



Informed Prostate Cancer Support Group Inc.

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



September 2017 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: <http://ipcs.org>

We Meet Every Third Saturday (except December)



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Next Meeting

Sept 16, 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

PROSTATE CANCER - 2
WORDS NOT A SENTENCE

Monday, September 11, 2017

Volume 10 Issue 9

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

August 19 Round Table. A panel of members talked of their experiences followed by questions and answers.

Members' Experiences:

1. **Stephen Pendergast**, age 71, retired engineer, from Rancho Penasquitos, still consulting and teaching. Current status: He has metastatic (Stage 4) hormone-sensitive prostate cancer, with a PSA of 0.16 on Lupron and Zytiga, and feels OK except for normal side effects of medications; mainly hot flashes and fatigue. He had periodic PSA tests after age 60, with BPH and frequent urination. Five years ago, his PSA reached 4.2, and a 12-core biop-

Video DVD's

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

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

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Editor: Stephen Pendergast

sy (it REALLY hurt, and should be done with better anesthesia) showed only one core positive, with Gleason = 6. He began attending IPCSG meetings, and decided on active surveillance. In retrospect, he would have preferred the new approach of mp-MRI scanning and MRI-guided biopsy (which is almost painless) instead of the traditional 12-core “random” biopsy. Two years later, his PSA reached 7.7, and his DRE was abnormal. Another standard biopsy was performed and showed full gland involvement, with Gleason now = 8. An MRI showed capsule extensions. A bone scan was negative.

Details from the biopsy cores showed that the original Gleason = 6 area still showed the same result, but much of the rest of the prostate had developed Gleason = 8 disease. (Note: visiting speakers to the group have said that Gleason = 6 never changes into Gleason = 7 or higher, but Stephen’s experience shows that a higher-grade cancer can arise separately, so PSA data needs to be watched closely. Nowadays, the mp-MRI scan would help with monitoring.)

He considered radiation and surgery, and selected Dr. Kane at UCSD for robot-assisted prostatectomy. First he waited 6 months for Lupron to bring his PSA down, and because his doctor wanted his biopsy scars to heal. The surgery (2 days in the hospital) revealed Gleason = 9, with full gland tumor activity, and positive margins. A Decipher genomic test showed he was at high risk for recurrence. He experienced 2-1/2 inches of penile shortening due to his urethra being cut and pulled up to reconnect, and had erectile dysfunction. He regained continence after removal of a catheter (done two weeks after surgery). After 6 weeks, he was able to resume activities at a gym.

One year after surgery, his (near-zero) PSA started rising. He took Trelstar to reduce his PSA prior to RT (a full course of salvage radiation therapy by EBRT at UCSD). Some transient constipation, but no other side effects. Unfortunately, the RT had nil positive effect! After the ADT wore off, his PSA continued to rise. The rate was very rapid. His PSA tripled in one month!

In January of this year, he had a C-11 PET/CT scan by Dr. Almeida, and the initial report was that the disease was still localized in the pelvic region (and perhaps suitable for more radiation), but re-evaluation of the images locally by Dr. Rossi resulted in a report that there were too many metastases among the lymph nodes for radiation to be an appropriate therapy. That was very depressing! Still no bone metastases. He felt the imaging was worth it, but expensive, at \$3,000. When his PSA reached 3, he went back on ADT. UCSD switched him from Lupron to Trelstar, but without explanation.

He switched to Prostate Oncology Specialists, not wanting to just do simple ADT until it failed. They did bone density and a cardiac stress test, finding no problems from his ADT to that point. He then started Lupron + Casodex, but a month ago, switched to Lupron + Zytiga and Prednisone. Regarding Zytiga: It’s made by Johnson & Johnson, and they have a foundation that helps people without insurance, to receive the drug at almost no cost. He’s paying (much higher) copays with his insurance. Cash price is \$10,000 per month.

The first systematic review of ADT + Zytiga and Prednisone involved 2200 “hormone-sensitive” men and showed it gave substantial improvement in overall survival and extended their time of freedom from progression of the cancer. Side effects were modest, but included some cardiac, vascular and liver toxicity. See [http://www.ejancer.com/article/S0959-8049\(17\)31110-3/fulltext](http://www.ejancer.com/article/S0959-8049(17)31110-3/fulltext)

Conclusions/recommendations: Keep going to IPCSG, keep good records, keep researching, and keep fighting. Be your own case manager, because your doctor has many other patients to deal with.

