Informed Prostate Cancer Support Group Inc.

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

March 2015 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

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

We Meet Every Third Saturday (except December)

Saturday, March 14, 2015

Volume 8 Issue 3

Next Meeting
March 21, 2014
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 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: Gene Van Vleet

PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

At the February meeting three men talked about their experiences in dealing with Prostate Cancer (PCa) and audience questions were fielded after each presentation.

David had his first PSA test in 1997 at age 55. It was 4 and his doctor had him do a biopsy. He was told there was evidence of PIN (pre-cancerous Dysplasia) and not to worry. Two years later his PSA was 6 and another biopsy was performed. It was still negative except for PIN. After another 2 years he did another PSA which was 8 and another

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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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biopsy was performed which showed 8 of 10 samples had cancer. He warned of understanding terminologies. He was told the results were POSITIVE---which is NOT GOOD. He was given no suggestions about how to treat so he investigated treatment possibilities and chose prostatectomy as the one most suited to his lifestyle desires and hope for longevity. When pathology was performed on the removed prostate, they saw 9 separate cancers. 3 were microscopic, 6 were larger and showed that the seminal vesicles had been penetrated--meaning the cancer was outside the prostate capsule and perhaps to other parts of the body. He was also concerned about erectile dysfunction. He had desire but was unable to perform. He was working at Walter Reed Hospital in Washington DC at the time and got involved in a communal program that they thought might help him. When reviewing his file and history they thought he had a good possibility of lymphatic invasion. He had ignored that part because when he looked at the pathology reports he saw "clear margins" and believed there were no issues.

Six years after surgery his PSA had begun to rise, starting at .04 and is now at .9. He suggested to an Oncologist at a Naval hospital that he went to see that maybe they should do an MP-MRI. The oncologist had not heard of that being used for PCa and when David asked about an f-18 bone scan, he was told they only do the TC99 bone scan which was not very useful. Fortunately through our forum, he learned about Dr. Mark Scholz of Prostate Oncology Specialist in Marina del Rey and went to see him. Dr. Scholz did recommend that he get an MP-MRI, which he did, He has now done other tests to verify that his cancer is confined to the prostate bed. He is in the process of deciding if he wants to radiate the area, perhaps get a biopsy of the area to confirm where it is, or do active surveillance since his doubling time is 15 months.

Ron spoke next, advising that he had just had his 6 year anniversary of coping with PCa and March is his 6 year anniversary of being involved with IPCSG. Ron has spoken to the group several times and wanted to updated us on his progress and learning. After 20 months on ADT (Androgen Deprivation Therapy--or Hormone Therapy) he discontinued it and has been watching his testosterone recover to a level of 400-500ng/dl. His PSA is still undetectable, utilizing the ultra-sensitive test, at <0.015ng/ml. He stressed the importance of the ultrasensitive PSA test--especially if you are experiencing or being treated for recurrence. When his testosterone was rising, he went from <50 to around 450 in a 5 week period and he felt as if he was going through puberty at high speed! As a matter of history, 6 years ago his PSA was 9.5 and a biopsy showed 5 cores positive with a Gleason 3+4=7. Many of the cores were high volume--70-90%. Within 2 months he decided on robotic surgery at Kaiser Permanente. Ten months later his PSA became detectable. He subsequently saw 6 different doctors, including those at Prostate Oncology Specialists, all of whom recommended salvage radiation. Being an engineer, he believed finding a target rather than radiating an area made more sense. He experimented with Avodart in hopes it would contain the rising PSA but had no success. When his PSA got to 1.0, he realized the had to do something. Thru research of DVD's from a PCRI Conference available from the IPCSG library, he learned about Dr. Almeida and Carbon 11 Acetate imaging. In Jan 2012, he had the imaging and in discussing the results with the doctor, it was pointed out that a lymph node was involved and that the usual salvage radiation would have been of no value. He experienced the mixed emotions of being happy he had not undergone radiation but then realized that he had metastatic cancer that needed to be dealt with. He consulted with Dr. A.J. Mundt at UCSD, but because of the contractual relationship of Kaiser with UCSD, protocol was to radiate the whole prostate bed and include the affected lymph node. He didn't want to do that so he decided to try medications to control the cancer growth. He went on Casodex and Proscar for a while, which worked fairly well for about 8 months after which the PSA began accelerating more quickly again.

