



Informed Prostate Cancer Support Group Inc.

"A 501 C 3 CORPORATION ID # 54-2141691"



JULY 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)



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Editor: Gene Van Vleet

Next Meeting

July 19, 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**

Saturday, July 12, 2014

Volume 7 Issue 6

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

We had two presentations during our June meeting. The following is a brief summary of their presentations that can be more fully understood by viewing the DVD of the meeting available in our library or through our website: ipcsg.org
Andrew Goldstein, PhD, Assistant Researcher, Jonsson Comprehensive Cancer Center, UCLA, spoke about new stem cell research on prostate cancer. Prostate cancer is a multifocal disease. If a removed prostate is examined there will be cancers of varying grades. In the early stages of cancer, stem cells have a specific role in driving the cancer but certain healthy habits such as reduced stress,

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 DVD's' button.

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antioxidants and exercise can help inhibit growth. The research focus is to try to identify which stem cells are active, which are dormant and which can be manipulated to reduce or eliminate tumors. Another condition presents itself when cancer recurs. A possibility is that the therapy that shrinks the tumor may not kill all the cells and they develop resistance or develop cells that survive and regrow. Andrew explored in detail many of these possibilities which can be more thoroughly understood by viewing the DVD of the meeting.

Irwin Goldstein, M.D. Director of Sexual Medicine, Alvarado Hospital, spoke about contemporary management of men with sexual dysfunction after prostate cancer treatment. He first discussed Peyronie's disease which is a painful bend in the penis during erection. During an erection, the wall of the penis needs to stretch equally. If it does not, it is Peyronie's disease. It is caused by plaque forming in the walls of the penis. At the end of 2013 a new drug was developed that can be injected to clear the plaque. Issues with orgasm originate from poor blood flow to certain areas of the brain which can now be treated with certain drugs. Erectile dysfunction has typically been treated with Viagra-type drugs or injection. A new study being performed under the direction of Dr. Goldstein makes use of stem cells injections to facilitate erections. Dr. Goldstein concluded with a discussion about the negative effects of lowering testosterone. It is worthwhile to view this discussion by viewing the DVD of the meeting. While absorbing this information, keep in mind that the discussion does not give consideration to the effect on prostate cancer for men on testosterone inhibiting drugs if they were to initiate a program of testosterone replacement.

FUTURE MEETINGS

July 19, 2014 - David S. Karow, M.D., Ph.D., Assistant Clinical Professor of Radiology, Director of Body MRI, UCSD will be presenting "New imaging innovations in prostate cancer detection and targeted biopsies".

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.

ON THE LIGHTER SIDE



Why is the alphabet in that order? Is it because of that song?

"We're so busy watching out for what's just ahead of us that we don't take time to enjoy where we are." — Bill Watterson

"Procrastinate now, don't put it off." — Ellen DeGeneres

"If I were two-faced, would I be wearing this one?" — Abraham Lincoln

"You can live to be a hundred if you give up all the things that make you want to live to be a hundred." — Woody Allen

"I like nonsense, it wakes up the brain cells." — Dr. Seuss

"As for monkeys, I would have five, and they would be named: See No Evil, Hear No Evil, Speak No Evil, Do Pretty Much Whatever The Hell You Want, and Expensive Attorney." — Tad Williams

"Do you know how helpless you feel if you have a full cup of coffee in your hand and you start to sneeze?" — Jean Kerr

Boy, were they wrong:

"We don't like their sound, and guitar music is on the way out." -- Decca Recording Co. rejecting the Beatles, 1962.

"The wireless music box has no imaginable commercial value. Who would pay for a message sent to nobody in particular?" -- David Sarnoff's associates in response to his urgings for investment in the radio in the 1920s.

"This 'telephone' has too many shortcomings to be seriously considered as a means of communication. The device is inherently of no value to us." -- Western Union internal memo, 1876

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"I have traveled the length and breadth of this country and talked with the best people, and I can assure you that data processing is a fad that won't last out the year." -- The editor in charge of business books for Prentice Hall, 1957

"I think there is a world market for maybe five computers." -- Thomas Watson, chairman of IBM, 1943

"There is no reason anyone would want a computer in their home." -- Ken Olson, president, chairman and founder of Digital Equipment Corp., 1977

INTERESTING ARTICLES

Advances in Diagnosis: Magnetic Resonance Imaging

Posted: 08 Jul 2014 03:47 PM PDT by Prostate Snatchers

BY RALPH BLUM

Prostate tumors are often multifocal, which means they tend to occur in more than one place within the gland. The digital rectal exam performed by the urologist will often miss tumors. The PSA test, used to screen for prostate cancer, has a sensitivity of about 70% and will often yield unclear results. And the random prostate biopsy, which seeks to identify tumors, while performed systematically, is also done blindly, resulting in roughly one-third false negative results.