2. **Bill Bailey**, age 73, Rancho Bernardo, semi-retired IT executive, divorced with two grown children. He was diagnosed with prostate cancer in November 2012, and seven months later had his prostate removed. He has required no further treatment, with his PSA remaining essentially at zero.

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He focused for us on the emotional impact. He had been through a divorce, and had an excellent counselor. He was told to treat his situation as an adventure. That has helped with his cancer journey.

He had a life-long dread of cancer, since age 16 when his father died of lung cancer with tremendous pain. As the oldest of 3 children, he was a primary caregiver to help with his father's surgical scar and pain. He avoided anything related to cancer, including PSA tests. Finally at age 68, his cardiologist (whom he saw semi-yearly after a minor heart attack 20 years ago) convinced him to get the test. He was having pain when bike riding, but was still resisting getting checked. The result was 9.5, and a recheck to confirm the result, was 14.5. Scary-high! (Before surgery, his PSA went even higher: 19.5) He didn't like the first urologist's manner and poor communication. He had fear and anxiety. But his DRE was positive, so he promptly had a (painful!) biopsy, which showed 6 of 13 cores positive, and a Gleason score of 4+3=7. He was confused by mixed signals as to how serious his disease was.

Getting information is a key to reducing fear. An initial focus was on understanding the biopsy, Gleason scoring and the criteria for selecting a treatment path. His best sources of information were the monthly IPCSG sessions, dvd's of past meetings and prostate cancer conferences, white papers (such as one from Johns Hopkins on Prostate Disorders) and books such as "Invasion of the Prostate Snatchers."

His support system includes the IPCSG (learning to become your own case manager, and networking with others), family members (he leaned on his grown children for the first time in his life), "core" friends that have done things together over the years, counselor/therapist/minister/priest, and other groups (he's in 3 choral groups and two bible study groups).

The surgeon he was referred to was cold, abrupt, short on information and egotistical. The radiologist he consulted was friendly and informative and made him much more comfortable. He then had MRI and CT scans for treatment planning, and they were not worrisome as to the radiation involved. He was very anxious while facing a subsequent PET (whole body) scan that might have shown other cancers, but it came back negative.

A key discussion was an hour-long phone conversation with a friend of a friend, who was a retired surgeon. He recommended going ahead with the surgery, despite Bill's negative feelings about his surgeon. He felt calm, logical and productive during this talk, and during others with friends, and had a robot-assisted prostatectomy soon after.

The surgery was a breeze, and he was released the next morning with no pain. He did have erectile dysfunction and incontinence, and they continue today. Supposedly, there was only a 10% chance of incontinence, but his surgeon was very thorough about getting every last bit of cancer (six hours of surgery vs. typical three) and apparently damaged nerves during that effort. He kept a journal of his emotions and mood throughout the process, and it helped his attitude. If he had the same situation today, he would opt for radiation instead of surgery, because of less side effects.

Epilogue: Tumors in his liver and pancreas were suspected in 2013, but found to be Non-Hodgkins Lymphoma, which is very treatable. He had chemo, and there is no trace of that cancer now, after four years.

3. Darrell Dixon, age 77, Oceanside, retired Ford dealership VP, married with grown children. Current status: His Gleason score is 4+3=7, and his PSA is 1.5 and rising. He has had several prostate cancer metastases, all apparently gone or inactive now. He's being treated with Keytruda in a UCSD clinical trial. Feeling wonderful. Loves art, architecture, and automobiles. Plays tennis three times a week.

In 2011, he was found to have Lymphoma, and had a rising PSA, which was biopsied (painful!). Two

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years of treatment for the lymphoma yielded success. He joined IPCSG and was on active surveillance, but searching (then and continuing today), including a trip to Tijuana for herbs + cannabis and so forth. By 2014 his PSA had risen to 17, and radiation was planned, but then a bone scan showed a growth in his spine, confirmed by biopsy. So he switched to ADT, using Lupron + Casodex, and his PSA dropped to 0.2. He wishes he had done radiation sooner, before the cancer metastasized.

