Informed Prostate Cancer Support Group Inc.

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

May 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)

Wednesday, May 09, 2012 Volume 5, Issue 4

Officers

President: Lyle La Rosh,
Vice President : Gene Van Vleet

Additional Directors

Dr. Dick Gilbert
John Tassi
George Johnson

Steering Committee

Judge Robert Coates
Victor Reed
Carlos Richardson
Robert Keck, Librarian
Bill Manning
E. Walter Miles
Jerry Steffen
Robert Werve, Treasurer

Next Meeting May 19th 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

The May meeting was well attended with 101 participating of which 10 were newcomers.

President Lyle LaRosh spoke about some topical issues. The biology of prostate cancer is being broken down, e.g. the stem cell research discussed by Dr. Andrew Goldstein in our March meeting, so that in the future men will not be faced with limited treatment options. Current testing is not predictive of the seriousness of the cancer. He clarified a difference between proton beam ration and IMRT. Proton beam radiation does not go through the targeted tumor but stops and radiates the target. The problem is getting the beam to go as far as need to treat the entire tumor. He clarified the terminology of Hormonal

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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Therapy which infers adding hormones but in the case of prostate cancer means reducing the hormone testosterone. It is more clearly understood for us to use the term Androgen Deprivation Therapy (ADT) from now on. He reminded us that PSA scores will vary with different laboratories. Therefore, make sure to use the same lab each time. Also, at the time of PSA testing, be sure to test for testosterone levels at the same time. Most doctors will not give this test if you don't ask for it.

George Johnson emphasized becoming your own case manager. Using his own experience as an example, his doctor was not telling him what his PSA score was and when he learned enough to ask about it, it was already at 14—-this coming 12 years after radiation therapy. Know what your PSA score is and keep track of it. If your PSA score is doubling in less than a year, get further testing. It is important to learn about the various treatments available and how they might alter your quality of life. Build a good knowledge base. A support group is an excellent source for this. Add to this by doing your own research. Take your time. Don't be pressured into decisions you don't fully understand. Get a second opinion from another unrelated doctor. Doctors within the same group will not likely contradict one another. Get copies of every test performed. Track them, keep them in a file and take your file with you when visiting your doctor. Make a list of questions to cover during your visits. Take notes on what you are told during visits. Most of all, remain positive. According to the American Cancer Society, the 10 year survival rate for prostate cancer is 98%.

George introduced members who would speak of their experiences. Their experience have been abbreviated by the editor. They are especially meaningful to those recently diagnosed or experiencing recurrence because they personify the thought and learning processes they underwent to arrive at decisions and what their results were. You can view the unedited presentations by purchasing the DVD of this meeting from our Library at the next meeting or through the website: http://ipcsg.org Click on the blue "Purchase DVD" button.

Gene Van Vleet relayed the experience of Bill Pitts who was unable to attend the meeting. Bill is a good example of Active Surveillance being followed over many years. Bill was initially diagnosed over 10 years ago with a PSA of 2.5 and a Gleason score of 3+3=6. He followed his progress with regular Color Doppler Ultra Sound tests with Dr. Duke Bahn and regular PSA tests. Late last year he decided that tumor growth warranted treatment and his PSA had risen to 10.9. He chose focal cryoablation on the left side of his prostate, freezing an area two-thirds of that side only. The treatment was performed by Dr. Osamu Ukimura of USC, who spoke to our group last July. His PSA was 0.95 three months after the procedure. His continence was maintained and with 25mg Viagra, he reports sex is as good as ever. Bill will soon post his full story in the Personal Experiences page of the website.

Tom Selgas is 72 years old. His PSA had climbed slowly to 8 in 1997 and remained at about that same level thru 2010. He had experienced urinary retention issues which resulted in two Transrectal Resections of the Prostate (TURP). In December 2010 his PSA rose from 8 to 9 then later to 10 causing him to consult with Dr. Pe of Hillcrest Urological Medical Group. He asked Dr. Pe to do a biopsy. Toms Gleason score was 4+3=7 and all 12 cores had cancer ranging from 30% to 80%. He then consulted with Dr. Carol Salem, a well respected surgeon within the same medical group. She advised that because of his previous urinary tract problems me might have difficulty with surgery and suggested he consult with Dr. A.J. Mundt, Chief of Radiology at UCSD about doing Intensity Modulated Radiation Therapy (IMRT). He then talked with Lyle LaRosh, attended an IPCSG meeting through which he learned of Dr. Mark Scholz of Prostate Oncology Specialists and readily made an appointment with him.

