Informed Prostate Cancer Support Group Inc.
"A 501 C 3 CORPORATION ID # 54-2141691"

# AUGUST 2014 NEWSLETTER

**P.O. Box 420142 San Diego, CA 92142**
**Phone: 619-890-8447 Web: http://ipcsg.org**

**We Meet Every Third Saturday (except December)**

Thursday, August 07, 2014 Volume 7 Issue 8

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Editor: Gene Van Vleet

**Next Meeting**
**August 16, 2014**
**10:00AM to Noon**

Meeting at

Sanford-Burnham Auditorium

10905 Road to the Cure, San Diego CA 92121

SEE MAP ON THE LAST PAGE

## What We Are About

Our Group offers the complete spectrum of information on prevention and treatment. We provide a forum where you can get all your questions answered in one place by men that have lived through the experience. Prostate cancer is very personal. Our goal is to make you more aware of your options before you begin a treatment that has serious side effects that were not properly explained. Impotence, incontinence, and a high rate of recurrence are very common side effects and may be for life. Men who are newly diagnosed with PC are often overwhelmed by the frightening magnitude of their condition. Networking with our members will help identify what options are best suited for your life style.

**Be your own health manager!!**

## PROSTATE CANCER IT'S ONLY 2 WORDS, NOT A SENTENCE

The guest speaker for our July meeting was David Karow, M.D., PhD., Assistant Clinical Professor of Radiology, UCSD who spoke about new imaging innovations for prostate cancer detection and targeted biopsies.

The challenge for imaging technology is to distinguish between indolent and aggressive prostate cancer. It is not good enough to just know if there is cancer or not, but rather to define its aggressiveness. The standard of care for patients with suspected low grade disease has previously been to perform repeat random biopsies to monitor the disease. More recently, the move has been toward

## Video DVD's

DVD's of our meetings are available in our library for $10ea. Refer to the index available in the library. They can also be purchased through our website: http://ipcsg.org Click on the 'Purchase DVDs" button.

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more imaging and fewer biopsies. Although he believes the role of imaging will become more important, he does not foresee it replacing the need for a biopsy. Using imaging to direct biopsies is a better way to proceed. Prostate MRI's can be used for surgical planning, targeted biopsies, active surveillance, radiotherapy planning and follow-up for rising PSA after treatment failure. They use multiparametric MRI's(MP-MRI) which give a more precise image. He showed slides comparing MP-MRI with CT and ultrasound images that clearly showed improved definition as well as slides showing images of the various sections of the prostate. They do not use an endorectal coil in their examination because they believe it distorts the gland and their procedure takes only 35 to 40 minutes. They can view neurovascular bundle invasion as well as extracapsular extension. MP-MRI images do have limitations for seeing low volume or low grade cancer, i.e. Gleason 3+3=6, which can be a positive factor for those following active surveillance. They are achieving about 85% accuracy in their program. The machine they use has a 3 Tesla magnet which is the most sophisticated available. By adding diffusion weighted imaging to the MRI process they can more precisely locate tumors. Dr. Karow showed many examples of images of patients which showed very clearly the location of tumors as compared to other techniques. He believes that such imaging can be utilized to establish biomarkers to be followed over time in a patient's records but does not see that it would replace the current biomarker techniques such as the Gleason test, but would be used in concert with them to get a more predictive result. A problem with such imaging is distortion. They have been able to refine their process to within 1mm which makes it effective to use for image guided biopsies. He discussed devices such as the Artemis system first used at UCLA and now INVIVO-Phillips that assist urologists in guiding the biopsy utilizing MP-MRI imaging. These techniques are now being used for UCSD patients when advisable.

Dr. Karow's presentation was highly informative and the technology should be recognized as a significant advance in helping us define the seriousness of our PCa. A lot of technical and visual information was presented in a short time, so obtaining a copy of the DVD will be most helpful in improving your understanding. Copies will be available for purchase at our next meeting and can be also be obtained through our website link: http://ipcsg.org/shop/

## FUTURE MEETINGS

**August 16, 2014** - Karen Kunz, Medical Science Liaison, Myriad Genetics. Prostate Cancer Treatment Decisions in the Genomic Testing Era

**September 20, 2014** - Roundtable Discussion. A panel of members will speak about their treatment experiences, followed by networking among members

**October 18, 2014** - A.J. Mundt, M.D., Professor and Chair, Department of Radiation Oncology UCSD, John P. Einck, M.D., Associate Clinical Professor Radiation Oncology UCSD: Radiation Therapy for Prostate Cancer: Current Treatments and New Developments.