In January 2016, he entered a clinical trial at UCSD, taking a combination of Xtandi, Zytiga & Prednisone. Side effects were disturbing – he felt he was aging rapidly. After a month, a tiny tumor was found in his right clavicle lymph node, and it grew rapidly to golf-ball size. It was found to be prostate-related, and he was dropped from the clinical trial after 4 months. The then tennis-ball-sized tumor was irradiated by Dr. Mundt in 13 treatments, whereupon it shrank and disappeared within two months. He continued on Xtandi alone. Dr. Andrew Perry of Anti-Cancer, a tennis friend, offered to culture his cancer in mice to determine what drug(s) would cure it. Those results are yet future....

IPCSG presenters led him to get a very enlightening C-II scan from Dr. Almeida, and also to get Provenge immune therapy from Dr. Dato (with not much obvious effect). In January this year, a routine PET scan showed his lymphoma was still gone, BUT something suspicious that led to an immediate MRI and diagnosis of a ping-pong-ball-sized brain tumor behind his right eye. After the surgery, the tumor was gone, and he felt great. The tumor bed was irradiated.

Multiple subsequent scans led to finding an adrenal gland tumor, also prostate cancer related (but mutated, as was the earlier lymph node tumor). It recently disappeared. He is now on Keytruda (an immune system stimulator) in a UCSD clinical trial, and feels it may have helped with the adrenal gland tumor. His spinal spots are stable and may be irradiated later. No current concerns, and pleased with all the medical procedures, though wishing he had chosen radiation a year earlier. Supporting steps: Diet, exercise, spiritual growth including art and home projects, and family support.

Questions: Is there a local group of prostate cancer specialists, as an alternative to traveling up to Marina del Rey in the LA area? Several were mentioned, but they are mostly urological oncologists. Contact the IPCSG group leaders for suggestions.

In connection with a questions about C-II scans, it was noted that PSMA scans for biochemical recurrence now appear to be better than C-II. Stanford and UCLA have PSMA for clinical trials, at a cost of \$2400 at UCLA. UCSF does a simultaneous Gallium-68 CT and Gallium-68 MRI scan, and two members present said their scans were covered by Medicare.

Anyone who would like to discuss with the speakers, may contact Gene Van Vleet, genevanvleet@outlook.com or 619-890-8447, who will get them in contact.

ON THE LIGHTER SIDE



"I'll give you something for gas."



"Take one of these with water half an hour before you wake up every morning."



"Your X-ray showed a broken rib, but we fixed it with Photoshop."



"If you remember, I did mention possible side-effects."

FUTURE MEETINGS

September 16 - **ADVANCES IN RADIATION THERAPY**



Brent S. Rose, M.D.

Assistant Professor Radiation Oncology University of California San Diego.

Brent Rose, MD, is a radiation oncologist who specializes in treating prostate cancer, head and neck cancer, skin cancer, brain metastases and primary brain tumors. As a radiation oncologist, Dr. Rose uses carefully targeted, high doses of radiation energy to destroy or damage cancer cells. His expertise includes conformal radiation therapy (CRT), intensity-modulated radiation therapy (IMRT), image-guided radiation therapy (IGRT) and high-dose rate (HDR) and low-dose rate (LDR) brachytherapy.

As an assistant professor in the Department of Radiation Medicine and Applied Sciences, Dr. Rose instructs medical students, residents and fellows at UC San Diego School of Medicine.

Dr. Rose is a dedicated clinical researcher who has published over 30 journal articles and textbook chapters. His interest include developing advanced imaging and treatment techniques to improve the efficacy and reduce the side effects of cancer treatments as well as studying health outcomes data to better understand the risk and benefits of treatment and enhance shared decision making with patients and their doctors.

He is a member of several organizations, including the American Board of Radiology and the American Society for Therapeutic Radiology and Oncology.

A native of Southern California, Dr. Rose completed his undergraduate degree (B.S. in Biology) and Medical School (M.D.) at the University of California San Diego (UCSD). Following Medical School, he moved to Boston where he completed his internship in Internal Medicine at the Beth Israel Deaconess Medical Center and Radiation Oncology Residency at the Harvard Radiation Oncology Program.