In recent years, Multi-parametric Magnetic Resonance Imaging (MP-MRI) has played an increasing role in prostate cancer detection. MP-MRI scans are now more effective in distinguishing cancer from normal prostate tissue. And although MP-MRI is not yet considered the standard tool for diagnosis, it can uncover cancer that has been missed during biopsy. Moreover, MP-MRI plays a significant role in helping to determine whether active surveillance is a safe procedure, or whether a patient requires definite treatment.

Advances in MP-MRI technology include specific targeting known as MRI-guided biopsy. Since cancers that occur in the anterior or front part of the prostate are often not being sampled because they are "out of the reach" of standard biopsy techniques, they often contain undetected areas of cancer. An optimal magnetic resonance imaging study employs a powerful magnet to create detailed images that are then displayed on a computer screen. According to K. J. Macura, MD, at Johns Hopkins:

Based on the scans, radiologists assign scores of 1 to 5 for the presence of prostate tumor on MRI, with 1 being definitely benign, 3 either benign or not (i.e. we can't tell), 4 being probably malignant, and 5 definitely malignant.

This greater specificity is valuable since a lower score indicates that a follow up biopsy may not be necessary, while high scores indicate that a confirmatory biopsy may be advisable, and that the disease may require up-grading.

There are various types of MRI equipment available. When my MRI was performed, the MRI unit was operating at "3T", T standing for Tesla and 3 the current state of the art technology, a unit of magnetic strength that provides hundreds of images and a detailed anatomy of the prostate. However as of 2014, most of the men I have spoken with have undergone MRI testing with the older, less comprehensive 1.5 Tesla unit.

And while the number of the MRI centers that use the latest technology is increasing, progress has been slow. So if you are scheduled to undergo an MP-MRI-guided biopsy using transrectal ultrasound and

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MRI guidance, make sure your MRI guidance is performed with the 3-Tesla machine. The results may make the difference between your being subjected to unnecessary, invasive treatment versus continued on active surveillance.

If necessary, make a fuss. It's your prostate cancer and your life.

PCa Risk Assessment Tools

From Prostate Forum posted June 27 2014

Dr. Matthew Cooperberg is a genitourinary cancer specialist at the University of California, SF's Helen Diller Family Comprehensive Cancer Center. He did his urologic oncology fellowship under the guidance of Dr. Peter Carroll.

Cooperberg developed a new prostate cancer risk assessment tool called the Cancer of the Prostate Risk Assessment (UCSF-CAPRA) score and has authored over 50 peer-reviewed scientific articles and nine chapters.

Prostate Forum recently spoke with him about prostate cancer risk assessment tools.

PROSTATE FORUM: Do you think the recent push to develop prostate cancer risk assessment tools is in some way a reaction to the anti-screening movement?

DR. COOPERBERG: No, it is something we've wanted to do for a long time. You'll hear from the US Preventive Task Force members and others that what we really need is a better test than PSA. But that's ridiculous. PSA is one of the most successful biomarkers in the history of oncology, but it's far from perfect. The question has always been what can we do to augment PSA and then to augment what we can learn from the biopsy. But we're not going to replace that first screening anytime soon.

I think it has taken a long time for the biomarker field to recognize that we need markers that can improve on the clinical gold standard, not just correlate with it. Because prostate cancer has such a long natural history, it takes decades of follow-up on specimens to really know who has done well and who hasn't as well as who is at risk of dying of prostate cancer and who isn't.

We started banking prostate tissue, blood, and urine at UCSF back in 2000 and it is really only now that we have enough follow up on what has happened to those men that the specimens are valuable. The same is true with most other research institutions. It takes a long time to build up the data and expertise to do this sort of research well.

Plus, technology is improving. Our ability to do RNA extraction from routinely archived pathology specimens is new. That didn't exist a few years ago and now it does. Our ability to get at the biomarkers has also been improving. But the goal has been the same for a long time.

PROSTATE FORUM: What advice would you give a newly diagnosed man?

