Informed Prostate Cancer Support Group Inc.

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

March 2013 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Sunday, March 03, 2013 Volume 6 Issue 1

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
Robert Keck, Librarian
Bill Manning
E. Walter Miles
Jerry Steffen

Next Meeting March 16th 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!!

Table of Contents

Editor: Gene Van Vleet

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

The February meeting included presentations by three men about their experiences in dealing with prostate cancer. Afterwards the group broke up into sub-groups by preferred treatment type for further networking.

The experiences of the men are recapped here. If you wish to contact any of them for further discussion, contact Gene Van Vleet (619-890-8447). You can also get the full details on the DVD of the meeting which is available in the library or from our website: ipcsg.org by clicking on the Purchase DVD

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.

(Continued from page 1)

button on the home page.

Mike Brekka is 54 and had his first biopsy (random) in August, 2011which indicated he needed to take action. His Gleason score was 4+3=7. He researched the many options and talked to 14 different doctors, nurses and practitioners as well as attending IPCSG meetings—all within a 90 day period. Lyle LaRosh of IPCSG encouraged him to see Dr. Duke Bahn in Ventura to get a Color Doppler Ultrasound (CDUS) analysis of the condition of his prostate. From the information provided by the CDUS, Dr Bahn did 4 targeted biopsies that clearly identified the location of his cancer. He recommended radiation treatment because the cancer was very near the lower sphincter which surgery would likely damage and cause incontinence. (Editor's Note: Mike had very informative slides of his CDUS and treatment cycle which can be viewed on the DVD of this meeting-- available through the website or the library). Additionally, he did bone scans and CT scans to ensure there was no involvement outside the prostate. Mike opted for image guided radiation therapy treatment with Dr. A.J. Mundt of UCSD. In November 2011, 4 months prior to the beginning of radiation treatment, he began androgen deprivation treatment (2 successive three month shots of Lupron) to knock down the growth of cancer prior to the initiation of treatment. His PSA at that time was 8.05. He pointed out that before radiation treatment was started in February 2012, they made use of the CDUS images to map out the target area. His PSA at that time was 0.1 and his testosterone was 8. He underwent 9 weeks of treatment which ended in April 2012. His testosterone levels recovered in about 4 months after his last shot. His PSA has remained low with a slight uptick on his last test which could be only a testing differential but if it begins rising he is comfortable that with the new imaging techniques such as carbon 11-acetate, any problem area can be located for treatment.

Ken Martone, age 65, was first diagnosed in September 2011 in the manner often followed. His primary care physician advised him his PSA was 4.2 and referred him to an urologist who promptly performed a random biopsy. Cancer was found in 3 of the 12 core samples. The resulting Gleason score was 3+3=6 and he was told he was on the edge to consider active surveillance. In November 2011 he chose to pursue active surveillance. He did a follow-up biopsy in March 2012 which changed from a 3+4=7. He then sent his original biopsy slides to Johns-Hopkins for verification who reported that they were in fact 3+4+7 not 3+3=6. This is an important lesson for newly diagnosed. It is advisable to have your initial biopsy scores verified. Ken did a lot of research on his own and also joined our group to further his knowledge. Ken consulted local doctors about radiation and surgery but after reading Dr. Scholz's book Invasion of the Prostate Snatchers obtained from our library, he decided to make an appointment with him. A CDUS was performed by Dr. Scholz which gave Ken a clear idea of the involvement and location of his cancer. Dr. Scholz also referred him to UCLA for a prostate specific MRI to help further confirm the status of his cancer. After further research and consultation with Dr. Scholz, Ken decided to do seed implant brachytherapy. He learned that Dr. Peter Grim in Seattle was the most prominent doctor in this therapy and opted for that treatment. 124 radioactive seeds were implanted into his prostate. He spent only 3 days in Seattle for the procedure. One day before in preparation, one day for the procedure, another day of rest after which he was able to come home. The procedure was done at the beginning of August 2012. Six months later his PSA was 2.26. Concerned about the target of .2 to .5 for this type of procedure, he learned that the range of time to reach the optimum could be 2 years because cells are still dying even though the radiation was expended. He reported that he now arises twice a night for urination compared to once before. Using 5mg Cialis daily, he is happy with his erectile function. In closing, Ken emphasized the benefit of becoming his own case manager and the knowledge derived by networking with our group.

