



Informed Prostate Cancer Support Group Inc.

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



DECEMBER 2010 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, December 20, 2010

Volume 3, Issue 12

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

*HAPPY
HOLIDAYS*

**Next Meeting
JANUARY 15th
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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Merry Christmas and Happy Holidays to everyone

from the team at IPCSG

As the year draws to a close we wish to thank all those who participated and contributed to make this another successful year for our group. We continue to be one of the best independently organized and funded prostate cancer support groups in the nation.

Over the last year we have welcomed 100 newcomers to our meetings. Our guest speakers have provided insight on new treatments and testing methods.

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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In our November meeting, Dr. Jeffry Gordon lectured on health care reform. In October, Dr. Richard Lam provided information about new drugs being studied and approved which included Provenge, Cabazitaxel and Abiraterone. In the September meeting President Lyle LaRosh presented information about the new Aureon test that predicts the probabilities of the future outcome of our disease and discussed at length the benefits of using Avodart and Proscar to curb the production of dihydrotestosterone. In the August meeting Lyle made an in-depth presentation about hormone therapy and in the July meeting he presented updated information about the Provenge drug recently approved by the FDA for use by men who have become refractory. In the March meeting Dr. Douglas Chinn lectured on cryoablation and high intensity focused ultrasound therapies. In January, Dr. A. J. Mundt presented information on the development of radiation equipment and Dr. Kevin Murphy presented research using viral mechanisms to illuminate and destroy tumors.

Other meetings focused on networking, with presentations and discussions by members of their treatment experiences.

DVD's of all meetings are available for purchase in our library or from our website: www.ipcsg.org by clicking on the "Purchase DVD's" button

Future Meetings

January 15, 2011. Round table discussions with break-out sessions by treatment type.

February 19, 2011. Robert A. Louie, Pharm.D, Senior Medical Science Liaison, Dendreon Corp. Subject: Provenge.

March 19, 2011 Dr. Irwin Goldstein, Director of Sexual Medicine at Alvarado Hospital.

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

Interesting Reading from Prostate Cancer Forum www.pcf.org

PROVENGE: UNDERSTANDING THE DEBATE BETWEEN SELECTION AND COST

Background

On April 29, 2010, the Food and Drug Administration approved sipuleucel-T (Provenge) for the treatment of advanced prostate cancer. This approval heralds the dawn of an entirely new era of generally safe treatments – immunotherapy – for patients with metastatic prostate cancer. The results of the pivotal Phase III clinical trial were published in *The New England Journal of Medicine* (July 29, 2010) by a team of investigators led by PCF-funded Philip W. Kantoff, MD, leader of the Dana-Farber/Harvard Cancer Center Prostate Cancer Program and a Provenge investigator. This trial involved 512 patients treated 2:1 with Provenge and placebo, respectively. Provenge-treated patients experienced a 22 percent reduction in the risk of death, which translates to a 4.1 month increased overall survival. Importantly, the increase in survival was not associated with a slowing of disease progression, i.e., PSA continued to rise and in some patients, radiologic scans of bone and soft tissue may have remained unchanged or even worsened. The un-

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coupling effect on survival and disease progression appears to be a common property of immunotherapy and might not be specific to Provenge.

Donald L. Trump, MD, president and CEO of the Roswell Park Cancer Institute, shared with *HemOnc Today* that “Provenge may be the only example of a cancer treatment wherein the standard measures of efficacy didn’t change. The PSA score didn’t decrease, patients with measurable lesions (tumor seen on X-rays or other scans) did not see those lesions change. None of the standard measures we use to say a treatment works were positive, and yet the overall survival improved.”

Provenge is an “autologous cellular immunotherapy” created by first collecting a patient’s white blood cells, which are sent to a specialized laboratory for processing. The laboratory “arms” these cells against prostate cancer treatment with a protein, prostatic acid phosphatase (PAP) and other immune-sensitizing agents. The “armed” cells are returned to the clinic where they are infused three times at two week intervals. The “armed” immune cells are thought to seek out prostate cancer and exert their ability to kill the tumor.

PCF has invested approximately \$9.7 million (1993 – 2010) to support immunotherapy research and the discovery and development of therapeutic cancer vaccines and inter-related treatments to boost a patient’s immune response against his tumor. In the case of Provenge, PCF first provided funding to Dr. Eric Small in 1999 (a member of the 13 center [Prostate Cancer Clinical Trials Consortium](#) that is co-funded by PCF and the Department of Defense) to support clinical research around measuring immune responses in patients treated with Provenge. Dr. Small and his colleagues at UCSF provided important early data in patients for the development of Provenge by Dendreon Corporation, the corporate sponsor of Provenge. Dr. Small first published PCF-supported clinical testing of Provenge in the *Journal of Clinical Oncology* in July 2000.

