



# Informed Prostate Cancer Support Group Inc.

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



## MARCH 2017 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142  
Phone: 619-890-8447 Web: <http://ipcs.org>



We Meet Every Third Saturday (except December)

### Officers

Lyle LaRosh  
President

### Additional Directors

Gene Van Vleet  
George Johnson  
John Tassi  
Bill Manning

### Honorary Directors

Dr. Dick Gilbert  
Judge Robert Coates  
Victor Reed

George Johnson, Facilitator  
Bill Manning, Videographer  
John Tassi, Webmaster  
Bill Bailey, Librarian  
Jim Kilduff, Greeter

### Next Meeting

**March 18, 2017**

**10:00AM to Noon**

Meeting at

Sanford-Burnham-  
Prebys Auditorium

10905 Road to the  
Cure, San Diego CA  
92121

SEE MAP ON THE  
LAST PAGE

Thursday, March 16, 2017

Volume 10 Issue 3

### 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 PCa 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: Stephen Pendergast

### PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

The February meeting was well attended by men and women gathering to participate in a roundtable meeting where 3 men spoke of their experiences in dealing with prostate cancer (PCa) after which the audience was segregated by treatment type for networking.

**Meeting summary, Feb 18, 2017  
prepared by Bill Lewis**  
Personal Prostate Cancer Experiences

### 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://ipcs.org> Click on the 'Purchase DVDs' button. The DVD of each meeting is available by the next meeting date.

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1. Richard Hansen, age 76, Del Mar, CA. His younger brother died of prostate cancer, after not getting it checked and treated promptly. Richard had a low PSA of 1.7 in 2012, but his regular annual DRE was abnormal. He had a random biopsy, then went to Prostate Oncology Specialists after concluding his urologist had been giving him a lot of misinformation. He got a Color Doppler Ultrasound, mpMRI, and targeted biopsy. The initial Gleason score was 6, but it was reevaluated at Johns Hopkins and found to be 3+4=7. By June 2015, there was moderate growth, so the protocol of the Ascende study in Canada was chosen: ADT (1 mo. Fermagon in 1/16 followed by 6 mo. Lupron; this was accompanied by Flomax, Gabapentin and ibuprofen), with 5 weeks of IMRT starting in May, and Brachytherapy (52 seeds) in June. By this past December, all side effects (which were relatively minor) wore off, and his PSA was 0.07. He is now on active surveillance.

He learned some very pertinent lessons: 1. A LOW PSA IS NOT ALWAYS RELIABLE as an indicator of prostate health. 2. Don't rely on urologists for comprehensive care. They may be misinformed. 3. Do your homework. Study your options. 4. You are your best case manager. 5. Take advantage of your IPCSG contacts and resources – they provide support, advice, literature, and may lead you to the Prostate Oncology Specialists, who are real experts. 6. Don't procrastinate on treatments – Richard felt he delayed more than needed. 7. The decision is really about side effects. Different treatments may be equally effective overall, but the side effects are different. Generally, the side effects are not as bad as you think. 8. Keep the faith. Keep on truckin'. 9. Keep vigilant and stay informed (Keep coming to the IPCSG!). 10. Stay strong.

2. Bill Lewis, age 65, Chula Vista, CA. His father died of prostate cancer, and his grandfather and several uncles had prostate cancer. In 2009, his (infrequently-checked) PSA score was 1.7. Next checks were in 2014 after continued frequent urination, a heart attack (100% blockage of a main artery), bankruptcy, aggravated business stress, medication-induced anxiety and loss of insurance coverage. PSA scores were 18, 9 and 10 during the year, followed by another drop in 1/15 on Proscar to 6. Gradually rising PSA led to an mpMRI scan, targeted biopsy, and bone scan by the end of 2015, indicating prostate cancer with many bone mets. Attempted cure by alternative medicine (I.V. Vitamin C, ozone, and a supplement called Safinur) failed, and a repeat bone scan showed "innumerable" metastases to bones all over his body, so Triple ADT (Lupron, Casodex and Avodart) was started in 6/16. PSA dropped over about 6 months from 73 (after having doubled in one month!) to 0.20. Insurance coverage through Kaiser had been obtained in 8/14, but their therapy ideas and pricing (on the high-deductible plan Bill could afford) were so unacceptable that all the scans in 2015 were paid out-of-pocket at an outside facility, and some medications were obtained from an alternate doctor.

