



# Informed Prostate Cancer Support Group Inc.

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



## September 2011 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: [www.ipcsg.org](http://www.ipcsg.org)

We Meet Every Third Saturday (except December)



Saturday, September 10, 2011

Volume 4, Issue 9

### 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

**September 17th**

**10:00AM to Noon**

**Remember, Sep-  
tember is Na-  
tional Prostate  
Cancer Awareness**

### Month!!

### Meeting at

Sanford-Burnham  
Auditorium

10905 Road to the  
Cure, San Diego CA  
92121

### 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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August's round-table meeting was well-attended by about 80 people including 13 newcomers. There were several presentations by members relating their experiences after which there were break-out sessions by treatment type for further networking with each other.

Following on last month's excellent presentation on Active Surveillance (AS) by Dr. Bahn it was fitting to have Bill Manning give an update on his status following his decision 2 years ago to follow AS (also known as Watchful Waiting). He was initially told by his doctor that he should consider surgery or radiation. After researching options and meeting with support groups, he visited Dr. Bahn

### 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.

who he had learned about from our group. As a result of this visit, which included a color doppler ultrasound test that showed no serious indication of cancer, he decided on AS. He has had follow-up visits with Dr. Bahn twice since then and through him also had a PCA3 test which further confirmed his decision for no aggressive treatment. He takes a PSA test about every 3 months which fluctuates in the 4's. Bill added that he has become a vegan, admitting that it works for him and his wife but it may not work for others because of the discipline involved. He recommended the movie Forks over Knives, now available on DVD, which is a collection of doctors findings, including Dr. Collin Campbell who is the author of The China Study. Their conclusion is that diet is a factor in reducing heart disease as well as cancer. Bill did emphasis that you have to be able to live with your decision to follow AS and not obsess about it. You must be comfortable with your decision and be proactive by following your indicators. Bill's final emphatic statement was that if he had taken the initial advice of his doctor and later found out what he now knows about AS, he would be one unhappy S.O.B.!!

Bob Keck is a 19 year survivor of prostate cancer and just celebrated his 77th birthday! Active Surveillance had not been heard of in the early 1990's when he first became aware he might have a problem. He first got a PSA test following on news during Prostate Cancer Month which offered a free PSA test. The resulted was a score of 21. At that time there were no support groups, leaving one at the will of the doctors. His doctor recommended a biopsy that resulted in a Gleason 5 (which was later rated a Gleason 6 by the biopsy taken following surgery) It was suggested that he could do surgery or radiation and he chose surgery because of a personal aversion to radiation therapy. He was 58 years old at the time. He was given a shot of Lupron to reduce the size of his prostate which also reduced his PSA to 13 before the surgery. Six months after the surgery, his PSA began rising. He know it should be undetectable following surgery so when it reached 1.0 he saw a urologist who recommended hormonal blockade He started treatment with Lupron, Eulexin (Flutamide) and Proscar. His PSA went down to 0.01 which at the time was considered undetectable. When his PSA reached this nadir, he would discontinue the drugs until his PSA rose to 1.0 and then revert to taking the drugs. He continued this for 4 cycles. He became concerned about developing resistance to the drugs, (refractory) so he decided to let the PSA go higher. It went up to 2 than leveled off so he began using only Proscar. Over a period of over 4 years his PSA rose to 6 using only Proscar. It should be noted here that after becoming involved with our group many years ago, he became aware of the Ploidy analysis. He took the test and found that he is diploid which indicates his is a less aggressive form of cancer. Bob is now under the care of Drs. Scholz and Lam of Prostate Oncology Specialists and he has switched to using only Casodex which has taken his PSA to down to .03. For the time being he has discontinued taking Casodex and plans to go back on again when his PSA reaches 6.

Noel Durkin gave an update about his cryoablation treatment by Dr. Bahn 14 months ago. After the treatment his PSA went down to 0.5 and after 14 months it is 1.5. It is predicted that his PSA will rise to about 3.0. Only one half of the prostate was treated. As part of his orientation at the time of the treatment, he was given a pamphlet about the likelihood of erectile dysfunction which could be aided by the use of a vacuum assist device. He gave a humorous dissertation about the use and the pitfalls of mis-using the device. Using the device for time periods longer than that recommended caused a problem with the penis that took over a month to overcome. He was advised to continue taking Avodart but discontinued taking it because we wanted his libido to return, which it has.