**November 15, 2014** - Richard Lam, M.D. Research Director, Prostate Oncology Specialists: Androgen Deprivation Therapy and recent treatment developments.

December, 2014. **NO MEETING**

## ON THE LIGHTER SIDE


**You think English is complicated? Ship by truck, and send cargo by ship? Have noses that run and feet that smell? Park on driveways and drive on parkways? How can a slim chance and a fat chance be the same, while a wise man and a wise guy are opposites? How can the weather be hot as hell one day and cold as hell another?**

**California Crazy Laws:**

**•No vehicle without a driver may exceed 60 miles per hour.**

**•Women may not drive in a house coat.**

**•Los Angeles: It is illegal for a man to beat his wife with a strap wider than 2 inches without her consent.**

**•Blythe: You are not permitted to wear cowboy boots unless you already own at least two cows.**

**•San Diego: It is illegal to shoot jackrabbits from the back of a streetcar.**

**•San Francisco: It is illegal to wipe one's car with used underwear.**

**If you can't beat them, arrange to have them beaten.—-George Carlin**

**I went for a walk last night and she asked me how long I was going to be gone. I said, 'The whole time.— Steven Wright**

**When you're in jail, a good friend will be trying to bail you out. A best friend will be in the cell next to you saying, 'Damn, that was fun'. — Groucho Marx**

**Even if you are on the right track, you'll get run over if you just sit there.— Will Rogers**

**A smile is a curve that sets everything straight.— Phyllis Diller**

**Black holes are where God divided by zero. — Albert Einstein**

**I think I've discovered the secret of life -- you just hang around until you get used to it. — Charles M. Schulz**

**I ask people why they have deer heads on their walls. They always say because it's such a beautiful animal. There you g. I think my mother is attractive, but I have photographs of her."— Ellen DeGeneres**

## INTERESTING ARTICLES

### The Power of a Word

Posted: 17 Jun 2014 08:09 AM PDT Prostate Snatchers blog
BY MARK SCHOLZ, MD

At an Active Surveillance Consensus Conference in 2007, it was openly bemoaned that the word "cancer" profoundly overstates the significance of low risk prostate cancer. The pathology experts who were present, however, shot down the idea of a name change saying, "Under the microscope it looks like a cancer, so it's cancer." At that time no one had a rebuttal, so the subject was dropped. Now studies confirm that Gleason grade six prostate cancer never metastasizes.

In retrospect, I wish the conference attendees had been able to rise up to the name-change challenge. Back when the makers of 7-Up wanted to emphasize the distinctness of their product compared to other soft drinks, they came up with the name "Un-Cola," a stroke of marketing genius. Since the pathology experts insist that low-risk disease is a cancer—we should undo the negativity of this word by renaming it: "The Un-Cancer." Alternatively, the SHADES of Blue classification system calls this harmless type of prostate cancer SKY BLUE.

Misinterpreting the significance of the word cancer leads everyone to think, "I had better be safe and remove the gland." The biggest challenge of educating people about prostate cancer is overcoming their preconceived notions, what they already think they know about cancer. Random biopsies are detecting cancers that are so small that even if they grow while under observation, they will still be curable. And for the minority of men on active surveillance who develop progressive disease, at least they have real proof that their cancer truly needs intervention, for this minority, it's not a paper tiger and undergoing treatment is justified.

