Informed Prostate Cancer Support Group Inc.

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

June 2012 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: www.ipcsg.org

We Meet Every Third Saturday (except December)

Saturday, June 09, 2012

Volume 5, Issue 5

Officers

President: Lyle La Rosh,

Vice President : Gene Van Vleet

Additional Directors

Dr. Dick Gilbert

John Tassi

George Johnson

Steering Committee

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Victor Reed
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Jerry Steffen
Robert Werve, Treasurer

Next Meeting June 16th 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!!

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Editor: Gene Van Vleet

Our guest speaker for the May meeting was Dr. Fabio Almeida who is developing new imaging processes to more effectively locate recurrent prostate cancer. He began by describing some of the basics of PET (positron emission topography) and CT (computerized tomography) imaging. FDG (fluorodeoxyglucose) is a standard agent that has been used for over a decade for PET and CT imaging. It takes advantage of sugar intake of cancer cells which is more than normal cells. The FDG sticks in the cell and thus enhances the image. The PET/CT medical imaging device combines images from PET and CT so that images acquired from both can be taken sequentially from the patient into a single super-imposed image. In

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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this way it is possible to determine what part of the anatomy the cancer is in. The problem with the use of FDG in relation to prostate cancer is that it gets eliminated by the kidneys through the bladder. Of course the bladder is in close proximity to the prostate so the benefits of this type of image is limited. One issue is that prostate cancer cells don't consume as much sugar as other cancers so that it can be imaged as effectively. Another issue with PCa imaging by CT or MRI is that it is depends on a size criteria for lymph nodes. They must be of a certain sized before it can be said they are involved. Therefore a lymph node smaller than that certain size might be missed.

One of the main issues with recurrent PCa is determining where it is. Currently there is no effective way of targeting where the lesion might be. The advantage of Carbon 11 Acetate is that rather than using the sugar of glucose mechanism, it gets incorporated into the cell membrane of the cancers. It does not get secreted to the bladder and through the urine. The effectiveness of Carbon 11 Acetate was tested against biopsies and found to be accurate within acceptable ranges. Further, there were no false positives. Questions have arisen as to the difference in effectiveness between Carbon 11 Acetate and another similar agent Carbon 11 Choline. Dr. Kotzerke imaged 12 patients with both and found the results to be the same.

When using Carbon 11 Acetate, they prefer to have no influence of antiandrogen agents to ensure they are not seeing the effect of hormone therapy on the cells.

Dr. Almeida then discussed the clinical trial being administered by his group. It started late last year. They are now studying follow-up results for three and six months. The have seen 93 patients so far with PSA ranging from 0.015 to 98 ng/ml with the mean being 6.5. The overall detection rate for recurrent discovery was 85%. They are finding that for PSA levels of 0.4 and below, detection is minimal. He then presented many slides portraying the images made visible by the Carbon 11 Acetate process that may not have been as clearly seen by CT or MRI images.

The logistics of Carbon 11 Acetate production are extremely difficult. The half-life of the carbon aspect is only 20 minutes, making it impossible to transport. It takes a dedicated cyclotron to produce it.. These and compliance with FDA regulations are big reasons the process is only being done by a few centers. The process is not covered by medicare or insurance because it is not yet FDA approved. The cost is approximately $3,000.

For those who are experiencing or suspecting they may be experiencing recurrence of prostate cancer, this may be a valuable new source for finding reliable answers. There is much more valuable information available on the DVD of this meeting than provided by this summary. You can purchase a copy through our library at our meetings or via our website: www.ipcsg.org Click on the blue Purchase DVD button.

Future Meetings

June 16th. Members share treatment experiences. Become your own case manager.

If you have leads to speakers related to the interests of our group please contact: lyle@ipcsg.org or gene@ipsg.org

NOTEWORTHY ARTICLES

Over-Treating Prostate Cancer

Posted: 05 Jun 2012 04:25 PM PDT http://prostatesnatchers.blogspot.com/

BY MARK SCHOLZ, MD

Prostate cancer treatment is out of control, and the U.S. Preventive Services Task Force* has stepped up with the recommendation to stop PSA screening. The recommendation to ban PSA testing surprises patients and doctors alike. After all, in a trial published in the New England Journal of Medicine PSA screening was shown to lower prostate cancer mortality in a trial published in the New England Journal of Medicine in 180,000 men.

