



CALIFORNIA PROSTATE CANCER COALITION

2017-2018

ANNUAL REPORT



BOARD MEMBER SAM WELLS PRESENTED WITH THE "SPECIAL ACHIEVEMENT AWARD" BY PRESIDENT MEREL GREY NISSENBERG AT THE KICK-OFF JANUARY 27, 2017 IN-PERSON BOARD MEETING

PROSTATE CANCER: INFORMED DECISION MAKING FOR PRIMARY CARE PHYSICIANS

The USPSTF has now clarified the importance of shared decision-making in prostate cancer. Its 2017 recommendation strongly encourages informed decision-making between clinicians and patients that supports personal values and preferences.

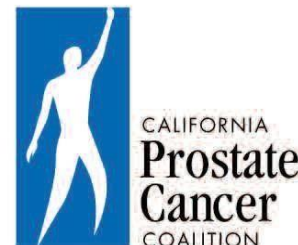
PLEASE REVIEW THE 10 PATIENT QUESTIONS AND ANSWERS ON THE REVERSE SIDE

1. Some aggressive prostate cancers produce only small amounts of PSA and therefore DRE's should always be performed in addition to the PSA test. Prior to the blood draw, the physician should tell the patient that the physician is only looking for potentially lethal prostate cancer.
2. After obtaining an initial PSA for a patient, the physician should refer to guidelines that stratify the patient's risk for life-threatening prostate cancer. Frequency of future PSA testing depends on that risk assessment. (www.mskcc.org/cancer-care/adult/prostate/screening-guidelines-prostate)
3. Having a father or brother with prostate cancer more than doubles a man's risk of developing prostate cancer. The risk is greater for men with several affected relatives, especially young relatives. Men who eat a lot of red meat or dairy products seem to have a higher chance of developing prostate cancer. Other possible risk factors include obesity, prostatitis, STD's, exposure to Agent Orange and lack of exercise.
4. To determine if a biopsy is warranted, asymptomatic patients with a high PSA and at least a 10-year life expectancy should have a repeat PSA. A free calculator (<http://tinyurl.com/caprisk>) can integrate PSA, age, family history, and other factors to generate risks of prostate cancer diagnosis and high-risk cancer diagnosis. Other tests used in some cases include free-versus-bound PSA and the PHI algorithm. (Journal of Urology Volume 185, Issue 5, Pages 1650-1655, May 2011)
5. Since the 1990s when PSA testing became widespread, there has been a >40% decline in prostate cancer mortality. (American Cancer Society). Most of this decline can be attributed to screening efforts and improvements in treatment for high-risk disease detected early through screening (Mohler, 0.6004/jnccn.2012.0016)
6. A large European randomized trial of screening vs. no screening (ERSPC) found a 21-29% reduction in prostate cancer mortality risk through PSA screening. (Schroder, NEJM 2012) A randomized trial in the U.S. (PLCO) found no benefit—but 79% of the men in the “usual care” arm of this study received at least one PSA test, so the trial authors concluded that the trial shows only that annual screening offers no clear benefit over ad hoc PSA testing associated with routine primary care. (Andriole, JNCI 2012) Thus the PLCO does not contradict the ERSPC, and there really should be no controversy about the fact that screening saves lives.
7. Risk of infection with a biopsy is minimized when the patient pre-medicates with antibiotics; and pain from a biopsy should be minimized with anesthetic compounds.
8. Most prostate cancers found today are low-risk and do not require treatment. Active Surveillance (AS) is an accepted alternative for low-risk, non-aggressive prostate cancer. Currently there are tools, including genomic and imaging tests, that help determine who is an appropriate candidate for AS. Overtreatment of low-risk disease does remain prevalent in the U.S., however, and patients should be referred to urologists who understand risk stratification of prostate cancer and who routinely offer the surveillance option to men with low-risk disease.
9. When cancer has progressed to the point that symptoms are present, the disease has usually spread and is no longer curable.
10. A man cannot begin to make any decision about his prostate health without knowing his PSA and keeping track of any changes. Focusing testing on men at highest risk of life-threatening disease helps balance the potential benefits and harms of screening.

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California Prostate Cancer Coalition

PSA testing is currently a man's best defense against dying of potentially lethal prostate cancer and against developing metastatic prostate cancer. Individuals have a fundamental right to choose whether or not they want to know if they have prostate cancer, prior to becoming symptomatic.



PROSTATE CANCER: INFORMED DECISION MAKING FOR MEN 40 AND OVER

There is much debate on the value of PSA testing and the diagnosis of prostate cancer.

