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

APRIL 2015 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Sunday, April 12, 2015 | Volume 8 Issue 3

Next Meeting
April 18, 2014
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 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.

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Editor: Gene Van Vleet

PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

The March meeting was a very meaningful presentation about case management by the Directors of the support group who have about 60 years' combined experience in dealing with our disease.

We think the DVD of this meeting, which will include the ability to separately view the slides, will be especially useful in helping you manage your own case. The DVD will be available in the library and on the website: http://ipcsg.org/shop/ by the April Meeting.

This recap only covers parts of what was pre-

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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.

The DVD of each meeting is available by the next meeting date.

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sented.

George Johnson, Director and Facilitator of our meetings, spoke about why and how you should manage your own case as well as what is different about dealing with prostate cancer.

Bill Manning, Director and Videographer who produces the DVD's of our meetings, spoke about case tracking--things you should know and measure. This included discussion of the Gleason score and what it means as well as the importance of tracking you PSA scores over time. The Partin Tables http://urology.jhu.edu/prostate/partintables.php were discussed as an important element in considering treatment options.

John Tassi, Director and Webmaster of our very informative website, spoke about the doctor selection process and preparing for your first and follow-up doctor's visits. He recommended gathering your health records and maintaining active files as you proceed. He spoke of developing questions for each visit and the value of not rushing into a treatment decision. Remember that the treatment decision is yours, not the doctor's. Getting a second opinion is always a wise choice.

Lyle LaRosh, President, and highly knowledgeable leader of our group, spoke about biopsy factors and determining where your cancer is. He talked of the value of imaging prior to any biopsy that can be used to direct the biopsy rather than getting a "blind" biopsy that can miss active tumors. He spoke of imaging techniques available to isolate the location of tumors for those newly diagnosed as well as those experiencing recurrence.

Gene Van Vleet, Director and Chief Operating Officer arranges for speakers, meeting agendas, controls finances, edits the newsletter and mans the phone hotline. He spoke of treatment selections and quality of life considerations. He recommended developing an understanding of the probable side effects of each treatment type. The most powerful tool to guide you is knowledge. Make sure you include your family in your learning, about your feelings and in your decision making.

FUTURE MEETINGS

April 18th - Steven G Pratt M.D., F.A.C.S., A.B.I.H.M The role of nutrition and lifestyle in the prevention of disease and optimizing health. www.superhealthyliving.com

May 16th - No yet committed

June 20th - T. Mike Hsieh, MD. Asst Professor of Surgery, UCSD. Sexual dysfunction including low testosterone and erectile dysfunction

July 18th - Donna Hansel MD, PhD, Division Chief of Anatomic Pathology UCSD and an expert in genitourinary pathology, will speak about the Gleason biopsy test.

ON THE LIGHTER SIDE

"The trouble with having an open mind, of course, is that people will insist on coming along and trying to put things in it." — Terry Pratchett, Diersgg

"The reason I talk to myself is because I'm the only one whose answers I accept." — George Carlin
"I suppose I'll have to add the force of gravity to my list of enemies." — Lemony Snicket, The Penultimate Peril

"Do your thing and don't care if they like it." — Tina Fey, Bossypants

"In theory, there is no difference between theory and practice. But in practice, there is." — Yogi Berra

"The chance of the bread falling with the buttered side down is directly proportional to the cost of the carpet." — Murphy's Law

You can't have everything. Where would you put it?

I bought a self-learning record to learn Spanish. I turned it on and went to sleep; the record got stuck. The next day I could only stutter in Spanish—Stephen Wright

Signs and notices:
On the grounds of a public school: "No trespassing without permission."
Sign in a non-smoking area: "If we see you smoking we will assume you are on fire and take appropriate action."
A hardware store in Oregon has a sign that reads: "Today's special. Below it says: So's tomorrow
Sign seen in London department store: "Bargain Basement Upstairs"

A man was telling his neighbor, "I just bought a new hearing aid. It cost me four thousand dollars, but it's state of the art. It's perfect." "Really," answered the neighbor. "What kind is it?" "Twelve thirty."

