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

MARCH 2018 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Friday, March 09, 2018

Volume 11 Issue 3

Officers

Lyle LaRosh
President

Additional Directors

Gene Van Vleet
George Johnson
John Tassi
Bill Manning

Honorary Directors

Dr. Dick Gilbert
Judge Robert Coates

George Johnson, Facilitator
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John Tassi, Webmaster
Bill Bailey, Librarian
Jim Kilduff, Greeter

Next Meeting
March 17, 2017
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

What We Are About

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

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Editor: Stephen Pendergast

PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

February 2018 – IPCSG -- Member Stories:

Bill Pitts -- Age 75, living in La Mesa, CA, and engaged to be married! He was first diagnosed in 2001. Although his PSA was only 2.5, he was inexplicably given a biopsy through a urologist at Kaiser (painful!), which gave a Gleason score of 6. This was shocking and depressing and caused

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Video DVD's

DVD's of our meetings are available in our library for $10ea. Refer to the index available in the library. They can also be purchased through our website: http://ipcsg.org Click on the 'Purchase DVDs" button.

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

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"controlled panic," since he was told he only had a month to decide on treatment. Due to prior distrust of doctors, he looked at options outside the medical profession, found the IPCSG with its "maverics like me," and learned a lot. Lyle LaRosh assured him that "You got time," and that he should see an oncologist. He went on a vegetarian diet, lost weight, and since quite thin, added fish and chicken. He joined a UCSF Medical Center clinical study that Lyle was in, and had excellent results for 4 years. Next he visited Dr. Duke Bahn in Ventura CA. A second biopsy gave Gleason 7 (3+4), but a 2nd review said it was only 6 (3+3). There followed a period of "Active Watching" with Dr. Bahn's Color Doppler exams annually. His PSA in 2004 was 4, and gradually rose to 6.7 by 2010. Then in 2011, his PSA rose to 9.3, and it was time to consider his first treatment. He went on a vegan diet, with green tea and turmeric. His PSA leveled off, and went down slightly. Dr. Bahn recommended radiation, but then he went to the IPCSG to hear a presentation on advances in Focal Cryoablation therapy. He went to USC Medical for the procedure by Dr. Ukimura. It was a single-day procedure, and he went home that same day. He had slight initial pain, but no side effects. Full urinary function as soon as the catheter was removed two days later. Takes Viagra/Cialis as needed. He eats no red meat nor dairy, walks & exercises at a gym, and practices healing visualization, prayer and meditation. His PSA is 1.0 and stable, and he remains on Active Surveillance. Focal Cryoablation worked for him!

Michael Brekka -- 59 years old, married with 3 adult children. His family history includes an older brother who was diagnosed with prostate cancer at age 50. In 2008, his PSA was 3.5. It rose to 6 early the next year, and was 7 in 2011. A biopsy at Kaiser showed Gleason 7 (4+3) on the left side and 6 on the other side, with perineural invasion on the left side. He found and attended IPCSG, talked with Lyle, and with many doctors (paying out of pocket, since Kaiser only covers their own doctors), including Dr. Flynn & case manager Barbara Barker at Kaiser, Dr. MacIntyre & Dr. Weinstein at Sharp, Dr. Ajay Shandu & Dr. Doug Rahn (Radiologists) and Dr. Chris Kane (Surgeon) at UCSD, Dr. Chuang (Urologist/Surgeon) at Kaiser, and Dr. A.J. Mundt (Dept. Chair) & Dr. Einck (Radiation Oncologist) at UCSD, all in 2011. He attended the Prostate Cancer Research Institute meeting in L.A. in September, 2011.

That year, he also went to Dr. Bahn, who did a Color Doppler ultrasound and biopsy, which confirmed Gleason 7 on the left side. A bone scan and a CT scan at Kaiser showed no metastases. Location of the lesions was near the urinary sphincter, indicating surgery would leave him incontinent if all the tumor was removed. He met again with Dr. Einck at UCSD, and spoke with Dr. Carter (Radiation Oncologist, and friend of a friend). He chose to do hormone therapy for 3 months, followed by radiation treatment and continuation of the hormone therapy as needed.