Starting with the ADT, Bill began a number of lifestyle changes, and continued others

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thought to be helpful to health. 1. Religion is an important factor, including priesthood blessings (see James 5:14 in the Bible), prayer (including personal, family, friends and the La Jolla LDS temple prayer roll available to anyone), and various religious-based practices. 2. Positive emotions, especially including watching funny YouTube videos daily. 3. Positive social interactions with coworkers, friends and everyone. 4. Food choices, including almost no sugar, no drinking of milk, very little red meat or fruits, many vegetables, and a flaxseed oil – cottage cheese blend developed by a German doctor named Johanna Budwig. 5. Following intuitions – the voice inside that is often our best guide. 6. Exercise, including biking to work and a new gym membership. 7. Service of many kinds, to neighbors, through church, and by assisting Haitian refugees. 8. Reasons to live – mainly family, but also the desire to promote and market a personally developed health aid. These lifestyle changes and others including many supplements taken, are all in accordance with a book about changes found to have been made by persons who have had remarkable recoveries from cancer. Further information is available from Bill at [lewis.bill@gmail.com](mailto:lewis.bill@gmail.com).

He is now a patient of Prostate Oncology Specialists as well as Sharp Rees-Steely, and likely steps will include “T-base hormone therapy” to prolong the time until hormone therapy resistance occurs (see article on how Development of Castrate Resistance Varies with Different Dosing Regimens, at [http://www.goldjournal.net/article/S0090-4295\(10\)01673-0/abstract](http://www.goldjournal.net/article/S0090-4295(10)01673-0/abstract)); genetic typing of the cancer to identify the best future therapies; and using advanced imaging to find a metastasis or two not close to vital organs, followed SBRT (intense radiation) to dissolve the tumor while Keytruda or some other immune system booster is administered.

3. Gene Van Vleet, age 78, San Diego CA. Annual DRE's led to finding an abnormality in 8/02, followed by a PSA test at 4.8 (vs. 1.8 in 1999). A random biopsy (no targeted biopsies then being available) showed Gleason 3+4=7, and it was staged as T2c (confined to the prostate). After retropubic surgery, the pathology results showed that the stage was T3b (the tumor was into the seminal vesicles, and was not fully removed in the surgery!). The PSA nevertheless dropped to <0.1. When it rose to 0.4 by 5/05, he received 33 EBRT's. A year later, he had a very serious bladder infection, probably due to the imprecise targeting of the radiation in that era. By 1/07, his rising PSA led his urologist to suggest he see an oncologist.

He found the IPCSG, Lyle LaRosh, and the Prostate Oncology Specialists. He also went onto various diets, succeeding and sticking best to the Mediterranean diet, and has also been faithful about exercising (and ramping up as needed). At first, he tried Proscar + Avodart, but that didn't work long. Then he used a high dose (150 mg) of Casodex with the usual Avodart dose. He hoped this would avoid the side effects that would come with

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Lupron shots. This worked for years, though each of three “holidays” left him with higher PSA’s each time he restarted the medications, suggesting resistance was developing. Regular imaging of various types showed some pelvic metastases, but relatively stable disease. In 2011, he had three 1-month doses of Lupron, after which he began to receive 3-month shots. After trying a holiday, his PSA rose to 13.6 so he began again in 2013 to receive 3-month Lupron shots along with the normal Casodex dose (50 mg), and his PSA dropped once more. In 4/14, he started Provenge therapy to bolster his immune system. Scans continued to show stable disease. But then his PSA rose to 0.9, and the cancer was attacked in 2015 with Xofigo (radium treatment of the bones monthly for 6 months) and with Xtandi (“super Casodex”). Almost no side effects, except minor fatigue, and his PSA came down to his lowest ever: 0.04!

