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

June 2016 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Sunday, June 11, 2017

Volume 10 Issue 6

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Editor: Stephen Pendergast

Next Meeting
June 17,2016
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!!

RECAP OF LAST MEETING

By Bill Lewis

May 2017 IPCSG Meeting - Member Stories

Dan Salas is a 66 year old attorney in San Diego. He had a twelve-needle biopsy last June after his PSA reached 8. There was a Gleason 3+3 score in 10% of a single core. In November he was biopsied again, which gave 3+4 in 4% of a core with 36% 3+3, and two other cores with some 3+3. His urologist wanted him to choose surgery or radiation within three months.

His personal path of investigation brought him to the IPCSG, and he was referred to Bernadette Greenwood of Desert Medical Imaging to learn about options. She recommended getting an MRI.

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. They now include the slides.

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An MRI (with 3 Tesla magnet from Siemens, said to be the best) at UCLA found no measurable cancer. Note that Gleason 6 tumors may not be detected, and are generally not considered serious. Dr. Schwartzberg here in San Diego reviewed the images and confirmed the conclusion.

He has a large prostate, of about 144 grams. He is unsure about next steps, whether he should continue on active surveillance and just deal with the BPH, get a new doctor, and so forth.

He recommends PSA monitoring, which worked for him. He feels the MRI was very valuable, and comforting about his situation.

Q: How is he dealing with the symptoms from his large prostate? Flomax worked very well for a number of years, but then stopped working. Now, Uroxatral is working for him. There are other similar drugs that are approved for use with BPH. Daily use Cialis is said to reduce the size of the prostate.

Comment: Zinc and pumpkin seeds are said to help with BPH.

Q: What about the Prolaris test? It was done on Dan's biopsy last June, and it was consistent with the Gleason score (i.e., it predicted little danger of death within ten years).

Comment: Avodart for 6-12 months can shrink the prostate. The new Mayo clinic in Phoenix is said to resolve BPH urinary problems without side effects by surgery.

Comment: One participant favors doing a yearly biopsy. (yeouch! How about MRI instead?) The participant also suggests surgery or proton beam treatment.

Q: Frequency of his PSA tests? Every four months.

Bill Manning will soon be 65 years old, and is a videographer. His current PSA is 7.7. He needs to urinate 1-2X per night. He found out about his elevated PSA as part of an insurance application in 2009, when his PSA was found to be 4.1. His application was refused, as he was not considered a good risk. A retest at Kaiser came out at about 6. So he underwent a 12-core biopsy, and 5% of one core was 3+3. His stage was T1c (localized early-stage disease of relatively low risk). Surgery was recommended, with radiation as an alternative. His wife wanted him to undergo surgery right away. He chose to do some research. A support group at Kaiser was helpful, but then he learned about the IPCSG, and has attended since 2009. He learned about Dr. Duke Bahn, and got a Color Doppler ultrasound scan. Dr. Bahn put him on active surveillance and rechecked in 6 months; Bill was still fine.

Dr. Bahn in 2013 wanted a biopsy (His 1st urologist said biopsy yearly; his 2nd said only needed after a change), since it had been four years since the original biopsy. Color Doppler ultrasound showed a change this time. So Bill agreed to a 7-core targeted biopsy. All the cores appeared to be negative. To get a second opinion, Bill chose to send the cores to Kaiser! Even they were surprised, since many of their patients insist on second opinions elsewhere. But Bill reasoned that they had the original samples from 2009 to compare. They agreed the new biopsy was negative.

Bill has chronic prostatitis and BPH (65 grams in 2009; 89 grams in 2015). So his PSA was climbing due to that. He's been told that his PSA would be normal if 7-9, based on the size of his prostate.

Bill got an MP-MRI scan done in 2015 by Dr. Schwartzberg of Imaging Healthcare Specialists, and it showed negative results. Dr. Schwartzberg said that active surveillance was fully appropriate for him. His PI-RADS score was 2 (which is relatively low).

Overall, he's "very low risk." So no treatment of any kind is needed at this time, and he has had none so far. He did change his diet. Perhaps his first biopsy was a false positive, and surgery could have been a terrible mistake. Another MRI is planned for this summer.

He feels the IPCSG has been a super-important factor in his life. It's too hard to sort through what's on the internet. It's more digestible in the presentations here. It really lowers the anxiety.

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Q: How is the size of the prostate measured? Ultrasound or MRI.

Q: Ever treated for prostatitis infection? No.

Q: Diet? Available by contacting him after the meeting.

