



## *“Fighting Prostate Cancer in California!”*

*www.prostatecalif.org*

# News

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### **PRESIDENT’S MESSAGE**

Welcome to the September 2017 issue of the CPCC Newsletter. We are busier than ever in September because this is Prostate Cancer Awareness Month. We need to keep spreading the word about Informed Decision-Making in prostate cancer and we must continue to advocate for the early detection of potentially lethal prostate cancer.

CPCC lost one of its founding Board Members, Stan Mikkelsen, on June 20, 2017. We are beyond grateful for Stan’s efforts over so many years to make CPCC a viable and effective organization to help prostate cancer patients and their families. Stan was part of the group of Board Members that helped to turn IMPACT into a permanent program for underserved men in California who are diagnosed with prostate cancer. Donations may be made to CPCC in Stan’s name.

We are very excited that we have a brand-new CPCC Brochure, the link to which is <http://prostatecalif.org/cpcc-brochure/>. In the brochure, we write about prostate cancer, diagnosis, treatment, support groups, and informed decision-making; and very importantly, we show what CPCC can do for patients and their families. We state on the cover that we are a proud participant in the National Alliance of State Prostate Cancer Coalitions (NASPCC), and there is much information contained in the 8 panels. Please let us know if you would like either full-size or pocket-size CPCC brochures for spreading the word.

Our Treasurer and Webmaster, Earl Jones, is doing a great job with both our website ([www.prostatecalif.org](http://www.prostatecalif.org)) and our Facebook Page “California Prostate Cancer Coalition – CPCC.” Our new Vice President is Tom Kirk, former President and CEO of US TOO. We would like to thank our former Vice President, Chad Little, for his efforts on behalf of CPCC.

Board Member Stan Rosenfeld led a very successful Southern California Support Group Leaders’ Workshop on June 19 at USC Norris Cancer Center in Los Angeles, and he will lead the Northern California Support Group Leaders’ Workshop on October 4 in San Francisco. Stan has been facilitating these Workshops for years, and in fact, his Support Group in Marin County just celebrated their 25<sup>th</sup> year with a big celebration. Stan has been leading that group for 17 years! Bill Doss is looking for volunteers to help him in his statewide project gathering Proclamations for Prostate Cancer Awareness Month, a project he has spearheaded for 13 years. Please contact him at [wdoss@surewest.net](mailto:wdoss@surewest.net) if you can help!! Board Member Joe Ferrara received a Humanitarian Award for his work with prostate cancer awareness, and Joe’s efforts over the last few years led to Marvel Comics coming up with several comic book covers promoting awareness of prostate cancer.

We have updated our Informed Decision-Making Laminate and continued its distribution on a national level ([www.prostatecalif.org/patient-guide](http://www.prostatecalif.org/patient-guide)). CPCC supplied 700 of these tools to the Vietnam Veterans of America for their Annual Meeting in August. We continue to wait for the updated final Screening Guidelines of the U.S. Preventive Services Task Force, which will likely change some of their PSA screening recommendations from a D to a C suggesting PSA testing for men 55-69 (but the C means that, in their opinion, the benefits and harms are balanced as to whether to screen such men). On the other hand, CPCC advocates for the early detection of potentially lethal prostate cancer and suggests that men get their baseline PSA at age 40 (or younger if they are high-risk); so, while the new Guidelines will be an improvement, they will not go far enough. (We submitted these same comments to the Task Force several months ago).

The Prostate Cancer Research Institute (PCRI) Meeting will take place in Los Angeles September 8-10. A few of us will be attending and will be distributing our new Brochures and our Informed Decision-Making Laminates there. As President, I will be representing CPCC at the 13<sup>th</sup> Annual Meeting of NASPCC in Washington, D.C. on October 13-15, and will be the prostate cancer advocate on an NCCN Advocacy Panel on Survivorship in Cancer planned for December

1, 2017. There are other activities coming up in November and December, such as Earl Jones' outreach event for education and testing in Los Angeles during Veterans' Day Weekend, which CPCC is helping to sponsor. Board Member Bill Doss is working with Komen's Race for the Cure to add a prostate cancer awareness activity to a breast cancer event they are holding in Sacramento which they hold every year in May.

You can see that there is a lot happening at CPCC. Please visit our Website [www.prostatecalif.org](http://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](mailto:mgrey@ucsd.edu) with suggestions for our organization!