INTERESTING ARTICLES

Xtandi Versus Casodex Before Chemotherapy

Interview with Dr. Neal Shore

Prostate Forum Volume 16 Number 10

Dr. Neal D. Shore is the Medical Director for the Carolina Urologic Research Center and the managing partner for Atlantic Urology Clinics. Dr. Shore has conducted more than 1 00 clinical trials.

Prostate Forum spoke recently with him about Xtandi.

PROSTATE FORUM: Let's start with talking about who you are, how you came to focus on prostate cancer, where you practice now and your current research.

DR. NEAL SHORE: I attended medical school and undergraduate training at Duke University. Then I did my General Surgery and Urology training at Weil-Cornell Medical Center and Memorial Sloan Kettering Cancer Center.

I've been in community practice since

1990.Around 1998 or 1999, I was astounded by the many unmet needs in urology: a lack of quality therapeutics, and even devices, to help cancer patients, as well as those with benign enlarged prostate (BPH), urinary incontinence, and erectile dysfunction.

At the time, I was doing a lot of prostatectomies, cystectomies, and nephrectomies. I saw that we didn't really have much in the way of systemic therapies for the patients we couldn't cure with these procedures.

I re-thought my academic experience and discussed these issues with my academic colleagues. I realized that we didn't know very much nor have many options for patients with advanced disease. We had some therapeutics that were in development, but when I spoke with various stake- holders in the pharmacologic and biotech-nology industries, and even within academia, I discovered that they were having a difficult time enrolling patients into early phase trials.

I became more and more interested in recognizing the unmet needs in prostate, bladder, and kidney cancer, especially for patients we weren't able to cure surgically.

At the time, I was ensconced within my clinical practice. Nonetheless, I decided to initiate a Clinical Trials Program in the late 1990s within my practice. Since our inception, we have participated in over 250 clinical trials, many which have led to new drug and device approvals.

Currently, as the director of the Carolina Urologic Research Center, we have nine full-time employees completely dedicated to doing high-quality research, I have completed my Certified Physician Investigator (CPI) certification multiple times.

Translational clinical research has had several significant breakthroughs over the years. There have been 6 new approved CRPC therapies since 2010 on top of the breakthrough of Taxotere {docetaxel) in 2004. We've made great progress in helping patients with advanced prostate cancer live longer and maintain a sound quality of life.

I've found it very rewarding.

What is Xtandi? How is it used in treatment strategies?

Xtandi, also known as enzalutamide, is four pills taken orally. It was developed in Dr. Charles Sawyer's lab with the help of a San Francisco-based company called Medivation. It is subsequently being co-developed, marketed, and researched with Astellas Oncology. They were able to look at the existing androgen receptor and the impact of the first-generation antiandrogens--Eulexin (Flutamide), Nilandron

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(Nilutamide), Casodex (bicalutamide)--and recognized that a more potent androgen receptor blocker was attainable.

Xtandi was formulated to have a much more potent and increased competitive binding effect on the androgen receptor. What differentiates a drug like Xtandi from the earlier generation lutamides is avoidance of the medication transitioning from being a partial antagonist to a partial agonist.

I became involved with the early Phase II Xtandi trials, and then became involved with the first Phase III trial called AFFIRM that led to Xtandi's approval in the post-chemotherapy population. We published those results in the New England Journal of Medicine; I'm proud to be a co-author.

In advanced prostate cancer therapeutics, we tend to investigate the most progressed patients, or patients with the highest tumor burden, because they're the closest to their mortality. Delaying disease specific mortality is the accepted yardstick for regulatory approval.

After the AFFIRM trial was positive, we did three more trials. The PREVAIL trial looked at Xtandi prior to chemotherapy. Those results, which came out this past year, were positive. At the same time, we started the TERRAIN trial, which compares Xtandi to Casodex prior to chemotherapy.