10 QUESTIONS TO ASK YOUR DOCTOR ABOUT YOU AND PROSTATE CANCER

- 1. I want to know my risk for developing aggressive prostate cancer. What tests are there to learn my risk?** The two basic methods for determining your risk for developing aggressive, life-threatening prostate cancer are the prostate specific antigen (PSA) blood test and the digital rectal exam (DRE).
- 2. What is a "baseline PSA" and what is the value of a "baseline PSA"?**

A baseline PSA is your initial PSA blood test at about age 40 that allows you and your physician to watch how your PSA varies over time.
- 3. What is the importance of family history, ethnicity and exposure to Agent Orange?**

A family history of prostate cancer, especially in a first degree relative (father, brother, son), increases your risk of developing prostate cancer. Certain ethnicities also carry a high risk of developing aggressive prostate cancer, i.e., African-American men have approximately twice the incidence and death rate from prostate cancer as Caucasian men. Prior exposure to Agent Orange may also increase the risk of developing aggressive prostate cancer.
- 4. If I have a PSA test and it comes back high, what other tests are there that I can have to determine if I need a biopsy?**

Your physician will want to rule out an infection and/or an enlarged prostate, both of which can cause the PSA levels to increase. A repeat PSA should be obtained. There are other tests such as free PSA, PCA3, PHI and others which may be useful in some instances. Free calculators can help integrate your PSA with your age, family history, and other parameters to estimate your risk of prostate cancer and high-grade prostate cancer. See <http://tinyurl.com/caprisk>.
- 5. What are the benefits of detecting aggressive or potentially aggressive prostate cancer early?** As with most cancers, the earlier aggressive prostate cancer is diagnosed the greater the chance that the cancer will still be confined to the prostate and thus curable.
- 6. What are the risks of NOT detecting an aggressive or potentially life-threatening prostate cancer early?** It will be more difficult, even impossible, to cure. Once the cancer escapes the prostate it can invade the lymph nodes and may spread to the bones and elsewhere (metastasis).
- 7. What are the risks of a biopsy?**

There is a risk of bleeding which is usually minor, and of an infection, which is reduced through pre-biopsy antibiotics. Most men would think this is worth the risk, but this is a personal decision.
- 8. If I have a biopsy and it reveals cancer, do I necessarily have to have treatment? What is "Active Surveillance"?**

You do not necessarily have to have treatment. If a relatively low-risk cancer is found, you may be a candidate for Active Surveillance, (AS), under which PSA and other tests are performed periodically to ensure that you receive timely treatment, if necessary.
- 9. Why shouldn't I wait until I have urinary or other symptoms to have my first PSA?**

When cancer has progressed to the point that symptoms are present, the disease has usually spread and is difficult or impossible to cure.
- 10. If I am willing to live with the potential side effects of a biopsy or of treatment, shouldn't the decision be mine?**

Weighing side effects of any possible testing, diagnosis and treatment against the chance of living a full life is a very personal decision based upon your own values. Most men would at least like to know if they have prostate cancer. Then you can make a joint decision with your physician as to what steps, if any, to take.

PSA testing is currently a man's best defense against dying of potentially lethal prostate cancer and against developing metastatic prostate cancer. Individuals have a fundamental right to choose whether or not they want to know if they have prostate cancer, prior to becoming symptomatic.

Knowledge is Power!

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California Prostate Cancer Coalition

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CPCC PRESIDENT'S MESSAGE:

MEREL GREY NISSENBERG

- THIS IS OUR FIRST *CPCC ANNUAL REPORT* AND WE ARE EXCITED TO SHARE OUR APPROACH, ACCOMPLISHMENTS AND GOALS 2017-2018. WE RECOGNIZE THAT IT TAKES MANY PEOPLE WORKING TOGETHER FOR A COMMON GOAL TO ACHIEVE SUCCESS AND MAKE A DIFFERENCE.
- MANY OF US WERE THERE AT CPCC'S ORGANIZATIONAL MEETING IN SEPTEMBER 1997, WHEN EXPERTS TOLD US WE COULD NEVER CREATE A STATEWIDE PROSTATE CANCER COALITION BECAUSE THE STATE'S TOO BIG. WELL, HERE WE ARE, HAVING JUST CELEBRATED **OUR 20TH YEAR!**
- THERE ARE SO MANY PEOPLE TO THANK: OUR FOUNDERS, NUMEROUS VOLUNTEERS, ADVISORS AND ADVOCATES, OUR SPONSORS, AND OUR DONORS. ON THE COVER OF THIS REPORT WE ARE FEATURING ONE OF CPCC'S OUTSTANDING ADVOCATES AND BOARD MEMBERS, SAM WELLS, WHOM WE RECOGNIZED IN JANUARY 2017 FOR HIS GREAT WORK.
- WE ALSO LOST SOME OF THOSE GREAT CONTRIBUTORS IN 2017. ONE OF OUR FOUNDERS AND ACTIVE BOARD MEMBERS, STAN MIKKELSEN, PASSED AWAY IN JUNE 2017. FORTUNATELY WE WERE ABLE TO SPOTLIGHT STAN'S MONUMENTAL WORK IN OUR CPCC SEPTEMBER NEWSLETTER, SUCH AS HIS LEADERSHIP IN THE *IMPACT PROGRAM* FOR SERVICES TARGETED TO UNDERSERVED MEN WITH PROSTATE CANCER IN CALIFORNIA, AND HIS LEADERSHIP OF CPCC-A.
- AT THE START OF THIS REPORT WE ARE PRESENTING CPCC'S *INFORMED DECISION-MAKING LAMINATE*, OUR DURABLE DECISION-MAKING TOOL DEVELOPED IN 2015 AND UPDATED SEVERAL TIMES, FOR BOTH PRIMARY CARE PHYSICIANS AND MEN AND THEIR FAMILIES. THIS HELPS TO STIMULATE AND SERVE AS A GUIDE FOR INFORMED DISCUSSIONS ON PROSTATE CANCER AND TESTING. THOUSANDS HAVE BEEN DISTRIBUTED AND THEY ARE NOW ALSO PART OF A NATIONAL AWARENESS AND EDUCATIONAL INITIATIVE OF THE NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS (NASPCC).
- YOU WILL ALSO SEE IN THIS REPORT THAT WE HAVE CREATED A VERY ACTIVE WORKPLAN FOR 2018. **TO OUR SPONSORS AND DONORS: THANK YOU FOR ALLOWING US TO DO OUR JOB AND WE APPRECIATE YOUR CONTINUING SUPPORT!**

FIGHTING PROSTATE CANCER IN CALIFORNIA SINCE 1997

"WE ARE DEDICATED TO SAVING MEN'S LIVES BY MAKING PROSTATE CANCER A KEY PUBLIC HEALTH PRIORITY IN CALIFORNIA"

2017-2018 ACTIVITIES/ACCOMPLISHMENTS:

- ORGANIZED AND CONDUCTED TWO SUPPORT GROUP LEADER'S WORKSHOPS, ONE HELD IN LOS ANGELES ON JUNE 19, 2017 AND ONE IN SAN FRANCISCO ON OCTOBER 4, 2017



BOARD MEMBER STAN ROSENFELD LEADING THE SOUTHERN CA SUPPORT GROUP LEADER'S WORKSHOP AT USC'S NORRIS CANCER CENTER IN LOS ANGELES

- PRODUCED THREE EDITIONS OF A REVITALIZED CPCC NEWSLETTER VOLUME 17, ISSUES 1-3 IN JUNE, SEPTEMBER AND DECEMBER
- CREATED A NEW CPCC EDUCATIONAL BROCHURE IN AUGUST WHICH GIVES INFORMATION ON PCA, SHARED DECISION-MAKING AND CPCC

- PRINTED, UPDATED AND DISSEMINATED THE INFORMED DECISION MAKING LAMINATED TOOL, INCLUDING OVER 700 DISTRIBUTED TO THE VIETNAM VETERANS ANNUAL MEETING IN AUGUST
- PREPARED COMMENTS ON THE DRAFT RECOMMENDATIONS OF THE US PREVENTIVE SERVICES TASK FORCE ON PROSTATE CANCER
- LED ANOTHER SUCCESSFUL PROSTATE CANCER SEPTEMBER PROSTATE CANCER AWARENESS PROCLAMATION CAMPAIGN