(Continued on page 3)

(Continued from page 2)

Tony Dente, age 74, first realized he had a problem in 2001. While on a cruise he decided to try scuba diving and in the effort to put on the wet suit felt it necessary to urinate 3 times. Immediately upon return, he visited an urologist and was diagnosed with metastatic prostate cancer which had spread to the lymph nodes. A year before, his PSA was 2.3 and his Gleason score was now 7. He initially consulted with Dr. Israel Barken who assured him he had plenty of time to research and make treatment decisions. With the assistance of his wife he did a lot of research and realized that he had ignored five basic symptoms of prostate cancer--frequent urination at night, lower back pain, burning sensation when urinating, burning sensation when ejaculating and a small amount of blood in the urine and semen. A relative and her friend who were fighting breast cancer told him of herbs prescribed by a doctor in Mexico. He used the herbs and a prescribed diet from 2001 to 2010. His PSA had risen to 4.2 and fell to undetectable during this period. In 2010 he again began experiencing very frequent night urination—as many as 8-10 times a night. He joined our support group, heard of Dr. Lam of Prostate Oncology Specialists and became a patient of him. A CDUS was performed that showed this prostate was very large. It was recommended that he start androgen deprivation therapy (ADT) with Zytiga (abiraterone) and prednisone but in order to qualify, he first had to do two infusions of chemotherapy. His issues with incontinence continued. The cancer was in his bones and lymph nodes. In June 2011 he underwent the new Provenge therapy which is a system of purifying and strengthening blood to enhance ones immune system. Unfortunately there is no way to verify the effectiveness of this treatment because it has no effect on PSA. In February 2012 he began chemotherapy (Jevtana) plus Xgeva shots to strengthen his bones. He did 4 infusions of chemo then took a rest. All the while he continued his fitness schedule playing tennis regularly. In December 2012 he began chemo again. His doctor is confident that new treatments will become available should chemo stop working adequately. Tony left us with good words of advice. Stay mentally active, stay physically active and make plans for the future.

Future Meetings

March 16. Dr. Carl Rossi, Medical Director of the Scripps Proton Therapy Center. New Scripps facility for proton beam therapy in relation to prostate cancer.

April 20 - Networking. Presentations by a few members' experiences followed by break-out sessions by treatment type.

May 18. Dr. Richard Lam, Prostate Oncology Specialists.

On The Lighter Side

"The way to achieve inner peace is to finish all the things you have started and have never finished." So, I looked around my house to see all the things I started and hadn't finished, and before leaving the house this morning, I finished off a bottle of White Zinfandel, a bottle of Bailey's Irish Cream, a package of

(Continued on page 4)

(Continued from page 3)

Oreos, the remainder of my old Prozac prescription, the rest of the cheesecake, some Doritos, and a box of chocolates, and a half bottle of scotch. You have no idea how good I feel right now.

So… a guy goes into a bar and in front of the bartender on the counter is a tiny little man playing a tiny little piano. "That's neat. Where did you get that little fellow?" he asks the bartender. "There's a Genie in the closet over there that will grant your wish," the bartender replies. The customer goes over to the closet and when he comes out a million ducks start falling from the sky. "Hey, what's up with that Genie of yours? I asked for a million bucks, not ducks," the customer says. "Well duh?" the bartender says. " You think I made a wish for a 12 inch pianist?"

IDIOT SIGHTING—I was at the airport, checking in at the gate when an airport employee asked, 'Has anyone put anything in your baggage without your knowledge?'
To which I replied, 'If it was without my knowledge, how would I know?'
He smiled knowingly and nodded, 'That's why we ask.'

NOTEWORTHY ARTICLES

Sexuality and Intimacy after Prostate Cancer Treatment
BY MARK SCHOLZ, MD

Posted: 26 Feb 2013 06:03 PM PST from Prostate Snatchers Blog

My life is turning into an evangelistic crusade to raise awareness about the risks of prostate cancer treatment. Tens of thousands of men are undergoing unnecessary radical prostate cancer therapy with dire sexual consequences. These inappropriate and often fatefully wrong treatment choices are made because men are often completely unaware of the irreversible effects of the treatment itself.

Thankfully, I am not alone in this battle to inform men about the harm associated with prostate surgery. Another prostate oncologist, Dr. Celestia Higano from the University of Washington, recently published a scientific review on this very topic in the Journal of Clinical Oncology (JCO). For those of you who haven't heard of the JCO, I consider it to be the most prestigious scientific cancer journal in the world.

Today's blog will offer quote seven selected sections from Dr. Higano's important article. To add some gravitas to the eye opening statements you are about to read, please realize that every one of her comments was referenced to a specific scientific report. In other words, these statements have nothing to do with opinions. They are genuine outcomes from published scientific studies.