After residency, Dr. Rose joined the UCSD Radiation Medicine and Applied Sciences faculty as an Assistant Professor where he specializes in advanced radiotherapy techniques for the treatment of genitourinary, central nervous system and head and neck cancers.

Dr. Rose's wife, Olga, is a pediatrician and they have a young son named Erik

INTERESTING ARTICLES

[Common Treatment for Early Prostate Cancer May Carry Heart Risk](#)

FRIDAY, Aug. 25, 2017 -- Because testosterone can help prostate tumors grow, men with prostate cancer are often given hormone-suppressing treatment.

But new research suggests that delivering the treatment in prostate cancer's early stages may, in turn, hike a man's odds for another illness -- heart failure.

The treatment in question is known as androgen-deprivation therapy.

The take-home message from the new study is that "patients with localized prostate cancer should be followed to minimize the health effects of androgen-deprivation therapy on the cardiovascular system," said study author Reina Haque. She's a researcher with the Kaiser Permanente Southern California Department of Research & Evaluation.

Haque's advice? "Patients should consider [heart-healthy] lifestyle changes, and physicians should actively monitor the patient's health for early signs of heart disease," she said in a Kaiser Permanente news release.

A prostate cancer expert who reviewed the study agreed.

This new data is important in deciding what treatment should be undertaken, if any, for early stage disease," said Dr. Elizabeth Kavalier, a urology specialist at Lenox Hill Hospital, in New York City.

Haque's research team noted that, in recent years, there's been an expansion in use of hormone-suppressing treatment for prostate cancer. The treatment was previously restricted to advanced prostate tumors, but now it's being given to a growing number of men with early-stage prostate cancer that has not spread to other parts of the body.

However, the safety and effectiveness of androgen-deprivation therapy for these men hasn't been investigated, the study authors said.

In the new study, Haque and colleagues assessed outcomes for more than 7,600 men with early stage prostate cancer. The investigators tracked the men for up to 12 years, starting when they were diagnosed

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between 1998 and 2008. The researchers factored in certain heart risk factors -- things such as overweight/obesity, history of smoking, diabetes, high blood pressure or if they required heart medications.

Initially, the men in the study were not undergoing any form of treatment but were being closely watched by their doctor to monitor the progression of their disease. But nearly 30 percent of the men did go on to receive androgen-deprivation therapy, the researchers said. Many of these men were younger than 60.

The study found the men with early-stage prostate cancer who did not already have heart disease, but who received hormone-depleting treatments had an 81 percent higher risk for heart failure.

Meanwhile, those who already had heart disease when they received the anti-hormone treatment also had a greater risk for heart rhythm problems, including a 44 percent increased risk of an irregular heart-beat.

These men were also three times more likely to develop "conduction disorder," which occurs when electrical impulses to the heart are interrupted.

One urologist experienced in the treatment of prostate cancer said that "there are two issues we need to look at to understand this report properly."

Dr. Nachum Katlowitz directs urology at Staten Island University Hospital in New York City. He said that, first of all, it's important to remember that "all treatments have risk."

"If androgen-deprivation therapy increases the risk of dying from cardiovascular disease, but decreases the risk of dying from prostate cancer, then we use it," he reasoned. "We watch for potential side effects. And sometimes, in select patients, the risk is greater than the benefit -- so we do not [advise the therapy]."

Secondly, Katlowitz said, the findings come as little surprise, since physicians have long known that the suppression of testosterone can raise a man's odds for common heart disease risk factors.

"To summarize, yes, androgen-deprivation therapy has risk," he said, but so does the option of not providing the treatment in men with prostate cancer. "It is up to the doctor working with the patient to decide if the benefits are worth the risks and side effects," Katlowitz concluded.

Study author Haque agreed.

"The findings allow men with localized prostate cancer to consider the positive and negative effects of androgen-deprivation therapy and discuss it with their physicians," she said. "If they move forward with the therapy, patients should work with their physicians to adjust their lifestyle to reduce the risk of cardiovascular disease."

The study was published Aug. 24 in the British Journal of Cancer.

The American Cancer Society has more about [hormone therapy for prostate cancer](#).

