Informed Prostate Cancer Support Group Inc.

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

June 2016 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: http://ipcsg.org

We Meet Every Third Saturday (except December)

Monday, June 20, 2016

Volume 9 Issue 5

Next Meeting
June 18,2016
10:00AM to Noon

Meeting at

Sanford-Burnham-Prebys Auditorium

10905 Road to the Cure, San Diego CA 92121

SEE MAP ON THE LAST PAGE

PROSTATE CANCER - 2 WORDS NOT A SENTENCE

What We Are About

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

Be your own health manager!!

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Editor: Gene Van Vleet

RECAP OF LAST MEETING

By The Editor

Note: I decided to add an "FYI" section to the newsletter which is placed following the Future Meetings section. Its intent is to list events and items of general interest. E-mail me if you know of such things. The cut-off date would be 10 days before the meeting.

Our guest speaker for the May meeting was Dr. Paul Dato, Medical Director Genesis Healthcare Partners, Subject: Immunotherapy Probabilities.

The first part of his presentation was supported by slides furnished by Dendreon, the makers of Provenge. Brad Harper from the company was in

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: www.ipcsg.org Click on the 'Purchase DVDs" button.

The DVD of each meeting is available by the next meeting date. They now include the slides.

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attendance. Provenge is used actively in Dr. Dato's medical group. Provenge is a modulating vaccine which studies in the IMPACT trials have shown that men who used this medication live longer. It is derived from your own cells. It can be used if you are no longer responding to hormone therapy, CRPC, and metastasis must be present. However there can be no visceral metastasis (spread to the liver, lungs or brain). Provenge is the first vaccine to be approved by the FDA for any cancer. It was approved in 2010 for prostate cancer (PCa) The immune system normally divides cells to attack invader tumor cells. In PCa the system may not be recognizing the tumor itself. PCa is able to hide itself within your body so your immune system cannot recognize it and cannot proceed to the cascade of events that lead to tumor cell death. Provenge is designed to reprogram your body's immune cells to attack advanced PCa cells, by jumpstarting immune cells already in your body. The main goal of the Provenge clinical study was not to lower PSA levels—it was to prolong survival.

Dr. Dato stated that one of the points he discusses with his patients is that PSA is only one of many factors. He called it "Patient/physician Stimulated Anxiety" because it has become the main focus for nearly every visit. With Provenge they look more at overall survival. Three years after the start of a follow-on clinical study it was found that Provenge had reduced the risk of death by 22.5%, which he stated is comparable to other treatments such as chemotherapy or other agents. They are trying to augment those other treatments through the use of Provenge,

To decide when is the right time for Provenge, arm yourself with information and have a candid discussion with your physician To determine the existence of metastatic bone cancer, make sure you get adequate imaging such as: technetium bone scan, NAF-18 scan, MRI, or carbon-11 choline or acetate PET scan.

Getting the Provenge treatment is a process of collecting your immune cells (called Leukaphresis) at a local blood draw center which takes 3 to 4 hours. The collected immune cells are sent immediately to an FDA approved Dendreon manufacturing facility, where your personal dose of Provenge is created. Then within 2 to 3 days your dose is infused at your doctor's office which takes about 2 hours. You may receive acetaminophen or an oral antihistamine such as Benadryl 30 minutes before the infusion. You need to stay at your doctors office 30 minutes after the infusion. This process is repeated 3 times 2 weeks apart. You should be brought to and from each treatment.

Side effects are always a concern. With Provenge they are generally mild to moderate and may include: chills, joint ache, back pain, fatigue, nausea, headache, and fever. They usually last no more than a day or two, if at all. More serious side effects should be immediately reported to your doctor.

Medicare does cover the treatment as do most private insurance companies. Should the need arise, eligible patients may be able to get Provenge free of cost through Provenge Uninsured Patient Program. Dr. Dato stated their practice has not had problems with insurance coverage.

The second portion of Dr. Dato's presentation focused on immunotherapy for PCa – advances and results. At present there is no effective cure available for metastatic disease, thus it becomes a chronic disease like diabetes or COPD or heart disease which is managed but the process cannot be reversed. Current therapies modestly enhance survival and may have undesirable side effects. As noted before, it is an immune suppressive decease--it hides itself or does things to turn the immune system off. Prostate cancer cells express many tissue specific proteins that could be targetable. The focus of current research is on where those targets might be and what the biomarkers are in order to develop appropriate therapies.