Michael received two 3-month Lupron shots (with 45 days of Casodex, to avoid a testosterone "flare"), which dropped his PSA from 8.5 to <0.1 and his testosterone from 683 to <10. At the time of the second Lupron shot, he started Radiation treatments for nine weeks. His PSA remained below 0.2

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for about a year after the second Lupron shot and the Radiation treatments. His testosterone stayed low for six months after the second Lupron shot, but then it wore off, and his testosterone was back to normal within 4 more months.

Two years after the Radiation treatments, his PSA had reached 0.5, and it has slowly risen (but at a gradually increasing rate) to 5.1 as of December 2017. This indicated the cancer was coming back. To image the cancer, he had a CT abdomen and pelvis scan, a PET/CT F18 whole body scan, a PET Axumin prostate scan, an mp-MRI, and a guided biopsy with ten cores on each side. The prostate cancer was found to be in the same location as before, contained within the prostate – no evidence of cancer in his bones or lymph nodes. The biopsy showed cancer in all cores, with Gleason = 7 (3+4). It is known that Radiation treatments have a 15-25% failure rate – and he's unfortunately in that group.

Physically, he's about "70% good" with respect to incontinence, erectile dysfunction and strictures. But the radiation he has had will somewhat limit his future treatment choices. Possibly he could have more IMRT radiation, though better to try low- or high-dose-rate Brachytherapy. Other options are Cryotherapy, High Intensity Focused Ultrasound, Surgery (difficult after radiation), ADT (Lupron and/or other drugs; recommended to him to be reserved until later), Irreversible Electroporation (Nano Knife; see prior newsletters for a review, or contact Dr. Ross Schwartzberg), and immunotherapy.

Bill Manning – In 2009, at age 57, he applied for some life insurance and was routinely tested for PSA, which came back as 4.1. His application was turned down! Three months later, his PSA had risen to 6.1, so he was biopsied. Among the twelve cores, only one had cancer, in only 5% of that core, with a Gleason = 6. Surgery was recommended. He began to educate himself, and was influenced by the China Study book, and by attending the IPCSG. He went to Dr. Bahn for Color Doppler ultrasound, and was told his cancer was "clinically insignificant." Active Surveillance was recommended.

He had some family history of cancer: His birth parents died of cancer at 64 and 65 years old, and an uncle died of prostate cancer (age unknown).

He returned to Dr. Bahn in 2010 and 2012, and found no significant changes, except for BPH (prostate enlargement).

In 2013, Dr. Bahn gave him a targeted biopsy, which came up negative, even on a second opinion. No cancer detected.

His PSA varied between 6.1 and 8.7, going up and down, in 2014-2017. This is in the normal range for his size prostate. He refused more biopsies. He went to Dr. Schwartzberg in 2015 and 2017 and got mp-MRI scans, which were negative. His latest PSA in January was 5.6 again. He's very glad to have not chosen surgery!

Although he had a healthy diet before 2009, since then he has been on a modified vegan diet (with eggs occasionally). It's a lot of work. He takes no medications.

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A story of STRESS: Bill and his wife lost their house in the recent "Lilac" wildfire in December. That day, they saw some smoke. He immediately started loading stuff in his car. The previous year, due to a serious heat wave, they prepared bins of key items, and Bill took photos of all their possessions in the house, including drawers and cupboards. First into the car was his vintage guitar, then computers, then bins they had prepared. He said, "You try to avoid freezing up or panicking. It helps to plan it all in advance." In retrospect, he could have grabbed mementos and other small things, but he and his wife were both thinking that they wouldn't actually lose their house.