The third trial, STRIVE, looks at Xtandi versus Casodex in patients in the MO and MI pre-chemotherapy disease state.

What are some of Xtandi 's side effects?

Some of the most common side effects that we see, which seem to be consistent through all of the studies, are fatigue, hot flashes, and occasionally mild diarrhea. Elevation in blood pressure has been reported, as well.

TERRAIN just reported, correct?

TERRAIN just reported, but it hasn't presented yet publicly. We've submitted our data to the American Urological Association (AUA). We are hoping to get some additional information on TERRAIN accepted as a late-breaking presentation at the upcoming AUA annual meeting. We also have an abstract submitted to the American Society of Clinical Oncology. I have participated in all of these trials, with the exception of PREVAIL, and have seen my patients whom have benefitted.

Can you talk about TERRAIN's results?

We acknowledge that TERRAIN met its primary endpoint, which was to show a statistically significant increase in the progression-free survival of the Xtandi arm.

TERRAIN was a double blind prospective trial. Those in the Xtandi arm had a median progression-free survival of approximately 15.7 months, whereas the progression-free survival in the Casodex arm was 5.8 months. That is a near 10-month difference with a hazard ratio of 0.44, which translates into a 56% reduction in the risk of progression for those on Xtandi versus those on Casodex. It was highly statistically significant: a p-value of less than 0.001.

What does this mean for patients? TERRAIN merely confirms what we already know about Xtandi.

I think it clearly confirms the activity of the drug. I think it demonstrates Xtandi's superiority in comparison with the earlier generation androgen receptor blocker Casodex.

I think that is the biggest take-home point. The side effect/safety profile appears comparable to the pre-chemotherapy population of the PREVAIL trial.

PREVAIL looked at Xtandi versus a control placebo, whereas TERRAIN compares Xtandi to another drug, Casodex, which clearly has activity. Casodex has been around for over 30 years now. In North America, it is approved at a 50 mg daily dose. In parts of Europe and perhaps in parts of Asia, as well, it is approved at higher dosages.

Is there anything else you think patients should know either about Xtandi?

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It has been a great breakthrough for patients to have an oral agent--four pills once a day. There are no other requirements for any other medications to take with it.

Xtandi is approved now by both the FDA and the EMA, which is the European Medical Authority, to receive Xtandi either before or after chemotherapy once they've developed advanced prostate cancer that is progressing and have had some form of androgen-suppressive therapy.

Xtandi is given in the form of a pill, as opposed to an intravenous or subcutaneous delivery.

The liver clears Xtandi. We will occasionally, like with any patient with advanced prostate cancer, monitor their liver func-tions, but there is no mandatory requirement for regular lab monitoring. Just as with all patients with advanced prostate cancer, we follow other important lab values that reflect disease progression and drug safety.

The pills can be taken with or without food, which gives patients some additional flexibility. If there are any problems with tolerability or lab abnormalities, we can dose reduce and titrate the medication.

Xtandi, along with the development of another oral medication called Zytiga (abiraterone), has been a great breakthrough for patients and their families. It has given patients the ability to take an oral medication daily. It slows down the disease in many patients. It isn't a cure, and we continue to conduct trials of medications to offer alternatives for patients who do not respond to therapy.

In some patients, a small percentage (no more than I 0%), may have initial resistance to Xtandi. We describe this as primary resistance. Eventually, patients develop what may be described as acquired resistance to these medicines. Some develop acquired resistance within a few months, others after a year or longer.

Can we predict who has primary resistance to Xtandi?

We're working on that now with some new biomarker assays. We are looking at different ways of identifying those patients. We've made some breakthroughs, but those assays are not yet commercially available in a large-scale way. They're only available through certain clinical trials. Prior to 2004, we had nothing for anyone with advanced prostate cancer. There was a lot of nihilism: you just threw your hands up and considered palliative measures.