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Dr. Scholz performed a Color Doppler UltraSound (CDUS) test which showed his cancer was very near the rectum and surgery would not be advisable. Dr. Scholz also recommended that he consult with Dr. A.J. Mundt. Dr. Scholz further recommended 6 months of ADT prior to IMRT treatment as well as starting a rigorous exercise program that included resistance or weight training. Tom joined a fitness program that included personal training to help offset muscle loss and cold sweats often associated with ADT. After the 6 month ADT period, he underwent 9 weeks of IMRT. His PSA six months after treatment was. 0.06. He has experienced fatigue from the treatment and is overcoming it with continued exercise and recently has begun acupuncture which he believes is helping.

David Sheehan, 79, had prostate surgery 2 years ago and rather quickly developed incontinence. He performed Kegel exercises which did improve his situation somewhat, but after a year the improvements stopped. To help with his incontinence, his doctor suggested either a sling or an AMS800 artificial sphincter device. After consulting with Dr. Lam of Prostate Oncology Specialists (who then consulted with his expert), the ASM800 device was recommended. It was installed last August after which he waited for 2 months for the body to accept the device before turning it on. There are three parts to the device and all three are connected with a tube. The first part which is the control center is about an inch long and about 1/8" thick which is placed in the scrotum. There are three switches on it. When he goes to bed he presses one of the switches to turn it off during the night which helps the system last longer. In the morning he turns it on with the second button which keeps the urine from flowing. During the day he uses the third switch to relieve his urine. The second part is a small balloon which contains a saline solution. The third part is the artificial sphincter which is wrapped around the urethra. When the artificial sphincter is filled with the saline solution, the urethra is closed and does not allow urine flow. When he presses the button to release the urine, the saline solution is released which allows the flow of urine. He detects urgency in a normal manner without discomfort and his urination pattern has not changed from what it was before prostate removal.

Michael Brekka was 52 when first diagnosed. His older brother also has prostate cancer. Initially his PSA was 3.5 then jumped up to 6 then back down to 3.5 at which time he and his doctor decided to just watch it. About a year ago it went back up to 6 and when he did a confirmation test it had gone up to 7. He had a biopsy last July through Kaiser Permanente which was 4+3=7 on the left side and 3+3=6 on the right side. The left side cores had 95% involvement. Over the next 90 days he spoke with 13 doctors and read many books on the subject. He joined IPCSG in August, consulted with Lyle, its President, and visited doctors at UCSD. Lyle convinced him to see Dr. Bahn of Prostate Institute of America which was an out-of-pocket expense of about $1,200. He considers this money well spent. Dr. Bahn performed Color Doppler UltraSound (CDUS) and biopsies. Michael showed powerpoint slides of the CDUS images that showed where the cancer was located. The conclusion by Dr. Bahn was that there was a considerable amount of cancer, it appeared to be piercing the peripheral zone and it was heading towards the lower sphincter of the urethra. Because of that, surgery was not an option because it would leave him permanently incontinent. Dr. Bahn advised radiation and ADT for 2 years. Michael chose IMRT at UCSD, ADT for 3 months before and 3 months after the treatment. Before starting treatment he had some base line tests that showed his PSA at 8.5 and his testosterone, normally 300 to 750, was on the high side. Along with his first shot of Lupron, he took Casodex to minimize the testosterone spike that usually occurs with the first shot. In February this year after 3 months ADT and before starting IMRT his PSA was <0.1 and his testosterone was 8. He then completed 9 weeks of IMRT in April this year and has taken his second Lupron shot. Michael emphasized becoming your own case

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manager and gathering data relating to your situation as opposed to believing studies based on averages.