Provenge and Patients

As with all new therapies, treating physicians are on a learning curve as to the best time in a patient’s disease course to administer Provenge. Optimization of Provenge therapy with other anti-neoplastic agents is also in very early stages of development. Kantoff expects that the vaccine will be assigned to patients who are asymptomatic or minimally symptomatic and refractory to hormone therapy. We expect that numerous clinical trials will test Provenge in combination therapy. Studies of Provenge very early in the natural history of prostate cancer, as well as combination therapy with an immunostimulatory agent, Ipilimumab are underway.

The market launch of Provenge has sparked debate over the price of treatment. The treatment is not a simple pill; it is individually prepared, using each patient’s cells to produce the infusion product. This individual biological therapy is expensive. The entire cost of treatment is \$93,000, resulting in a median of 4.1 months of prolonged survival, according to the study published in *The New England Journal of Medicine*. Pricing is based on Dendreon Corporation’s assumption that patients and their insurance companies are willing to pay around \$23,000 for each additional month of life gained. Reimbursement will be a complex issue but is being managed effectively by private insurance companies as well as Medicare. We expect that those patients that might benefit from this therapy will receive coverage at some level.

Dendreon Corporation projects that they will only be able to produce enough Provenge for 2,000 patients during this initial year of commercialization. This capacity will increase by mid-2011. Even then, supply will be short and qualified providers will seek fair standards for patient selection. The key factor is the development of a laboratory method to predict patients most likely to respond. PCF is funding research

to help in the decision process but these studies are at an early stage.

Ideally, for the more than 2.5 million American men living with prostate cancer, the use of Provenge should remain a personal decision, made by a patient and his physician without the added concern of cost. However, until production increases and we have a better understanding of how Provenge works, and why it works for some patients and not others, and how to optimally administer the therapy, the cost debate will likely persist. All controversy aside, Provenge is playing a vital role in validating the potential of immunotherapy and is offering new hope to patients and their families. Further research on Provenge, and immunotherapy in general, is highly merited.

SCIENTISTS FIND PROTEIN THAT MAY HELP CONTROL PROSTATE CANCER

Discovery could aid in limiting tumor growth and progression, expert says

By Robert Preidt

Friday, Dec. 3 (HealthDay News) -- A protein that regulates prostate stem cell self-renewal and also plays a role in the transformation of healthy cells into prostate cancer cells has been identified by U.S. scientists.

The findings, which involve the Bmi-1 protein, could prove important in efforts to find ways to control cancer growth and progression, according to the research team, from the University of California, Los Angeles.

Previous research had found that Bmi-1 is associated with higher-grade cancers and is predictive of poor patient outcomes. But until now, its role in prostate stem cell maintenance and prostate cancer have not been clear.

The UCLA study was conducted using cells and laboratory animals.

"We conclude ... that Bmi-1 is a crucial regulator of self-renewal in adult prostate cells and plays important roles in prostate cancer initiation and progression," study senior author Dr. Owen Witte, director of the Broad Stem Cell Research Center at UCLA, said in a university news release.

"It was encouraging to see that inhibiting this protein slows the growth of even a very aggressive prostate cancer because that could give us new ways to attack this disease," he added.

The study was published online Dec. 2 in *Cell Stem Cell*.

HEALTH INSURANCE NEWS

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

www.HealthCare.gov now provides new information about private insurance benefits and pricing to improve competition and lower costs

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

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for consumers to learn about and compare their insurance choices. HHS' Office of Consumer Information and Insurance Oversight (OCIO) 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.

More than ever, start educating yourself on the pros and cons of your current health and drug plans for 2011. You have options. Don't let distractions such as TV commercials, breakfast/lunch seminars, and fancy mailings sway your decision. Your health care at this time in you life should overshadow short term frugality which could be disastrous later on.

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, PLEASE volunteer your effort to assist our cause.

ALSO NOTE: Dennis Walker made contact with a service that may be very helpful to you. There is a non-profit California organization that specializes in assisting you to obtain medical coverage that best suits your needs. It is called HICAP (Health Insurance Counseling and Advocacy Program). The San Diego number is 858-565-8772. Contact them if you need help making choices.