CPCC ADVOCATE BILL DOSS RECEIVING PROCLAMATION FROM SENATOR TED GAINES

- PROVIDED LEADERSHIP FOR, AND ATTENDED THE 13TH ANNUAL MEETING OF THE NATIONAL ALLIANCE OF STATE PROSTATE CANCER COALITIONS IN WASHINGTON, DC IN OCTOBER
- ADVOCACY WORK CONTINUED WITH THE CALIFORNIA DEPARTMENT OF PUBLIC HEALTH, THE CALIFORNIA DIALOGUE ON CANCER AND THE CALIFORNIA DEPARTMENT OF HEALTH CARE SERVICES
- FOUGHT FOR THE CONTINUATION OF THE IMPACT PROGRAM
- CONTINUED WEBSITE AND FACEBOOK FREQUENT SOCIAL MEDIA POSTS
- VISIBILITY AND MATERIAL SHARING AT AWARENESS EVENTS SUCH AS THE KOMEN BREAST CANCER RACE FOR A CURE IN MAY, THE PCRI PROSTATE CANCER CONFERENCE IN LOS ANGELES IN SEPTEMBER, AND THE ZERO PROSTATE CANCER RACE IN NOVEMBER

- LED A "HERO'S PROSTATE CANCER" COMIC BOOK AWARENESS CAMPAIGN WITH IDW PUBLISHING GROUP AND OTHER PROSTATE CANCER GROUPS, INCLUDING DISTRIBUTION TO THE NASPCC ANNUAL MEETING PARTICIPANTS

Portrait of a Hero & His Family

Real men get tested!

- Prostate cancer affects one in seven US men.
- It is the second largest cancer killer of men.
- Men should get regular screenings starting at age 45, earlier if they are from a higher risk group.
- Those at higher risk for prostate cancer include: African American men, men with a family history of prostate cancer, and veterans exposed to chemical agents.
- If detected early, prostate cancer is very treatable and usually curable.
- In many cases it can be monitored without treatment through a program of active surveillance.

Heroes, talk to your doctors about your individual risks and concerns. Your family needs you!

What Every Hero Should Know: *Get the Facts! Get Empowered! Get Tested!*

September is National Prostate Cancer Awareness Month

 CALIFORNIA Prostate Cancer COALITION
 California Prostate Cancer Coalition
www.prostatecalif.org

 NASPCC
 National Alliance of State Prostate Cancer Coalitions
www.naspcc.org

 SANTA CRUZ COUNTY Prostate Support Group
 Santa Cruz County Prostate Support Group
www.scprostate.org

 Us TOO
 Us TOO International Prostate Cancer Education and Support Network
www.usfoo.org

FEATURED ADS TO RAISE PROSTATE CANCER AWARENESS

PLANNED PROGRAM PRIORITIES FOR 2018

- QUARTERLY ELECTRONIC NEWSLETTER
- SUPPORT GROUP LEADERS' WORKSHOPS
- QUARTERLY WEBINARS
- STATEWIDE PROSTATE CANCER SYMPOSIUM
- EDUCATION & TESTING EVENTS IN MINORITY AND UNDERSERVED COMMUNITIES (OUTREACH)
- EXPANDED OUTREACH INITIATIVES IN COMMUNITIES
- CONTINUED WORK ON THE "INFORMED DECISION-MAKING LAMINATE"

OUR 2017-2018 BOARD OF DIRECTORS

1. ARTHUR "TONY" BLAIN, MD: CHIEF MEDICAL EXECUTIVE FOR CA STATE PRISON LOS ANGELES COUNTY, PROFESSOR OF FAMILY MEDICINE AT UCSD SCHOOL OF MEDICINE
2. BARRY CHAUSER, MD: DEPARTMENT OF RADIATION ONCOLOGY, SETON MEDICAL CENTER
3. MARC A. DELL'ERA, MD: ASSOCIATE PROFESSOR, DEPARTMENT OF UROLOGY, UC DAVIS
4. BILL DOSS: ADVOCATE AND EDUCATOR: PCA SURVIVOR
5. DOTTIE FERRARA: SANTA CRUZ COUNTY SUPPORT GROUP STEERING COMMITTEE MEMBER
6. JOE FERRARA: 13-YEAR PCA SURVIVOR, SANTA CRUZ COUNTY SUPPORT GROUP STEERING COMMITTEE MEMBER
7. JOSEPH E. SCHERGER, MD, MPH, VICE PRESIDENT FOR PRIMARY CARE AND CHAIR OF ACADEMIC AFFAIRS, EISENHOWER MEDICAL CENTER IN RANCHO MIRAGE, CA
8. ARTHUR LURVEY, MD, FACP, FACE: MEDICAL DIRECTOR, NORIDIAN HEALTHCARE SOLUTIONS
9. CAROL MARCUSEN, MSW-LCSW, BCD: DIRECTOR, SOCIAL SERVICES, USC
10. BEVERLY NICHOLSON, RN, CNS, CPCC NEWSLETTER EDITOR: HAS FACILITATED THE UC DAVIS GREATER SACRAMENTO SUPPORT GROUP LEADER SINCE ITS FOUNDING 25 YEARS AGO
11. STAN ROSENFELD: SUPPORT GROUP WORKSHOP LEADER, MARIN SUPPORT GROUP LEADER, PCA SURVIVOR
12. SAM WELLS: ADVOCATE, PCA SURVIVOR