Despite continued Lupron, Xtandi and Avodart, his PSA rose to 0.6 by 9/16. An Auxumin (F-18 Fluciclovine) PET/CT scan showed all his bone metastases but one had healed, so he is now starting therapy to dissolve the remaining tumor with SBRT, while also receiving Keytruda to maximize his immune response.

In response to questions, he noted that he has taken Xgeva for bone strengthening since starting Lupron, and has had bone density scans every two years.

#### FUTURE MEETINGS

- **March 18—Advances in MRI Scans as an Option Prior to a Biopsy and to Perform More Accurate Targeted Biopsies—James A. Cooper, MD, Diagnostic Radiologist, Imaging Healthcare Specialists**
- **April 15—to be determined**

### **2017 Moyad + Scholz Mid-Year Update**

#### **Prostate Cancer Research Institute**

Marina del Rwy Marriott, Saturday, March 25, 2017 8:00am – 4:00pm

<https://www.facebook.com/events/691139317721550/>

Our first featured speaker, Carl Rossi, MD, the leading expert in proton therapy from Scripps Proton Therapy Center, will be giving a presentation about the current state of radiation therapy, intensity modulated proton therapy, re-radiating after failed radiation, and more. Additionally, Robert Dreicer, MD, a world renowned oncologist, will be discussing the latest treatments for advanced prostate cancer - immune therapy, hormone therapy, chemotherapy, clinical trials, and much more. PCRI's Executive Director, Mark Scholz, MD, will be discussing active surveillance for men with newly diagnosed cancer and will cover issues that surround a new diagnosis, from imaging scans and biopsies, to genetic testing.

## ON THE LIGHTER SIDE

### The Seven Dwarves of ~~Menopause~~ **ADT**



Itchy, Bitchy, Sweaty, Sleepy, Bloated, Forgetful & Psycho

### Medical Definitions for Rednecks

**Barium** - What the undertaker does to 'em once the doctors are through with 'em.

**Benign** - What a child be after they be eight.

**Cauterize** - To have gotten noticed by a woman.

**Cyst** - To give someone in need a helpin' hand.

**Dilate** - It sure beats dyin' early.

**Impotent** - Significant and distinguished.

**Node** - To have been acquainted with someone in the past.

**Pap Smear** - To insult or belittle your own father.

**Pathology** - The study of trails.

**Rectum** - Crashed 'em and totaled 'em.

**Tumor** - Not just one more.

**X-Rayed** - For adult audiences only.



## INTERESTING ARTICLES

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[Can bipolar cycling of testosterone really cure prostate cancer?](#)

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<https://prostatecancerinfolink.net/2016/12/05/can-bipolar-cycling-of-testosterone-really-cure-prostate-cancer/>

Posted on December 5, 2016 by Sitemaster

Some readers will already have seen headlines like [this one from The Vancouver Sun \[http://www.vancouversun.com/news/](#)

[world/98his+disease+disappeared+98cured+advanced+prostate+cancer/12467516/story.html\]](#) and/or [this one from Fox News \[http://www.foxnews.com/health/2016/12/01/man-cured-prostate-cancer-after-being-given-testosterone-to-shock-tumors.html\]](#) (which originally seems to have come from *The Sun* in the UK).

There is inevitably excitement around such news reports, and it needs to be said that the concept of

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“bipolar” cycling of high and low levels of testosterone has been around for a while, but these new data **may be** the stimulus needed for large, randomized trials of this type of therapy in carefully selected groups of men with advanced forms of prostate cancer.

As yet, unfortunately, we have not been able to identify the original press release that has to be the source of this story, but here is what we currently know.

