



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

Volume 19, Issue 1
Winter 2019

PRESIDENT’S MESSAGE

Welcome to the Winter 2019 edition of the California Prostate Cancer Coalition (CPCC) Newsletter. I hope that you all had a wonderful holiday season and I am wishing you a healthy and happy 2019!

This was a busy year for CPCC. For the first time we held a Fall Face-to-Face Board Meeting, our second Face-to-Face Board Meeting of 2018. This important meeting took place at the Westin LAX, making it easier for Board Members flying in from other locations in California to attend. Our Secretary, Tiffany Razzo, who is now Office Manager of the Uro-Oncology Office at M.D. Anderson in Houston, even flew in to continue her Secretarial duties at the Board Meeting. Our first Face-to-Face Board Meeting for 2019 will take place in the Spring, followed by another in the Fall, following our decision in 2018 to hold two such Face-to-Face Board Meetings per calendar year.

One item discussed in detail at the Face-to-Face Board Meeting is CPCC’s **Statewide “Patient Conference on Prostate Cancer” cosponsored by UCSF, which we are planning for June 8, 2019.** It will take place on one of the UCSF medical campuses. Drs. Eric Small, Matt Cooperberg and Felix Feng will be intimately involved with the planning and execution. This Conference will be our first statewide prostate cancer meeting since 1997, so we are especially excited. See the “Save the Date” flyer in this newsletter and stay tuned for further details!

CPCC welcomes new Board Members **Frank Balthis**, a veteran support group leader in both Santa Barbara and Santa Cruz, and **Leonard S. Marks, MD**, Professor of Urology at the David Geffen School of Medicine at UCLA and the inaugural holder of the Jean B. deKernion Endowed Chair in Urology. We will profile these committed prostate cancer advocates in future newsletters.

CPCC was represented at the 14th Annual Meeting of the National Alliance of State Prostate Cancer Coalitions (NASPCC) in Washington, D.C. on October 12-14, 2018 by Tom Kirk, CPCC Vice President, and me. It was a superb Meeting, as always, and 14 sponsors helped make the Meeting a reality; some also participated in the presentations and panels. See the Report of the 14th Annual Meeting at: <https://tinyurl.com/y8lrqvhp>. The NASPCC Annual Meeting was followed by an invite-only Roundtable Discussion on Bone Health Access, an important topic since some insurance companies and Medicare Advantage Plans are instituting or have instituted “step therapy” requirements. Step therapy means that patients must fail another treatment first before the company will pay for the more expensive, but physician-recommended treatment. This requirement will no doubt restrict patients’ access to treatments that their physicians think best for them and is a major challenge that we face. NASPCC is leading the charge of prostate cancer patients on this important topic. For more details, please see <https://naspcc.org/index.php/bone-health-access-roundtable>.

Near the end of this Newsletter is the **Flyer for the Online Prostate Cancer Support Group that is run by CancerCare and co-sponsored by NASPCC** (at CancerCare’s invitation). It’s an amazing, free, outstanding opportunity for all prostate cancer patients to improve their quality of life with the assistance of a licensed social worker. Any questions about it, please contact achesler@cancercare.org or mgrey@ucsd.edu.

Another CPCC goal for this fiscal year is the creation, production and distribution of a Laminated Tool on Active Surveillance which will look somewhat like CPCC’s Informed Decision-making Laminate. We need volunteers to help with this project.

Best regards, Merel Grey Nissenberg, President



Improving Access, Counseling & Treatment for Californians with Prostate Cancer

The IMPACT Program provides free access to treatment and counseling for uninsured and underserved men with prostate cancer in California. CPCC has been a stalwart supporter of the IMPACT Program since its inception 17 years ago, always helping to publicize the program and writing letters of support for continuation of their efforts.

The program's funding was renewed in 2018. The UCLA Department of Urology, the program administrator, received \$9.3 million of funding from the state of California. Since its beginning more than 2,200 men have received prostate cancer treatment services under the IMPACT Program backed by more than \$85 million in support from the California Department of Health Care Services. IMPACT contracts with more than 600 health care providers across the state who treat men enrolled in the program, as well as with mental health professionals, local health departments, hospitals, outpatient facilities, pharmaceutical companies and others for the additional services patients need. (UCLA News Release, August 8, 2018)

At the CPCC Face-to-Face Meeting in November 2018, the Board welcomed Ericka Maldonado-Aviles, IMPACT Program Administrator at UCLA, to give us an update about the program. She explained that IMPACT will have new, very strict requirements to keep up their funding. She is concerned that the number of men enrolled in the program is down. One reason is that since the Affordable Care Act was passed, people assume that everybody is insured. In addition, men may not be aware that even if they have insurance, IMPACT may be able to help cover out-of-pocket expenses that they cannot afford.