*Best regards, Merel Grey Nissenberg, President*

## California Designates September 2017 as Prostate Cancer Awareness Month

*This resolution was sponsored by Senator Ted Gaines at the request of William Doss, CPCC Board member. Since 2005, Bill has spearheaded a statewide project to increase the number of legislative bodies issuing proclamations to recognize Prostate Cancer Awareness Month throughout California. If you are interested in participating in this project or wish to learn more, contact Bill at email: [wdoss@surewest.net](mailto:wdoss@surewest.net).*



### California Senate Concurrent Resolution Number 27 Prostate Cancer Awareness Month September 2017

**Introduced by Senator Gaines, February 23,  
2017**

**SCR 27 designates  
September 2017 as Prostate Cancer Awareness  
Month in the State of California.**

**WHEREAS**, Prostate cancer is the most frequently diagnosed cancer in men aside from skin cancer. An estimated one in eight men will develop this disease in his lifetime; and

**WHEREAS**, The American Cancer Society estimates that there will be 161,360 new cases of prostate cancer in the United States in 2017, resulting in an estimated 26,730 deaths; and

**WHEREAS**, An estimated 14,520 men in California will be diagnosed with prostate cancer this year, and an estimated 3,130 men in California will die from this disease; and

**WHEREAS**, Men of African American descent have the highest prostate cancer incidence rates in the world, and their prostate cancer mortality rate in the United States is more than twice that of any other ethnic group of men; and

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

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

**WHEREAS**, The five-year survival rate approaches 100 percent when prostate cancer is diagnosed and treated early, but it drops to 29 percent when it spreads to other parts of the body; and

**WHEREAS**, Treatment options for prostate cancer vary depending on a man's age, the stage and grade of his cancer, and his other existing medical conditions; and

**WHEREAS**, The American Cancer Society recommends that a man should have an opportunity to make an informed decision about whether to be tested for prostate cancer based on his personal values and preferences; now, therefore, be it

**Resolved** by the Senate of the State of California, the Assembly thereof concurring, That the Legislature hereby proclaims the month of September 2017 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.

## IDW Comic Books Feature Ads to Increase Awareness about Prostate Cancer

**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






To reach comic book fans all over the world with a message about the importance of prostate cancer screening, four nonprofit prostate cancer groups joined forces to run an ad in August in twenty-five different comic books from IDW Publishing. The one-page ad highlights a portrait of a “hero” with his family and offers helpful facts to readers about prostate cancer.

“Last year, Marvel produced five comic books with variant covers featuring heroes in blue costumes to raise awareness about prostate cancer,” says Joe Ferrara, proprietor of award winning comic bookstore, Atlantis Fantasyworld, in Santa Cruz,

California. Ferrara, a twelve-year survivor of prostate cancer, is a board member of both the Santa Cruz County Prostate Cancer Support Group and the California Prostate Cancer Coalition. “This year we are very excited to work with the NASPCC, US TOO International and IDW Publishing to reach a global readership with the important message of testing for prostate cancer. Real men get tested! It can save lives.”

The issues hit the shelves in August to allow them to be available in September for Prostate Cancer Awareness Month. The comic books retail for \$3.99 and can be ordered in amount from any comic book store in the world.

Comic book titles and sale dates:

- August 9: First Strike #1, GI Joe #9, Optimus Prime #10, Time and Vine #2, Teenage Mutant Ninja Turtles #73, and X-Files #17.
- August 16: Rom vs. Transformers: Shining Armor #2, Clue #3, G.I. Joe: Real American Hero #243, Judge Dredd #5, Saucer State #4, and Star Trek: Boldly Go #11.
- August 23: 24: Legacy #5, Ghostbusters 101 #6, M.A.S.K.: Mobile Armored Strike Kommand #10, Micronauts: Wrath of Karza #5, Orphan Black: Deviations #6, Rom #14, Teenage Mutant Ninja Turtles Universe #13, Wynonna Earp: Season Zero #3, and X-Files: Origins: Dog Days of Summer #3.
- August 30: Back to the Future: Time Served #23, Dread Gods #2, Kull Eternal #3, and Transformers: Lost Light #9.

The ad is a joint effort by IDW Publishing Group, California Prostate Cancer Coalition, National Alliance of State Prostate Cancer Coalitions, Santa Cruz County Prostate Support Group, and US TOO International Prostate Cancer Education and Support Network.

*Information provided by IDW Publishing Group Press Release and Joe Ferrara*

## Focus on Prostate Cancer Treatment in California

### Faced with Many Options, Men with Prostate Cancer Get Help Choosing the Right Treatments: Software Developed by UCLA Urologist Helps Men Avoid Decisions They Might Regret



*Like many men diagnosed with prostate cancer, Bill Pickett faced a tough question when he came to UCLA for treatment: how to fight it?*

Prostate cancer is one of the more curable cancers — it has a 96 percent survival rate 15 years after diagnosis, [according to the American Cancer Society](#). The options men have after a diagnosis have different side effects and trade-offs. So choosing, for example, between radiation therapy or surgery, can be complicated for a person.