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He visited with Dr. Mundt again who suggested getting another Carbon 11 acetate imaging test to see if changes had occurred. This test showed it was still in the same lymph node but it had grown about 25%. In the interim he had researched and decided to go on the Firmagon drug right after the second Carbon 11 acetate scan. After just a few days his testosterone dropped to undetectable and in a short while his PSA dropped from 3 down to 1.8 and was going down slowly by 25% per month. He decided to consult with Dr. Mundt again who, because of his relationship and discussions with Dr. Almeida, agreed to radiate just the affected lymph node. Because of his negative experience with some doctors and technicians, Ron requested to review the treatment plan for his radiation. Not feeling totally confident, he reviewed it with Dr. Mundt who agreed that it encompassed an area larger than desired. Finally a new plan was agreed upon and in November and December of 2013 he underwent focal radiation of the one lymph node. Not wanting to take a chance on cancer also being somewhere else, he continued the ADT therapy using Firmagon, during treatment. Five weeks after completing radiation he took his first PSA test which was undetectable---going from .5 before radiation to <0.015 afterwards. He stopped Firmagon in August of 2014 which took him back to the stage discussed in the opening of his remarks--testosterone 400-500, PSA undetectable.

Ron concluded by expressing his gratitude for support he has received from several prostate cancer support groups including IPCSG, He had to work hard to overcome the stress of experiencing the ups and downs of dealing with the cancer, going from a single, unattached man with no family nearby, to developing a new relationship with a lady friend. He now has developed and appreciates happiness--an unthought-of benefit of dealing with prostate cancer!

Bill spoke of his learning and decision to do no invasive treatment by following Active Surveillance. In mid-2009 he had applied for some extra life insurance which required a physical--including a PSA test. It came back at 4.1 with was over their standard (and the standard of many Urologists) of 4.0. If it had been 3.9 he would have been approved, but was rejected at 4.1. He re-tested at Kaiser Permanente and got a 6.0 reading. Not knowing what that meant at the time, his Urologist promptly advised that a biopsy was needed. As Bill succinctly states, he was put on the PCa conveyer belt, did a biopsy and was simply told he had cancer. He asked how much and how bad? Answer: of the 12 cores, 1 had a little bit of cancer in one. What would you like to do, surgery or radiation? He decided he wanted to do research to learn more about it. He discussed the situation with his wife, who at that time, thought that you must treat it--not research it. Kaiser did offer a personal consultation and also has a support group that he attended and got some useful information. In that group he met Ron (of the previous presentation) who suggested attending a meeting of the IPCSG group. He felt he learned a vast amount from the first meeting with IPCSG-the most important of which was to put on the brakes and not plunge into treatment as suggested by his urologist. He since learned he was low risk and did not need to be on the conveyor belt to invasive treatment. He met with a surgeon who, of course, said he was a real good candidate. He was relatively young and healthy so chances of failure were low. In the meantime he was learning and at a meeting with his urologist the words "watchful waiting" was weakly mentioned. So he looked into that and also picked up the book "The China Study" to learn about the benefits of a better diet. He has since become a vegetarian. With all this knowledge he decided on Active Surveillance in lieu of any invasive treatment. This meant you needed multiple tools in your tool box to be watchful. He saw Dr. Duke Bahn and underwent a Color Doppler Ultrasound test. Dr. Bahn advised there was involvement but that he didn't believe there was anything of clinical significance and told him to return in six months to check for any change, They now had a baseline. He did so and was told that his condition was essentially the same and to continue to do PSA's every 6 months, get DRE's and come back in a year. The next annual test brought the same result. Bill regressed to talk about the PSA rise to 6 when this all started. It want back

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down to the 4's and bounced around from there to 6 over time. When his Urologist saw the 6 he recommended a biopsy every year. Bill asked why and the Urologist did not intelligently respond. That Urologist has now retired and he has a new Urologist who reviewed his case and agreed that just watching it was a good thing. In 2013 when he visited Dr. Bahn he said he would like to do a biopsy. Bill asked for evidence as to why he should. Dr. Bahn said something had changed in the Color Doppler image and he wanted to do a biopsy to check it out. Bill reluctantly agreed. A targeted biopsy of seven needles was done in the exact area of concern. Nothing was found. He decided to send the biopsy samples to Kaiser to double check the result. Kaiser was totally surprised by the request but agreed to do it. They confirmed the findings and saw some PIN (mentioned earlier above) but nothing to worry about. At one point his PSA jumped to 7.5 at which his new Urologist calmly suggested re-testing sooner than 6 months and it came back in at 6.