The data come from an ongoing Phase II study called [the RESTORE trial \[https://clinicaltrials.gov/ct2/show/NCT02090114\]](https://clinicaltrials.gov/ct2/show/NCT02090114), which is being conducted here in the USA and is led by Dr. Samuel Denmeade at Johns Hopkins in Baltimore. “RESTORE” stands for RE-sensitizing with Supraphysiologic Testosterone to Overcome REsistance. The way this type of treatment works is by use of a technique called bipolar androgen treatment (BAT), in which the patients receive treatments that can rapidly lower and raise testosterone levels by alternating the use of androgen deprivation alone and testosterone supplementation while ADT continues. We had mentioned the development of this trial in [an earlier commentary \[https://prostatecancerinfolink.net/2015/01/08/what-is-bipolar-androgen-deprivation-therapy/\]](https://prostatecancerinfolink.net/2015/01/08/what-is-bipolar-androgen-deprivation-therapy/) back in 2015.

What seems to be “different” about the RESTORE trial as compared to earlier forms of BAT is that it is being used in men who are castration resistant **and** who have **already progressed** after initial treatment with either abiraterone or enzalutamide. The men in the RESTORE trial who meet the entry criteria are all on standard forms of LHRH agonist therapy (e.g., Lupron or Zoladex or similar); they are then being treated with intramuscular injections of testosterone (either testosterone cypionate 400 mg or testosterone enanthate 400 mg) every 28 days. When they progress on testosterone cypionate or enanthate, the men are then retreated with daily doses of either abiraterone 1000 mg daily or enzalutamide 160 mg daily, depending on which drug they had received before.

According to the data presented by Denmeade at the meeting in Munich:

- 47 patients have been treated to date.
- All 47 patients seem to have received at least three cycles of treatment.
- 6/47 patients (13 percent) tested positive for a protein called AR-V7 prior to BAT.
- PSA levels
  - Decreased significantly in about 40 percent of all the men in the trial
  - Decreased by > 50 percent in about 30 percent of men in the trial
  - 1/47 patients (2 percent) had PSA levels that dropped to zero after 3 months and remained at zero for 22 cycles.
  - All 6 patients who were AR-V7-positive prior to treatment were AR-V7-negative after BAT.
  - With respect to side effects,
    - 1 patient reported an increase in pain.
    - 1 patient reported a problem with urine retention.

The RESTORE trial seems to have originally been designed to enroll 30 men who had CRPC and had progressed on abiraterone acetate and another 30 men who had CRPC and had progressed on enzalutamide. So the data presented by Denmeade in Munich are preliminary.

What Dr. Denmeade is actually quoted as saying is that:

*I think we may have cured one man whose PSA dropped to zero after three months and has remained so now for 22 cycles. His disease has all disappeared.*

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However, Dr. Denmeade also pointed out that:

*We are still in the early stages of figuring out how this works and how to incorporate it into the treatment paradigm for prostate cancer.*

and

*Some men also have objective responses with a decrease in the size of measurable disease, mostly in lymph nodes. Many of the men have stable disease that has not progressed for more than 12 months.*

There is already a newer, ongoing, randomized, multi-center trial in the US that is comparing BAT + enzalutamide in men who have become resistant to abiraterone acetate. This is [the so-called TRANSFORMER trial \[https://clinicaltrials.gov/ct2/show/NCT02286921\]](https://clinicaltrials.gov/ct2/show/NCT02286921) that is scheduled to enroll a total of 180 participants. Dr. Denmeade is the lead investigator for this trial too. At present, Johns Hopkins is the only center that is enrolling patients.

Of course one of the really critical questions is whether forms of BAT can be used much earlier in the disease to arrest progression before a patient becomes castration resistant at all. We'll probably need to see how patients do on the TRANSFORMER trial before anyone is going to be willing to look at that opportunity. In the meantime, "One swallow does not make a summer", but the first swallow each year gets a lot of people excited (your sitemaster included)

[Conference call/webinar on bipolar androgen therapy \(BAT\)](#)

The Answer Cancer Foundation held an educational conference call/webinar on the subject of bipolar androgen therapy in the treatment of advanced prostate cancer. For those who were unable to catch the live show, it is now possible to listen to the entire presentation and watch Dr. Denmeade's slide presentation if you <https://www.youtube.com/watch?v=dU5EoW9270k&feature=youtu.be> for the Youtube link. If you just want to be able to review Dr. Denmeade's slides, please [http://media.wix.com/ugd/be9e43\\_d98deb26fb014a769e3b887d6d0e4105.pdf](http://media.wix.com/ugd/be9e43_d98deb26fb014a769e3b887d6d0e4105.pdf).