CPCC urges prostate cancer support groups and other prostate cancer advocates to help educate men about this valuable resource. Ms. Maldonado-Aviles shared a new colorful IMPACT flyer that is available to help educate men about this program. Copies can be obtained by calling the IMPACT program.

IMPACT eligibility criteria are 18+ years of age, a California resident, with little or no health insurance, and a confirmed diagnosis of prostate cancer through a biopsy. The program offers prostate cancer treatment for up to 12 months, nurse case management and individual counseling. For more information, call 1-800-409-8252 or visit www.california-impact.org.

Focus on Prostate Cancer Treatment in California: An Introduction to Focal Therapy for Prostate Cancer

Rajiv Jayadevan MD, Leonard S. Marks MD

For decades, men who were diagnosed with prostate cancer had only two options for treatment: removal of the entire prostate via surgery (radical prostatectomy), or radiation of the entire prostate. Known as radical therapies, the goal of both of these treatments is to leave no living prostate tissue behind. Unfortunately, a substantial proportion of men who undergo radical prostatectomy or radiation develop bothersome side effects such as erectile dysfunction and incontinence (the involuntary leakage of urine). These side effects are known to significantly affect a patient's quality of life.

In the past 10 years, MRI of the prostate has become exceedingly sophisticated. We are now able to visualize tumors within the prostate – something that was not possible using traditional transrectal ultrasound imaging. With MRI we often see tumors that occupy only a small portion of the prostate. Several new technologies have been developed with the goal of only treating these small areas of cancer rather than the entire prostate gland. Known as **focal therapies**, the rationale of these treatments is to destroy the tumor while preserving the surrounding healthy prostate tissue. If successful, the patient is cancer free after treatment and does not suffer the side effects that often accompany radical treatment.

Focal therapies are mainly being used for patients with intermediate-risk prostate cancer confined to a single area of the prostate. These patients have Gleason score 7 tumors (ISUP Grade 2 or Grade 3 disease). Current research shows that men with low-risk prostate cancer are often better served by active surveillance, and those with high-risk prostate cancer have greatest benefit with radical treatments. For the approximately 30% of patients with intermediate-risk disease, focal therapy is a promising option for treatment if the patient meets the above criteria. Focal treatment of prostate cancer is currently being carried out via several different technologies. These include high-intensity focused ultrasound (HIFU),

An Introduction to Focal Therapy for Prostate Cancer Continued:

cryotherapy, focal laser ablation, photodynamic therapy, and irreversible electroporation. Patients should know that although many of these technologies have demonstrated encouraging results, they are still relatively new and therefore long-term oncologic data on success rates is often lacking.

Cryotherapy

Cryotherapy was the first focal therapy used for prostate cancer, introduced in the mid-1990s. It is FDA approved for the destruction of prostate tissue. The process involves placing needle-like cryoprobes directly into the prostate via the perineum (the area between the anus and scrotum) while the patient is under general anesthesia. The probes are guided into place using transrectal ultrasound, and then cooled to extremely low temperatures. The result is the formation of an ice ball that encompasses the tumor. Cells within the ice ball may be killed immediately by the cold temperatures, or later via an inflammatory response. The targeted area is allowed to thaw and is usually cooled at least once more to ensure adequate cellular injury and destruction. Patients typically stay in the hospital for one day and are sent home with a urethral catheter for drainage of urine for up to a week.

One of the difficulties of traditional cryotherapy is the monitoring of the ice ball in real time, since a large percentage of transrectal ultrasound waves are reflected by it. This makes adequate visualization of the frozen tissue difficult. New MRI-compatible cryoprobes have been developed, allowing for MRI-guided cryotherapy with highly precise temperature monitoring. Even with MRI-compatible technology, however, precise control of the ice ball diameter remains difficult. When implemented, cryotherapy is generally used to destroy one half or more of the prostate rather than just a small portion. Ice balls have the potential to extend beyond the prostate capsule, which can result in unwanted side effects by harming the nerves and blood vessels that run just outside of the prostate.

In an analysis of 1,160 men who received cryotherapy, the three-year cancer recurrence free rate was 75.5%. Up to 3.6% of men developed incontinence, and erectile dysfunction was reported in up to 42% of patients. These results are encouraging when compared with side effects reported after radical treatments.

High-Intensity Focused Ultrasound (HIFU)

HIFU has been used extensively in the treatment of non-urollogic cancers and was first introduced for prostate cancer treatment in 1995. Like cryotherapy, HIFU is FDA approved for the treatment of prostate tissue. This focal therapy modality works by directing ultrasonic waves at a target of cancer. The targeted cells absorb the ultrasonic waves and convert them to heat, which subsequently kills or damages the cells.