Rob Hildt, 70, was first diagnosed 16 years ago with a PSA of 31.8 and a Gleason of 4+3=7. His doctor at the time put him on Zolodex and Flutamide (a precursor to Casodex). In two months his PSA dropped to 0.5. He spoke with a number of radiologists, oncologists , urologists and did library research to learn about the disease. He decided because of his previously high PSA that he needed to take action. His research at that time indicated the results of radiation and radical prostatectomy were about the same. He decided on external beam radiation in September, 1996. From then until 1999 his PSA ranged from 0.5 to 4.9 which indicated radiation was not totally successful. He began taking Casodex and Proscar in Feb 1999 and changed from Proscar to Avodart in July 2008. He stayed on these drugs for 10 years. His PSA ranged from 0.1 to 3.4 in April 2009. He then had a biopsy performed that was 4+5=9 which sufficiently panicked him into doing cryoablation at UCLA without doing further testing which would have shown that the cancer had escaped the prostate. This left him incontinent and with ED for a time, but both are improving although not as good as before. He stressed that he was not against cryoablation but rather that more information was needed on which to base his decision. There are now many more tests available to find out the cancer location. Further, he later learned from Dr. Lam that the biopsy reading after radiation was not reliable. Not being happy with his urologist he went back to his GP, Dr. Geoffrey Gordon, who is acquainted with Lyle LaRosh and our group. Dr. Gordon suggested that he contact Lyle who promptly introduced him to Dr. Richard Lam of Prostate Oncology Specialists. At that time his PSA had shot up to 9.1. Dr. Lam put him on 3 tablets of Casodex (150mg) per day after which his PSA dropped to 2.7. By September 2010 his PSA had risen to 10.2, so he then tried Nilutamide to which he had a negative reaction and in May 2011 he and Dr. Lam developed an integrated strategy of Lupron and adding the Provenge immunotherapy treatment in December 2011. Dr. Lam felt that, although controversial, it would take 4 to 6 months for Provenge to take effect. In the meantime, he began taking the newly approved drug Zytiga (abiraterone). He underwent imaging tests that showed some spots on his hip and spine. After consulting with Dr. A.J. Mundt of UCSD he had the spots radiated in December 2011. He is still on Lupron, Zytiga and Xgeva (for bone health) and Avodart. His PSA pre-Zytiga was 24.2 and is now 0.3. His circulating tumor cell count prior to Zytiga was 4 and is now 0. In closing, Rob emphasized being your own case manager and working with knowledgeable doctors and specialists. He highly recommends weight bearing exercise and a diet that excludes red meat, milk and sugars. Keeping a positive mental attitude is very helpful. His current plan is to get his PSA as low as possible then discontinue all drugs for a while to see if Provenge has begun to work.

Ron Abbott, 59, has a recurrence of prostate cancer after radical prostatectomy. He knows it is stage 4 metastatic located in one lymph node and no where else. To determine this he participated in a Jan. 1012 clinical trial using a special Carbon 11-Acetate PET/CT imaging process for recurrent prostate cancer which will be the subject of the May 19th meeting. When 56 years old Ron was diagnosed from a second biopsy in Feb 2009 he was a Gleason 3+4=7 with 5 positive cores, stage T1c and his PSA had risen to 9.4. He stated that he was diagnosed late because he did not educate himself well enough and trusted his doctor too much. A patient of Kaiser Permanente, he felt his treatment alternatives were limited so he chose robotic prostatectomy. His decision process included the desire to get rid of "the mother ship" and that if there was a recurrence after surgery, radiation would be a back-up plan that would not exist if he started with radiation. Ten months after surgery his PSA was 0.1 and by Oct 2010

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it was 0.2—considered biochemical recurrence. He then consulted radiation oncologists including Dr. Lam of Prostate Oncology Specialists, all of whom recommended salvage prostate bed radiation. His concern about doing this recommended treatment was that it was "shooting in the dark" and that the long treatment period of radiation might only result in added side effects. He thought there must be a better way to locate the target. He researched alternatives and decided on a seek and destroy strategy. His PSA reached 1.17 in November, 2011—a doubling time of 103 days which prodded him to intensify his research. At the PCRI conference he had learned of new PET/CT scan methods which seemed superior to current CT and MRI scans. He consulted Dr A.J. Mundt of UCSD and other oncologists who indicated that with the aid of this new type of scan they could probably reduce the treatment cycle from 8 or 9 weeks to 1 week. Further research led him to Dr. Fabio Almeida at the Arizona Molecular Imaging Center in Phoenix. They were doing a clinical trial on the Carbon 11 Acetate PET/CT scan. He talked at length with Dr. Almeida (WHO WILL BE OUR SPEAKER MAY 19TH). Ron qualified for the clinical trial and went to Phoenix for the procedure. Dr. Almeida discussed the results thoroughly with him and advised that there was involvement in one lymph node and nowhere else. He was gratified with the results and had another consultation with Dr. Mundt at UCSD who presented the case to the Joint UCSD/Kaiser Tumor Board which resulted in an expert recommendation to radiate the prostate bed including the suspicious lymph node. Dr. Mundt was willing to do a focal treatment of the lymph node but with the clear understanding that Ron would be going against his recommendations. Ron is still looking for alternatives. He feels it is unfortunate that the medical community is unwilling or unable to consider special situations, but rather comply only with standards of treatment that may not yet include recent developments. Ron is still on Casodex and Proscar and may soon have to go on Lupron. He may soon do the focal radiation treatment.

