Our mission is to provide FREE high-quality prostate cancer treatment to low-income California men with little or no health insurance.

Who is Eligible to participate in the Program?

To qualify for the FREE treatment men must be a California resident 18 years of age or older with no or little health insurance with a prostate cancer diagnosis.

FREE Treatments for prostate cancer paid for by IMPACT include:

- Radical Prostatectomy
- External Beam Radiation Therapy
- Brachytherapy
- Hormone Therapy
- Watchful Waiting
- Chemotherapy

IMPACT will also provide FREE:

- Prostate cancer treatment for an initial 12 months.
- Help in finding a doctor or hospital close to your California neighborhood where you can receive prostate cancer treatment.
- Short-term individual counseling for you and short-term joint counseling for you and your spouse or partner.
- Provide patient with nutrition information and how it relates to prostate cancer.

IMPACT partners with community providers, local health departments and other community-based health organizations to establish a growing network of health facilities statewide that evaluate and treat patients in their local communities across the state of California. Currently IMPACT has over 600 contracted health care providers statewide, covering the state from Northern California's Humboldt and Siskiyou Counties to Southern California's Los Angeles and San Diego Counties

Whom Do I Call?

For information about IMPACT call: 1-800-409-8252, email IMPACT at info@california-impact.org or visit the IMPACT website at www.california-impact.org.

New Program offers Tumor Sequencing and Potential New Clinical Trial Options

Strata Oncology and UCSF Helen Diller Comprehensive Cancer Center have launched a new initiative called Stratify Prostate™ to provide no-cost tumor sequencing and new clinical trials options to 10,000 men with metastatic prostate cancer, with the goal of broadening access to precision medicine. Stratify Prostate seeks to provide patients access to the latest and best in precision medicine, regardless of geography.

The precision medicine revolution has been slow to come to advanced prostate cancer, but the tide is turning. A new class of drugs in clinical trials, targeting BRCA mutations, has demonstrated promising results in metastatic prostate cancer. Through Stratify men with prostate cancer are eligible to receive a tumor sequencing test, at no cost, to determine if their tumor may harbor a mutation that makes them eligible for one of these trials. Any man with metastatic prostate cancer is eligible to participate and can do so under the care of his current healthcare provider. No new medical procedures are required for participation. The program is available to patients anywhere in California and nationwide. To learn more, visit www.stratifyprostate.com.

California Prostate Cancer Coalition Participates in Community Event

On November 18 the first “annual” ZERO Prostate Cancer 5 K Run/Walk was held in Sacramento. CPCC Board members Bill Doss and Beverly Nicholson represented CPCC. The CPCC Shared Decision-making Laminates, CPCC brochures and cloth bags with the CPCC logo were distributed at the exhibit table. The event was very successful, providing a new avenue to increase prostate cancer awareness in the Sacramento area.



L to R: Beverly Nicholson, Bill Doss and Darlene Doss “man” the CPCC exhibit table at the Sacramento ZERO race.

California Prostate Cancer Coalition Information

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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

CPCC is a 501(c) (3) not-for-profit public benefits corporation (EIN 94-3349907) 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 quarterly newsletter, maintaining our website, sponsoring educational conferences, and other related programs. Please help us continue to work for you! Thank you.

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
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