**Defining the Un-Cancer—The Basic Components of SKY**

| | **Favorable** | **Ambiguous Zone** | **Unfavorable** |
|---|---|---|---|
| Color Doppler or Multiparametric-MRI | < 10 mm in maximum tumor dimension | 11-17 mm maximum tumor dimension | > 18 mm max tumor dimension |
| Highest Gleason Grade | Grade 3 + 3 = 6 | 3 +4 = 7 | 4 + 3 = 7 or higher |
| PSA Density | Under 0.13 | 0.14 to 0.17 | Over 0.18 |

**Further In-depth Testing for SKY**

New technology is also providing new insight into how favorable cancer can be distinguished from unfavorable cancer. The biggest advance is better imaging of the prostate. Other new blood and genetic tests such as Prolaris, Oncotype, MDx, OPKO 4K and Mitomics, can also ferret out the cancers that are prone to behave more aggressively or have been missed on the initial random biopsy.

**The Drawbacks for Active Surveillance**

The main concern is that the initial random biopsy missed a higher grade tumor somewhere else in the prostate. Most centers address this problem by doing random biopsies over and over. Repeated random biopsies are unpleasant and they can cause serious infections. Multiple biopsies have also been asso-

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ciated with higher impotence rates and worse urinary symptoms. A better way is to rely on modern imaging with color Doppler ultrasound or multiparametric MRI (MP-MRI). Also, because with active surveillance prostate gland is left intact, there is the possibility of a new, higher grade cancer developing. The privilege of keeping the prostate intact entails the responsibility of close monitoring. Then, if a new higher grade cancer subsequently develops, it can be detected and treated at an early stage.

Anxiety and uncertainty about living with untreated cancer is also a problem, one that is often magnified by the treating physicians, surgeons or radiation doctors who often send an ambivalent and lukewarm message about active surveillance to their patients. This half-hearted attitude is probably rooted in the doctor's own uncertainties about untreated cancer. Despite all these very real issues, however, studies show that men on an active surveillance program are no more anxious than men who have had surgery or radiation and are being monitored after therapy to make sure their cancer stays in remission.

**It's Hard to Teach an Old Dog New Tricks**

It's easier to teach a proper golf swing to a true beginner than to someone who has previously developed bad habits. The mind of a child learns a new language much more easily than the cluttered mind of the adult. Good first impressions are valued so highly because we all know how hard it is to undo a bad first impression. Changing the mindset of doctors and patients about how to treat something called CANCER is going to be a slow process.

Men need to realize that survival rates with low-risk prostate cancer managed with observation are extremely favorable. Studies show that survival with active surveillance matches the survival of men getting immediate surgery. Men need to guard themselves from being rushed into unnecessary treatments that have irreversible side effects.

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## Some With Prostate Cancer May Not Get Best Advice

MONDAY, July 14, 2014 (HealthDay News)

Many men may not be getting the best advice when it comes to managing low-risk prostate cancer, two new studies suggest.

In the first study, researchers found that most men are getting their prostate removed or undergoing radiation therapy when carefully watching the cancer may be just as effective without the risks and side effects of surgery or radiation.

"The variation of treatment of low-risk prostate cancer by physicians was striking," said lead researcher Dr. Karen Hoffman, an assistant professor at the University of Texas MD Anderson Cancer Center in Houston.

Hoffman added that the doctor who diagnoses the cancer has the biggest influence on what treatment the patient will choose.

"The diagnosing urologist influences a man's treatment fate. The urologist not only influences up-front treatment versus observation, but also the type of treatment," she said.

Hoffman found that doctors who were older were more likely to recommend surgery or radiation rather than observation. Moreover, men were more likely to have surgery or radiation therapy if their urologist did that procedure, she added.

The rate of observation as opposed to other treatments across urologists ranged from almost 5 percent to 64 percent of patients. For men diagnosed by radiation oncologists, the rate of observation also varied from 2 percent to 47 percent, Hoffman said.

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There may be a financial incentive at work here, said Dr. Anthony D'Amico, chief of radiation oncology at Brigham and Women's Hospital in Boston. He was not involved in the study.

"You make a diagnosis and there is a financial incentive in keeping the patient," he said. However, the urologist may also believe in treating the patient rather than choosing observation, he said.

D'Amico advises that any man diagnosed with prostate cancer get a second opinion. "With prostate cancer, there are options for treatment and sometimes surveillance is the right thing to do. So, men really need to get a second opinion in conjunction with their primary care physician, who knows their overall health and their wishes," he said.