Bill Ashley gave a detailed presentation about the insulin diet. He started the diet 2 months ago and it has resulted in the first PSA drop since he was diagnosed nearly 2 years ago. On this diet one eats foods that keep insulin levels from spiking. It resulted from the discovery that men with diabetes have a lower

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incidence of prostate cancer and it was surmised that it was because they have low insulin levels. On this diet you must eat foods with a low insulin index and eat more modest quantities. He first learned of this diet from Drs. Scholz and Lam. He chose the diet because he wanted to extend his active surveillance period awaiting FDA approval of the new drugs we are hearing about. The diet can also be used to reduce the chances of recurrence or increase the effectiveness of treatment. His presentation included complex descriptions and graphs that need to well understood. It is recommended that you view his presentation on the DVD of this meeting or talk with Bill if you have an interest in learning about this diet.

Robert Werve gave us an update on his condition. We have been following him since he joined the group after learning of his very aggressive form of prostate cancer. In 2007 his PSA was 1.7 and he was shocked to learn during a physical in 2008 that it had soared to 348. He was then brought into our group by Carlos Richardson, former Secretary/Treasurer. He tried the vegan diet for 9 months with no result, then tried Casodex for a short time and became refractory in 5 weeks. He drove the PSA down twice, once with Lupron and another with Casodex with nadirs of 30 and 60 but it then began doubling every 5 weeks and by October of 2008 it was back to 288 when he chose to become a patient of Drs. Bob Leibowitz and Jeff Turner of Compassionate Oncology. He began chemotherapy consisting of androgen deprivation for 14 months and 5 months of chemo with many different drugs in composition. It was a stressful period of feeling very poorly and losing 20 pounds, but by March of 2009 his PSA was undetectable. In January of 2011 his PSA had gone up to 7 and he decided to try the new drug Provenge. By the time he began the program 6 weeks later it was up to 40. The PSA skyrocketed again and by May, 2011 it was up to 243. He does have bone metastasis. He returned to Drs. Leibowitz/Turner and was given the recently approved drug abiraterone, trade name Zytiga. Within 3 weeks his PSA had dropped to 49 and 2 weeks later it was back to 58 and last week it was 78 which indicates that Zytiga was beginning to fail. Robert is now in the process of considering another round of chemotherapy or other drug trials that may be of benefit. Robert's experience is a disheartening sequence of events yet an example of hope for those that persevere. Those of us that have been with him through his periods of ups and downs have the highest regard for his perseverance and positive mental attitude. We all wish him the best of luck in pursuing new avenues of treatment.

More detailed information about the presentations are included in the August meeting DVD which can be purchased for \$10 from our library or through our website: [www.ipcsg.org](http://www.ipcsg.org).

### **Future Meetings**

September 17, 2011. Dr. A.J. Mundt, Chief of Radiation Oncology-latest developments and Dr. John Einck, Radiation Oncologist-Brachytherapy, both of UCSD.

October 15 and November 19, 2011 still being finalized.

January 21, 2012. Dr. Richard Lam, Prostate Oncology Specialists-Review and update on prostate cancer treatment.

February 18, 2012. Dr. Richard Safrin, Head of Pathology at Alvarado Hospital, who will speak about Gleason testing.

## NOTEWORTHY ARTICLES

Member Dennis Walker does a lot of important research for our group. He provided an article about triple hormonal blockade/androgen deprivation therapy that is very worthwhile information. Although too lengthy to reproduce here we encourage you to read it by accessing the following website: <http://www.ustoowichita.org/pdf/Triple%20Hormonal%20Blockade%20ADT3.pdf>

### Playing “Chicken:” Sometimes You Both Lose

Posted: 06 Sep 2011 08:45 AM PDT on <http://prostatesnatchers.blogspot.com/>

#### BY MARK SCHOLZ

I have never seen a real game of chicken where two cars race head on toward each other to see who will swerve first, i.e., who is chicken. However, we are seeing an actual game of chicken being played out before our eyes on the national stage. In one car are the pharmaceutical companies that are charging mind-boggling prices for their new cancer drugs. FDA approval of a new medicine is like hitting the lottery because the insurance companies are legally obligated to pay for the drug. Recouping the cost of developing a new drug is certainly justifiable. Even so, in my recent blog I cited the example of Zytiga (abiraterone), an effective new pill for prostate cancer that retails for \$5,000.00 per month.

The other car in this game is the insurance companies, who, to control costs, have begun imposing artificial restrictions on coverage of Zytiga by insisting that chemotherapy be administered first, before Zytiga can be prescribed. By imposing this artificial restriction the insurance companies are getting involved in making decisions about treatment that historically have been left to the doctor. The insurance company's rationale is that the studies of Zytiga that led to FDA approval were performed in men after chemotherapy, so in theory we don't know if Zytiga will work before chemotherapy. What a travesty! Any cancer expert—for that matter, anyone with common sense—can tell you that starting treatment earlier works better than waiting until the disease is more advanced.