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## Vascular-Targeted Photodynamic Therapy Shows Promise in Low-Risk Prostate Cancer

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By Matthew Stenger

Posted: 1/3/2017 12:21:40 PM

Last Updated: 1/3/2017 12:21:40 PM

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Key Points

- Vascular-targeted photodynamic therapy was associated with a lower rate of disease progression in men with low-risk prostate cancer.
- The treatment approach was well tolerated, and it may allow men to consider a tissue-preserving approach and defer or avoid radical therapy.

In a European phase III trial reported in *The Lancet Oncology* [<http://www.thelancet.com/journals/lanonc/article/>

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[PIIS1470-2045%2816%2930661-1/fulltext](#)], Azzouzi et al found that padeliporfin vascular-targeted photodynamic therapy was associated with a reduced rate of disease progression vs active surveillance in men with low-risk prostate cancer.

#### Study Details

In the open-label trial, 413 patients with Gleason pattern 3 disease and no previous treatment from 47 sites in Europe were randomized between March 2011 and April 2013 to receive vascular-targeted photodynamic therapy (n = 206) or active surveillance (n = 207). Photodynamic therapy consisted of 4 mg/kg of intravenous padeliporfin over 10 minutes with optical fibers inserted into the prostate to cover the treatment zone and subsequent activation by laser light at 753 nm with a fixed power of 150 mW/cm for 22 minutes and 15 seconds. Active surveillance consisted of biopsy at 12-month intervals and prostate-specific antigen measurement and digital rectal examination at 3-month intervals.

The co-primary endpoints were treatment failure (histologic progression of cancer from low to moderate or high risk or death at 24 months) and absence of definite cancer (absence of any histology result positive for cancer at month 24) in the intent-to-treat population.

#### Reduced Disease Progression

Median follow-up was 24 months. Disease progression at 24 months was found in 28% of the photodynamic therapy group vs 58% of the active surveillance group (adjusted hazard ratio = 0.34,  $P < .0001$ ). Negative prostate biopsy at 24 months was found in 49% vs 14% (adjusted risk ratio = 3.67,  $P < .0001$ ).

#### Adverse Events

The most common grade 3 or 4 adverse events were prostatitis (2% in the photodynamic therapy group vs < 1% in the active surveillance group), acute urinary retention (2% vs < 1%), and erectile dysfunction (1% vs 1%). The most common serious adverse event in the photodynamic therapy group was urinary retention, which occurred in 15 patients (7%); urinary retention resolved in all patients within 2 months. The most common serious adverse event in the active surveillance group was myocardial infarction (3 patients, 1%).

The investigators concluded: “Padeliporfin vascular-targeted photodynamic therapy is a safe, effective treatment for low-risk, localized prostate cancer. This treatment might allow more men to consider a tissue-preserving approach and defer or avoid radical therapy.”

The study was funded by Steba Biotech.

**Mark Emberton, FMedSci**, of [University College London](#), is the corresponding author of *The Lancet Oncology* article.