HIFU is carried out via a transrectal ultrasound probe that can simultaneously visualize the prostate and destroy a target of tissue. Prostate imaging via the HIFU transrectal ultrasound probe is poor, however, and detecting changes to a treated target in real-time is not possible. Instead, changes to prostatic tissue during HIFU are calculated by the refractive index – a measurement based on the speed of light traveling through a material.

HIFU for prostate cancer was first introduced as a treatment for the entire prostate gland, and in recent years has more gained acceptance as a form of focal therapy. Some trials have reported cancer-free rates of 95% following rebiopsy of the treated area to evaluate for residual cancer. Rates of continence have been reported at 90-100%, and erectile function rates range from 77-100% following treatment. MRI-based HIFU is also emerging with the benefit of accurately measuring temperatures within the treatment zones to ensure tissue destruction.

Focal Laser Ablation

Focal laser ablation involves placing a needle-like probe into a prostatic tumor under imaging guidance. Guiding the probe into place can either be done under MRI, with the patient within the MRI machine, or by using an MRI-ultrasound fusion device. When a fusion device is used, lesions seen on MRI are superimposed onto live transrectal ultrasound images and then targeted with the laser fiber. Once in place, a laser within the probe heats the tissue to high temperatures in order to cause cell death.

Focal laser ablation for prostate cancer first began as a procedure that was carried out entirely within an MRI machine and required general anesthesia. Several studies were published on this technique and found residual cancer in 4-40% of treated patients. UCLA has recently carried out two small clinical trials that investigated the safety and efficacy of focal laser ablation in the clinic setting. Patients only required local anesthesia, and were discharged home the same day of the

An Introduction to Focal Therapy for Prostate Cancer Continued:

procedure. At biopsy performed in 10 patients 6 months after focal laser ablation, 3 patients had no residual cancer, 3 had only very small areas of low-risk Gleason 6 disease, and 4 had persistent clinically significant tumors.

Erectile function and continence were unchanged at the time of the 6-month biopsy. UCLA will soon carry out a third clinical trial to test a new focal laser ablation device that employs a superior temperature sensor. This sensor will have the ability to more accurately determine the area of tissue destruction.

Photodynamic Therapy

During photodynamic therapy, synthetic agents called photosensitizers are administered to a patient intravenously. These photosensitizers are taken up by various tissues within the body and are activated by light. When used for treating prostate cancer, laser probes are inserted into the prostate via the perineum to activate the photosensitizers. Once activated – usually for around 20 minutes – the photosensitizers generate free radicals of oxygen which damage local blood vessels and cells. Very little research has been published to date on the use of photodynamic therapy for treating men with prostate cancer. In the largest study published thus far, 85 men were treated with photodynamic therapy and 74% had no cancer seen on prostate biopsy performed 6 months later.

Irreversible Electroporation

Irreversible electroporation is a form of focal therapy that uses electrical currents to destroy tissue. Several small probes are inserted into the prostate via the perineum and electric current is run between them. The electric current creates nanometer-sized holes in the walls of cells, which triggers cell death. The treated tissue is not subject to drastic changes in temperature. One study of 34 men who underwent irreversible electroporation found that 74% of the patients were free of clinically significant disease on biopsy performed 8 months after treatment.

Conclusion:

Focal therapies are poised to play a larger role in the treatment of patients with low-volume, intermediate-risk prostate cancer. Short-term studies have demonstrated adequate cancer control with limited side effects. Patients considering focal therapy should know that robust long-term data on these treatments is sparse. To date, cryotherapy, HIFU, and focal laser ablation are FDA-cleared for the destruction of prostate tissue.

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Focus on California Prostate Cancer Support Groups: UC Davis Comprehensive Cancer Center /Dignity Health Cancer Institute of Greater Sacramento Prostate Cancer Support Group

- Meets the 3th Thursday of each month, 1:30 pm to 3:30 pm
 - Meeting Location:
Even Months: UC Davis Comprehensive Cancer Center Auditorium, 4501 X St., Sacramento, 95817
Odd Months: Mercy San Juan Medical Plaza, 6555 Coyle Ave, Room 150, Carmichael, 95608
 - Free, registration not required
 - For more information call 916 962-8892 or email Beverly Nicholson, RN at beverlynicholson@comcast.net
- Need information about support groups in California? Go the CPCC web site to locate the nearest support group to you at <http://prostatecalif.org/>*