The house was totally destroyed. When they were allowed back in, they found that cast iron skillets had warped in the fire, but their fire-resistant filing cabinet had survived. The lock melted, and the drawers were stuck. Firemen cut it open for them with a chop saw and the "jaws of life." Three-fourths of his files, including his backup hard drives, and some memorabilia, survived. But cd's did not survive.

They had almost gone shopping that morning, but he had a feeling they should stay home. Likewise, a feeling the night before led him to put some stuff by the front door.

Bill noted that the insurance company is not your friend, though they are not your enemy either. They put you through the wringer in making a claim. Read the fine print on your policy, including all the codes on the declarations page. Have your agent tell you what's not covered.

He's living in a rental home in Escondido that was unfurnished when they first moved in. They had a bed and two folding chairs. They are rebuilding. Life goes on, but the challenges aren't over yet.

A video of the February IPCSG meeting, including the three presentations (with copies of the slides) and Bill Manning's story of the fire and loss of his home, will be available via the website shortly before the next meeting, or at the March meeting.

At the beginning of the meeting, Director Gene Van Vleet announced the availability of Dr. Marc Scholz' (Prostate Oncology Specialists) new book "**Key To Prostate Cancer**". Thirty doctors including Drs. Richard Lam and Jeffrey Turner (also of Prostate Oncology Specialists) contributed. It is presented in a manner so that you can identify your stage of prostate cancer and read those portions of the book most pertinent to you. Copies are available for sale in the IPCSG library, on website www.keytopc.com and just recently on www.amazon.com .

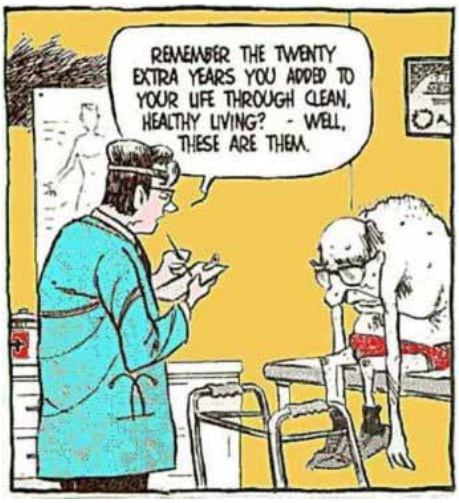
Gene also mentioned a seminar by **SBP Insights** that will present an in-depth look at diseases, including prostate cancer, that need a cure. Speakers will be SBP scientist Nicholas Cossford, PhD; Patient Hank Nordoff, Chairman of the Board SBP; and Christopher Kane, MD. Professor & Chair of Urology, UCSD. This will be held March 15, 5:30 - 7:30pm at the same auditorium where IPCSG meets.

The Cat in the Hat on Aging

I cannot see,
I cannot pee,
I cannot chew,
I cannot screw.
Oh, my God, what can I do?
My memory shrinks
My hearing stinks
No sense of smell
I look like hell
My mood is bad – can you tell?
My body's drooping
Have trouble pooping

The Golden Years have come at last
The GOLDEN YEARS CAN KISS MY ASS!

- Dr. Seuss



"We had a little trouble mixing your prescription. Can you stop back in 20 minutes?"

"It was a placebo surgery. I cut him open and just stitched him back up. I guarantee his phantom chest pains will be gone."

FUTURE MEETINGS

- March 17, 2018 Meeting - SUCCESSFUL LIVING - DISCUSSION
- April 21, 2018 Meeting — Dr. HSIEH – SEXUAL FACTORS

For further reading:
http://spendergast.blogspot.com/2018/03/prostatecancernews-2018-03.html
For Comments, Ideas and Questions, email to Newsletter@ipcsg.org

INTERESTING ARTICLES

Is MRI/TRUS fusion-guided prostate biopsy cost-efficient for all patients?

https://prostatecancerinfolink.net/2018/02/28/is-mri-trus-fusion-guided-prostate-biopsy-cost-efficient-for-all-patients/

Posted on February 28, 2018 by Prostate Cancer Infolink Sitemaster

Slowly but perhaps inexorably we seem to be seeing increasing scientific and clinical justification for the argument that all men thought to be at risk for a diagnosis of prostate cancer should be given an MRI scan prior to any form of prostate biopsy. The question of whether such a diagnostic strategy is cost-efficient has received much less attention, but will be crucial to the acceptance of such a diagnostic strategy here in the USA — as will access to high quality MRI scans and a large enough pool of skilled uroradiologists who can "read" such MRI scans with a high level of consistency and accuracy.