So without further ado let's start with the first quote from the article:

Quote #1: "Unfortunately, many couples believe that even if they have problems with erectile dysfunction (ED) … they will be able to resume their normal sexual practices through the advances of modern technology.[4] They are not informed that *sexual function will never be the same* after any form of therapy and they are often unprepared for the changes in their sexual and intimate relationship." (Italics mine)

Quote #2: "PDE5 inhibitors (Viagra, Cialis) and other erectile aids are not successful for all patients with ED and, even when effective, half the patients stop using them within one year.[11] Why couples stop using ED therapies has not been adequately investigated , but disappointment that sex life is not the same … likely contributes to this outcome."

Quote #3: "In a Memorial Sloan-Kettering series of 475 men … 20% of men who had radical prostatectomy (RP) had climacturia at one year, and climactauria as associated with both painful orgasm and penile shortening.[13]" (*Climacturia* means that orgasm results in the ejaculation of urine instead of semen).

(Continued on page 5)

(Continued from page 4)

Quote #4: "At the Karolinska Institute, 1,288 patients had either open or robotic-assisted laparoscopic RP, and of the 691 men who were sexually active, 38% reported climacturia at least sometime during sexual activity. Of the men who reported climacturia, 72% had climacturia less than half the time, 17% more than half the time, and 11% all the time.[14]"

Quote #5: "In a review of 1,459 men who had RP at New York University, climacturia was found to decrease from 44% at 3 months to 22% at 24 months after surgery. Climacturia is a common complication of RP but is often overshadowed by concerns about ED and overt urinary incontinence.[14-16]"

Quote #6: "In a study of VED (vacuum erectile device) use after RP, the length and circumference of the penis decreased in 63% of patients who did not use a VED after RP compared with only 23% who did.[18-20]"

Quote #7: "Surgery can also result in Peyronie's disease (also called, "crooked penis") in up to 16% of patients.[23]"

When patient are informed of the dire consequences of surgery they are often mystified as to why urologists, who must be aware of the damage surgery causes, continue vigorously to recommend it. I have heard many patients voice the opinion that urologists are driven by a selfish desire for financial gain.

The financial motive, however, fails to ring true. As medical procedures go, prostate surgery is poorly reimbursed. Also, when urologists are diagnosed with prostate cancer they themselves often proceed with a radical prostatectomy. So money is not the primary issue. Rather, consider that performing surgery is part of the very fabric of a surgeons' persona. From a surgeon's point of view, *if you are not operating, you are not a surgeon*.

Men considering surgery for prostate cancer need to be aware of its substantial risks. And when getting advice about which treatment to select, patients also need to realize that surgeons usually can't provide balanced advice. They are too close to the trees to see the forest.

How Is Prostate Cancer Measured

Reprint from Zero News

Men diagnosed with prostate cancer often ask, how is prostate cancer measured? The most commonly used system to measure prostate cancer is the American Joint Committee on Cancer TNM system. This approach helps physicians and patients monitor and treat prostate cancer. Here's an answer to how prostate cancer is measured.

Prostate Cancer Stages

The TNM system is based on five factors.

"T" refers to tumor. Experts have assigned a number from 1 to 4 to describe how far the tumor has developed based on a digital rectal examination (DRE). The higher the number, the more the tumor has developed. For example, when looking at how is prostate cancer measured:

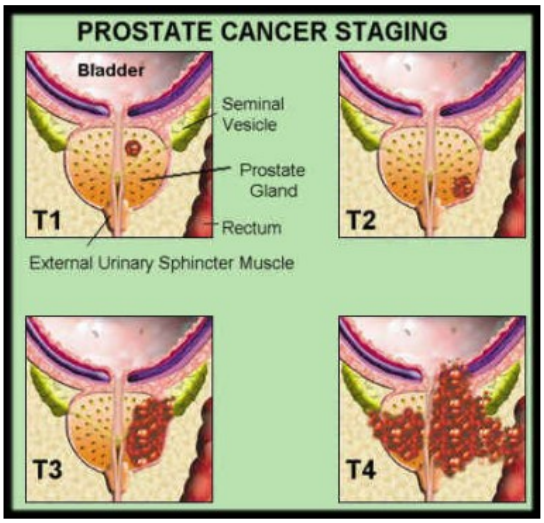
T0 means there is no evidence of a prostate tumor

T1 means the prostate tumor cannot be felt by the physician during a DRE or viewed using diagnostic imaging. However, the tumor may have been discovered during a prostate biopsy or surgery for an enlarged prostate.