Future Meetings

May 19th, 2012. Dr. Fabio Almeida, Medical Director, Southwest PET/CT Institute-Arizona Molecular Imaging Center. Subject: An ongoing clinical trial for Carbon-11-Acetate PET/CT imaging for recurrent prostate cancer. SEE NEXT PAGE FOR PARTICULARS

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

SUBJECT OF IPCSG MAY 2012 MEETING
By Dr. Fabio Almeida
www.azmolecular.com/index.html

Carbon-11-Acetate PET/CT imaging for Prostate Cancer

An Ongoing Open Clinical Trial at the Arizona Molecular Imaging Center in Phoenix

In patients with prostate cancer, the recurrence after treatment is unfortunately frequent, occurring within 10 years in 20–50% of patients after radical prostatectomy (RP) and in 30–40% of patients after external-beam radiation therapy (EBRT). Tumor recurrence is commonly assessed by a progressive increase of serum prostate-specific antigen (PSA) that typically precedes the clinically detectable recurrence. After RP, a PSA level >0.2ng/mL, confirmed by two consecutive measures, can be associated with either residual or recurrent disease. After radiation therapy (RT), a PSA value of 2ng/mL above the nadir represents persistent or recurrent disease.

Management of recurrent prostate cancer depends strongly on whether recurrence is confined to the prostatic bed (local failure), to the regional lymph nodes in the pelvis or if distant spread has occurred. Although the trend of PSA increase has been proposed as a predictive method for discriminating local from distant recurrence, only imaging procedures are capable of discriminating between these three scenarios.

Several imaging methods, including computed tomography (CT), magnetic resonance imaging (MRI), and bone scans (BS), are currently used, but none of these are very effective at detecting recurrences early enough to help select patients for salvage therapy with a curative intent.

Positron emission tomography integrated with CT, which combines the most advanced performance for both techniques, has become one of the primary tools in the restaging of cancer patients. The PET tracer 18F-FDG (fluorodeoxyglucose) is widely used for a variety of cancers, but presents limitations in imaging prostate cancer. Although 18F-FDG may accumulate in aggressive and undifferentiated tumors, most prostate cancers often presents with poor uptake of 18F-FDG, probably because of the high incidence of well-differentiated tumors. Furthermore, 18F-FDG is secreted into the urinary system, often interfering with pelvic pathologic findings and therefor significantly limiting its usefulness.

Among the different PET tracers that have been specifically evaluated for prostate cancer imaging, Carbon -11-Acetate (C11-Acetate) is demonstrating utility for detecting recurrent prostate cancer. Acetate is an essential component of phospholipids of the cell membrane. Cell proliferation and up-regulation of fatty-acid synthase are two mechanisms suggested for the increased uptake of this tracer in prostate cancer.
Due to recent changes in FDA regulation regarding new radiopharmaceuticals such as C11 agents, access to C11-Acetate now requires participation in an approved clinical study. The Arizona Molecular Imaging Center has worked with the FDA to open an approved Phase II clinical investigation and is pleased to be able to offer Carbon-11-Acetate PET/CT imaging studies for localizing recurrent prostate cancer. Because this type of scan requires an on-site cyclotron, we are one of the few sites in the country capable of doing these studies and currently we are the only FDA approved private site for C11-Acetate. Our center is also equipped with state-of-art PET/CT imaging which provides an extra advantage in the detection of

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small lesions. Our C11-Acetate study requires only a single intravenous injection of the tracer and imaging can be completed in less than 20 minutes.

Preliminary results from studies with C11-Acetate PET imaging in our ongoing clinical trial have been very encouraging and are demonstrating a direct benefit to many patients that would not be achievable with any other traditional imaging technique. In those patients studied thus far, the overall detection rate of recurrent or metastatic disease has been 87%. When separated into various PSA levels, the detection rate has been 71% for PSA 0.2 – 1.0ng/mL, 89% for 1.0 – 2.0ng/mL and 93% for > 2.0ng/mL. Most patients are still in early follow up, however in several patients with initial follow-up after additional therapy (radiation therapy directed toward the recurrence or metastasis) there has been a significant decrease in PSA. Much more to come as we proceed with our study…

For information about participating in this clinical trial please visit ClinicalTrials.gov web site http://clinicaltrials.gov/ct2/show/record/NCT01304485 or call Dr. Fabio Almeida directly at 602.331.1771

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.

