Informed Prostate Cancer Support Group Inc.

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

August 2012 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: www.ipcsg.org

We Meet Every Third Saturday (except December)

Monday, August 13, 2012 Volume 5, Issue 7

Officers

President: Lyle La Rosh,

Vice President : Gene Van Vleet

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George Johnson

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Next Meeting August 18th 10:00AM to Noon

Meeting at

Sanford-Burnham Auditorium

10905 Road to the Cure, San Diego CA 92121

SEE MAP ON THE LAST PAGE

What We Are About

Our Group offers the complete spectrum of information on prevention and treatment. We provide a forum where you can get all your questions answered in one place by men that have lived through the experience. Prostate cancer is very personal. Our goal is to make you more aware of your options before you begin a treatment that has serious side effects that were not properly explained. Impotence, incontinence, and a high rate of recurrence are very common side effects and may be for life. Men who are newly diagnosed with PC are often overwhelmed by the frightening magnitude of their condition. Networking with our members will help identify what options are best suited for your life style.

Be your own health manager!!

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Editor: Gene Van Vleet

JULY 2012 MEETING NOTES

The July meeting was well attended with 102 participating of which 12 were newcomers.

Our guest speaker was Dr. Franklin Gaylis, Medical Director of Genesis Healthcare Partners who focused his comments and advice on active surveillance and on advances in management of recurrent prostate cancer.

Active Surveillance (AS) is a controversial subject. A majority of men diagnosed with prostate cancer are older than age 65 years and have low to intermediate risk disease. 90% of these patients will undergo active treatment that is unlikely to extend their life span, in contrast to

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.

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younger patients or those with higher-risk disease, thus the unnecessary treatment of non-threatening disease appears to be most common in older men. The challenge is to separate who has low risk disease, who has intermediate risk disease and who has high risk disease. PSA screening has led to increased detection of indolent prostate cancer which is unlikely to progress or affect the patient. In the era of screening prostate cancer, about 50% are considered to have low risk diseases which pose a low risk to longevity and quality of life within 10-15 years of diagnosis. Most men who die during AS die from other causes. Active Surveillance is an alternative to immediate intervention (usually surgery or radiation) that involves careful follow-up with the option of delayed treatment at a time when intervention will prevent harm from disease. It requires careful follow-up with clinical enhanced (DRE), biochemical (PSA), imaging such as dynamic contrast (DCE-MRI) and pathological (biopsy) tests. About 30-40% of those men on AS will require some form of treatment in their lifetime. On the brighter side, the mortality rate of men with low risk disease is less than 3% at 10 years. Dr. Gaylis is actively pursuing through his Genesis group, Scripps and Sharps to achieve a consensus on protocol for AS.

Suggested is:

- Stage T1C (Nothing felt at DRE exam)
- Gleason score 6
- No more than 2 positive cores and no individual core with greater than 50% cancerous
- PSA density <0.15ng/ml/cc which looks at the size of the prostate in relation to the PSA level

When to Subsequently Treat:

- Patient Request
- Increased tumor volume or aggressiveness determined clinically by DRE, MRI or PSA progression and pathologically by progression through follow up biopsies of Gleason score to >7 and progression to > 2 involved cores.

Active Surveillance is a reasonable management strategy for men with low risk prostate cancer who have long life expectancy; however they tend not to accept this form of therapy despite evidence of its efficacy and safety.

Dr. Gaylis then focused his presentation on advanced prostate cancer which he defined as biochemical failure subsequent to primary treatment (most commonly surgery or radiation), androgen sensitive metastatic disease or castrate resistant prostate cancer (CRPC) which has previously been termed hormone refractory or androgen independent. Life extending treatment options for advanced prostate cancer include:

Immunotherapy which activates a patient's own immune system to seek out and attack PCa. Provenge (sipuleucel T) is the notable agent which stimulates the immune system to combat the growing tumor. It is best used in early stages of the disease after failing ADT. Its drawback is that there is no typical evidence that it is working, such as reduction of PSA or metastasis. However, it has been proven to extend life.

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Hormone therapy which blocks male hormones such as testosterone that prostate cancer cells need to grow.

First line hormonal treatment (LHRH) agonists and antagonists are treatments that dramatically drop the testosterone to very low levels. They include Leuprolide (Lupron) and Degaralix (Firmagon). Lupron is an agonist which means it binds to the receptor causing a rise in testosterone for 3 weeks and then shuts it off. Firmagon is an antagonist which means it binds to and blocks the receptor quickly.