Statement from President Donald J. Trump on National Prostate Cancer Awareness Month

<https://www.whitehouse.gov/the-press-office/2017/09/01/statement-president-donald-j-trump-national-prostate-cancer-awareness>

During National Prostate Cancer Awareness Month, I join my fellow Americans in supporting those who battle prostate cancer and reaffirm our Nation's commitment to making this a world free from cancer.

We have good reason to be hopeful about overcoming prostate cancer. The rate of new prostate cancer cases in the United States has fallen nearly 6 percent on average each year over the past decade. During this same time, the rate of deaths due to prostate cancer has also fallen by more than 3 percent

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on average each year. Men diagnosed with prostate cancer are living longer lives than ever thanks to innovative research and improvements in cancer treatment. Our Nation applauds these ongoing efforts to enhance the lives of Americans and provide comfort and support in the fight against cancer.

Nonetheless, in fighting prostate cancer, we are still mindful that it remains the second leading cause of cancer deaths among men. My Administration remains dedicated to finding better diagnostic and treatment options through the 21st Century Cures Act, as well as research collaborations between the Department of Health and Human Services, private industry, and the academic community. In addition, the National Institutes of Health is investing in research that will improve upon current approaches to combatting prostate cancer. Through these efforts and others, American men can experience a healthier future.

This month, I encourage men to talk with their healthcare providers about their risk for prostate cancer. I also call upon all Americans to do their part in raising awareness of this disease. We pray for Americans currently fighting prostate cancer and recognize the progress yet to be made in finding its cure.

[Decision aids and decision-making in prostate cancer risk](#)

<https://prostatecancerinfolink.net/2017/08/30/decision-aids-and-decision-making-in-prostate-cancer-risk/>

Posted on August 30, 2017 by Sitemaster

While electronic and other decision aids can be helpful in providing men with information and education about prostate cancer, their value in helping them to make the best decisions is less clear. A newly published report by Stamm et al. in the Canadian Journal of Urology [<https://www.ncbi.nlm.nih.gov/pubmed/28832310>] appears to support your sitemaster's concerns.

Stamm et al. conclude that: Providing patients [with a decision aid] without a personal interaction [with a knowledgeable clinician] resulted in a greater chance of undergoing PSA-based screening without improving knowledge about screening or understanding of the consequences of this decision. This effect was exacerbated by a shorter term provider relationship. With complex issues such as the decision to pursue PSA-based prostate cancer screening, tools cannot substitute for direct interaction with a trusted provider.

In assessing the results of this study, it is important for experienced patients and advocates to remember that the vast majority of men, when faced with their first opportunity to consider whether they should have a screening PSA test, have almost no knowledge about the potential implications of such a test at all. Nor have they usually accumulated the information that would guide them about the subtle implications involved in the results of such testing. And this is one of the inherent problems associated with shared decision-making too.

Shared decision-making about having a PSA test to assess individual risk for prostate cancer is now encouraged by the American Urological Association and by the Choosing Wisely initiative; it is also encouraged by the new draft guidance issued by the US Preventive Services Task Force (which is still to be formally finalized). However, the process of education and SDM takes time, and is therefore challenging for clinicians, most of whom (and particularly primary care providers) are under constant time constraints and have constant competing patient priorities.

Your sitemaster is in complete agreement with the conclusions drawn by Stamm et al. — that a decision aid without a thorough discussion with a knowledgeable clinician — is probably far from helpful when it comes to the decision about whether or not a particular man should have a PSA test to assess his risk for prostate cancer. We also understand why the length of the relationship between the patient and

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the clinician may be highly influential to the results of this study.

The decision whether or not to have a PSA test for risk of prostate cancer is closely related to what one might want to do when you get the results of that PSA test. And what one might do if the results of that PSA test were even slightly elevated is becoming more complex rather than less complex.

While your sitemaster is all in favor of the idea that those men who want to have PSA tests to assess their risk for prostate cancer (for whatever reason) should be able to and encouraged to do this (as and when it is appropriate), he is also of the opinion that, as a society, we still utterly fail to initiate education for men about risk for prostate cancer until it is far too late — with the consequence that all too many men rush into getting PSA tests with almost no real understanding of the implications or the potential consequences. This is a serious public health issue that needs to be better addressed.