Some have questioned the expertise of the Task Force panel because there was no representation by urologists, radiation therapists or medical oncologists, the types of doctors usually responsible for treating prostate cancer. Actually, the credentials of the panel members appear entirely appropriate to comment on screening, an area of medicine usually handled by primary care doctors. The panel members consisted of 12 MD's and four PhD's trained in primary care, public health and statistics.

The Task Force has been taking massive criticism for recommending the end of PSA screening. While conceding that PSA screening may save lives, their judgment was that too few lives are saved to justify the thousands of men getting radical treatment they don't need. They also point out that at least a hundred thousand men annually are burdened with a diagnosis of CANCER when this particular type of cancer is very rarely life-threatening. The sad thing is that even though most prostate cancers are harmless, a robust surgical and radiation industry can't seem to stop treating ill-informed patients who assume that anything called cancer needs immediate treatment.

Invasion of the Prostate Snatchers was written to counter this dangerous ignorance. Throughout the entire book, Ralph Blum and I explained why something termed CANCER, as long as it is preceded by the work PROSTATE, in many cases should be totally harmless. Ralph himself is a living example, diagnosed more than 20 years ago and still in possession of his prostate. Of course, confusion inevitably arises because certain types of prostate cancer can indeed be dangerous. Not dangerous like lung or pancreas cancer which can kill within months of diagnosis. But, over a decade or two, prostate cancer does indeed kill a minority of men. Demise from cancer certainly qualifies as "dangerous," even if the death is much postponed.

Because there is so much confusion about the different types of prostate cancer our book pays special attention to the modern methods for distinguishing between the good and bad types. Suffice to say in this brief blog, as long as there is a modicum of attention to detail, telling the difference between the good and the bad types is usually pretty simple. Far more difficult is getting the uninitiated to slow down and study the situation before taking irreversible action. In the rushed process leading up to treatment, many fail in their struggle to believe that something termed CANCER really represents no threat at all. Others, even more sadly, never hear their over-enthusiastic doctors marshal a single argument against immediate treatment.

So the Task Force is shooting PSA, the messenger, when doctors and patients are the real culprits. PSA is not the problem. *The real problem is rushing to immediate biopsy at the very first sign of a PSA elevation*. A *million men have mindless biopsies every year*. I call them mindless because most men undergo biopsy before they have any idea of what they are getting into. They are not pre-informed that most men over 50 have cancer cells in their prostate, and that a biopsy will be positive 20% of the time. So when bad news comes, usually via a phone call, emotional hell breaks loose. After all, isn't CANCER a call to action? Unfortunately, the urologists the doctors designated to treat prostate cancer are surgeons, who are by

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definition, *men of action*.

The Task Force is correct in their view that too many men are being frightened in unnecessary radical treatment. The problem is a million men undergoing mindless biopsy, not PSA screening. PSA elevation should precipitate further testing, prostate imaging and most of all, education. My next Blog will outline the process of how to handle an elevated PSA.

*Previous blog written about this topic can be found here: **http://prostatesnatchers.blogspot.com/2011/10/discontinue-psa-screening.html**

Advanced Prostate Cancer Drug May Help at Earlier Stage

In study, one-third benefited from taking Zytiga plus hormone therapy for 6 months before surgery

By Amanda Gardner

HealthDay Reporter

WEDNESDAY, May 16 (HealthDay News) -- A drug approved to treat advanced prostate cancer appears to help men who have localized high-risk prostate cancer if given before surgery.

Adding Zytiga (abiraterone) to conventional hormonal treatments eliminated or nearly eliminated the prostate cancer in one-third of men with this often-lethal form, according to new research to be presented at next month's annual meeting of the American Society of Clinical Oncology (ASCO) in Chicago.

"This is one of the first -- if not the first -- study to show that you can make prostate cancer in the prostate gland itself disappear in a reproducible number of patients," ASCO official Dr. Nicholas Vogelzang said at a Wednesday press conference.

Commenting on the findings, Dr. Jay Brooks, chairman of hematology/oncology at Ochsner Health System in Baton Rouge, said, "This is exciting. It's a novel way to eliminate cancer before surgery."

However, Brooks, who was not involved in the study, cautioned that the findings were still preliminary and need further investigation.