Novel treatments such as Casodex, Nilutamide and Flutamide which are anti-androgen agents that bind to the receptor and block It for a while but can stimulate it which can cause the PSA to increase, but when you take it away, the PSA comes down. The new treatment nearing approval is MDV3100 (enzalutamide) which just blocks the receptor and does not stimulate has high promise. It lowers PSA and is showing that it reduces the disease in some patients.

Second line hormonal treatment agents are another type of testosterone lowering medication which affects prostate tumors that are growing despite first line hormonal treatment e.g. Lupron and Casodex. Abiraterone (Zytiga) has been recently approved which blocks another enzyme that comes from the adrenal gland. Patients on this medication must be monitored closely to alleviate possible side effects. It is necessary to supplement this treatment with low dosage prednisone.

Chemotherapy includes chemicals to improve overall survival and reduce pain. They include Taxanes, Jevtana and Docetaxel. Not being within his area of expertise, Dr. Gaylis did not further comment on this area.

Dr. Gaylis closed with a brief discussion of bone health. When you take away testosterone bone growth is inhibited. There are two forms of Denosumab; Prolia which improves bone mineral density which reduces fracture and Xgeva which reduces time to skeletal related events or fractures. He strongly cautioned that these two drugs should not be taken together. Zometa (an infusion) also improves bone health.

Dr. Gaylis opened his presentation for general questions and very generously stayed to respond to all. **A lot of cutting-edge detailed information was included in this presentation. You are encouraged to get a copy of the DVD of this meeting from our library or through our website:** www.ipcsg.org

Future Meetings

August 18 . Dr. John Grimaldi, D.O. Subject: Newest techniques in treating impotence and incontinence. www.grimaldiurology.com

September 15. Information Exchange. A few selected members will talk of their experience after which sub-groups by treatment type will network.

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

NOTEWORTHY ARTICLES

A Landmark Study: Surgery for Prostate Cancer

Posted: 31 Jul 2012 06:19 PM PDT prostatesnatchers

BY MARK SCHOLZ, MD

Between in 1994 and 2002, 731 men with an average PSA of 7.8 and age 67 volunteered to have either immediate surgery or observation based on a coin flip. The New England Journal of Medicine reported the 10-year survival statistics this week. What follows is a summary of the statistical outcome of the study. I think the raw numbers speak for themselves.

Of the 364 who had surgery, 21 men died of prostate cancer. Of the 367 assigned to observation 31 men died of prostate cancer. So with observation, the risk of dying was less than 9%. However, there was still a 6% chance of dying even with immediate surgery. The net difference between observation and immediate surgery was 3%.

During the first 30 days after surgery there were a number of very serious side effects including one death. Additionally, there were two men with blood clots in their legs, one stroke, 2 with blood clots in the lungs, 3 heart attacks, 1 man with renal failure requiring dialysis, 10 who required additional corrective surgery, 6 who required additional blood transfusions and 6 who still had urinary catheters more than 30 days after surgery.

Forty-nine men (17%) who had surgery compared to 18 men (6%) who underwent observation "have a lot of problems with urinary dribbling," some losing larger amounts of urine than dribbling but not all day," others who "have no control over urine," and the remainder who "have an indwelling catheter."

Two hundred thirty one men (81%) who had surgery compared to 124 men (44%) who underwent observation had erectile dysfunction defined as the inability to attain an erection sufficient for vaginal penetration.

Further statistical analysis of a subgroup of men with High-Risk prostate cancer indicated an 8% improved chance of not dying of prostate cancer compared to observation. Also, men who had surgery who were in the Intermediate-Risk or High-Risk category were 10% less likely to develop bone metastases within 10 years compared to the men on observation.

There was no difference in the incidence of mortality or metastases between surgery and observation in the men in the Low-Risk category.

This high-quality study, published in the most prestigious medical journal in the world evaluating the risks and benefits of surgery, required 18 years to perform. It shows a barely discernible benefit resulting from immediate surgery for men with High-Risk prostate cancer. These findings are quite similar to another large randomized trial of surgery versus watchful waiting that reported 15-year results in the New England Journal of Medicine in May 2011.

