



Informed Prostate Cancer Support Group Inc.

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



July 2016 NEWSLETTER
P.O. Box 420142 San Diego, CA 92142
Phone: 619-890-8447 Web: <http://ipcs.org>
We Meet Every Third Saturday (except December)



Tuesday, July 05, 2016

Volume 9 Issue 6

Officers

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Gene Van Vleet
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Judge Robert Coates
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John Tassi, Webmaster
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Next Meeting

July 16, 2016

10:00AM to Noon

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

SEE MAP ON THE
LAST PAGE

**PROSTATE CANCER - 2
WORDS NOT A SENTENCE**

What We Are About

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

Be your own health manager!!

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Editor: Gene Van Vleet

SPECIAL NOTE

Gene Van Vleet has resigned his duties as Chief Operating Officer of IPCSG effective Aug. 24th. His duties included being editor of the newsletter. A volunteer replacement is urgently needed. Contact Lyle LaRosh, President, 619-892-3888 e-mail: llarosh@aol.com

RECAP OF LAST MEETING

By The Editor

The June meeting began with a short presentation by Patrick Olberg representing the YMCA LiveStrong Program. He was brought to us by ac-

Video DVD's

DVD's of our meetings are available in our library for \$10ea. Refer to the index available in the library. They can also be purchased through our website: www.ipcs.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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tive member Ron Abbott. Patrick presented a free 12 week health and wellness program for survivors already available at the Peninsula Family YMCA 4390 Valeta St. San Diego, CA 92107. POberg@ymca.org 619.226.8888 and Dan McKinney Family YMCA 8355 Cliffridge Ave. La Jolla, CA 92037 Jen Foley: JFoley@ymca.org 858.453.3483. More YMCA facilities will be involved soon. For complete information contact Patrick.

Two members presented their experiences. First up was Jim C. who made note of the value of the information he gathered from our group including personal conversations with men who had experienced types of radiation that he was most interested in. Two years ago his doctor felt irregularity during a digital rectal exam (DRE) and his PSA had reached a level of 6. He was referred to a Urologist who did a biopsy with the result of 6 out of 14 cores having cancer and a Gleason score of 4+3=7. He was told he was an intermediate risk. The Urologist talked up surgery, but Jim said he wanted a second opinion. He was referred to Dr. Mundt at UCSD. Dr. Mundt noted during their meeting that one of the cores was a Gleason 8 which led him to being really confused which made him realize he needed to arm himself with more information. With the help of his primary care physician he began investigating alternatives and for a period of about a year, his PSA did not change. Dr. Mundt referred him to our group from which he gathered a lot of information and learned from the blogs of Dr. Scholz and Mr. Blum which led him to get a second reading of his biopsy. His Urologist seemed uninformed about this request and nothing was done for several months. His helpful PCP referred him to a Urologist at UCSD and in their first meeting it was suggested he get a second reading of his biopsy! This was accomplished in two weeks and the result came back as a 4+3=7---no 8. He ended up choosing IMRT therapy with Dr. Mundt. It has been 6 months since he finished and his PSA is at 0.36. He stressed the value of finding a doctor you can trust. He made note of the value of exercise during and after treatment. He is an avid tennis player which minimized after-effects during and after treatment.

Next up was Jim E. who chose to talk about ProstVac, an immunotherapy drug that is not yet approved.

As a point of general information he said he was a Vietnam veteran and that the VA ruled that agent orange was a cause of many diseases including PCa and therefore anyone that served there is likely entitled to some benefits.

To trace his history when he was diagnosed with PCa, a biopsy showed a Gleason score of 3+3=6. He opted for surgery in the fall of 2002 and the pathology of the removed prostate determined that he had a Gleason of 9 and that the cancer was not confined to the prostate! The following spring, he underwent IMRT radiation therapy after which his PSA was 0.3. For the following 10 years he was on hormone treatment of Lupron plus Casodex. Two years ago the PSA began to climb and he underwent a bone scan and CT scan. The bone scan was clear but the CT scan showed an iliac tumor in his pelvic region of a size 2.1 X 1.3 centimeters.

At that point in time he was being treated by the VA and he thought his options would be one of two drugs: abiraterone (Zytiga) or enzalutamide (Xtandi). The VA works in conjunction with the UCSD Oncology Department. They led him to consider the ProstVac clinical trial. This trial is testing the viability of its vaccine to recognize PCa cells and then attack them. It is comprised of two vaccines. In the trial you would get injections of the two vaccines or injections of one of the vaccines plus a placebo or injections of 2 placebos. He asked why he should opt for this study given his condition. The response was that if his condition worsened he could drop out and seek other treatment. He chose to contribute to medical science and joined the trial. He started in June of 2012. It was a 6 month study with injections every 2 weeks at the facility and self-injections on a periodic basis. As it progressed, the injection timing

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widened to 4 weeks and it ended in December, 2012. A CT scan was performed in September, 2012 and his tumor measured 1.8 X 1.0 centimeters. Another CT scan in December measured the tumor at 1.6 X 0.8 centimeters. Every 6 months he goes to the UCSD Oncologist. He gets a bone scan every year, which have remained clear and he gets a CT scan every six months which, unfortunately, are showing that the tumor is growing and is now at a size a little larger than the first scan. It is now 2.3 X 2.0 centimeters.