The latest addition to the literature documenting the clinical and diagnostic value of this strategy is a paper by Mehralivand et al. in *JAMA Oncology*. This multi-center research group has shown that the use of a high-quality MRI scan prior to biopsy could be used to reduce the rate of biopsy by 18 percent in a cohort of 400 patients. They then were able to validate this result in a different cohort of 251 patients.

Basically, the research team was able to show that, based on the assumption that any man with a Gleason score of 3 + 4 = 7 had clinically significant prostate cancer, their MRI model — in which all patients received an MRI scan and then an MRI/TRUS fusion-guided biopsy that included targeted biopsies of suspi-

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cious areas of the prostate ***and*** a systematic 12-core biopsy — demonstrated

- A lower false-positive rate than the baseline model (46 vs 92 percent)
- A small reduction in the true-positive rate (89 vs 99 percent)
- No increase in the number of patients with missed, clinically significant prostate cancers

A summary report on the paper by Mehralivand et al. can be found on the PracticeUpdate web site.

However, the question of cost-efficiency is going to be crucial.

When a man is diagnosed with prostate cancer today, it is commonly done only by the use of a 12-core, systematic, TRUS-guided biopsy at a suite in a urologist's office and review of the biopsy cores by a suitably qualified pathology laboratory. The exact cost for the biopsy and the pathology review varies (significantly) across the country and so it is impossible to provide an "exact" average cost.

In contrast, when a man is given a specialized prostate MRI, and the MRI scan is reviewed by a suitably qualified uroradiologist, we are now dealing with a different set of costs overall:

- The costs of the MRI for all patients
- The costs associated with uroradiological review of the MRI for all patients
- The costs for the MRI/TRUS fusion-guided biopsy (inclusive of the 12-core, systematic biopsy, and any targeted biopsies of visible areas of risk) for the 82 percent of patients who still need a biopsy
- The costs of the pathological review of the biopsy specimens

It seems highly unlikely that this four-part cost is lower than the two-part cost associated with a simple TRUS-guided, 12-core biopsy.

So from a cost-efficiency perspective, the question becomes: What costs have been saved if we do the MRI and the MRI/TRUS fusion-guided biopsy? And these cost savings include the following:

- The costs of the MRI/TRUS fusion-guided biopsy for the 18 percent of patients who didn't need that biopsy based on their MRI result
- The costs saved because 18 percent of patients never had a biopsy and therefore were never at risk for the short-term complications and side effects of prostate biopsy (most particularly, prostate infections and, more seriously, hospitalizations as a consequence of more severe forms of prostate infection)
- The costs associated with unnecessary, invasive treatment of men with low-risk forms of prostate cancer that didn't ever get diagnosed.

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For the payor community to be willing to embrace the idea of standard MRIs prior to all prostate biopsies the amount of money saved is going to need to be close to the additional costs associated with the more sophisticated, four-part as opposed to two-part diagnostic process.

It would be interesting to know whether a knowledgeable and specialized healthcare economist could assess these costs with a relatively high degree of accuracy.

Unnecessary Prostate Biopsies Can Be Avoided With MRI-Based Risk Prediction Model

http://www.cancernetwork.com/prostate-cancer/unnecessary-prostate-biopsies-can-be-avoided-mri-based-risk-prediction-model

Cancernetwork Dave Levitan

Feb 26, 2018

Incorporating MRI-derived parameters into a clinical risk model could cut down on the number of unnecessary biopsies performed in patients with suspected prostate cancer, according to a new study. This method could still maintain a high rate of diagnosis of clinically significant cancers.