To summarize, starting in June 2009 to the present Bill has been under Active Surveillance. He continues the 6 month testing and is considering adding to his tool box the Multi-Parametric MRI to verify his status. In reflecting back to where he was in 2009 and how he could have taken the recommended path at that time vs how his life has benefited from Active Surveillance, he credits learning from our support group and the support of his wife who has observed his growth of knowledge and now believes that the path he is taking is well founded.

Bill, we all wish we could take a ride on your ship!!.

If you would like to communicate with any of the presenters, contact: gene@ipcsg.org for contact information.

The foregoing only recaps the presentation of the 3 men. DVD's of this meeting. which includes the Q&A of each member, will be available by March 21st at the library or through the website: http://ipcsg.org/shop/

FUTURE MEETINGS

March 21st - CASE MANAGEMENT – WHAT YOU SHOULD KNOW. Presented by your Directors who total over 60 years' experience to help you become empowered

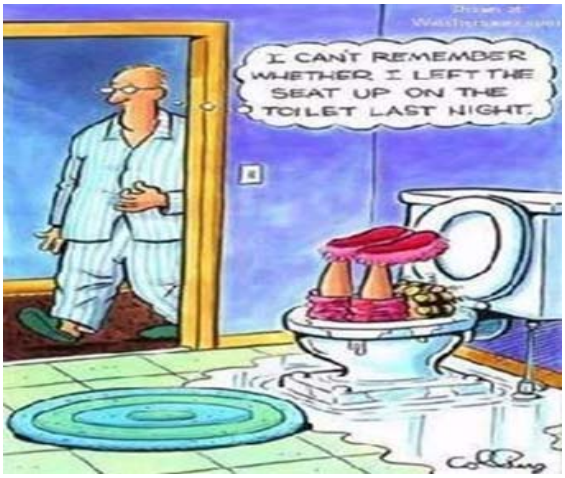
April 18th - Steven G Pratt M.D., F.A.C.S., A.B.I.H.M The role of nutrition and lifestyle in the prevention of disease and optimizing health. www.superhealthyliving.com

May 16th - No yet comitted

June 20th - T. Mike Hsieh, MD. Asst Professor of Surgery, UCSD. Sexual dysfunction including low testosterone and erectile dysfunction

July 18th - Donna Hansel MD, PhD, Division Chief of Anatomic Pathology UCSD and an expert in genitourinary pathology, will speak about the Gleason biopsy test.

ON THE LIGHTER SIDE



What do you get when you cross an elephant and a rhino? el-if-i-no

The fight we had last night was my fault, my wife asked me what was on the TV and i said dust.

When I told the doctor about my loss of memory, he made me pay in advance.

"I gotta 'A' in spelling." "You dope! There isn't any 'A' in spelling."

There's one thing good about being poor - its inexpensive.

“Some people say, “Never let them see you cry.” I say, if you’re so mad you could just cry, then cry. It terrifies everyone.” — Tina Fey

“Even if you are on the right track, you’ll get run over if you just sit there.” — Will Rogers

“It’s clearly a budget. It’s got lots of numbers in it.” — George W. Bush

“Come! Come sit by me. It’s a nice bench. Nice and lovely on the butt.” “You’re drunk.”
“Yeah, and you’re ugly, but do I complain about it? No! Because I don’t complain about things that I can’t change. That’s called intelligence.” — Sara Wolf, *Lovely Vicious*

“I went for a walk last night and she asked me how long I was going to be gone. I said, 'The whole time.” — Steven Wright

“It is one of the defects of my character that I cannot altogether dislike anyone who makes me laugh.” — W. Somerset Maugham, *The Moon and Sixpence*

INTERESTING ARTICLES

Active surveillance 'may be appropriate' for intermediate-risk prostate cancer

From Medical News Today Last updated: Sunday 22 February 2015 at 12am PST

Researchers have suggested that patients with favorable intermediate-risk prostate cancer could be treated with active surveillance, similar to the way in which patients with low-risk prostate cancer currently can be.