The bottom line is very clear: For men with Low-Risk disease, where surgery is concerned, the treatment is definitely worse than the disease. Even more striking, is the relatively small survival benefit for surgery in men with High-Risk disease. One can't help but wonder if the substantial risks of immediate treatment-related side effects outweigh the small benefit in survival.

Prostate Cancer Screening: Ready for a Comeback?

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From The Atlantic July 30, 2012

The newest data says that abandoning PSA screening for prostate cancer would be a huge step backwards, going against the increasingly anti-PSA conversation of late.

It started in 1987, with the introduction of the prostate-specific antigen (PSA) blood test. Six years later, an Atlantic story on this revolutionary innovation contextualized its importance:

For many in the field the PSA test changed everything. Simple to perform, not hugely expensive, free of embarrassment and discomfort, it seemed to provide doctors with a way to detect prostate trouble early and accurately. If the PSA level jumped, the next step would be a biopsy - a more unpleasant and costly business, but one justified by the potential gravity of the situation. If the biopsy indicated cancer, a surgeon might be called in. The operation, called a radical prostatectomy, removes the prostate and thus the source of the problem. If performed before the carcinoma spreads, surgery is often successful, in that it ends the threat from cancer. But the procedure is dangerous - it may kill up to one out of a hundred patients outright - and fraught with possible side effects, such as impotence and incontinence. Even so, physicians reasoned, quick detection of prostate cancer would save thousands of people from awful deaths every year.

That was 1993, and the optimism of the PSA test's early years was already beginning to wane. The very person responsible for developing the screening procedure, Normal Yang, told The Atlantic that he regretted his own innovation:

"It's gone out of control," he says. "People don't know what they're doing, and it's going to be a terrible mess. I feel sick about it. It's a disaster for the healthcare system - a horrible disaster. We've rushed ahead and created a nightmare."

Since then, the debate over whether PSA screening is helping or hurting has raged, but it continued to be used widely. The test, some have argued, is not accurate enough, and it does nothing to decrease the death rate. The evidence showed that 48 patients would need to undergo radical prostatectomy -- enduring not just the risks of the operation, but the potential subsequent effects -- in order to save one life.

In 2011, the U.S. Preventive Services Task Force definitively recommended against PSA screening in all men.

But they hardly had the final say in the matter. Earlier this month, the American Society of Clinical Oncology weighed in with its own cost-benefit analysis. Although it maintained that general screening should be discouraged, the ASCO recommended that physicians discuss the risks and benefits of the PSA test with men who have a life expectancy of greater than ten years.

Today could end up going down as another turning point in the debate, and a significant one at that. A new study in the journal Cancer, which is published on behalf of the American Cancer Society (which itself is ambivalent about screening for prostate cancer) argues that the test is life-saving after all. In doing so, the article jumps all the way back to the pre-PSA era, comparing data from 1983-1985 to more current reports, and predicting that the number of men with metastatic cancer at the time of diagnosis would be three times as high without early screening. As many as 17,000 cases of this most serious form of prostate cancer, the authors maintain, are prevented each year by the PSA test:

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Yes, there are trade-offs associated with the PSA test and many factors influence the disease outcome. And yet our data are very clear: not doing the PSA test will result in many men presenting with far more advanced prostate cancer. And almost all men with metastasis at diagnosis will die from prostate cancer.

The study is observational, and as such cannot tell us definitively whether there is a direct causal relationship between PSA screening and the fewer cases of metastasis at diagnosis. But in going against what is quickly becoming the new common logic of prostate cancer, it should make experts take pause before turning their backs completely on early screening.

HealthWatch: Laser Treatment For Prostate Cancer

NEW YORK (CBS 2) – Prostate cancer is the most common cancer in men, with almost 200,000 cases each year. It's also the second-leading cause of cancer-related death in men.

Now, though, a new treatment for prostate cancer is being put to the test, and it uses lasers and lights to try to zap cancer in its tracks.

Bill Pupplo was diagnosed with prostate cancer four months ago.

"I had a high PSA," Pupplo said. "I went to a urologist and did a biopsy, and they found out that I had cancer."

Pupplo was going to take a wait-and-see approach since his cancer was caught very early. Then doctors at NYU Langone Medical Center told him about an experimental treatment that targets the cancer cells without destroying the prostate. "The real appeal of an approach like this is that it's non-invasive," NYU Langone's Dr. SamirTaneja said.