He noted that side effects of surgery or radiation include impotence, incontinence and rectal bleeding. "So, you should not just go with the first person who diagnoses you," D'Amico said.

For the study, Hoffman's team collected data on a little more than 2,000 men, aged 66 and older, diagnosed with low-risk prostate cancer from 2006 through 2009. The diagnosis was made by urologists, the researchers noted. Among these men, 80 percent received treatment and 20 percent were observed.

In the second report, a team led by Dr. Grace Lu-Yao, a professor of medicine at the Rutgers Cancer Institute of New Jersey and Robert Wood Johnson Medical School in New Brunswick, N.J., found that hormone treatment did not improve survival in men with prostate cancer that had not spread beyond the prostate.

"The data do not support the practice of using hormone therapy as the sole therapy for elderly patients with localized prostate cancer," Lu-Yao said.

Because hormone therapy is associated with side effects such as osteoporosis, diabetes and decreased muscle tone, doctors must carefully consider the reasons for using this treatment as the primary treatment for older men with low-risk localized prostate cancer, she said.

Using federal government data, Lu-Yao's team collected information on almost 67,000 Medicare patients, diagnosed between 1992 and 2009. These men had not had surgery or radiation within 180 days of diagnosis, the researchers said.

During an average of 110 months of follow-up, hormone therapy was not associated with improved survival, the researchers found.

In fact, 15-year survival in men, whether their cancer was fast- or slow-growing, didn't differ if they received hormone therapy or not, the researchers found.

Survival among men with slow-growing cancer was about 90 percent with or without hormone therapy. For men with fast-growing cancer, survival was about 78 percent among both men treated with hormone therapy and men who weren't.

Both studies were published online July 14 in the journal JAMA Internal Medicine

## NETWORKING

The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is "networking". We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all. Many aspects of prostate cancer are complex and confusing. But by sharing our knowledge and experiences we learn the best means of prevention as well as the latest treatments for survival of this disease. So bring your concerns and join us.

Please help us in our outreach efforts. Our speakers bureau consisting of Lyle LaRosh, Gene Van Vleet and George Johnson are available to speak to organizations of which you might be a member. Contact Gene 619-890-8447 or gene@ipcsg.org to coordinate.

Member and Director, John Tassi is the webmaster of our website and welcomes any suggestions to make our website simple and easy to navigate. Check out the Personal Experiences page and send us your story. Go to: http://ipcsg.org

Our brochure provides the group philosophy and explains our goals. Copies may be obtained at our meetings. Please pass them along to friends and contacts.

Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them

## *FINANCES*

We want to thank those of you who have made special donations to IPCSG. Remember that your gifts are tax deductible because we are a 501(c)(3) non-profit organization.

We again are reminding our members and friends to consider giving a large financial contribution to the IPCSG. This can include estate giving as well as giving in memory of a loved one. You can also have a distribution from your IRA made to our account. We need your support. We will, in turn, make contributions from our group to Prostate Cancer researchers and other groups as appropriate for a non-profit organization. Our group ID number is 54-2141691. Corporate donors are welcome!