Trying to shrink a tumor with chemotherapy and/or radiation before surgery is standard for other types of cancer, such as breast or colon, but hasn't to date shown a benefit in prostate cancer, study author Dr. Mary-Ellen Taplin, associate professor of medicine at Harvard Medical School and Dana-Farber Cancer Institute in Boston, explained at the news conference.

Localized high-risk prostate cancer, which is defined as prostate cancer in men with a prostate-specific antigen level above 20, high-grade disease (a Gleason score of 8 or more), and stage T3 disease (indicating the tumor has spread through the prostate), carries with it a poor prognosis.

Standard hormonal therapy, which stops the production of male hormones (androgens), has not been shown to be effective in this type of cancer when given before surgery. Nor has the surgery, which removes the entire prostate.

Zytiga blocks production of testosterone, which can promote the growth of prostate cancer cells, but in a different way than established hormonal treatments.

This small, phase 2 trial involved 56 men with an average age of 58, all of whom had had at least three positive biopsies for prostate cancer.

For the first three months, 27 men received the standard hormonal therapy leuprolide alone, followed by leuprolide plus Zytiga for another three months.

The remaining 29 men received the two-drug combination for the whole six months, after which all men in both groups underwent prostate surgery.

One-third of the men who had received leuprolide plus Zytiga for the entire six months saw complete or nearly complete elimination of their cancer.

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By comparison, only 15 percent of men in the other group experienced these results, the investigators found.

Those who received the combination for only 12 weeks had much lower response rates.

The participants also received low doses of the steroid prednisone to prevent side effects from Zytiga, although side effects overall were minimal, said Taplin.

It's not clear at this point why some men responded to the combination therapy while others did not, and that is an area that needs to be studied, the researchers said.

"In highly select people who have this aggressive type of prostate cancer, I think this is an important area to investigate," Brooks noted. "We need to figure out which patients would potentially benefit."

According to study author Taplin, the research received some funding fromJohnson & Johnson, the maker of Zytiga. She said the drug is currentlyU.S. Food and Drug Administration-approved for patients with advanced prostate cancer that does not respond to hormone therapy, and costs about $5,000 per month.

The data and conclusions of research presented at medical meetings should be viewed as preliminary until published in a peer-reviewed journal.

Announcements

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 continues to develop our new website that we believe is simple and easy to navigate. **Check out the Personal Experiences page and send us your story**. Go to: http://www.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.

Our Steering Committee meets for lunch, usually at Baci's restaurant (preferred) at noon on the first Tuesday of each month. All members are welcome! Please call Lyle La Rosh at 619-892-3888, to make reservations and to verify location.

Library Announcement "To all those who have borrowed books, tapes or DVD's please return them at the next meeting"

HEALTH INSURANCE NEWS

Affordable Care Act gives consumers new tools, makes health insurance market more transparent

Created under the Affordable Care Act, www.HealthCare.gov was launched July 1, 2010, and is the first website of its kind to bring information and links to health insurance plans into one place to make it easy for consumers to learn about and compare their insurance choices. HHS' Office of Consumer Information and Insurance Oversight (OCIIO) worked to define and collect detailed benefits and premium rating information from insurers across the country, and starting October 1, 2010, consumers will also be able to find information about health insurance options such as: Monthly premium estimates; Cost-sharing information, including annual deductibles and out-of-pocket limits; Major categories of services covered; Consumer's share of cost for these services; Percent of people in the plan who pay more than the base premium estimate due to their health status; Percent of people denied coverage from a health plan.

More than 225 insurance companies have provided information about their individual and family plans for more than 4,400 policies, including policies in every state and the District of Columbia. Consumers can search for and compare information on plans available based on age, gender, family size, tobacco use and location.

NOTE

California law requires that you have an annual 30-day period beginning on your birthday during which you may purchase any Medicare supplement coverage that offers benefits equal to or lesser than, those of your current coverage. You are eligible to purchase such plans without regard to your health status, claims experience, receipt of health care or medical condition. This only applies if you currently are on Medicare.

Mr. David Weil from Health Insurance Counseling and Advocacy Program (HICAP) provided information about their free services in our October, 2011 meeting. HICAP is a non-profit program that assists with counseling about medicare coverage and billing issues, including appeals. They do not make recommendations but rather provide information to help individuals make decisions about available coverage. They also assist with Long Term Care Insurance. The local phone number is 858-565-8772 or, if calling from a cell phone outside of the San Diego Area, 800-434-0222. Website: http://www.cahealthadvocates.org/HICAP/sandiego.html

If you have particular knowledge that would be helpful to our goal of creating a base of information, please volunteer your efforts to the committee. Contact Gene Van Vleet, e-mail gene@ipcsg.org or cell phone 619-890-8447 who may redirect your inquiry to an appropriate person for response.