Thin, fiber-optic needles are positioned over the prostate, where cancer cells are identified. The patient is then given an IV drug that's activated by light. After about ten minutes, the lasers are turned on, shining light on the prostate through the fiber optics.

"Wherever the light meets the drug, blood vessels are destroyed, and hopefully the prostate cancer in that location is destroyed as well," Dr. Taneja said.

A big benefit of the procedure is that it may destroy cancer without causing serious side effects. That could mean the treatment causes no sexual, urinary, or reproductive problems, which traditional treatments can often lead to.

"Standard therapies for prostate cancer are, right now, surgery, radiation, [and] in some cases freezing the prostate, but they all aim to destroy the entire gland," Dr. Taneja said.

Pupplo will have another biopsy and an MRI in six months to see if he's cancer-free.

"At least now, I've done something that may work, so I have something to hope for," Pupplo said.

The procedure is not yet considered an alternative to surgery and radiation for more advanced or aggressive cancer, but doctors are hopeful that it may become one.

Medivation and Astellas Announce PDUFA Action Date for Enzalutamide NDA

SAN FRANCISCO, CA and TOKYO -- (Marketwire) -- 08/03/12 -- Medivation, Inc. (NASDAQ: MDVN)

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and Astellas Pharma Inc. (TSE: 4503) today announced that the U.S. Food and Drug Administration (FDA has assigned a Prescription Drug User Fee Act (PDUFA) action date of November 22, 2012 for the review of the investigational agent enzalutamide **(formerly MDV3100)** New Drug Application (NDA) for the potential treatment of men with castration-resistant prostate cancer previously treated with docetaxel-based chemotherapy. The companies announced on July 24, 2012 that the FDA accepted the enzalutamide NDA filing for review and granted Priority Review Designation.

About Enzalutamide

Enzalutamide is an oral, once-daily investigational agent that is an androgen receptor signaling inhibitor. Enzalutamide inhibits androgen receptor signaling in three distinct ways:
it inhibits 1) testosterone binding to androgen receptors; 2) nuclear translocation of androgen receptors; and 3) DNA binding and activation by androgen receptors.

Prostate Cancer Among African American Men Reaches 'Epidemic' Proportions, Senate Says

Huffington Post 8/03/12

Despite ongoing debate about the benefits of PSA testing for men at risk for prostate cancer, and recent research on the best course of treatment for those who have been diagnosed, the U.S. Senate passed a resolution Thursday acknowledging that awareness and prevention of the disease is as critical as it's ever been for African American men.

According to The Hill, the Senate resolution, which was introduced by Sen. John Kerry (D-Mass.), urges federal agencies to address what they're now calling an "epidemic" by supporting education, awareness outreach and research specifically focused on how prostate cancer affects black men.

"Prostate cancer is an epidemic -- it kills every 16 minutes," Kerry said in a press release. "This disease killed my dad, but I was lucky to beat it ten years ago, I introduced this resolution in the Senate to bring attention to this silent killer, how it disproportionately affects African Americans, and the need for additional federal investment in prostate cancer research, education, and awareness," he said.

Each year, some 504 in 100,000 African American men are diagnosed with prostate cancer, the National Cancer Institute reports. And while the disease is curable when detected early, it remains the second most lethal cancer in men, killing over 30,000 men each year, a disproportionate number of which are black.

Research efforts continue to explore why, including recent studies that point to higher rates of vitamin D deficiency among blacks, genetic differences compared to whites and even ancestry. For example, in 2009, researchers found a higher prevalence of prostate cancer in men of West African descent.

In addition to Kerry, other sponsors of the Senate measure -- which passed by unanimous consent -- are also prostate cancer survivors, The Hill reports

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Announcements

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 continues to develop our new website that we believe is simple and easy 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 meeting"

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

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 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 (OCIIO) 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. This only applies if you currently are on Medicare.