Cancer cells may modulate the immune system by reducing tumor antigens on their surface making it difficult to detect. They express proteins which turn off your immune system and induce a microenviron-

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ment to release substances suppressing immune response and promoting tumor cell survival by itself.
The status of therapeutic vaccines:

- Sipuleucel-T (Provenge). It is the only FDA approved immunotherapy for solid tumor.
- GVAX (tumor cells genetically modified to secrete GM-CSF-- Granulocyte Macrophage Colony Stimulating Factor). GM-CSF was first identified in 1977 and is a cell regulating protein produced by immune cells, endothelial cells and fibroblasts. It activates and recruits antigen presenting cells in order to stimulate our own immune system. When it was looked at as a single agent there was PSA response but there is no long term data to show that it improves survival. It is used in Provenge. There was early termination of the phase lll trial due to study protocol issues--no data available as a single agent. It may have a role in combination therapy.
- ProstVac-VF. It is based on smallpox and fowpox viruses. It targets PSA. The Phase ll trial suggested efficacy and pre-chemo, phase lll trial is ongoing.

Dr. Dato went into more detailed and complex explanations on other approaches which are better understood by viewing the detailed associated slides which are available on the DVD of the meeting.

The Genesis Provenge experience:

- First patient infused September 2012
- To date 145 infusions performed on 47 patients
- No serious or protracted reactions--3 with significant (>101degrees) fever all self limited, One received only 2 infusions due to vascular access issues not related to Provenge
- Selection Process
    - Metastatic CRPC
    - Asymptomatic or minimally symptomatic
    - No visceral metastases (spread to the liver, lungs or brain)
    - No significant co-morbidities
    - Early identification of conversion from CRPC without metastasis to beginning of metastasis
    - Results: Limited by inherent nature of treatment. No objective antitumor response parameter that says Provenge is working for you. It is based on the survival data that came out of the study and good data that has now gone out 3-4 years that further supports that data.

Dr. Dato closed stating that the future looks bright. We already have Provenge. He suspects that ProstVac-VF will be approved and there are a number of early phase trials underway. The challenges with be optimal management ---biomarkers, agents, sequencing, combination therapy as well as the economics of drug costs, patient co-pays and reimbursement.

DVD's of the meeting will be available by the next meeting in the library or on our website: www.ipcsg.org/shop. NOTE: DVDS will also include the slide files.

FUTURE MEETINGS

Jun 18. Roundtable. A panel of members talk of their experiences followed by Q&A, then break-out sessions by treatment type for networking. ALSO a short presentation by Patrick Oberg re: YMCA health and wellness program.

July 16. John Grimaldi, DO. Subject: Treating impotence and incontinence. www.grimaldiurology.com

FYI

Our President, Lyle LaRosh has been focusing on increasing prostate cancer awareness. He recently was interviewed on KFMB radio. Swipe this link to your browser to listen to it. Lyle's part is about 10 minutes into the broadcast. http://www.760kfmb.com/story/15884059/its-your-money-and-your-life

Those of you needing Crestor (rosuvastatin) or Avodart (Dutasteride) RX it should be generic now. Check with your pharmacy.

2016 PROSTATE CANCER CONFERENCE. Los Angeles Airport Marriott. September 9-11. http://pcri.org/2016-prostate-cancer-conference

2ND ANNUAL FUNDRAISER CRUISE FOR PROSTATE CANCER AWARENESS. September 15. Special rates for IPCSG members. Contact: gene@outlook.com or 619-890-8447

Estimated number of USA PCa survivors as of 1/1/2016 = 3,306,760
Age group and number of Survivors:
0-39 = 1,340
40-49 = 27,390
50-59 = 263,280
60-69 = 904,380
70+ = 2,110,380 (64%)

Median Age at Diagnosis = 66
Estimated New Cases for 2016 = 180,890
5-year relative survival rate = 99% (compared to Pancreatic Ca = 7%)
10-year = 98%
15-year = 95%

Treatment Patterns (%) by Age (2010-2012, SEER data)

Age	RT Alone	All Surgery	No RT or Surgery
18-64	23%	54%	23%
65-74	36%	36%	29%
75+	33%	19%	48%

Note: PCa specific data above, was extrapolated and edited by member Dennis Walker from large multi-

ON THE LIGHTER SIDE

"You may carry on one bag and one personal item. No trunks."

Darwin awards:

The chef at a hotel in Switzerland lost a finger in a meat cutting machine and after a little shopping around, submitted a claim to his insurance company. The company expecting negligence sent out one of its men to have a look for himself. He tried the machine and he also lost a finger... The chef's claim was approved.