Active surveillance (AS) is a treatment method whereby the course of the cancer is monitored carefully, with an expectation to start treatment immediately if the cancer is found to progress. AS is currently considered for prostate cancer patients who have a life expectancy of at least 10 years and whose disease is considered to be low-risk.

In the study, published in JAMA Oncology, the researchers state that no direct comparison has been made between low-risk prostate cancer and favorable intermediate-risk prostate cancer pertaining to rates of prostate cancer-specific and all-cause mortality following courses of high-dose radiotherapy.

Such a comparison is relevant, according to the study authors, as AS is currently only considered appropriate for patients with low-risk prostate cancer per the guidelines of the National Comprehensive Cancer Network (NCCN).

If patients with favorable intermediate-risk prostate cancer have rates of prostate cancer-specific and all-cause mortality comparable to those experienced by patients with low-risk prostate cancer then AS could also be an appropriate form of treatment for them, allowing these patients to avoid the clinical risks that come with brachytherapy - a form of high-dose radiotherapy.

Currently, radiation therapy is the most common form of treatment for patients with all forms of prostate cancer. Another new study, also published in JAMA Oncology, reports that around 57.9% of prostate cancer cases are treated with radiation therapy, whereas only 9.6% of cases are treated with watchful waiting or AS.

"There remains an increased use of treatments in men diagnosed as having prostate cancer and underuse of active surveillance in men with low-risk disease. There is an increased use of radiotherapy among all risk groups and in particular patients with indolent disease with limited correlation according to tumor biological characteristics and patient health," state the authors.

'Similarly low mortality estimates' observed following brachytherapy

For the study concerned with the implications for AS in men with favorable intermediate-risk prostate cancer, Dr. Ann C. Raldow and colleagues analyzed data for 5,580 men with localized prostate cancer that were treated at the Prostate Cancer Foundation of Chicago from 1997-2013.

They calculated the estimated risks of prostate cancer-specific and all-cause mortality following brachytherapy and compared findings for patients with low-risk prostate cancer with those for patients with favorable intermediate-risk prostate cancer.

A total of 605 patients (10.84%) died during the follow-up period. Among these, 34 patients (5.62% of total deaths) died specifically due to prostate cancer. Overall, the authors report that the men with favorable intermediate-risk prostate cancer did not have a significantly greater risk of mortality compared with men with low-risk prostate cancer.

Specifically, 8-year estimates for prostate cancer-specific mortality were 0.48% for men with favorable intermediate-risk prostate cancer, compared with 0.33% for men with low-risk prostate cancer. Similarly, for all-cause mortality, the estimate was 10.45% for men with favorable intermediate-risk prostate cancer

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and 8.68% for men with low-risk prostate cancer.

"Despite potential study limitations, we found that men with low-risk prostate cancer and favorable intermediate-risk prostate cancer have similar and very low estimates of PCSM [prostate cancer-specific mortality] and ACM [all-cause mortality] during the first decade following brachytherapy," report the authors.

The authors urge that their findings should be interpreted with caution as they are based on data taken from a single institution and were not obtained from a randomized clinical trial. However, they also note that a randomized trial of AS against treatment is currently being conducted in the UK.

In a related commentary, Dr. Fred Saad of the University of Montreal, Canada, suggests that these findings require careful reflection:

"Although I am a urologist who has been practicing active surveillance for most of my low-risk patients for many years, I suggest that we continue to be very cautious, and extremely selective, in offering AS to patients with any features of intermediate-risk prostate cancer."

Statins May Help Improve Prostate Cancer Survival: Study

MONDAY, March 9, 2015 (HealthDay News)

Cholesterol-lowering statin drugs may slow down prostate cancer in men who are also taking medication to reduce their levels of male hormones, according to new research.

Taking a statin alongside androgen deprivation therapy slowed the progress of prostate cancer by about 10 months, said the study's lead author, Dr. Lauren Christine Harshman, an assistant professor at Dana-Farber Cancer Institute and Harvard Medical School.