Then there was a great breakthrough with the development of Taxotere (docetaxel) chemotherapy. From 2004 to 20I0, we had a six-year hiatus.

Suddenly, from 20IO to today, we've developed two oral medications in the form of Xtandi and Zytiga, an immunotherapy Provenge (sipuleucel-T), another chemotherapy drug Jevtana (cabazitaxel), and a radio pharmaceutical Xofigo (radium-223). We now have five new therapies on top of Taxotere that are life-prolonging, which is really quite remarkable.

There are another half a dozen therapies in development--targeted oral agents, immunotherapies, other chemotherapies--to add to this really impressive armamentarium of approval in a very short period of time.

Are there any other areas of research that you're particularly excited about?

I've been very involved in the last couple of years in looking at new kinds of genetic biomarkers to help us better understand who should undergo a biopsy in the first place.

I've also been doing work with other biomarkers to try to understand how we can avoid doing a series of repeat biopsies in those with an initial negative biopsy. We'd like to be better about avoiding unnecessary biopsies by improving our sensitivity and specificity.

Other genomic assays I've worked on aim to identify after diagnosis the aggressiveness of a man's disease. We know that almost 40-50% of patients probably have a very slow-growing, or what we describe as indolent, form of the disease and could potentially be safely actively monitored in active surveillance.

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On the other end of the spectrum, we have another 50-60% of patients who may have a more aggressive form of prostate cancer that, if not treated, could ultimately spread and develop into metastatic disease. I've been doing a lot of work with these genomic assays. Eventually, it will give us an ability to be more precise based upon individual patients' molecular biology. We will be able to be more precise as to whom we test. And then, once we find disease, we'll be able to be more precise about whom best to treat or not to treat. I think we also need to do a better job of combining and sequencing these newly approved therapies so that we understand which patients would be best served. We still need to do a lot of work in aggressively treating patients diagnosed with high-risk disease.

Lastly, we still have 30,000 men who die of cause-specific prostate cancer every year, despite the new breakthroughs we just discussed. I think anyone who is involved in genitourinary oncology, whether he or she is a urologist, a medical oncologist, or a radiation oncologist, would like to decrease the actual cause-specific mortality.

Prostate cancer is number two, right after lung cancer, for cancer-related mortalities in North America. I sometimes say to my patients, "I'd like everyone to die a natural death of old age," which is really a euphemism for a cardiovascular event.

People are living a lot longer now because of better cardiovascular healthcare. The average American male is living longer. Those who have an aggressive form of prostate cancer have a longer time to develop complications of higher tumor burden. I 'm seeing patients in their 80s who are dying of advanced prostate cancer, but not cardiovascular processes.

We have some amazingly talented basic science researchers who are unraveling the molecular pathways and the mutations and aberrations that occur amongst individual patients and during therapies. It's an exciting and promising era for prostate cancer research.

Robot, Robot, Burning Bright …

Posted: 07 Apr 2015 from Prostate Snatchers Blog

By RALPH BLUM

If you have read some of my previous blogs you probably will be aware that I am not an advocate of radical prostatectomies in any shape, way or form. But since the robot-assisted laparoscopic prostatectomy (RALP) is the flavor of the monthwith both prostate cancer patients and their urologists, it seems pertinent to zero in on some of the information you need to know if you are considering this procedure.

There is something alluring about the idea a surgeon sitting at an attached console and manipulating a robot's mechanical arms to perform this highly complex and intricate operation. But if you are under the impression that it is the robot making those small incisions in your abdomen to perform the operation, think again. It is the skill of the surgeon that will preserve (or not) your sexual function by avoiding damaging the miniscule nerves that run along each side of the prostate and control erections. It is the surgeon's experience that will (or not) protect the sphincter that allows you to retain urinary control. And it is the surgeon's expertise that will ensure a positive, long-term outcome.