It would really depend on what they've been diagnosed with. Get past the "c-word" and recognize that what we call prostate cancer may range in seriousness from something you will never have to worry about your whole life to something that needs to be taken very seriously.

Unfortunately, I think some people never really get past the "you've got cancer" part of the conversation. The first point is that it is almost never an emergency. Even men with high-risk disease typically have at least a few months to begin treatment. And men with low risk disease can often defer treatment for years and in many cases forever. The most common cause of death in men with prostate cancer is heart attack, just as in men without prostate cancer.

My first piece of advice is to really understand the details of your own individual tumor: your individual Gleason score, how extensive your cancer is, and how all those variables interact with each other. This will help you understand where you fall in the spectrum of disease risk—low, intermediate or high—

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based on a CAPRA score or a nomogram or something that goes beyond the NCCN risk groups.

The second piece is that we're increasingly aware that diet, lifestyle, and exercise play an important role in prostate cancer progression. Men who are able to make positive changes in their diet and exercise habits live longer and better than those who do not. And moreover, since most men with prostate cancer die of heart attacks, it's a win-win to adopt better diet and lifestyle practices. That is another area of patient education for us here at UCSF.

My final bit of advice is make sure you're treated in a high volume center with clinicians who have a bit of experience with the disease, know their own outcomes, and can stand behind their own numbers.

PSMA-based imaging traces even treatment-resistant prostate cancer

From Science Daily June 9, 2013, source: Society of Nuclear Medicine

Anti-androgen hormonal therapy, also called chemical castration, can be an important defense against further disease progression for patients with prostate cancer that has traveled and grown in other areas, or metastasized -- but some cases simply do not respond to this treatment. A groundbreaking molecular imaging agent has been developed to help clinicians find as much cancer as possible, whether it is responding favorably or not, in an effort to improve clinical decision making for these patients, say researchers at the Society of Nuclear Medicine and Molecular Imaging's 2014 Annual Meeting.

The imaging technique championed by this study is called F-18 DCFBC PET/CT, developed at Johns Hopkins University in Baltimore, Md., by study co-author Martin G. Pomper, MD, PhD. F-18 DCFBC is a unique small-molecule PET agent that searches for and attaches to prostate-specific membrane antigen (PSMA), which signals more strongly from malignant prostate cells than from normal cells. The study further proves the effectiveness of the imaging agent by providing substantial clinical data for both castration-sensitive and castration-resistant prostate cancer patients.

"Currently there is a great unmet need in prostate cancer management and drug development for a functional imaging agent that is able to detect prostate cancer and monitor response to therapy," said Steve Cho, MD, PhD, assistant professor of nuclear medicine and PET in the department of radiology at Johns Hopkins University School of Medicine. "Unfortunately, a truly reliable functional imaging agent for prostate cancer does not exist, but several exciting metastatic cancer imaging agents have been in development over the last several years. We are working toward improvements beyond the current capabilities of conventional bone and CT imaging, and a small-molecule PSMA-based PET radiopharmaceutical such as F-18 DCFBC is one such possibility."

The agent is injected prior to PET imaging, and the particles emitted by the radiolabel, fluorine-18, are then detected by a specialized scanner performing both positron emission tomography and computer tomography (PET/CT). This hybrid imaging system uses both functional and structural data to create a composite image of anatomy and physiology with "hot spots" where the imaging agent is binding to PSMA targets in the body, otherwise known as tumor uptake.

This study includes the first 12 patients from an ongoing trial, including five cases of castration-sensitive and seven cases of castration-resistant cancer, both with rising PSMA levels and evidence of metastases. Hot spots representing tumor uptake were correlated with serum prostate-specific antigen and folate levels as well as castration-resistant status. Results of the study showed F-18 DCFBC uptake was comparable to conventional imaging in relation to the lymph nodes, some bone and viscera, including the adrenal glands and pancreas. Lower DCFBC uptake was seen in highly scarred bone metastases when compared to other kinds of growths, but DCFBC PET was found to be more sensitive than conventional imaging for detecting bone metastases, especially within the cervical spine and areas showing degenerative changes, as well as in subcentimeter-sized lymph nodes. Additionally, a higher uptake of the agent was observed in castration-resistant bone metastases, and a direct link was found between PSMA levels and tu-

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mor-agent uptake. Further studies are required to get a comprehensive picture of the value of F-18 DCFBC PET for this patient population.

