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

JUNE 2011 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Monday June 6, 2011 Volume 4, Issue 5

Officers

President: Lyle La Rosh,
Vice President : Gene Van Vleet

Additional Directors

Dr. Dick Gilbert
John Tassi
George Johnson

Steering Committee

Judge Robert Coates
Victor Reed
Carlos Richardson
Robert Keck, Librarian
Bill Manning
E. Walter Miles
Jerry Steffen
Robert Werve, Treasurer

Next Meeting June 18th 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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The May meeting was centered on networking, with presentations by 4 men relaying their experiences followed by break-out sessions by treatment type where members could discuss specific concerns with others.

Sonny Low discussed his experience with information gathering and doctors to arrive at his decision to follow active surveillance. His PSA had begun to rise and he had 2 biopsies as well as taking the Aureon test that indicated a low level of PCa which helped him arrive at his decision. He has improved his diet and exercise to assist in staying healthy.

Lou Tornillo is experiencing an aggressive form of PCa that includes a PSA as high as 1,000, and bone metastasis in his ribs and spine. He has

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://www.ipcsg.org. Click on the 'Purchase DVDs" button.

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been treating it with intermittent hormone therapy, using Lupron 90-day shots. He reported loss of libido, low incidence of flushing/sweats and decreased pain. His PSA has gone as low as 5. He has researched the effectiveness of Casodex, Proscar and Avodart which he may switch to in the near future.

John V. discussed his thorough study of options, totally involving his wife in the entire process. His PSA had been rising from 2.4 in 2004 to 8.7 in April 2010. They chose robotic surgery as being the most fitting for their desired lifestyle. He spoke of his recovery process which included his experience in dealing with impotence and incontinence. He too has improved his diet and exercise program to help maintain good health.

Bruce Appel was introduced to us by member Jim Kilduff, a long-time friend. His message was primarily one of how poor decision-making along with inappropriate treatment led to very bad experiences. He opted for radioactive seed implants (brachytherapy) ignoring the advice of 2 of 3 doctors consulted. He had a large prostate and had been warned that the procedure might not be appropriate because of the increased risk associated with his large prostate . He went ahead with the procedure in which 232 seeds were implanted, increasing the chances of ancillary damage. He has experienced severe incontinence and impotence as a result. In hindsight, he believe a prostatectomy would have been better suited for him.

Each of the presentations contained much more valuable information than can be adequately summarized here. DVD's of this meeting which include the full presentations are available for $10 in the library or through our website www.ipcsg.org by clicking on the button Purchase DVDs.

.Future Meetings

June 18, 2011. Bernadette Greenwood, Invivo Corp. www.invivocorp.com, Prostate MRI and Prostate MRI guided procedures.

July 16, 2011. Dr. Duke Bahn, Director of Prostate Institute of America & Dr. Osamu Ukimura, Professor of Urology-USC. Ultrasonography and Focal therapies for prostate cancer.

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

August 20, 2011. Topical discussions and break-out sessions by treatment preference.

NOTEWORTHY ARTICLES

Newly-Diagnosed Prostate Cancer

Posted: 31 May 2011 11:02 AM PDT in Prostate Snatchers Blog

BY MARK SCHOLZ

Now that prostate cancer has become a treatable disease—like hypertension or diabetes for example—new problems have surfaced. Selecting effective treatment has become complicated by plethora of different treatment options you are presented. Here is a very brief introduction to the types of therapy available for men with newly-diagnosed prostate cancer.

No Treatment

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It is now becoming clear that thousands of men undergo aggressive treatment every year for a type of prostate cancer that will never be life-threatening. Active Surveillance, which means that treatment is only administered if the cancer continues to grow, is becoming more and more popular for men with the *Low-Risk* type of prostate cancer.

Local treatment

Surgery, radioactive seed implantation, targeted beam radiation and cryosurgery are all local treatments, which when administered by experts, can be expected to eradicate the cancer within the prostate with a high degree of consistency. There are two potential drawbacks with all of these options. First, these treatments can cause irreversible side effects to adjoining structures such as nerves that control erections, urinary, and rectal function. Second, if the cancer has already spread outside the prostate the treatment may not cure the cancer.

Systemic treatment

Other options are designed to treat cancer both in the prostate and throughout the rest of the body. These options include herbal, hormonal, immune and chemotherapy treatments. The disadvantage of systemic treatments is that while they suppress the cancer, they usually fail to eradicate it completely. Systemic treatment aims to convert prostate cancer into a *chronic,* non-progressive condition and keep it stable for many years. Each type of systemic treatment is associated with its own unique spectrum of side effects.

Combinations

This approach—systemic plus local treatment—is used for selected patients with aggressive prostate cancer who have a high risk of relapse with local therapy alone. Combination treatment offers the best chance for cure in patients with disease that has already spread or metastasized outside the prostate.

Selecting Treatment

The aggressiveness of each individual's cancer is determined by *typing.* The extent and grade of the cancer can be estimated with blood tests, biopsy information and scan results. For more details about "typing" your cancer see the brochure titled *What's Your Type* available at **pcri.org**.