I really don't know how this scary game of chicken is going to end. No insurance company has endless resources. Yet, thanks to effective research being performed by the pharmaceutical companies, many new (and expensive) drugs are coming on the market. Presently in my daily practice, people who meet the criteria—men who have had previous chemotherapy—and have adequate pharmaceutical insurance, are getting coverage for their Zytiga pills. Also, Johnson and Johnson, the manufacturer of Zytiga has a generous program for drug access for people who can't afford the drug. Even so, at some point the costs to society are going to become unsustainable. Just like the game of chicken, if both the parties wait too long to take corrective action, we can anticipate a horrendous crash.

### Long-term safety and tolerability of FIRMAGON

Copied from PR Newswire

PARSIPPANY, N.J., Sept. 1, 2011 /PRNewswire via COMTEX/ -- New data, published today in the Journal of Urology, demonstrated the long-term safety and tolerability of FIRMAGON® (degarelix) a gonadotropin-releasing hormone therapy (GnRH) for advanced prostate cancer when used over three years.(1) The new study (CS21A) was an open-label extension of the pivotal Phase III study (CS21) in which FIRMAGON® was shown to be non-inferior to leuprolide in reducing testosterone to castrate levels through one year of treatment.(1) In a retrospective analysis of CS21, risk of PSA failure was significantly lower in patients receiving degarelix versus leuprolide up to 1 year.(2) The extension study showed

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in an exploratory analysis that for patients who remained on FIRMAGON®, PSA suppression and the risk of PSA failure remained consistent over the long term (42 months).(1)

In addition, the extension study evaluated patients who crossed over from leuprolide to FIRMA-GON® after one year in an exploratory analysis. At a median follow up of 27.5 months the data showed that the risk of PSA failure had decreased.(1)

Longer time to PSA failure is thought to be desirable as it may be indicative of time to castration-resistant prostate cancer (CRPC) and may delay initiation of second-line therapy, which includes chemotherapy.(3) Time to castration resistance is also an important predictor of CRPC survival.(4)

"This extension study supports using FIRMAGON® as first line-line androgen deprivation therapy(1) in patients with advanced prostate cancer locally advanced prostate cancer," said E. David Crawford, MD, Head, Section of Urologic Oncology and Professor of Urologic and Radiation Oncology, University of Colorado Denver, US. "The data from the Phase III open-label extension study showed that FIRMA-GON® provided advanced prostate cancer patients with safe and effective testosterone and PSA control over the long term, reducing the risk of PSA failure."

Prostate cancer is the second leading cause of cancer death amongst men in the Western world.(5) Up to 40% of men diagnosed with prostate cancer will eventually develop advanced disease, and although most respond to initial medical or surgical castration, progression to CRPC is inevitable(6). The average survival for patients with CRPC is two to three years.(6)

FIRMAGON® works by immediately inhibiting the GnRH receptors in the pituitary gland and suppressing the luteinising hormone, which decreases production of testosterone by the testicles with no initial surge. Prostate cancer is dependent on testosterone for its growth, so the goal of therapy is to rapidly reduce testosterone levels to slow the growth of cancer cells.

FIRMAGON also reduces levels of prostate-specific antigen (PSA). Unlike luteinizing hormone-releasing hormone (LHRH) agonists, such as leuprolide, an established treatment for prostate cancer, FIR-MAGON does not induce an initial testosterone surge. FIRMAGON is administered monthly by subcutaneous injection. The starting dose is 240 mg, followed by monthly maintenance doses of 80 mg. FIRMA-GON is available for order through traditional and specialty pharmacy distributors. The average monthly cost of one year of FIRMAGON treatment is comparable to other hormone treatments for advanced prostate cancer.

## Announcements

Member Lawrence Weaver has advised us of a new study (not related to prostate cancer) being offered by UCSD that may be of interest to you.

Below is information extracted from their web site: <http://celiaccenter.ucsd.edu>

The Wm. K. Warren Medical Research Center for Celiac Disease at the University of California, San Diego offers a low-cost celiac disease screening program for those in San Diego and the surrounding areas.

What is Celiac Disease: Celiac Disease is a digestive disease that damages the small intestine and interferes with the absorption of nutrients from food. People with celiac disease cannot tolerate gluten, a protein found in wheat, barley and rye.

Purpose of this research study: We estimate that approximately 25,000 people in the San Diego area

have celiac disease; however, 90% of these individuals have yet to be diagnosed. Our goal is to understand why individuals who are at high risk for celiac disease have not been screened and why so many people remain undiagnosed.