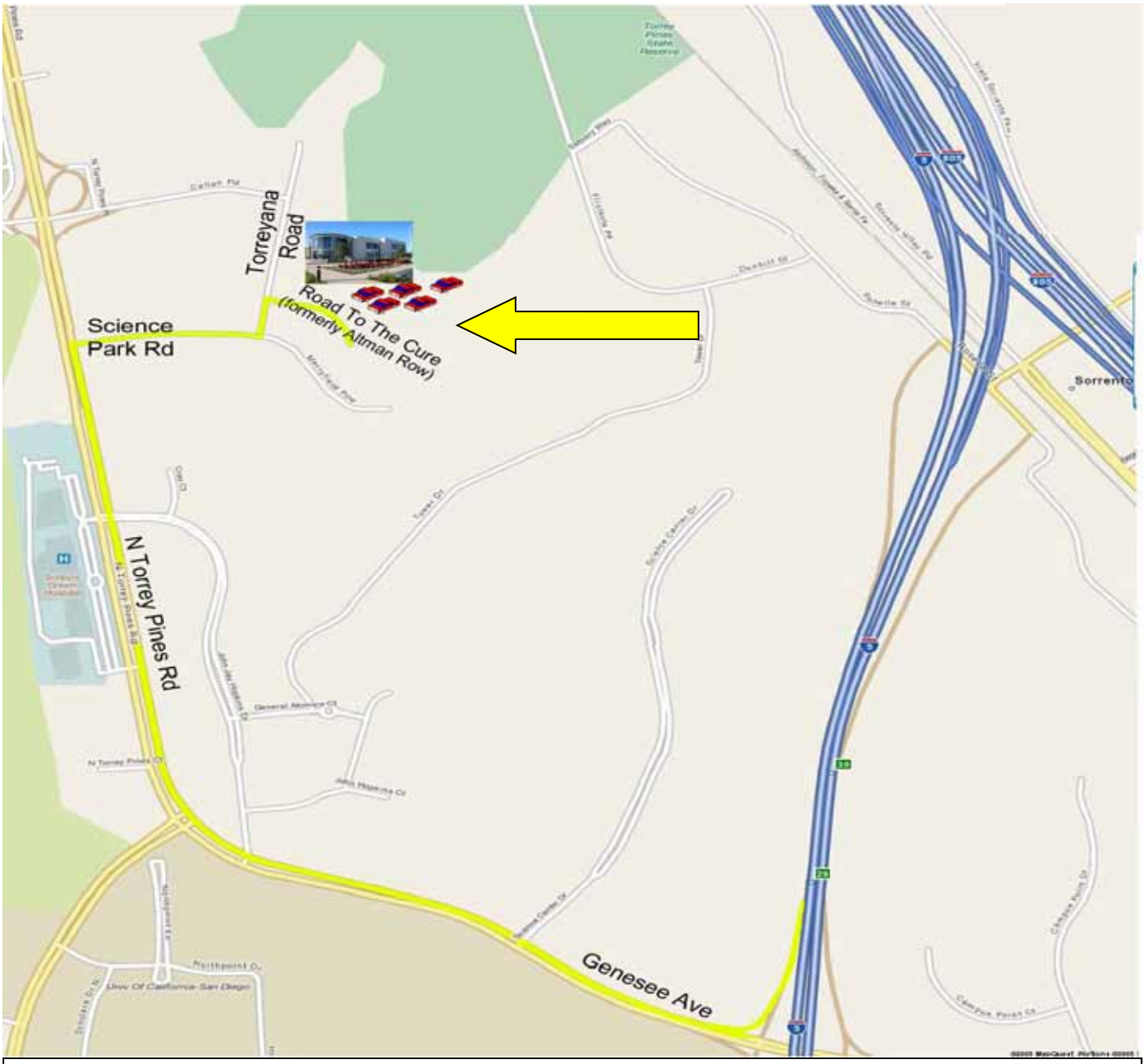
If you have the internet you can contribute easily by going to our website, http://ipcsg.org and clicking on "Donate" Follow the instructions on that page. OR just mail a check to: IPCSG, P. O. Box 4201042, San Diego CA 92142

## WE NEED HELP

All services for our group are performed by volunteers. As is usual in our type of organization we have a few doing a lot for many. We need people to step up and help in the following areas:

1. Fund Raising. We need help from anyone with any knowledge or willingness to become involved in acquiring grants to support our organization. We need someone to organize fund raising activities.
2. Information Technology. Any techies out there that can help take advantage of the facilities available where we meet--such as live remote conferencing.

Anyone interested please contact: Gene Van Vleet, Chief Operating Officer. 619-890-8447 gene@ipcsg.org orLyle LaRosh, President 619-892-3888 lyle@ipcsg.org




## Directions to Sanford-Burnham Auditorium
## 10905 Road to the Cure, San Diego, CA 92121

Take I-5 (north or south) to the Genesee exit (west).
Follow Genesee up the hill, staying right.
Genesee rounds right onto North Torrey Pines Road.
**Do not turn into the Sanford-Burnham Medical Institute or Fishman Auditorium**
Turn right on Science Park Road.
Turn Left on Torreyana Road.
Turn Right on Road to the Cure (formerly Altman Row).