Prostate cancer patients are more involved in treatment selection than those diagnosed with any other type of cancer. This is because with early-stage disease the best choice is based on *quality of life* considerations, not merely with survival. Therefore only by examining the potential side effects of each treatment option, and comparing it with the other choices, can important distinctions and decisions be made among the alternatives.

Even though patient involvement in the treatment selection process is an absolute requirement, there are potential pitfalls. Clear and objective reasoning may be difficult during a time of shock and grief brought on by the diagnosis of cancer. Strong emotions are also stirred up as one is forced to face the possibility of treatment-related, life-altering side effects that impact sexual, rectal, and urinary function. Patients can be prone to hurried treatment decisions instead of waiting until they have a full understanding of all the information. Despite reassurances, it is hard for patients to escape the lingering fear that unless they act swiftly, the cancer will grow and spread.

Specific Recommendations for Selecting Treatment

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Don't rush into immediate treatment!

Obtain thorough and proper staging to determine the likelihood that the cancer has spread to a location in the body distant to the prostate.

Educate yourself thoroughly about this disease via sources such as the Internet, books, and support groups focused on prostate cancer.

Whenever possible, seek advice and treatment from doctors who *specialize* in treating prostate cancer.

Cancer Vaccine Holds Promise In Early Stage Prostate Cancer

New data from ongoing studies with PROSTVAC®, a vaccine in development for the treatment of prostate cancer, will be presented this weekend at the 2011 ASCO Annual Meeting in Chicago, USA. The data suggest that PROSTVAC® may be able to slow disease progression in early stage prostate cancer.

An estimated more than 780,000 new cases of prostate cancer are diagnosed worldwide every year and more than 250,000 people die each year from the condition.

Previously, a large, double-blind, randomized, placebo controlled Phase 2 trial in patients with metastatic castration-resistant prostate cancer showed that PROSTVAC® extended the median overall survival with 8.5 months compared to placebo. In addition, recent studies suggest that the vaccine's potential may be even greater if used in earlier disease settings, where it seems to slow disease progression.

PROSTVAC® is being developed in collaboration with the National Cancer Institute (NCI). The results that will be presented at ASCO by investigators from NCI were from a Phase 1 study in 21 patients with locally recurrent prostate cancer after primary radiation therapy. Patients received an initial vaccination with subcutaneous injection of PROSTVAC® and booster intraprostatic injection of PROSTVAC®. More than 80% of the patients had stable or improved PSA on study, thus suggesting that PROSTVAC® was able to control the disease progression.

This study is one of six ongoing studies, currently conducted by the NCI with PROSTVAC® as monotherapy or in combination with other therapies in different disease settings, including early stage disease.

- This is a small study. However, PROSTVAC® is currently being investigated in various clinical studies in nearly 400 patients, and preliminary results from several of these studies confirm the same positive trend. In time we hope to confirm these results in larger studies, as was the case with the Phase 2 study which showed an improved survival in patients with advanced prostate cancer, and thereby validate a therapeutic effect in both early and late stage disease, commented Anders Hedegaard, President & CEO of Bavarian Nordic.

With the ongoing studies, a total of nearly 900 patients will have participated in PROSTVAC® clinical trials and later this year, Bavarian Nordic expects to initiate the pivotal Phase 3 trials that are intended to form the basis of approval of the vaccine for metastatic disease. The study will include up to 1,200 patients.

Source:
Bavarian Nordic

Johns Hopkins Health Alerts

PCA3 and Gene Fusion: Two New Prostate Cancer Biomarkers in Development

Biomarkers are substances like prostate-specific antigen (PSA) that can be measured in blood, urine or other body fluids and used to detect or monitor a disease. Researchers are investigating a number of potential biomarkers that, in the future, may improve upon the PSA test's ability to detect prostate cancer and identify potentially life-threatening tumors. Two promising biomarkers are PCA3 and gene fusion.

PCA3. PCA3 is a test that measures a gene that is overexpressed (60 to 100 times greater) in prostate cancer cells versus noncancerous cells. Cells shed by the prostate containing the PCA3 gene are detectable in the urine. Researchers report that the lower the level of PCA3 in the urine, the less likely prostate cancer is present. Because PCA3 is not produced or is produced only minimally by noncancerous cells, the presence of conditions like benign prostatic hyperplasia (BPH) or infection is less likely to produce falsely elevated PCA3 levels. PCA3 testing is most reliable when done in conjunction with a digital rectal exam (DRE).

Researchers report that when performed after a DRE, the results from PCA3 testing are valid in 98 percent of cases. If the test is performed without a DRE, validity drops to 80 percent. Researchers believe that rather than replacing PSA screening, the PCA3 test may help identify or rule out cancer in men with elevated PSA levels but no prostate cancer on the initial biopsy. In addition, some evidence suggests that the test may be useful in helping to identify men who are appropriate candidates for active surveillance. Currently, PCA3 testing is available only through clinical trials in the United States.