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For further reading:

<http://spendergast.blogspot.com/2017/03/prostate-cancer-news-2017-03.html>

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

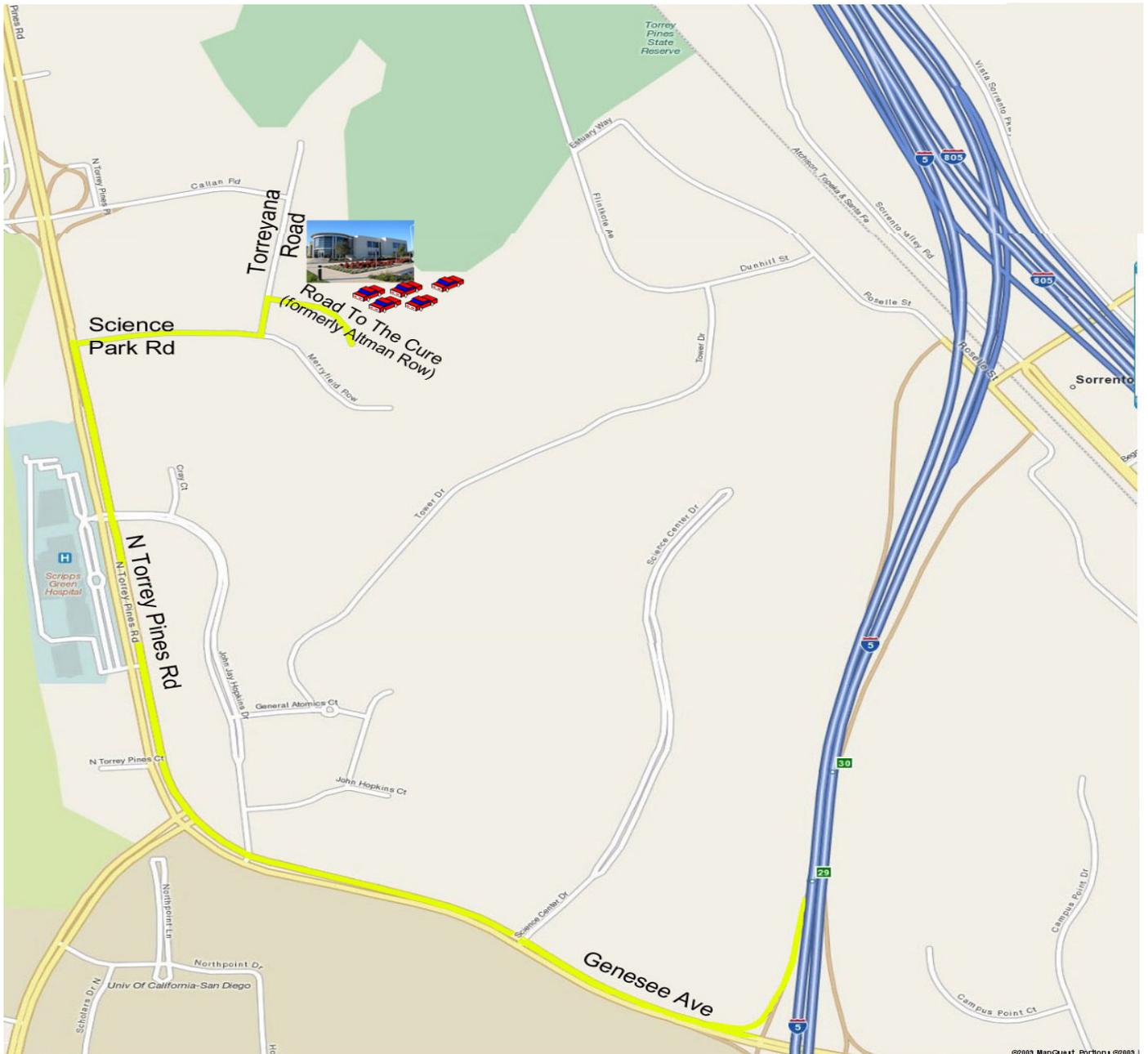
Ads about our Group are in the Union Tribune 2-3 times prior to a meeting. Watch for them.

## 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://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-Prebys 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-Prebys Medical Discovery Institute or Fishman Auditorium**

Turn right on Science Park Road. Watch for our sign here.

Turn Left on Torreyana Road. Watch for our sign here.

Turn Right on Road to the Cure (formerly Altman Row). Watch for our sign here.