“When you’re diagnosed with prostate cancer, you realize that each treatment can have very different side effects,” said Pickett, who lives in Los Angeles and came to UCLA for treatment in summer 2016. “You really have to think about what’s most important and about which treatment is best for you.”

Recent [research in the Journal of Clinical Oncology](#) shows that as many as 15 percent of prostate cancer patients later regret their treatment choice.

Such difficulties led Dr. Christopher Saigal, vice chair of urology at UCLA, to develop a tool to simplify the choices for men and reduce what he calls “decisional conflict,” when patients experience stress about which treatment — and consequent risks — to choose.

The tool, an online computer program called WiserCare, asks men with prostate cancer to answer questions about personal values and goals and based on those answers provides a ranking of suggested treatments.

The program works by using algorithms that incorporate medical evidence and modeling to quantify the relative strengths of what a patient says he values. For example, has he answered that having the longest life possible is less important than avoiding a side effect like decreased sexual function? The software then suggests treatment options, which the men can weigh to decide which treatment option is best for them.

“As doctors, we want to offer a patient-centered plan that gives patients the power to leverage all the clinical evidence we have and choose a treatment that fits with their personal preferences,” Saigal said.

Pickett is one of the more than 300 men at UCLA who have used the tool. It’s currently available to all prostate cancer patients at UCLA and is being adopted at a growing number of institutions, including Johns Hopkins and Northshore University. After completing the questionnaire online, Pickett decided that a new clinical trial would be the right choice for him.

“By the time I was done using the tool, I knew which treatment I wanted to have,” Pickett said.

The trial involved taking oral drugs and subcutaneous injections in hopes of making the surgery to remove the prostate gland — known as a prostatectomy — more successful. Pickett underwent surgery at the end of January and now has no signs of the cancer in his body. He continues to be closely monitored for any cancer recurrence using the prostate-specific antigen test.

While the common side effects of a prostatectomy include incontinence and decreased sexual function, physicians suggest different exercises patients can use to get better control of bodily functions like urine flow. Pickett is using a variety of methods — including Kegel exercises to strengthen the pelvic floor muscles — to manage the side effects of his surgery. *Continued on Page 5*

“With my treatment, I just wanted the best chance at success,” Pickett said. “I’ve been doing well post-surgery, and my side effects have been getting better each day.”

Prostate cancer is one of many diagnoses that highlights the benefits of personalized medicine. While Pickett, 66, decided a clinical trial followed by a prostatectomy was best for his situation, Saigal said that other men with different preferences choose different treatments. Personalized tools like the one Saigal created aim to give patients the greatest chance at success — whatever that may mean to them.

“There is so much data out there now on this diagnosis that patients can be overwhelmed,” Saigal said. “Software programs like these help patients to unlock the power of those data and apply them to their personal situation.”

Saigal is measuring the impact of the software on patient decision quality and said his team has found improvements in patient satisfaction, increased knowledge about prostate cancer and reductions in feelings of uncertainty after making a treatment decision.

“As doctors, we need to put a greater emphasis on patient preferences when guiding them through their treatment,” he said. “It’s important for patients to be as involved as they can be when it comes to decisions about their own health.”

*UCLA News Release 08/04/2017 Reprinted with permission <https://www.uclahealth.org/faced-with-many-options-men-with-prostate-cancer-get-help-choosing-the-right-treatments>*

### **Marin Prostate Cancer Information and Support Group**

- **Meets every Tuesday, 7:00pm to 8:30pm**
- **Meeting Location: Medical Library, Marin General Hospital, 250 Bon Air Road, Greenbrae, CA**
- **Free, registration not required**

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

## **Focus on California Prostate Cancer Support Groups**

### **Marin Prostate Cancer Information and Support Group Celebrates Twenty-Five Years of Service**



On August 1, 2017, the Marin Prostate Cancer Information and Support Group gathered at the Falkirk Cultural Center in San Rafael to celebrate a quarter of a century of men helping men with prostate cancer. The event was attended by 140 survivors, caregivers, doctors, hospital administrators and health care professionals.

The group, now led by CPCC Board Member Stan Rosenfeld, was founded by historian Lionel Ashcroft, who died of prostate cancer in 2006. Rosenfeld started going to the group when he was diagnosed and became the group facilitator two years later.