"Patients on a statin have a significantly longer time to progression," Harshman said.

The study's findings were presented recently at a meeting of the American Society of Clinical Oncology (ASCO) in Orlando, Fla. Research presented at meetings is generally viewed as preliminary until published in a peer-reviewed journal.

The study did not prove a cause-and-effect link between statins and prostate cancer survival, just an association.

Prostate cancer feeds on male hormones, which are called androgens and include the commonly known hormone testosterone. Cancer doctors often treat prostate cancer by using medications to suppress androgen levels in a man's body.

Previous research has associated statin use with improved prostate cancer outcomes, said Dr. Charles Ryan, an ASCO expert and associate professor of medicine and urology at the Helen Diller Family Comprehensive Cancer Center at the University of California, San Francisco.

For the current study, Harshman and her colleagues reviewed medical data from 926 prostate cancer patients being treated with androgen deprivation therapy.

About 31 percent of the men were taking a statin at the time they began prostate cancer treatment. Researchers noted that statin users were less likely to be initially diagnosed with aggressive prostate cancer.

Tracking the men's progress, researchers found that statin users had about 27.5 months of progression-free survival on androgen deprivation therapy. Men not taking statins had about 17 months of progression-free survival, according to the study. The link remained statistically significant even after accounting for other factors, the study authors said.

There are a couple of potential ways that statins might affect prostate cancer, Ryan and Harshman said.

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The body produces male hormones "based on a cholesterol backbone," Ryan said. By reducing cholesterol levels, statins might cause a reduction in available androgens by inadvertently robbing the body of a key building block for those hormones.

On the other hand, statins might interfere with the process through which prostate tumor cells absorb male hormones, Harshman said.

Laboratory tests have shown that statins tend to crowd out androgens, beating them in line to be absorbed by prostate cancer cells, she said.

Follow-up research and clinical trials are needed to verify this effect, Ryan said. Additionally, he noted that in this study the men were taking statins due to high cholesterol levels, not to improve their cancer treatment.

"It's a good observation, but it still requires further study and validation," he said.

Harshman agreed that a randomized clinical trial is needed.

"The main thing is, what can you get out of this effect? How does it change therapy?" she said.

Activating the Mind/Body Connection

Posted in Prostate Snatchers blog 24 Feb 2015

BY RALPH BLUM

Once you have found a medical team you trust, and have decided which treatment option is best for you (and that may be no immediate treatment), the single most important thing you can do is take an active role in your own recovery. Respected psychiatrist and cancer researcher Dr. David Spiegel wrote, "Medicine has focused so much on attacking the tumor that it has tended to ignore the body coping with the tumor, and the social and psychological variables that influence the somatic response to tumor invasion."

As your immune system is the most powerful defense your body has against cancer, it is your task to do everything you can to support it. We all know that exercise and proper diet contribute to general good health and, therefore, to a healthy immune system. And most cancer survivors agree that vitamins and herbal supplements support maximum immune function and have made them a part of their recovery program. But your task doesn't stop there.

Research in the field of psychoneuroimmunology attests to the central role our emotions play in supporting our immune system and promoting healing. What you think and feel can directly impact your health. And it is generally agreed that the most potent immune suppressor is chronic emotional stress that floods the body with adrenaline and cortisone derivatives that interfere with the immune system's ability to seek out and destroy cancer cells. Of course this is a Catch 22, because a cancer diagnosis inevitably triggers a roller coaster of negative emotions—fear, anger, anxiety, resentment, grief, despair—all of which, when held onto, act to suppress the immune system. You can't expect to prevent these negative feelings. The trick is to acknowledge them, and then refuse to get stuck in them.

Blood tests have shown strikingly improved immune function among people who emote, and even those who confide their feelings to a diary show better immune function. Having an intimate group of supportive friends, or simply meeting with others in a support group once a week can improve your chance of recovery. Practicing simple meditation and visualization (there are dozens of pre-recorded guided imagery and relaxation tapes available) supports your immune system and promotes healing. And then there's my favorite immune booster: laughter. When you laugh, natural killer cells increase, as do T cells

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and B cells that make disease-fighting anti-bodies. So whatever other supplements you take, be sure to include laughter.