RALP has advantages over other forms of radical prostatectomy in terms of pain, blood loss, and recovery time. No small thing. But keep in mind that any complex surgery comes with risks: the small risk of heart-attack, stroke, blood clots in the legs that could travel to the lungs, reactions to anesthesia, and infection of the incision sites. And because there are many blood vessels near the prostate gland, there is also the risk of prolific bleeding, in which case blood transfusions might be necessary—which carry their own risk. But your risk level depends primarily on your overall health, your age, and the skill of your surgical team.

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Having said that, I realize how tempting it is to go for closure. But is surgery—robotic- assisted or otherwise--really closure? Statistics show that is debatable. And in terms of the side-effects that most men are concerned about (urinary incontinence and impotence) there is little difference between robotic -assisted surgery and laparoscopic surgery performed without the robot. Bottom line, the most important factor with either procedure is the surgeon's experience and skill.

Opinions differ about how many robotic-assisted operations a surgeon needs to perform to become really proficient, but surgeons at community hospitals rarely have sufficient experience. And you do not want to be part of a surgeon's steep learning curve. Dr. Vipul Patel, of the Global Robotics Institute in Celebration, Florida, appears to be leading the pack having performed some 8,000 robotic prostatectomies.

It's apparently hard to resist the lure of a robot. But any kind of radical prostatectomy is both costly and risky, so don't let your natural desire for closure blind you to the risks of such a challenging surgery—especially if you are 70 or over. In fact if you have low-risk prostate cancer and are over 65, you have a 20% chance of dying of cancer in the next 20 years compared to a 60% chance of dying of something else. So buyer beware!

Malecare is partnering with the University of Minnesota on an exciting new study. The Restore study, funded the National Cancer Institute at NIH, is looking at how prostate cancer treatment affects gay and bisexual men, our life and sexual partners, and our family and friends who provide care for us during treatment.

As a thank you, all participants will receive a $50 Amazon gift card for a 60-90 minute telephone interview.

One focus of this study is on how different types of treatment affect sexual functioning and gay relationships. The researchers need this information to design better treatments for the sexual and relationship effects of prostate cancer treatment.

The study is in two parts. Right now, we want to interview (by telephone or online chat) men living in the US about your experience during and after treatment. We want to interview some partners and caregivers. Later this year, you will receive an email inviting you to complete an online survey. We are hoping this will be one of the largest and most comprehensive studies of gay and bisexual men with prostate cancer ever conducted.

To learn more or to see if you are eligible, please click here:
https://umn.qualtrics.com/SE/?SID=SV_87cqEE3rPF9tTeZ

For the interviews, the researchers particularly want to hear the experience of:

- Gay, bisexual and other men who have sex with men who received different kinds of treatment for prostate cancer
- African/Caribbean American gay and bisexual men treated for prostate cancer
- Single gay/bi men treated for prostate cancer (about dating and/or sex after treatment)
- Success stories: Anyone who has successfully restored their sexual functioning after prostate cancer treatment (particularly if you have strategies to share).
- Partners of gay and bisexual men with prostate cancer. This is the first study in the world to examine the effects of prostate cancer in partners/husbands/boyfriends.

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- Caregivers. This is the first study of caregivers of gay/bi men with prostate cancer. (The focus of the caregiver interviews is not on sex, but about the experience of helping gay/bi men with prostate cancer through treatment).

Please agree to be interviewed. Also, if you have a partner (or ex-partner) or caregiver who could help, please forward this email to them. To learn more, please go to www.restorestudy.umn.edu; call toll free 1-844-262-9845; or email: restorestudy@umn.edu.

Thank you for considering this invitation.

Please feel encouraged to email your questions or comments to me at darryl@malecare.org

Darryl
Darryl Mitteldorf, LCSW
Executive Director
Malecare
Men fighting cancer, together

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 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://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.