UC Davis Comprehensive Cancer Center / Dignity Health Cancer Institute of Greater Sacramento Prostate Cancer Support Group Celebrates 25th Anniversary



Pictured above: Dr. Ralph deVere White presents recognition plaque to Beverly Nicholson, RN, group facilitator

The UC Davis Comprehensive Cancer Center/Dignity Health Cancer Institute of Greater Sacramento celebrated its 25th anniversary on November 15, 2018 with a luncheon and program held at Mercy San Juan Medical Center. It was attended by over 60 members and supporters of the group. Ralph deVere White, Senior Advisor Emeritus and Emeritus Distinguished Professor of Urology at UC Davis and retired Director of the UC Davis Comprehensive Cancer Center, was present to commemorate this milestone and to give a plaque of recognition to Beverly Nicholson, RN, group facilitator. He reviewed the progress made in the treatment of prostate cancer in the past 25 years and congratulated the group for its service to the Sacramento community.

The support group was the first one established in the Greater Sacramento area. It was started at the request of Dr. deVere White. In 1992 he realized that men with prostate cancer needed additional education and support to deal with their cancer and treatment options. Beverly Nicholson, RN, was asked to organize the group by her manager, Pamela Taylor, RN. With the support of Ms. Taylor, Carolyn Guadagnolo, MSW, Social Worker and other team members, the first meeting was held on November 11, 1992 with four attendees. In the months and years that followed, the enthusiasm and membership of the support group continue to grow. During the past 25 years, the list of attendees has grown to a roster of over 300 people.

Through several job changes, Ms. Nicholson was able to continue facilitating the group with the support of her supervisors. The group achieved another first - becoming the first group co-sponsored by two health care organizations in the area when Ms. Nicholson accepted a new position at Mercy San Juan Medical Center in 1996. Since her retirement in 2015, Ms. Nicholson continues to lead the group as a volunteer with the able assistance of co-facilitators Michael Mair, RN, Dignity Health Nurse Navigator, Bill Doss, Rollie Swingle and Spencer Le Gate, peer navigators. The UC Davis Comprehensive Cancer Center and the Dignity Health Cancer Institute of Greater Sacramento continue to work together to provide meeting locations, publicity and other assistance to promote the group's mission. For more information about the group call 916 962-8892 or email Beverly Nicholson, RN at beverlynicholson@comcast.net

Northern California Prostate Cancer Support Group Leaders' Workshop A Success

The annual CPCC Northern California Prostate Cancer Support Group Leaders' Workshop was held on November 28, 2018 in San Francisco. This all-day workshop was facilitated by CPCC Board Member Stan Rosenfeld. The goal of the meeting was to learn from speakers and from attendees about what works in leading meetings and helping men to make good treatment and life decisions. The highlight of the meeting was the opportunity for the attendees to share common concerns, best practices and challenging situations frequently encountered by support group leaders. In addition, Lawrence Fong, MD, Professor of GU Cancer at UCSF spoke to the group.

Thanks to the UCSF Urology Department for providing the meeting room and other support to help make the workshop a success. For information about future workshops, contact Stan at email: vegstan2@ix.netcom.com. Plans for the next Northern and Southern California workshop will be announced later this year.

California Prostate Cancer Coalition Participates in New Community Event in Sacramento



Left to Right: Beverly Nicholson, Anna Pessah, Ryan Pessah and Bill Doss at “Hops and Handlebars”

On November 10, 2018 CPCC participated in a unique prostate cancer awareness fundraiser in Sacramento called “**HOPS & HANDLEBARS**”. The event was held at a local brewery and featured a mustache contest, a pop-up market, photo booth, raffle and cake walk. Board members Bill Doss and Beverly Nicholson distributed the CPCC Shared Decision-making Laminates, CPCC brochures and cloth bags with the CPCC logo at the exhibit table. They had the opportunity to talk about prostate cancer to a lively, interested and younger crowd in attendance while enjoying the fun atmosphere at the venue.

The event was very successful, thanks to the energetic and innovative efforts of the organizers, Anna and Ryan Pessah. They started the event to honor Dr. Benjamin Pessah, Ryan's father. Dr. Pessah, a podiatrist who cared deeply for his family and patients, was diagnosed with an aggressive prostate cancer in February 2014 and passed away in April 2016.

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.

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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 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.




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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.cancercare.org/support_groups/126 to complete our online registration process. Internet access is required.





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UCSF Helen Diller Family
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The California Prostate Cancer Coalition (CPCC) and
The UCSF Helen Diller Family Comprehensive Cancer Center Present

THE 2019 PATIENT CONFERENCE ON PROSTATE CANCER:

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June 8, 2019 8:00 a.m. to 5:00 p.m.

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