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.

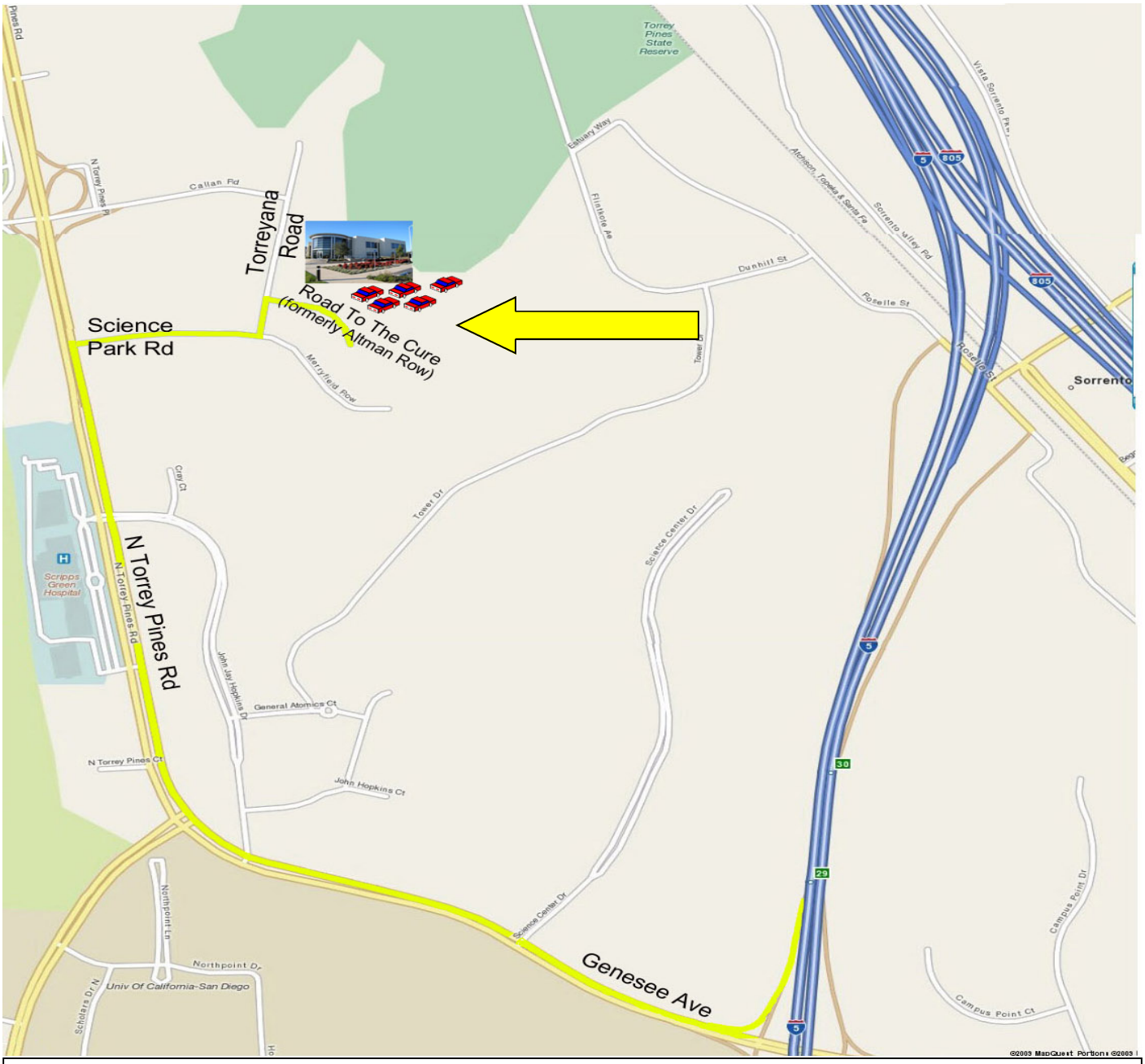
Anyone interested please contact:
Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org
Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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



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).