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-

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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.

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.

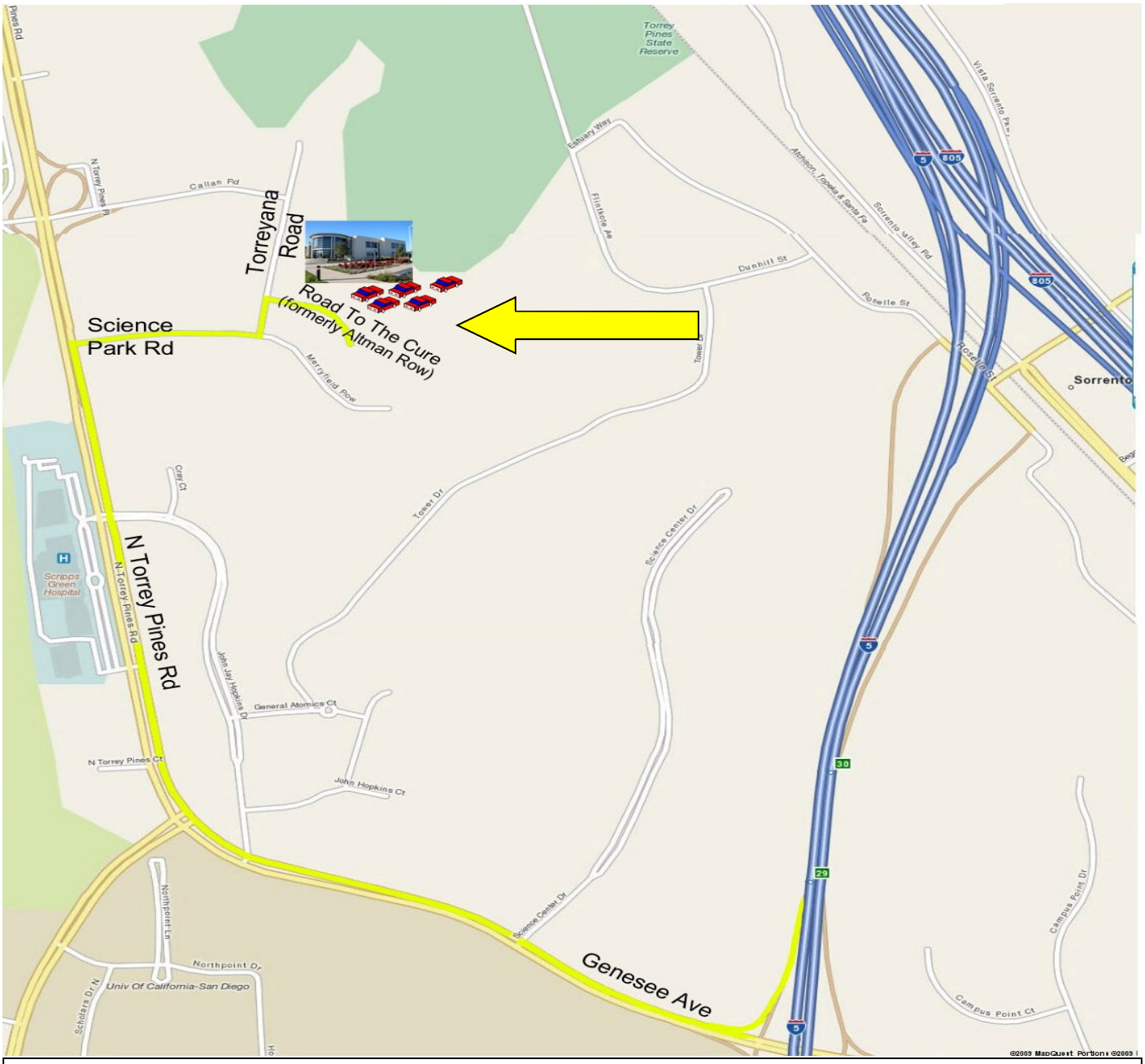
Anyone interested please contact:
Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org
Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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).