As a female shopper exited a New York convenience store, a man grabbed her purse and ran. The clerk called 911 immediately, and the woman was able to give them a detailed description of the snatcher. Within minutes, the police apprehended the snatcher. They put him in the car and drove back to the store. The thief was then taken out of the car and told to stand there for a positive ID. To which he replied, "Yes, officer, that's her. That's the lady I stole the purse from."

When a man attempted to siphon gasoline from a motor home parked on a Seattle street by sucking on a hose, he got much more than he bargained for... Police arrived at the scene to find a very sick man curled up next to a motor home near spilled sewage. A police spokesman said that the man admitted to trying to steal gasoline, but he plugged his siphon hose into the motor home's sewage tank by mistake. The owner of the vehicle declined to press charges saying that it was the best laugh he'd ever had.

INTERESTING ARTICLES

98 percent cure rate for prostate cancer using stereotactic body radiation therapy, research shows

From Science Daily April 18, 2016 Source:UT Southwestern Medical Center

A five-year study shows that Stereotactic Body Radiation Therapy (SBRT) to treat prostate cancer offers a higher cure rate than more traditional approaches, according to researchers at UT Southwestern Medical Center Harold C. Simmons Comprehensive Cancer Center.

The study -- the first trial to publish five-year results from SBRT treatment for prostate cancer -- found a 98.6 percent cure rate with SBRT, a noninvasive form of radiation treatment that involves high-dose radiation beams entering the body through various angles and intersecting at the desired target. It is a state-of-the-art technology that allows for a concentrated dose to reach the tumor while limiting the radiation dose to surrounding healthy tissue.

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"The high cure rate is striking when compared to the reported five-year cure rates from other approaches like surgery or conventional radiation, which range between 80 to 90 percent, while the side effects of this treatment are comparable to other types of treatment," said Dr. Raquibul Hannan, Assistant Professor of Radiation Oncology and lead author for the study. "What we now have is a more potent and effective form of completely noninvasive treatment for prostate cancer, conveniently completed in five treatments."

Conventional treatment options for early stage prostate cancer include:

•Prostatectomy, the surgical removal of the prostate gland, which can be done with minimally invasive techniques and robotic assistance;

•Brachytherapy, in which doctors implant numerous small radioactive seeds about the size of a grain of rice into the prostate gland using multiple large needles inserted through the skin in the operating room. Once implanted, the seeds release their radioactivity directly into the prostate gland; and

•External beam radiation, which involves 42 to 45 treatments administered over two or more months, five days a week.

"The current form of radiation is 44 treatments given over nine weeks. In contrast, the SBRT therapy we used allows the delivery of highly focused radiation in only five treatments, allowing patients to return to their normal lives more quickly," said senior author Dr. Robert Timmerman, Director of the Annette Simmons Stereotactic Treatment Center at UT Southwestern, and Professor and Vice Chairman of the Department of Radiation Oncology. "SBRT is both more convenient and has increased potency."

UT Southwestern served as the lead site for the multi-institutional clinical trial, which involved first-time prostate cancer patients diagnosed with stage I or stage II (low and intermediate risk) prostate cancer. A total of 91 patients were treated prospectively and followed for five years, with only one patient experiencing a recurrence of his cancer. The findings are published in the European Journal of Cancer.

Terry Martin of McKinney, Texas, -- about an hour outside Dallas -- said the fewer number of treatments was a compelling advantage when he was evaluating treatment options.

"I live 45 minutes away from UT Southwestern. The difference between being treated five times versus 44 times is enormous," said Mr. Martin, a retired airline pilot. "I felt that I was back to normal just 10 days after finishing treatment."

In addition to shorter treatment times, researchers found that side effects were not necessarily different compared to other forms of prostate cancer treatment. In the short term, the side effects of SBRT can include urinary issues (urgency, frequency and burning) and rectal irritation, which are often temporary and reverse within four weeks of treatment. Researchers found a small risk of longer-term urinary and rectal complications, which is also comparable to conventional treatments. Decrease in erectile function was seen in 25 percent of patients, fewer than with conventional radiation or surgery, said Dr. Hannan.

To reduce the side effects associated with SBRT, current clinical trials at UTSW are using a unique and biodegradable rectal spacer gel to protect the rectum. UTSW is currently the only accredited site in Texas at which this spacer gel can be used.

Other clinical trials at the UTSW Department of Radiation Oncology are seeking to expand the application of SBRT to high-risk (Stage III) prostate cancer patients. "Our hope is that the high potency of this form of treatment will significantly improve treatment of these patients," says Dr. Hannan, the principal investigator of the high-risk prostate SBRT trial.