From its inception, weekly meetings were held to ensure that no man had to wait more than a week to receive support and information. Over one thousand men and women have shared their experience and wisdom with newly diagnosed men during the thirteen hundred meetings held. Now twenty to thirty men attend the meeting each week. The group has earned the support of area physicians including Dr. Peter Carroll, head of the University of California at San Francisco’s Department of Urology, who attended the celebration.

## Joe Ferrara Wins Bob Clampett Humanitarian Award



Joe Ferrara, CPCC Board member, received the Bob Clampett Humanitarian Award for his work with Prostate Cancer Awareness at San Diego Comic-Con International this summer. Ferrara, owner of Atlantis Fantasyworld in Santa Cruz, is a twelve-year survivor of prostate cancer. For the last ten years he has served on the steering committee of the Santa Cruz County Prostate Cancer Support Group and for the last five years he has also served on the Board of Directors of the California Prostate Cancer Coalition.

"It is such an incredible honor to accept this award on behalf of all the courageous men and their families who live with this disease on a daily basis" says Ferrara." It takes a village and this award represents a significant step in advancing the awareness of Prostate cancer to the general public."

### **The Bob Clampett Humanitarian Award**

Comic-Con International's Humanitarian Award is presented in the name of famed animator Bob Clampett, who would have turned 100 in 2013. Clampett created the TV series Beany and Cecil, designed such popular characters as Porky Pig and Tweety Bird, and directed 84 classic Warner Brothers cartoons. Clampett was a regular guest a Comic-Con in the 1970s and early 1980s. After his death in 1984, the humanitarian award was created to honor those people in comics and the popular arts who have worked to help others. The recipient is chosen by the Comic-Con committee, and the award is given out annually during the Eisner Awards ceremony.

## California Prostate Cancer Coalition Mourns Loss of Stanley Mikkelsen, One of CPCC's Founders and Legendary Prostate Cancer Advocate



On June 20, 2017 Stanley Mikkelsen, a founding member of CPCC, died suddenly at the age of 88. During his life, Stan worked tirelessly for prostate cancer causes, serving on the CPCC Board of Directors, and serving as CPCC Treasurer, Support Group Facilitator, President of CPCC-Advocates, and as a volunteer for the American Cancer Society.

In 1997 Stan joined a group of determined individuals who pooled their talents, energy and time to fight to eliminate suffering and death from prostate cancer. From this initial effort, the California Prostate Cancer Coalition (CPCC) was founded.

As a member of the CPCC Board of Directors, Stan played a major role in developing and implementing programs undertaken by CPCC. Among Stan's most significant contributions was the leadership role he played in the saving of The IMPROving Access, Counseling & Treatment (IMPACT) Program. The IMPACT Program provides treatment services to men diagnosed with prostate cancer but without sufficient personal health insurance coverage. In 2003 when the IMPACT Program was targeted for elimination by the newly elected Governor of California, Stan led a team of CPCC members to develop and implement a "resistance" campaign, rallying individuals concerned about men facing prostate cancer and informing legislators about the significant consequences of eliminating this safety net for men. His efforts stopped actions to eliminate the program. When IMPACT faced the same threat in 2004 Stan again led CPCC's efforts to save the program. *Continued on Page 7*

When it was determined that a more stable solution was needed, Stan found a legislator to sponsor a bill to put IMPACT into statute, thus providing significantly more stability for the program. SB650 was passed in 2005 after being introduced by State Senator Debra Ortiz.

From that point on, CPCC became and continues to be a significant player in the prostate cancer landscape, both statewide and nationally. Stan and the CPCC team that he led became known and recognized in the hallways of the Capitol in Sacramento.

From the beginning, the impetus for many platforms and initiatives came from “prompts” and often “shoves” from Stan. He always had our backs, and the backs of prostate cancer patients everywhere in California. He was tireless in his desire to serve the cause. Providing support for support groups within California was a very strong personal passion of

Stan’s. Support groups throughout the state are stronger, better, and will continue to benefit from his actions.

Stan’s dedication and commitment to CPCC and the cause for men’s health was reflective of his life. His actions reflected his belief in duty and honor to all, especially his family. He was preceded in death by his wife, Valeri, after 34 years of marriage. That loss did not deter him from enjoying and supporting his three sons, Mark, Todd, and Chris, and their families, including seven grandchildren.

Stan was a man of determination. That was evident in everything he did. In recent years, he often commented on “getting old”, but he never commented on “getting tired”. Those involved in the battle against prostate cancer can take comfort in the fact that Stan beat prostate cancer.

- *Merel Grey Nissenberg, President*

## California Prostate Cancer Coalition Information

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### 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:

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