"Transrectal systematic biopsy remains the standard of care for diagnosing prostate cancer. Use of this biopsy has led to an increased detection of low-grade cancers, which can result in overtreatment," wrote study authors led by Sherif Mehralivand, MD, of the National Cancer Institute in Bethesda, Maryland. "It would be desirable to reduce the biopsy rate in men who ultimately prove to have benign conditions or low-grade disease."

As multiparametric MRI and MRI-transrectal ultrasound (TRUS) fusion-guided biopsy have become more common, attempts to standardize reading of MRI have emerged. The investigators hypothesized that incorporating MRI-derived prostate volumes and categories from the Prostate Imaging Reporting and Data System Version 2 (PI-RADS v2) into a clinical risk model could reduce biopsy rates.

They included 400 patients in a development cohort, and 251 patients in a validation cohort. All patients underwent MRI, MRI-TRUS fusion-guided biopsy, and 12-core systematic biopsy. All detected lesions were assigned a category based on PI-RADS v2 guidelines, from 1 to 4, and this, along with MRI-derived prostate volume, was incorporated into a model that included age, ethnicity, and other commonly used variables. The results of the study were published in *JAMA Oncology*.

In the development cohort, 193 patients (48.3%) had clinically significant prostate cancer; in the validation cohort, 96 patients (38.2%) had clinically significant disease. The risk for clinically significant prostate cancer was inversely associated with prostate volume, and increased with prostate-specific antigen density and PI-RADS v2 category.

Compared with the baseline model, the model incorporating MRI increased the area under the curve (AUC) from 72% to 84% ($P < .001$) in the development cohort. In the validation cohort, the AUC increased from 64% to 84% ($P < .001$) with the MRI model.

Both false-positive and true-positive rates were improved with the MRI model. The net reduction in false positives using the MRI model, when compared with performing a biopsy in all patients with positive MRI results, was equivalent to performing 18 fewer unnecessary biopsies per 100 men, and with no increase in the number of clinically significant prostate cancers that would go undiagnosed. Overall, the MRI model could help avoid 38% of biopsies, compared with 6% with the baseline clinical risk model.

NETWORKING

The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is "networking". We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all. Many aspects of prostate cancer are complex and confusing. But by sharing our knowledge and experiences we learn the best means of prevention as well as the latest treatments for survival of this disease. So bring your concerns and join us.

Please help us in our outreach efforts. Our speakers bureau consisting of Lyle LaRosh, Gene Van Vleet and George Johnson are available to speak to organizations of which you might be a member. Contact Gene 619-890-8447 or gene@ipcsg.org to coordinate.

Member and Director, John Tassi is the webmaster of our website and welcomes any suggestions to make our website simple and easy to navigate. Check out the Personal Experiences page and send us your story. Go to: http://ipcsg.org

Our brochure provides the group philosophy and explains our goals. Copies may be obtained at our meetings. Please pass them along to friends and contacts.