Q: Ever follow up with his original surgeon about the lack of need for a radical prostatectomy? No, but in 2009, the apparently eagerness of the surgeon to operate on him disturbed both his wife and him, so was a motivation to learn more before going back -- and he never returned to that doctor.

Q: Pharmaceuticals taken? No, but tried Saw Palmetto with no effect. Now trying Stinging Nettle root. Someone else tried Super Beta Prostate, but didn't see a discernible effect.

Comment: Treatment for chronic prostatitis should be 3 months of antibiotics. Reply: Bill would be reluctant to take that much antibiotics, since he doesn't have an obvious raging infection.

Comment from George Johnson: Take your wife with you when you meet with doctors for discussions. She will hear things you miss.

Jack Harrison, age 87, small manufacturing business owner in Rancho Bernardo. Coming to IPCSG for 10 years.

Current status: PSA 2.9, Gleason = 9, Bone metastases in the spine and ribs and hip. Taking Zytiga, Lupron, Casodex and Metformin. Feeling very good, with positive outlook.

His diagnosis came in 1990 from his general practitioner's digital rectal exam. His PSA was then measured at 20. Biopsy showed Gleason = 6. Urologist recommended surgery. He studied options at the UCSD basement library, interviewed a radiologist and another surgeon, then underwent surgery. Quick recovery, and resumed work -- but major negative effect on his sex life. Post-surgery, the Gleason actual score was found to be 9 (5+4) with positive margins (i.e., bad news!). The San Diego Tumor Board recommended radiation, and he had 6000 rads of EBRT, with no real side effects. His insurance company dropped him after those treatments.

In March 1993, his PSA was still only 0.15, but it gradually rose. His doctors didn't warn him about how serious it was that the PSA was rising.

In 1997, his PSA reached 8.9, and then he was (belatedly) put on Lupron and Casodex, causing the PSA to return to undetectable. He had all the usual side effects of Lupron: Tough on bones, loss of strength, slowing down, enlarged breasts, weight gain, and incontinence (in combo with prior surgery).

He heard about intermittent treatment at an early PCRI (Prostate Cancer Research Institute) meeting from Dr. Stephen Strum, tried it for 8-10 years and felt better. As the PSA went up, he would use the drugs, and go off when the PSA went back down. No urologist he saw would agree it was a good idea, but it worked for him. Regained some vitality.

In 2011-2014, his PSA was rising again, and he started Leukine (for stimulating the immune system) with Cytoxan and Lupron. In 2014, he had Provenge treatment while continuing Lupron and Casodex. In 2016, he started Zytiga with Lupron and Casodex. This year, he had focal IMRT on his spine, which seems to have cleared up the mets there. Has some loss of strength and is slowing down a bit. His current program involves a healthy diet, exercise and walking with his wife, a good spiritual program and keeping active and positive. Current PSA = 3. No pain.

He recommends reading and understanding the Partin Tables before any surgery. That would have ruled out surgery in his case, since he had a high Gleason, positive margins and a high PSA. Unfortunately, it wasn't known until after the surgery. (Nowadays, MRI would give the needed information.) He regrets having done the surgery with the limited info he had back then.

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He recommends the PAACT magazine, which is free and has very good information.

Q: Continued taking Lupron with other medicines added? He managed his own Lupron dose until 2006, intermittently, sometimes being off it for a couple of years. Since then, he has been on it continuously, even when other medications were added.

Comment from George Johnson: Intermittent hormone therapy such as Jack used has been used successfully by others, but is not suggested by any doctors in San Diego that he is aware of. He invited Bob Keck to share his 24-year experience: He had surgery in 1992. After 4 years, his PSA started rising again. Dr. Bob Liebowitz from L.A. came to speak to the IPCSG and talked about intermittent hormone therapy. His Gleason was 6 and his PSA was 21. Ever since, he has intermittently used hormone therapy: first Lupron and Eulexin, then Casodex and Avodart, and more recently with added Metformin. The Metformin greatly slows his PSA rise. Now his PSA cycling from 0.1 to 6 takes about a year and a half, and then he goes back on the drugs. In contrast, Gene Van Vleet only succeeded in taking a holiday from Casodex for 3 months. George was successful for 4 years on Casodex intermittent use, but now takes it continuously. He only took Lupron once.

Q: Jack's doctor? Mark Scholz, of Prostate Oncology Specialists, since 2006.