UT Southwestern has been a leader in pioneering use of SBRT. Dr. Timmerman, Director of Image-Guided Stereotactic Radiation Therapy, Medical Director of Radiation Oncology, and holder of the Effie

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Marie Cain Distinguished Chair in Cancer Therapy Research, has served as the lead investigator in several national trials designed to evaluate the efficacy and safety of SBRT to treat other types of cancer, including cancer in the lung, liver, and spine. A range of clinical trials of SBRT therapy are under way at Simmons Cancer Center, including new investigations evaluating use of SBRT for cancers in the breast and larynx.

Imaging biomarker distinguishes prostate cancer tumor grade

From Medical Xpress June 1, 2016

Physicians have long used magnetic resonance imaging (MRI) to detect cancer but results of a University of California San Diego School of Medicine study describe the potential use of restriction spectrum imaging (RSI) as an imaging biomarker that enhances the ability of MRI to differentiate aggressive prostate cancer from low-grade or benign tumors and guide treatment and biopsy.

"Noninvasive imaging is used to detect disease, but RSI-MRI takes it a step further," said David S. Karow, MD, PhD, assistant professor of radiology at UC San Diego School of Medicine and the study's senior author. "We can predict the grade of a tumor sometimes without a biopsy of the prostate tissue. This is taking all that's good about multi-parametric MRI and making it better."

The addition of RSI to a pelvic MRI added between 2.5 to 5 minutes to scanning time making it a fast and highly accurate tool with decreased risk compared to contrast MRI which involves injecting patients with dye, said Karow.

In the study, published online June 1, 2016 in Clinical Cancer Research, the authors said RSI-MRI corrects for magnetic field distortions found in other imaging techniques and focuses upon water diffusion within tumor cells that exhibit a high nuclear volume fraction. By doing this, the ability of imaging to accurately plot a tumor's location is increased and allows for differentiation between tumor grades. The higher the grade, the more aggressive the cancer. Patients can have more than one tumor with different grades, however. Karow said RSI-MRI can be used to guide treatment or biopsy to target the region of highest-grade cancer.

An early diagnosis of prostate cancer typically improves a patient's prognosis. According to the National Cancer Institute, prostate cancer is the second leading cause of cancer death in men in the United States, with more than 26,000 estimated deaths this year and 180,890 new diagnoses predicted. The average age at the time of diagnosis is 66.

At UC San Diego Health, more than 1,000 patients have been imaged with RSI-MRI since 2014 and a subset have subsequently undergone MR-fused ultrasound guided prostate biopsy, said J. Kellogg Parsons, MD, MHS, UC San Diego School of Medicine associate professor of surgery and study co-author.

"Previously, we relied completely on systematic—but random—biopsies of the prostate to diagnose cancer, which has been the standard practice in our field for years. Now, we use RSI-MRI to precisely target specific areas of concern and enhance the accuracy of our diagnosis," said Parsons, surgical oncologist at Moores Cancer Center at UC San Diego Health.

"Greater accuracy means improved care tailored to each individual patient. With RSI-MRI, we are better able to identify which cancers are more aggressive and require immediate treatment, and which ones are slow growing and can be safely observed as part of a program called active surveillance."

Although this study focused on 10 patients, more than 2,700 discrete data points were evaluated. Next steps include introducing the technology to other hospitals and to study whether it can be used in isolation from other screening tools. In prior papers published in the journals Abdominal Radiology and Prostate Cancer Prostatic Diseases, the same authors reported that RSI-MRI increases detection capability and can perform better than traditional multi-parametric MRI when used in isolation.

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These data suggest that RSI-MRI could eventually serve as a stand-alone, non-contrast screening tool that would take 15 minutes compared to a normal contrast-enhanced exam lasting 40 to 60 minutes.

"What our evidence shows so far is the imaging benefit is coming from RSI-MRI," said Karow. "I think this technique could become standard of care and mainstream for the vast majority of men who are at risk for prostate cancer. Full contrast MRI is expensive and risky for most men. This is the kind of exam that could be done on a routine clinical basis."

Anders Dale, PhD, professor of radiology and neurosciences and co-director of the Multimodal Imaging Laboratory at UC San Diego, and Nate White, PhD, assistant professor of radiology, initially co-invented RSI-MRI to characterize aggressive brain tumors.

"RSI-MRI could be a transformational imaging technology for oncologists in the same way CT scans altered the way effects of treatment are quantitated from plain X-rays," said Jonathan W. Simons, MD, Prostate Cancer Foundation president and Chief Executive Officer. "Based on the investigations at UC San Diego, this is a particular promise that needs more validation. Now testable is the hypothesis that RSI -MRI could identify oligometastatic prostate cancer that became curable through its identification by RSI-MRI."