Gene fusions. A gene fusion is a hybrid gene formed from two previously separated genes. Scientists have discovered that many prostate cancer patients have gene fusions involving the ERG and TMPRSS2 genes that create a new gene that is thought to promote the development of prostate cancer -- and, possibly, a more aggressive form of the disease. Gene fusions are now being detected in urine and have promise as new biomarkers for prostate cancer. More research is needed, however, before this method of testing moves into the mainstream.

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

The medical insurance committee, comprised of Bill Pitts, Dennis Walker and Gene Van Vleet assists in making choices that provide them the best coverage suitable to their situation The committee cannot be expected to make recommendations for suitable medical coverage but rather should be a resource of information to help you determine what options are most suitable for your situation.

Our committee members are willing to provide you with education and resources.

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.

PLEASE, volunteer your effort to assist our cause.

Announcements

Member and Director, John Tassi continues to develop our new website that we believe is much simpler and easier 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" Some copies of the book "China Study" have been donated by Robert Werve. This is very informative reading. Bob Keck Librarian

Snail Mail Recipients Notice!

Snail mail is expensive. E-mail is not. If you have changed to e-mail let us know. Send your information to: gene@ipcsg.org.

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.
3. Assistance with editing and publishing monthly newsletter.

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

NETWORKING

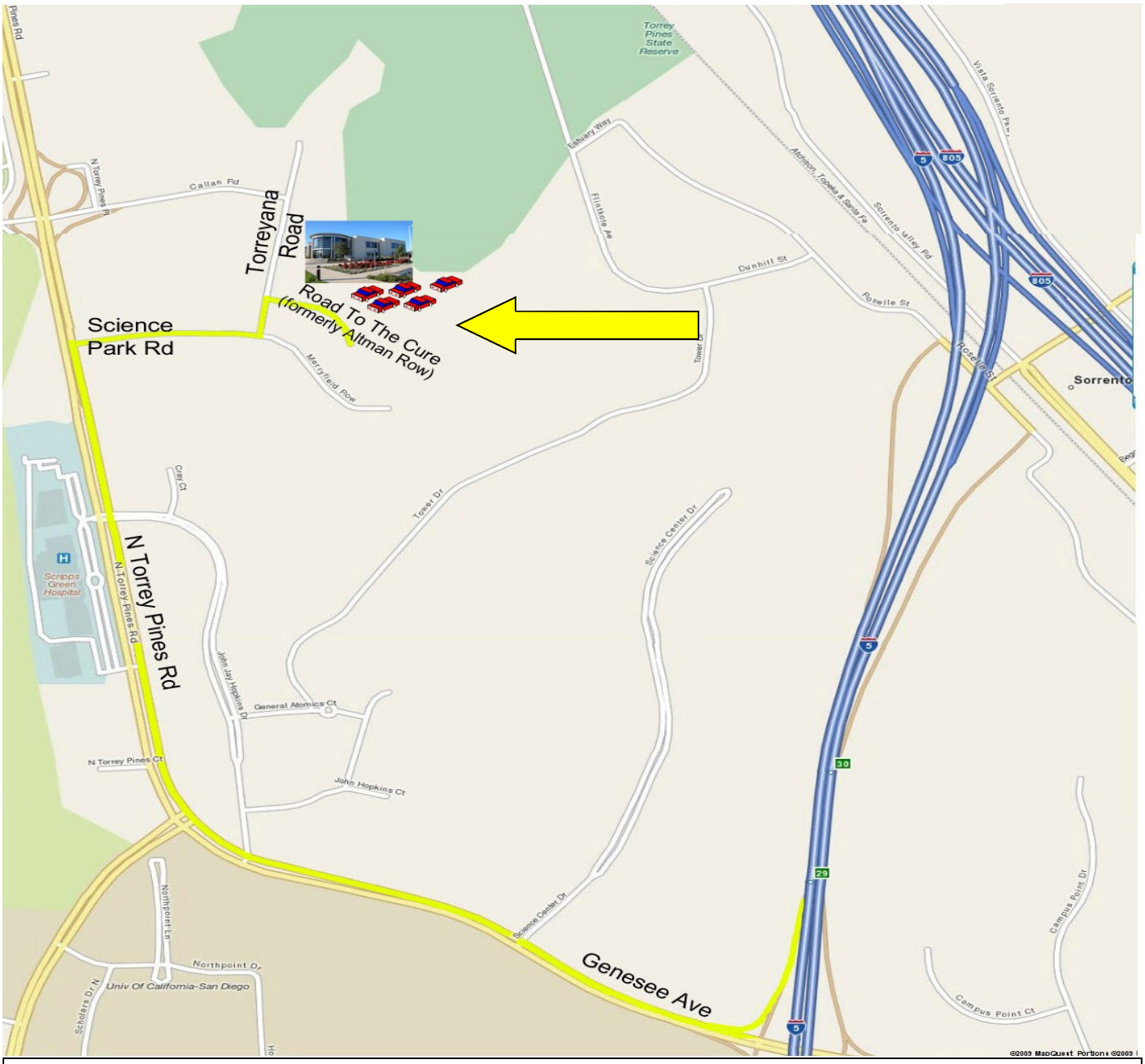
The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is "networking". We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all. 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.

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).