When: This low-cost celiac disease screening program is beginning October, 2010. Please see our website for official start date and updates about the study.

What kind of test will be given: The IgA tissue transglutaminase antibody (tTG) test is recommended for screening for celiac disease. It is a blood test that is simple and quick.

Cost: \$29.25. Who: Adults

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**

## **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](http://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 (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.

### **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@ipcs.org](mailto:gene@ipcs.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.

### **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](mailto:gene@ipcs.org)

Lyle LaRosh, President 619-892-3888 [lyle@ipcs.org](mailto:lyle@ipcs.org)

### **NETWORKING**

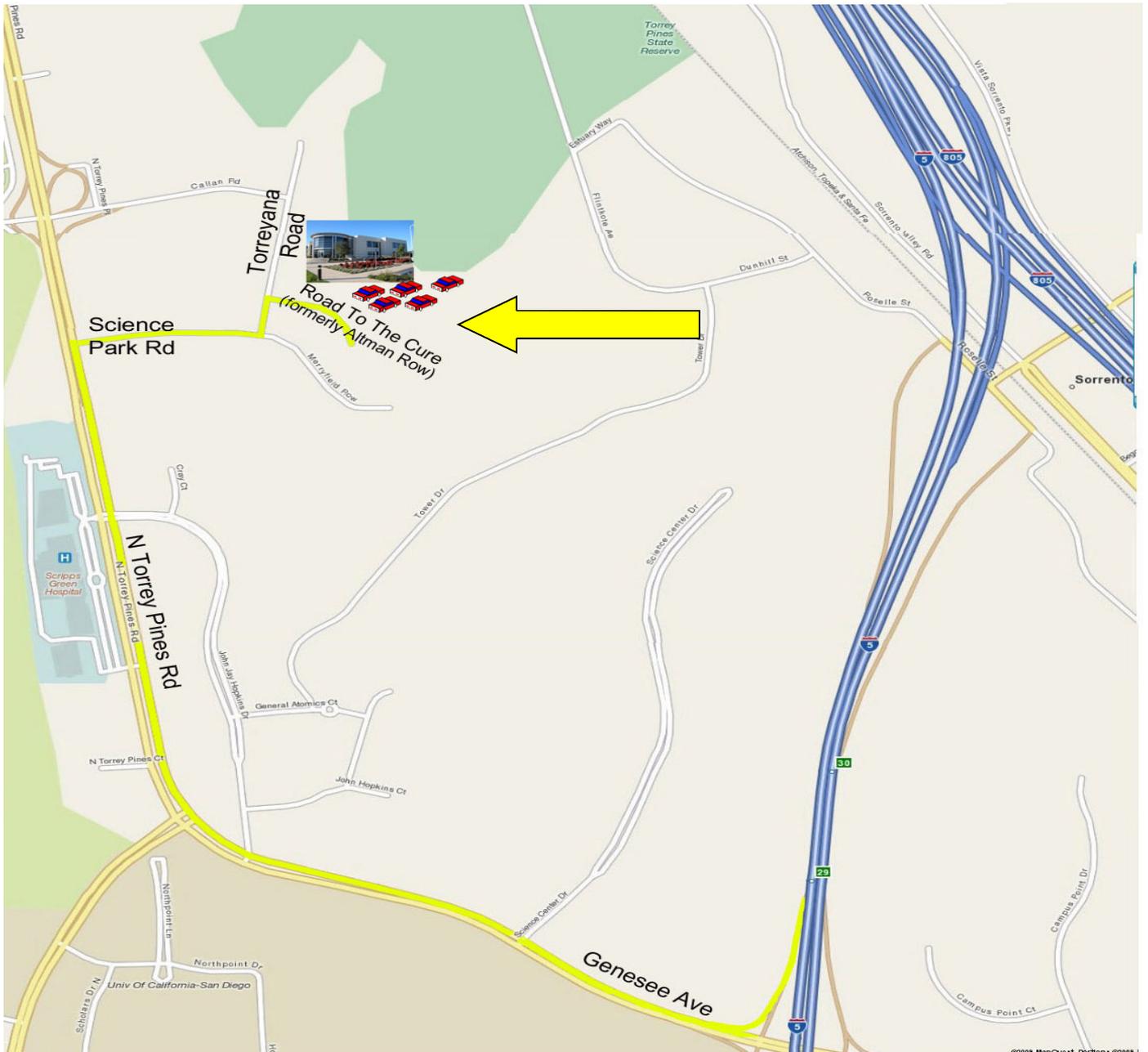
The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is "networking". We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all.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