For Additional Reading go to: <http://spendergast.blogspot.com/2017/09/prostatecancer-news-2017-09.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.

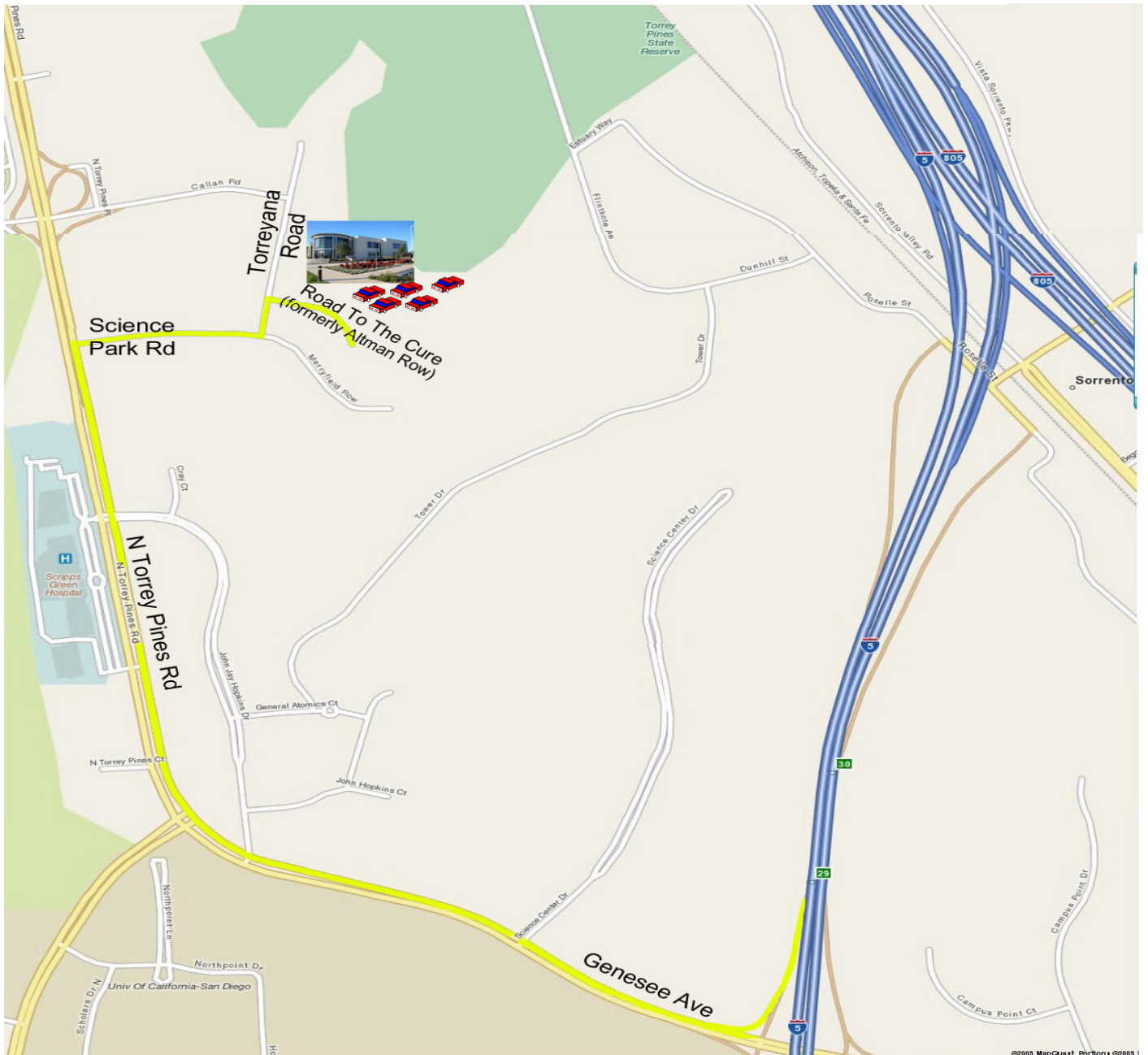
Ads about our Group are in the Union Tribune 2-3 times prior to a meeting. Watch for them.

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.