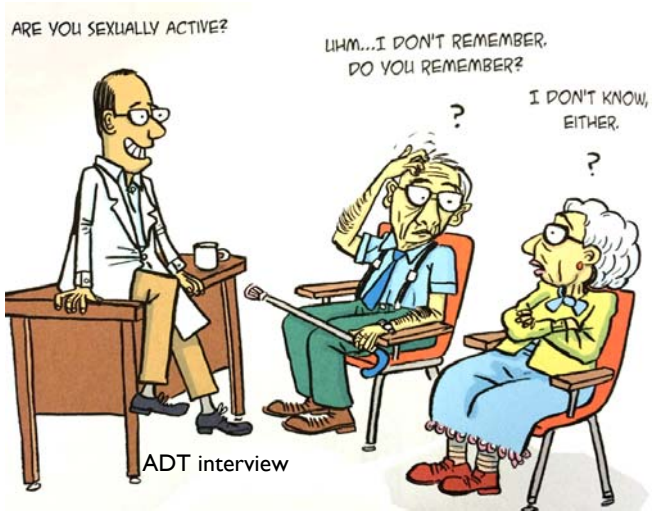
Comment: When your energy is down, try some American Ginseng. (But Jack noted that it didn't work for him.)

DVD's of the meeting will be available by the next meeting date via the website: www.ipcsg.org/shop or from the library at the next meeting. Slides are included in a file on the DVD.

FUTURE MEETINGS

- Jun 17. **HORMONE THERAPY (ADT), EFFECTIVENESS - RESULTS - SIDE EFFECTS** . group discussion - A large number of our members are now on hormone therapy, and others may become candidates for this therapy if their initial treatment fails or they have a recurrence. There are a variety of forms and combination of ADT, called CAB, SAT, BAT, etc. and their effectiveness varies depending on the individual. There are also a variety of side effects, some very severe on the quality of life factors. George Johnson will lead the discussion. He has nine years of experience with different forms of ADT and he will encourage our members to share their experiences and successes. This discussion will also surface some of the controversies about low testosterone supplements.

ON THE LIGHTER SIDE



ADT interview

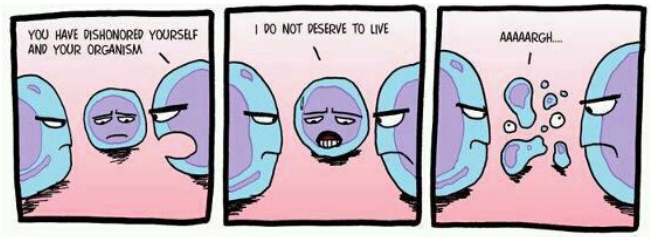

Getting the Lupron shot

"This needle made him faint. Maybe he would've been more comfortable if I had put some ink in it."

After my recent Prostate Exam, which was the most thorough I've ever had, the Doctor left and the nurse came in.

As she shut the door, she asked me a question I didn't want to hear ....

She said ...."Who Was That Guy?"



What Cancer Cells Refuse to do. APOPTOSIS cellular harakiri

INTERESTING ARTICLES

Abiraterone Plus ADT Ups Prostate Cancer Patient Survival

[https://goo.gl/NhxP7O]

Natasha Persaud, Digital Content Editor

June 03, 2017

Combining abiraterone with androgen deprivation therapy (ADT) for men with locally advanced or metastatic prostate cancer (PCa) initiating long-term hormone therapy improves overall survival by 37%, researchers reported at the 2017 American Society of Clinical Oncology in Chicago and published in the New England Journal of Medicine.

The finding, from the STAMPEDE trial (NCT00268476), may change the standard of care.

"These are the most powerful results I've seen from a prostate cancer trial -- it's a once in a career feeling. This is one of the biggest reductions in death I've seen in any clinical trial for adult cancers," lead investigator Nicholas James, PhD, of the University of Birmingham in the UK, said in a press release.

During 2011 to 2014, Dr James and his colleagues randomly assigned 957 men to ADT alone and 960 men to a novel combination of ADT plus abiraterone acetate (1000 mg daily) and prednisolone (5 mg daily). The vast majority (95%) of patients (median age 67; median PSA 53 ng/mL) were newly diagnosed and the remainder had PCa relapse. Overall, 52% of patients had metastatic disease and 48% non-metastatic disease (20% node-positive or node-indeterminate and 28% node-negative). Among non-metastatic PCa patients, local radiation treatment was required for negative nodes and recommended for positive nodes. ADT was administered for 2 years or disease progression.

Over a median of 40 months, 262 men in the ADT-alone group and 184 in the combination group died. The combination arm experienced significant benefit with treatment compared with the ADT-alone arm (3-year overall survival 83% vs 76%; 3-year failure-free survival 75% vs 45%; and 3-year progression-free survival 80% vs 62%).

"Abiraterone is already used to treat some men whose disease has spread but our results show many more could benefit," Dr James stated. "In addition to the improvements in survival and time without relapse, the drug reduced the rates of severe bone complications, a major problem in prostate cancer, by more than a half. I really hope these results can change clinical practice."