OFFICERS:

13. MEREL GREY NISSENBERG, ESQ, CPCC PRESIDENT, FUNDRAISING AND DEVELOPMENT, FOUNDING BOARD MEMBER
14. WESTLEY SHOLES, CPCC-A PRESIDENT: 20-YEAR PSA SURVIVOR AND FOUNDING MEMBER
15. THOMAS KIRK, CPCC VICE-PRESIDENT: FORMER PRESIDENT & CEO OF US TOO INTERNATIONAL, 2004-2016
16. EARL JONES, CPCC TREASURER AND CPCC WEBMASTER: PCA SURVIVOR
17. TIFFANY RAZZO, CPCC SECRETARY: MD ANDERSON CANCER CENTER, GENITOURINARY MEDICAL ONCOLOGY DEPARTMENT, HOUSTON, TX

Leadership changes for 2017 and 2018 included the election of Beverly Nicholson to the Board in January 2017, the passing of Stan Mikkelsen in June, the resignation of Chad Little as Vice-President and the appointment of Tom Kirk to that role at the June 14th meeting; and the resignation of Larry Barman to meet health challenges in July. The organization started 2017 with 19 members on the Board roster that recognized 21 former members (of which 7 were Founding Members) and ended 2017 with 16 Board Members and 24 Past Board Members (of which 7 were Founding Members). Dottie Ferrara was added to the Board at the January 10, 2018 Board Meeting making 17 Members of the Board of Directors for 2018.



PRESIDENT MEREL GREY NISSENBERG IN FRONT OF PROSTATE CANCER AWARENESS DISPLAY AT SETON MEDICAL CENTER IN DALY CITY, CA FOR THE FIRST 2018 CPCC BOARD MEETING



SOME OF OUR CPCC BOARD MEMBERS: EARL JONES, DOTTIE AND JOE FERRARA, BARRY CHAUSER, MD, MEREL GREY NISSENBERG, STAN ROSENFELD, BILL DOSS, BEVERLY NICHOLSON AND TOM KIRK GATHERED FOR OUR BOARD MEETING JANUARY 10, 2018 READY FOR A NEW YEAR OF CHALLENGES

CALIFORNIA PROSTATE CANCER COALITION

We are the CALIFORNIA PROSTATE CANCER COALITION, a 501(c)(3) non-profit organization made up of prostate cancer patients, family members, physicians and other individuals interested in prostate cancer.

- WE ADVOCATE FOR THE EARLY DETECTION OF POTENTIALLY DEADLY DISEASE
- WE ARE MAKING PROSTATE CANCER A KEY HEALTH CARE PRIORITY IN CALIFORNIA
- WE NETWORK ALL THE PROSTATE CANCER SUPPORT GROUPS IN THE STATE
- WE DISSEMINATE INFORMATION RELATING TO PROSTATE CANCER, INCLUDING A DURABLE, LAMINATED AWARENESS AND EDUCATION TOOL
- WE ADVOCATE FOR PROSTATE CANCER LEGISLATION AND FUNDING AND HELPED MAKE IMPACT FOR UNDERSERVED MEN A PERMANENT STATE PROGRAM
- WE ADVOCATE FOR THE HIGHEST QUALITY OF LIFE FOR PROSTATE CANCER PATIENTS AND THEIR FAMILIES
- WE PERFORM OUTREACH TO, AND INVOLVE ALL COMMUNITIES
- WE PUBLISH A NEWSLETTER
- WE MAINTAIN A WEBSITE: WWW.PROSTATECALIF.ORG
- WE CONDUCT ANNUAL WORKSHOPS FOR PROSTATE CANCER SUPPORT GROUP LEADERS

JOIN THOSE WHO HAVE CONTRIBUTED, PLEASE DONATE TO CPCC
Donate online at www.prostatecalif.org or send your check to:

CPCC, 6709 La Tijera Blvd., Suite 473, Los Angeles, California 90045.

Contributions are Tax-Deductible.
We are a 501(c)(3) not-for-profit organization.
Our Tax ID Number is 94-3349907.

*CPCC is a Proud Participant in the
National Alliance of State Prostate Cancer Coalitions*