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 4 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" 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@ipcs.org.

More PC Meetings:

The Prostate Cancer Research Foundation (PC-Ref) meets on the 2nd Saturday of each month at Alvarado Hospital, 6655 Alvarado Rd. They start at 10:00 AM for newcomers and at 11:00 AM for every one. Check out the website at: <http://www.pcref.org> or phone them at (619) 906-4700.

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@ipcs.org

Lyle LaRosh, President 619-892-3888 lyle@ipcs.org

NETWORKING

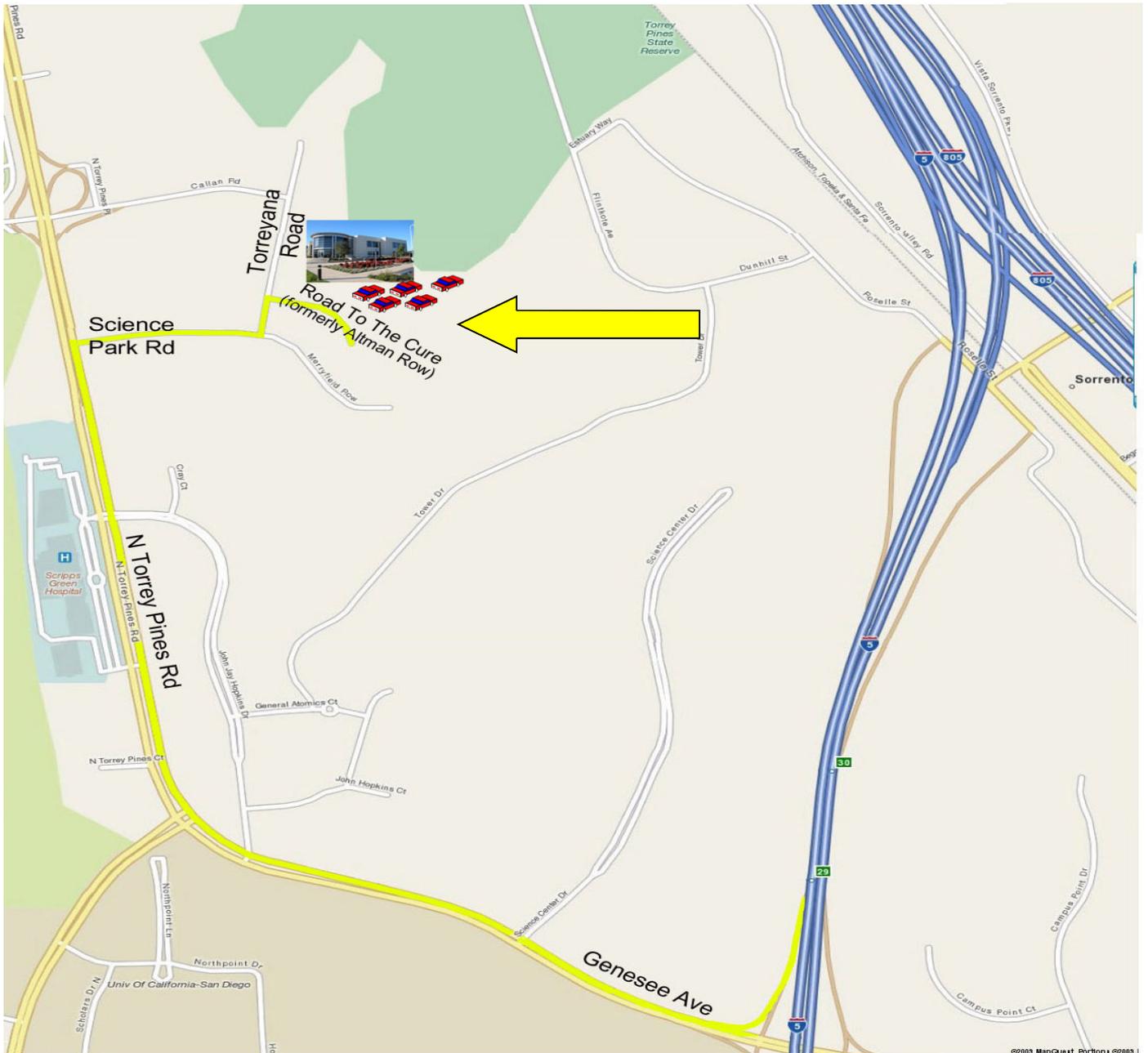
The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is "networking". We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all.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