T2 means the physician felt the tumor during DRE, but believes the cancer is limited to the prostate gland. There are subdivisions within T2: T2a means the tumor involves half or less of one side of the prostate; T2b means the tumor affects more than half of one side only; and T2c means the tumor has affected both sides of the prostate gland

T3 means the prostate tumor involves the prostate capsule and may also affect the seminal vesicles. The seminal vesicles are a pair of organs that secrete fluid that is part of semen. T3a means the tumor has reached beyond the prostate capsule but has not affected the seminal vesicles. A T3b tumor has extended to the seminal vesicles.

T4 designates a tumor that has invaded other structures (other than the seminal vesicles), such as the rectum, pelvic wall, or bladder.



(Continued on page 6)

(Continued from page 5)

"N" refers to whether the prostate cancer has spread to the lymph nodes. An N0 designation means the cancer has not advanced, and an N1 means it has reached one or more lymph nodes in the pelvic area.

"M" refers to metastasis, which is the spread of the cancer to areas beyond the prostate gland. A designation of M0 means the cancer has not spread, while M1 means it has extended beyond the prostate to the bones or other sites. Within this category, M1a means prostate cancer has spread to lymph nodes; M1b means cancer has reached the bones; and M1c means prostate cancer has spread to other organs, with or without involving the bones.

The other two components of the TNM system are the PSA level at the time prostate cancer is diagnosed, and the Gleason score, which is based on the findings of the prostate biopsy or surgery. Generally, a PSA level of greater than 4 ng/mL is considered an indication a prostate biopsy should be done. The Gleason score can range from 2 to 10, and the higher the number, the poorer the prognosis. For example, scores of 2 to 5 indicate low-grade prostate cancer; 6 to 7 are intermediate prostate cancer; and 8 to 10 is an indication of high-grade prostate cancer.

When doctors combine all this information, they have a better indication of how prostate cancer is measured and a patient's prognosis. Generally, there are 4 stages of prostate cancer:

Stage I prostate cancer is limited to the prostate and usually grows slowly. The Gleason score is 6 or less and the PSA is less than 10.

Stage IIA and IIB prostate cancer are cancers that cannot be felt or detected on imaging tests. Although prostate cancer has not spread beyond the gland, the cells are typically somewhat abnormal and may grow more rapidly than normal cells. For stage IIA, PSA levels are higher than 10 and Gleason scores are 6 or less, or PSA is less than 20 and the Gleason score is 7. For stage IIB, the Gleason score can be anything and the PSA level is greater than 20, or the Gleason score is 8 or greater regardless of the PSA level.

Stage III describes prostate cancer that has spread beyond the prostate to adjacent tissues and possibly to the seminal vesicles. Men who have reached this stage of prostate cancer can have any Gleason score and PSA level.

Stage IV is prostate cancer that has spread to other parts of the body, including the lymph nodes, liver, and bones. The Gleason score and PSA level can be at any figure.

Recognizing and understanding how prostate cancer is measured can help patients and their healthcare providers make better decisions about how to treat the disease. Be sure to ask your healthcare provider questions about how prostate cancer is measured so you can then tackle choosing your treatment for prostate cancer.

Managing the side effects of ADT — a new review

From Prostate Cancer Info Link Posted on February 27, 2013 by Sitemaster

According to a new analysis and review of recent, published data, the "numerous well recognized adverse effects" of androgen deprivation therapy (ADT) include "vasomotor flushing, loss of libido and impotence, fatigue, gynecomastia, anemia, osteoporosis and metabolic complications, as well as effects on cardiovascular health and bone density."

Conversely, of course, ADT has many well-recognized benefits when used in appropriate patients, and numerous trials have documented the benefits of ADT — alone and in combination with other forms of treatment.

Ahmadi and Daneshmand (of the USC Institute of Urology, USC/Norris Comprehensive Cancer Center at the University of Southern California) carried out a PubMed database search of all prospective clinical studies published between 2000 and 2012, including randomized and non-randomized clinical trials and meta-analysis studies concerning preventive and therapeutic interventions for the various side effects of ADT. They then used the highly regarded Oxford 2011 Levels of Evidence classification system to categorize selected studies according to the projected treatment benefits of the different possible interventions.

Here are their core findings:

- The drug gabapentin appears to have moderate efficacy for the long-term treatment of hot flashes.
- Combined resistance/aerobic exercise programs can lead to significant improvement in fatigue, sexual function and cognitive function.
- Home-based and/or group exercise programs can also improve fatigue and unfavorable metabolic changes.
- The drug denosumab can increase bone mass density in the lumbar spine, hip, and radius, reduce risk for vertebral fractures in men receiving ADT for non-metastatic prostate cancer.
- The drug metformin, when used in conjunction with lifestyle interventions is a safe, well-tolerated intervention for adverse metabolic changes.
- The drug toremifene can be used to improve patients' lipid profiles.
- Intermittent ADT improves early side effects, such as hot flashes, sexual activity, fatigue, and quality of life, although its effect on long-term side effects remains inconclusive.