Aside from skin cancer, prostate cancer is the most prevalent form of cancer among men in the United States, according to 2014 statistics from the American Cancer Society. About 233,000 new cases of prostate cancer are expected to be diagnosed and about 29,480 prostate-cancer related deaths are estimated this year.

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!

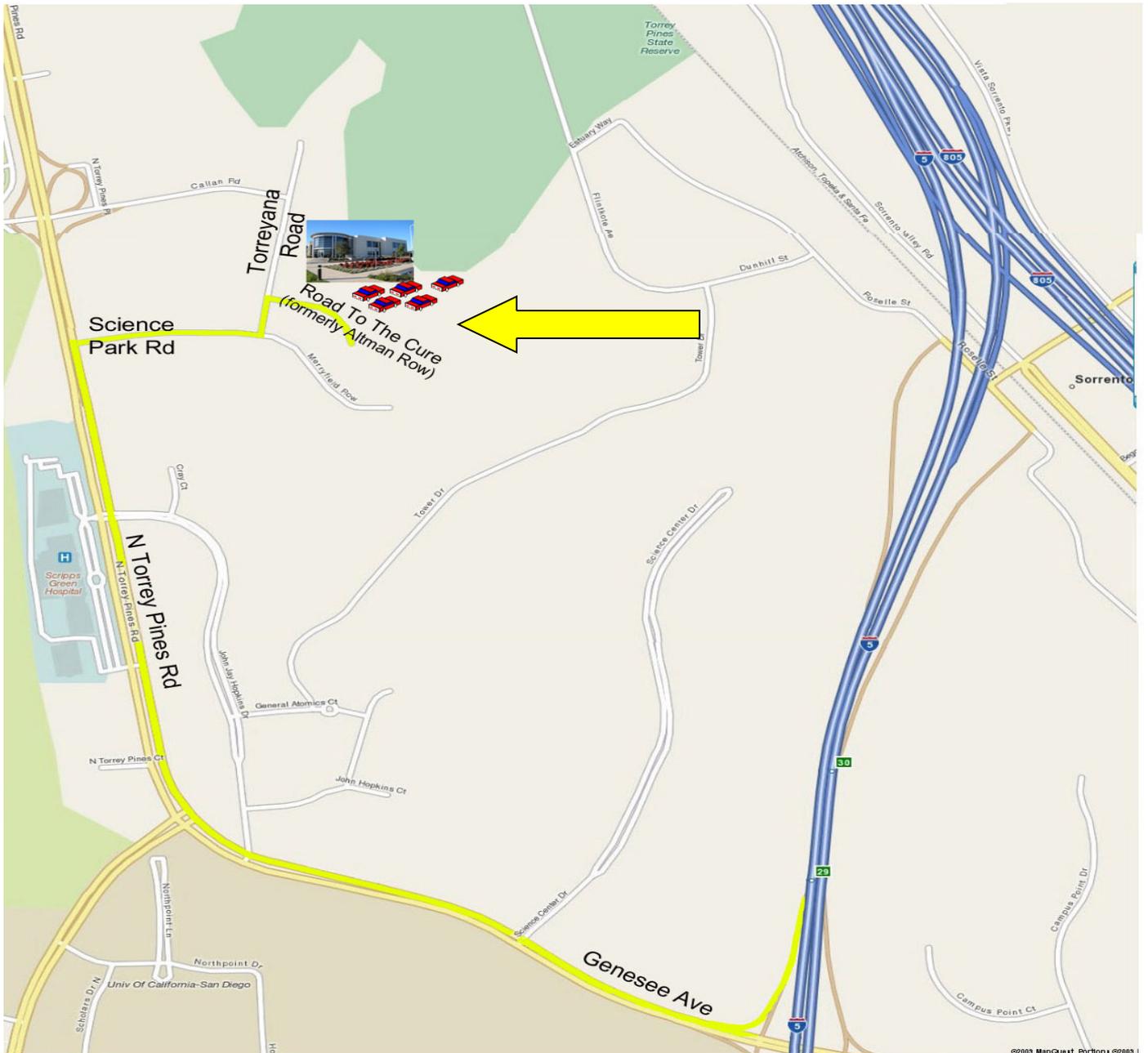
If you have the internet you can contribute easily by going to our website, <http://ipcsg.org> and clicking on “Donate” Follow the instructions on that page. OR just mail a check to: IPCSG, P. O. Box 4201042, San Diego CA 92142

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 or Lyle 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).