Above all, the will to live, a sense of optimism, and your belief in your chosen treatment play a huge role in your recovery. Combining the will to live with hope—the deeply confident expectation that you can beat this cancer—has a profound healing effect.

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.

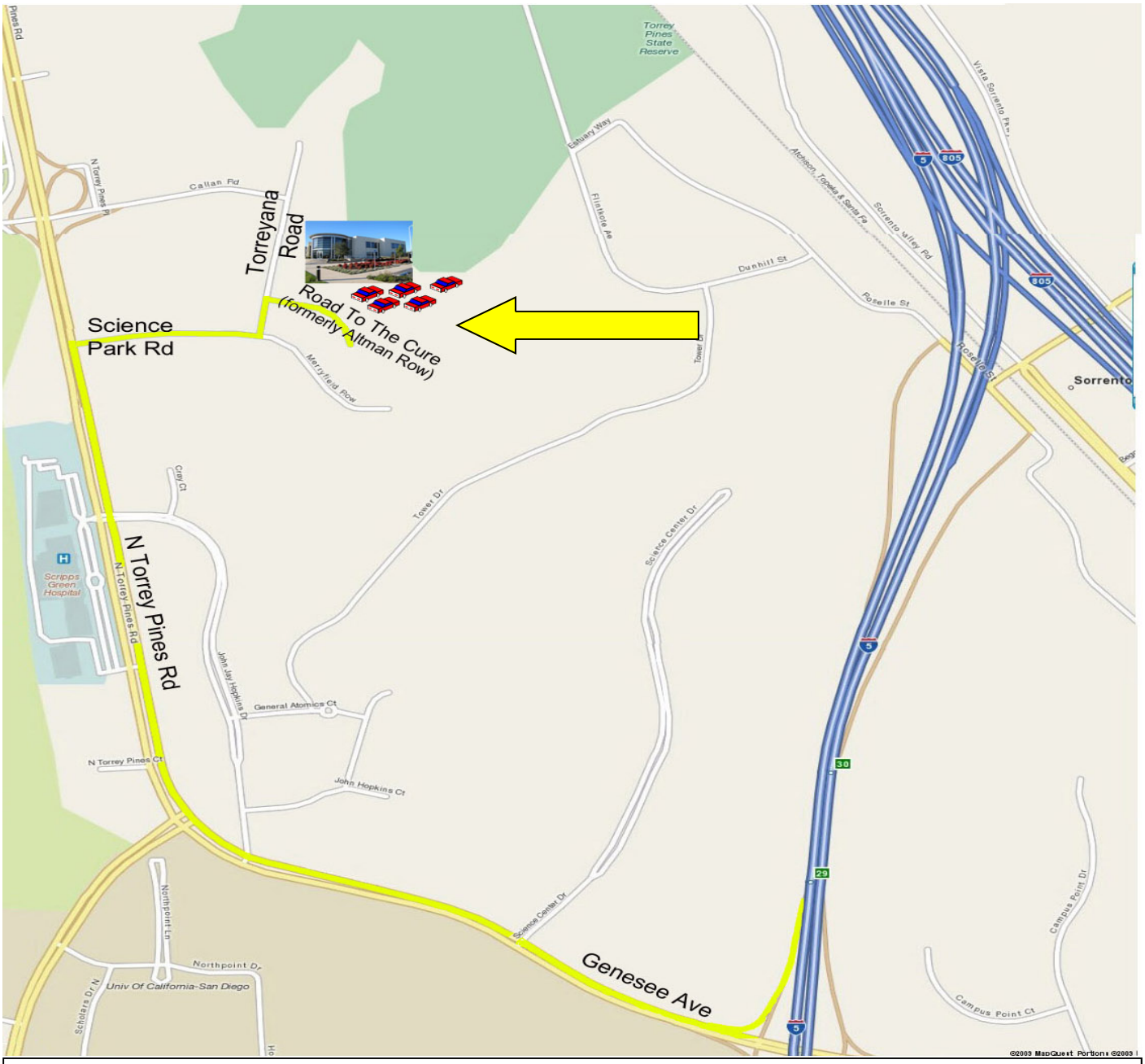
Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them

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 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).