The authors are, however, careful to add the following statement, with which The "New" Prostate Cancer InfoLink is in complete concurrence:

Despite significant improvement in management strategies for the side effects of ADT, the best way of preventing side effects is to use ADT only when it is absolutely indicated.

We have long felt that the greatest risk associated with the clinical application of ADT is when it is used too early — i.e., to manage PSA levels as opposed to actually managing real clinical issues — or for longer than it is actually needed.

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

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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.

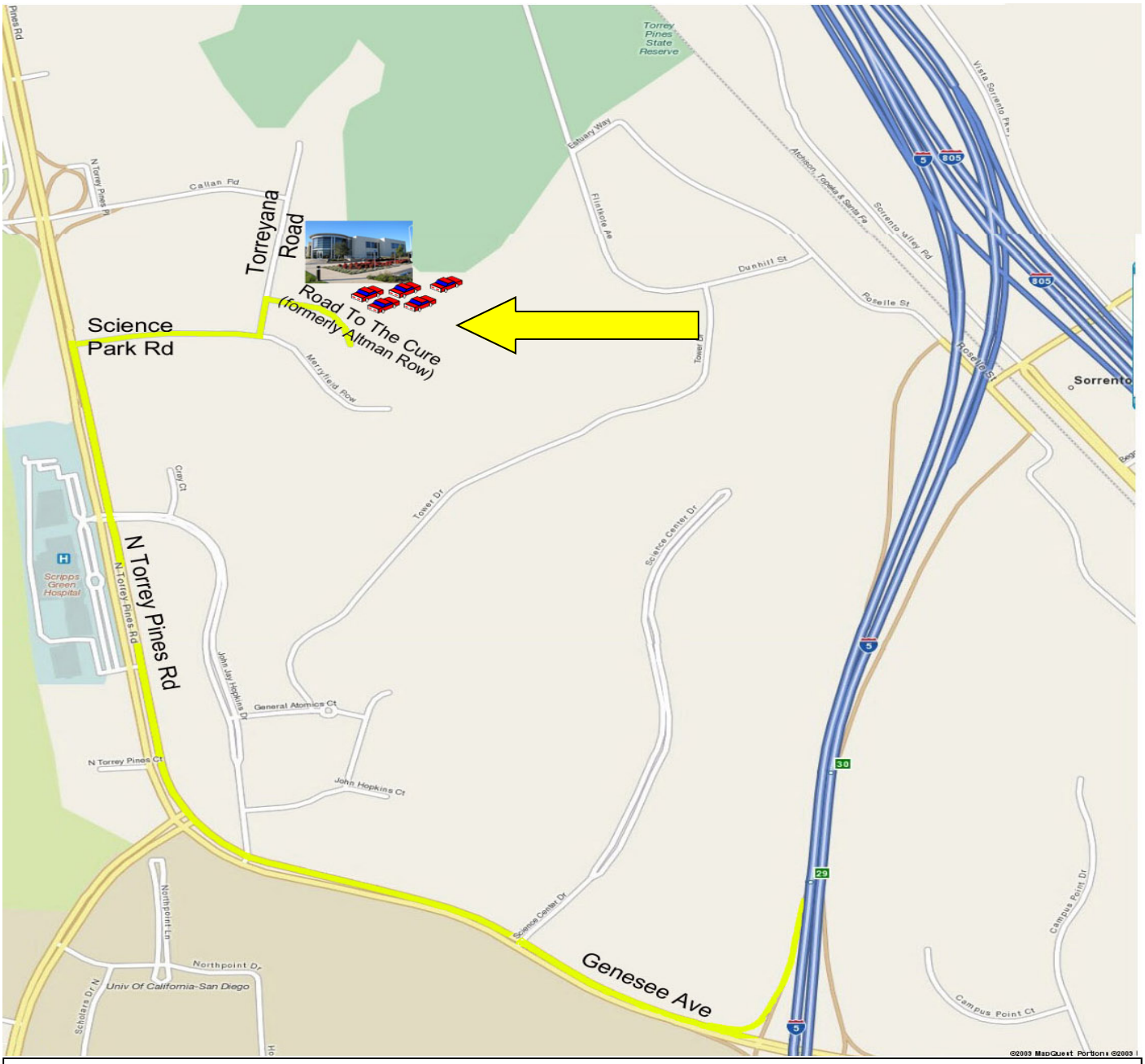
Anyone interested please contact:
Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org
Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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).