According to the investigators, adverse events were consistent with experience for castration-resistant prostate cancer.

References

1. James ND, de Bono JS, Spears MR, et al. Abiraterone for Prostate Cancer Not Previously Treated with Hormone Therapy. New Eng J Med. ASCO Abstract LBA5003.

2. Adding abiraterone to standard treatment improves prostate cancer survival by 40 percent. Cancer Research UK; June 3, 2017. [news release]

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Clinical trial uses small molecule to treat men with incurable prostate cancer [https://goo.gl/KXmXJj]

May 31, 2017

NewYork-Presbyterian and Weill Cornell Medicine have begun the first clinical trial in the United States that uses a small molecule to treat men with progressive prostate cancer that has spread beyond the prostate and is no longer responding to hormonal therapy. The Phase 1 study has completed its second round of patient enrollment, with the first six patients having undergone dosing. The researchers will be discussing the trial on June 5 at the 2017 American Society of Clinical Oncology meeting in Chicago.

The researchers are using the small molecule Lutetium 177Lu-PSMA-617 to target prostate-specific membrane antigen (PSMA), a protein that is abundantly expressed in 85-90 percent of metastasized prostate cancers. The small molecule binds to PSMA and delivers precise radiation therapy intended to shrink the cancer -- even in cases in which cells have yet to form a visible tumor on a bone or CT scan.

The trial primarily seeks to determine the highest dose level of the drug that can be given without significant side effects. PSMA-targeted therapy is thought to be one of the most promising approaches in treating metastasized prostate cancer.

"This trial represents a new frontier in the treatment of metastatic prostate cancer," said Dr. Scott Tagawa, medical director of the genitourinary oncology program at NewYork-Presbyterian/Weill Cornell Medical Center and The Richard A. Stratton Associate Professor in Hematology and Oncology at Weill Cornell Medicine. "While this type of therapy has shown promise, this is the first trial of its kind in the United States. So far, patients are doing well."

While this trial is the first of its kind in the United States, this same approach to treat metastatic prostate cancer has gained traction in recent years in Germany, where physicians can treat patients who have exhausted standard treatment options under "Compassionate Use" laws. German physicians who are able to provide this treatment in a "Compassionate Use" setting have shown Lutetium 177Lu-PSMA-617 can reduce the volume of tumors in the body and lead to remission of the cancer.

NewYork-Presbyterian and Weill Cornell Medicine have been at the forefront of PSMA-targeted 177Lu therapy for more than a decade. Dr. Neil Bander, the Bernard and Josephine Chaus Professor of Urological Oncology at Weill Cornell Medicine and a urologic oncologist at NewYork-Presbyterian/Weill Cornell Medical Center, developed the first monoclonal antibodies that could bind to PSMA in prostate cancer cells. As a result of Dr. Bander's efforts, PSMA has become recognized as the best known prostate -cancer specific cell surface molecular target. The lead antibody he developed, J591, was shown to be able to target virtually all prostate cancers in patients while also avoiding healthy tissue and normal organs.

Source:
http://news.weill.cornell.edu/news/2017/05/first-clinical-trial-of-new-targeted-molecular-therapy-in-us-takes-aim-at-incurable

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ADT ("hormone" therapy), side effects, and QOL - Dr. Paul Schellhammer weighs in

by Jan Manarite

For men who are starting on androgen deprivation therapy (ADT, also known as "hormone" therapy), there is often little help, or little discussion in the doctor's appointment. But there are solutions.

Mike Scott (President of PCaI & InfoLink) just finished **2 online recorded sessions (see below)** on this subject with **Dr Paul Schellhammer** (urologist and PC patient), **Tony Crispino** (well-known advocate & coauthor on new AUA PC guidelines) and **Paul Carpenter** (well-known advocate). **Rick Davis** (Answer Cancer), and I also joined 1 of the calls.

The recordings are called ***Living Well with Prostate Cancer*** **Part 1** [https://goo.gl/IAkXEI] – and **Part 2**. [https://goo.gl/bknSiz]

Here are some helpful tips in the recordings:

- The use of estrogen patches for hot flashes, bone health and even libido in some men.
- The importance of exercise for overall health, prostate health, and even mental health.
- The idea that patients need to initiate more conversations with medical professionals about how they feel – and nurses at the clinic they go to may be more receptive than doctors at times.