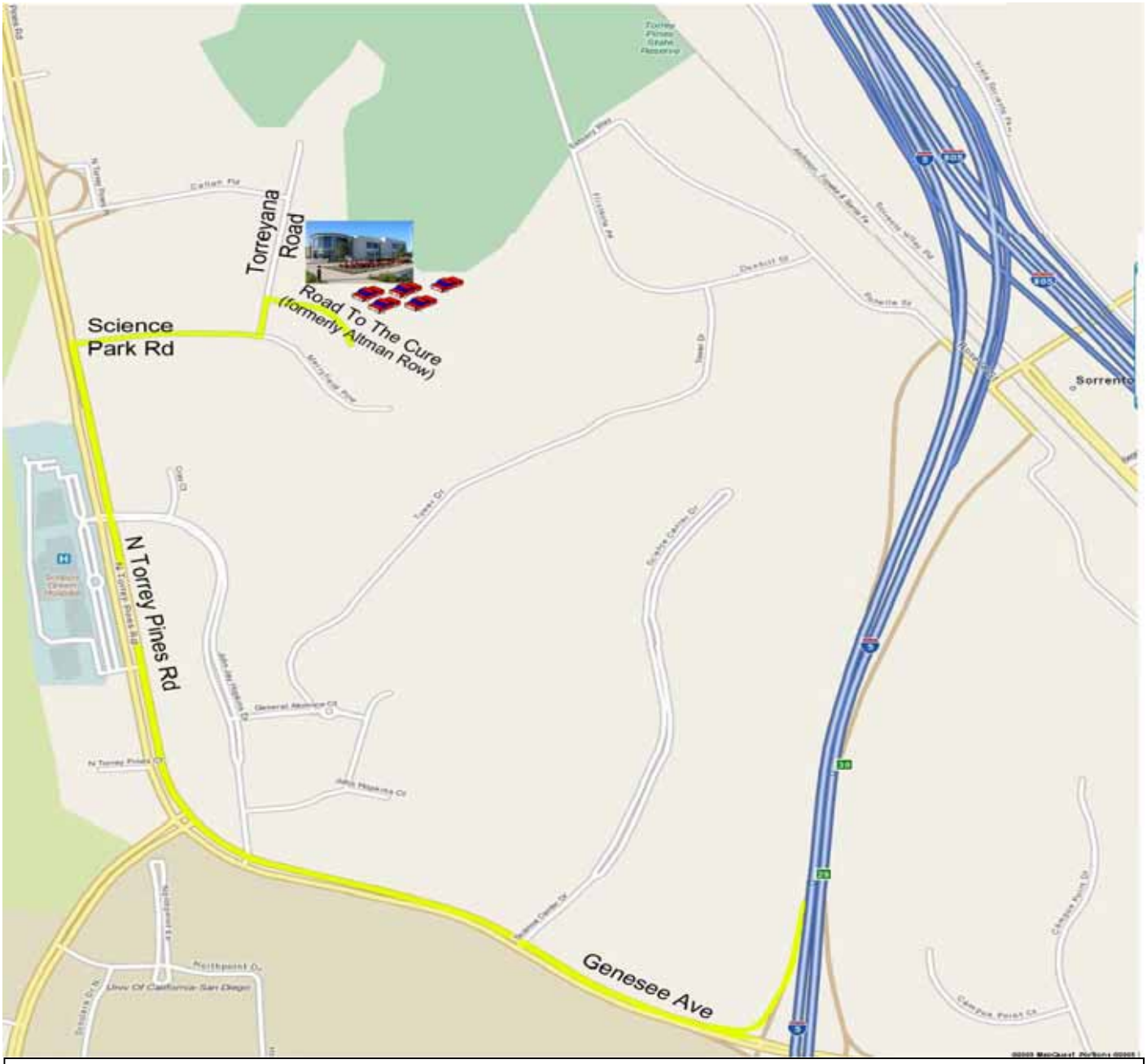
Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them.

FINANCES

We want to thank those of you who have made special donations to IPCSG. Remember that your gifts are tax deductible because we are a 501(c)(3) non-profit organization.

We again are reminding our members and friends to consider giving a large financial contribution to the IPCSG. This can include estate giving as well as giving in memory of a loved one. You can also have a distribution from your IRA made to our account. We need your support. We will, in turn, make contributions from our group to Prostate Cancer researchers and other groups as appropriate for a non-profit organization. Our group ID number is 54-2141691. Corporate donors are welcome!

If you have the internet you can contribute easily by going to our website, http://ipcsg.org and clicking on "Donate" Follow the instructions on that page. OR just mail a check to: IPCSG, P. O. Box 4201042, San Diego CA 92142



Directions to Sanford-Burnham-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.