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

NETWORKING

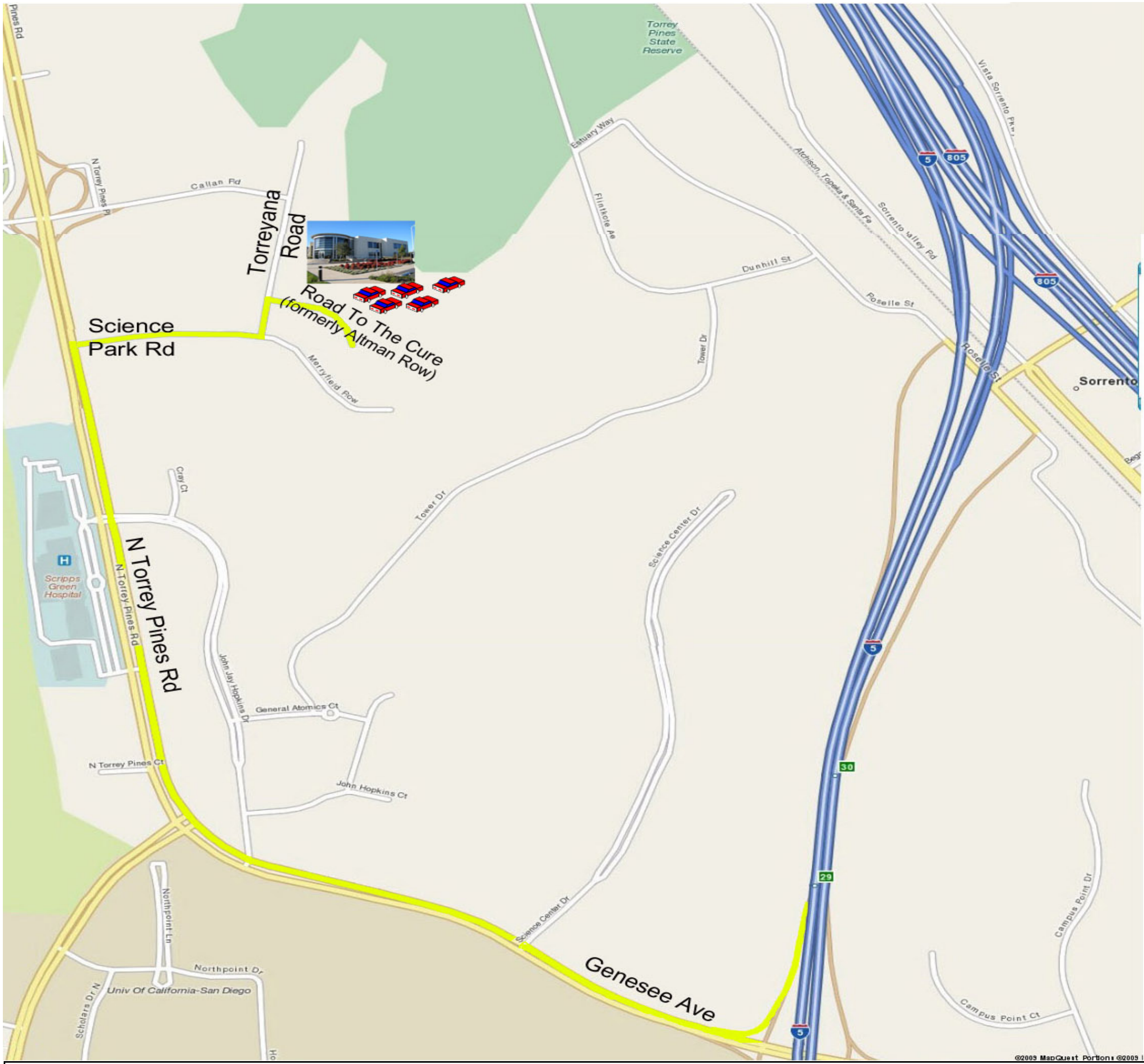
The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is "networking". We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all. 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 2-3 times prior to a meeting. Watch for them.



Directions to Sanford-Burnham-Prebys Auditorium
10905 Road to the Cure, San Diego, CA 92121

Take I-5 (north or south) to the Genesee exit (west).
Follow Genesee up the hill, staying right.
Genesee rounds right onto North Torrey Pines Road.
Do not turn into the Sanford-Burnham-Prebys Medical Discovery Institute or Fishman Auditorium
Turn right on Science Park Road. Watch for our sign here.
Turn Left on Torreyana Road. Watch for our sign here.
Turn Right on Road to the Cure (formerly Altman Row). Watch for our sign here.