Mr. David Weil from Health Insurance Counseling and Advocacy Program (HICAP) provided information about their free services in our October, 2011 meeting. HICAP is a non-profit program that assists with counseling about medicare coverage and billing issues, including appeals. They do not make recommendations but rather provide information to help individuals make decisions about available coverage. They also assist with Long Term Care Insurance. The local phone number is 858-565-8772 or, if calling from a cell phone outside of the San Diego Area, 800-434-0222. Website: http://www.cahealthadvocates.org/HICAP/sandiego.html

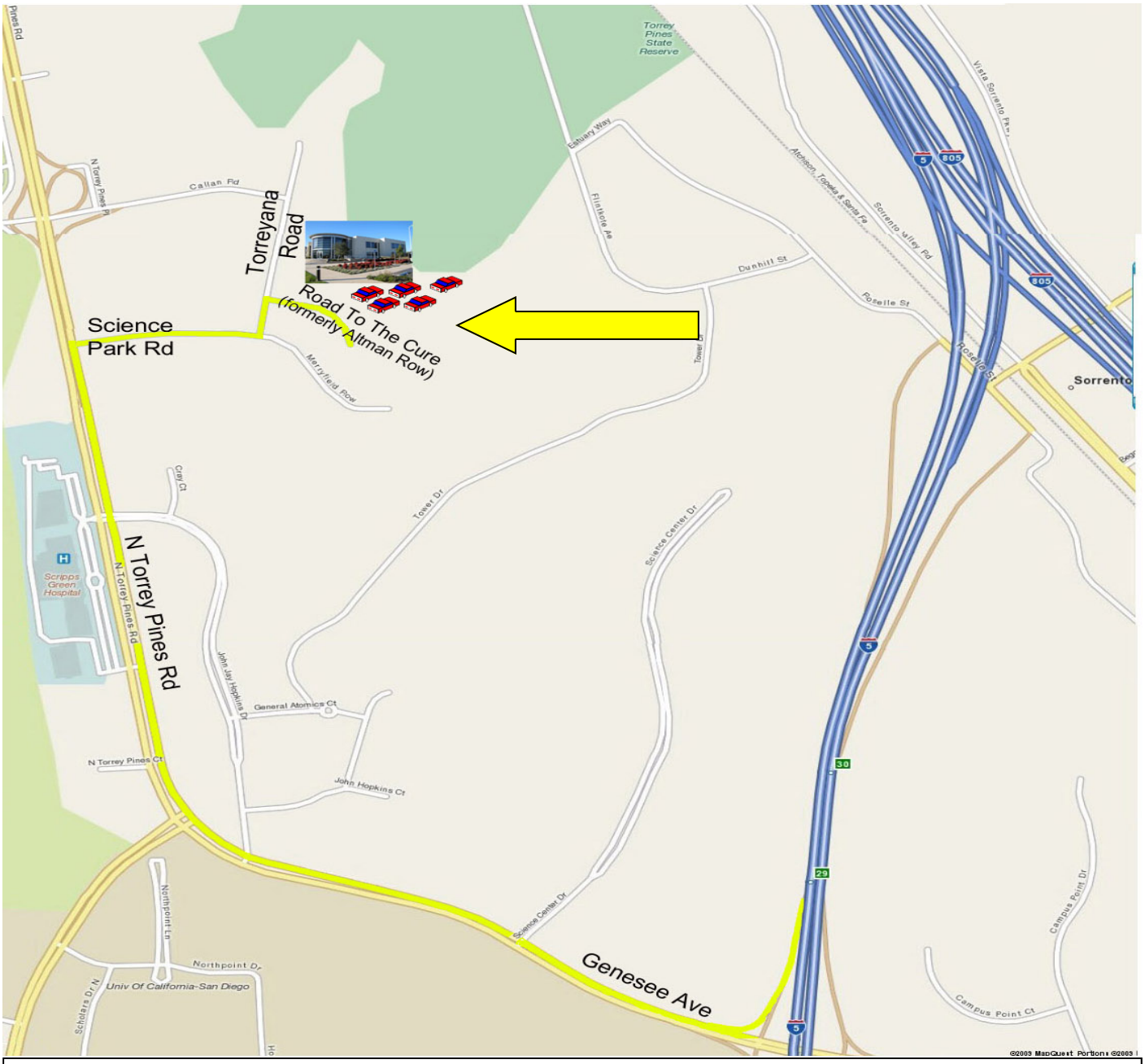
If you have particular knowledge that would be helpful to our goal of creating a base of information, please volunteer your efforts to the committee. Contact Gene Van Vleet, e-mail gene@ipcsg.org or cell phone 619-890-8447 who may redirect your inquiry to an appropriate person for response.

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,



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).