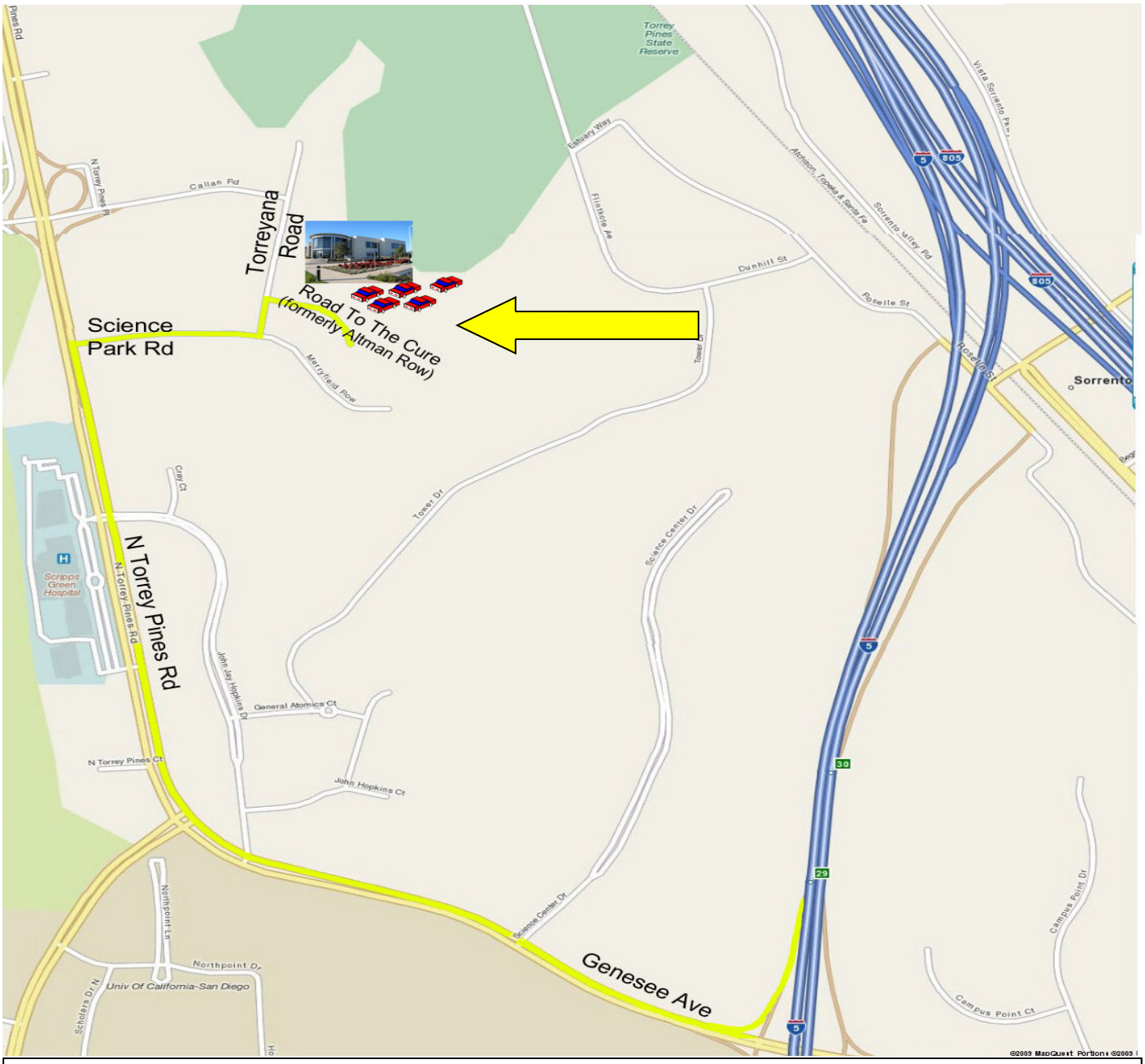
Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them

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).