The value of Richard Wassersug's book [http://amzn.to/2rNpeay] and helpful website, www.LifeOnADT.com

Since Mike hired me in October of 2016, we have been in regular discussion and planning of projects to help prostate cancer patients, including the conference we produced in Florida in March of this year. Moving forward watch the InfoLink Social Network for events and posts about what we are planning for you (patients, partners, and caregivers) this upcoming year.

Thank you. And please feel free to contact me directly any time.

Jan Manarite
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Florida

Visit The "New" Prostate Cancer InfoLink Social Network at:
http://prostatecancerinfolink.ning.com/?xg_source=msg_mes_network

For Additional Reading go to: http://spendergast.blogspot.com/2017/06/prostatecancer-news-2017-06.html

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.

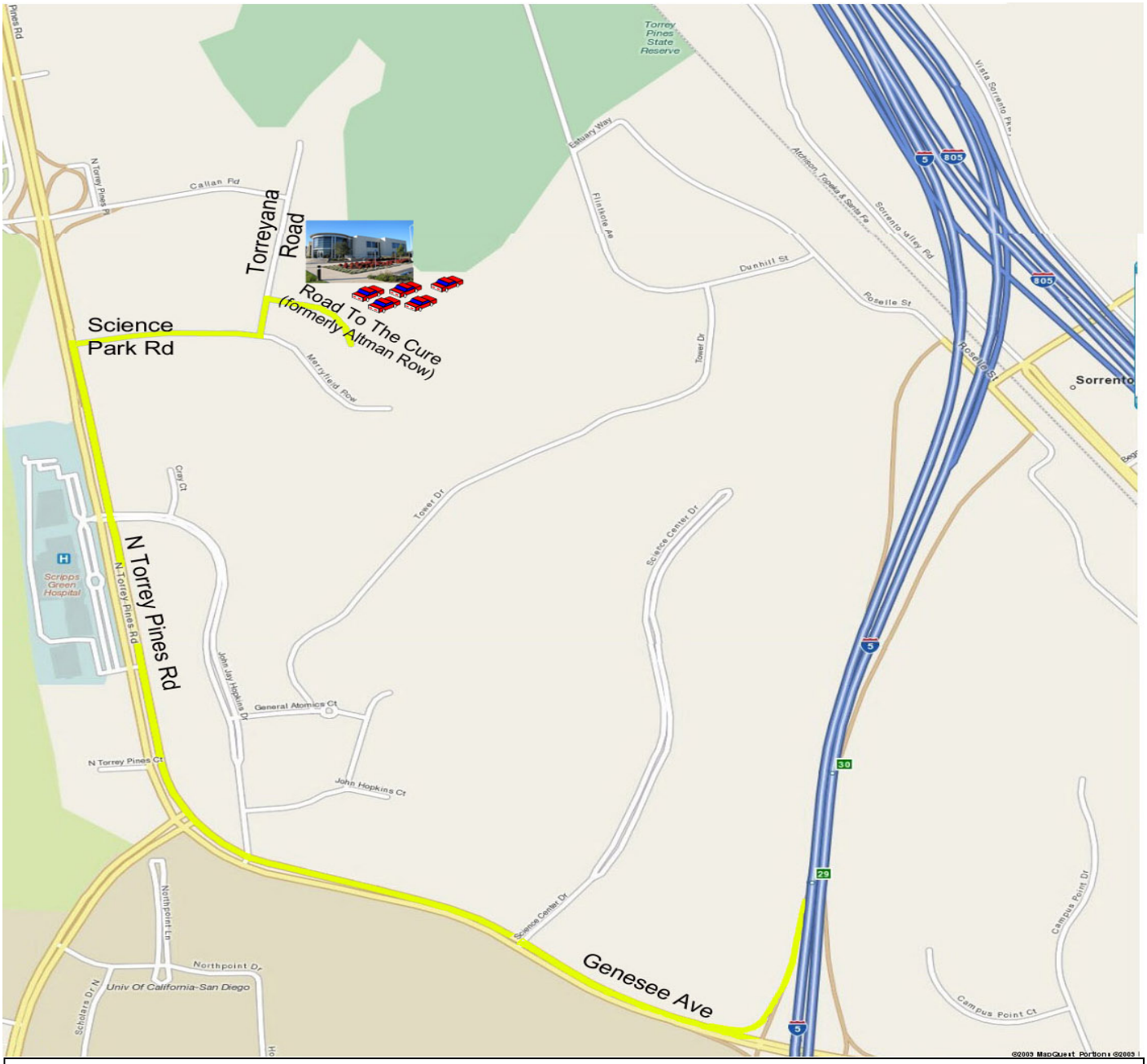
Ads about our Group are in the Union Tribune 2-3 times prior to a meeting. Watch for them.

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.