He said he feels good so far and made note of the benefits of “eating what comes out of the ground and swims in the ocean”, but he does eat red meat on occasion. He exercises an hour every day.

His PSA has been gradually climbing to over 6. He is soon going to see his Oncologist and he will find out if it will be recommended that he be put on Zytiga or Xtandi.

The foregoing are recaps of the men’s presentations. Should you wish to talk further with either of the men, contact Gene @ 619-890-8447 email genevanvleet@outlook.com. The DVD of the meeting will included their complete presentations. 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.

FUTURE MEETINGS

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

August 20. Uncommitted.

September 17. Round Table. A panel of members talk of their experiences followed by Q&A, then break-out sessions by treatment type for networking.

October 15. - Fabio Almeida, M.D. Medical Director, Phoenix Molecular Imaging - Southwest PET/CT Institute, Yuma. Updates on Molecular Imaging and new clinical trials.

Nov 19. Richard Lam, M.D., Research Director, Prostate Oncology Specialists: Updates and recent treatment developments.

December. No Meeting.

FYI

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

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

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

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

ON THE LIGHTER SIDE



A recent study has found that women who carry a little extra weight live longer than the men who mention it.

Money talks ...but all mine ever says is good-bye.

I changed my password to "incorrect". So whenever I forget what it is the computer will say "Your password is incorrect".

It is much easier to apologize than to ask permission.

You're not fat, you're just... easier to see.

America is a country which produces citizens who will cross the ocean to fight for democracy but won't cross the street to vote.

If you think nobody cares whether you're alive, try missing a couple of payments.

Entered what I ate today into my new fitness app and it just sent an ambulance to my house.

Waking up this morning was an eye-opening experience.

A procrastinator's work is never done.

I used to think I was indecisive, but now I'm not too sure.

Whatever you do always give 100 %. Unless you are donating blood.

There are three kinds of people: Those who can count and those who can't

ALL ABOUT GLEASON SCORING

Interpreting A Pathology Report: 15 Biopsy and Gleason Questions Answered by a Leading Pathologist ,Jonathan Epstein, MD, Johns Hopkins University

Reprint from PCRI Newsletter

Patients should personally review their pathology report. The report is an expert description of the information obtained from the needle biopsy. Typically, a copy of the report can be provided by the treating physician.

Although a urologist will typically be the person who presents the results of the biopsy to the patient, the official pathology report is generated by a pathologist—such as myself—a specialized physician with many years of training in the study and diagnosis of specimens removed by surgery or by needle biopsy.

The major components communicated in the report are the Gleason grade, which is a measure of how aggressive the tumor looks under the microscope, and the quantity of cancer. The quantity is judged

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two ways: The number of biopsy cores containing cancer (assuming, as is usually the case, that the biopsy was performed using standard random techniques). For example, if only 2 of 12 cores contain small amounts of cancer, the quantity of cancer (the presumed size of the tumor) would be small. At the other end of the spectrum consider the situation where 10 of the 12 cores contain cancer and each core is more than 50% replaced with cancer. In this case, the presumed size of the tumor would be large. So, the quantity of the cancer within the prostate, as judged by the needle biopsy, is based both on how many cores contain cancer and the extent of the cancer replacing normal gland tissue within each single core.

The field of prostate pathology is immense and practically impossible to compress into a single article so to convey the basic elements of prostate pathology, the most efficient and concise approach is to address fifteen common questions I frequently encounter:

1. WHAT IS THE “GLEASON GRADE” OR “GLEASON SCORE?” WHAT DO THE NUMBERS IN THE GLEASON SCORE MEAN, FOR EXAMPLE, 3+4=7 OR 3+3=6?

The Gleason grading system assigns a pattern to the cancer cells depending on their appearance under the microscope, using numbers from 1 to 5. However, it is important to realize that in these modern times patterns 1 and 2 are only used very rarely. Therefore, on a needle biopsy, the pathologist almost always reports the grade as pattern 3, 4 or 5. A higher number is assigned by the pathologist when the appearance of the cancer cells deviates more from visual appearance of normal prostate gland tissue. For example: If the cancerous tissue looks much like normal prostate tissue, it is pattern 1. If the cancer cells and their growth patterns look very abnormal, it is pattern 5. Patterns 2 through 4 have features in between these extremes.

Since prostate cancers in a single patient often have areas with different grades, the first pattern, when assigning a “score,” is the most common pattern seen after review of all the biopsy specimens, i.e., the pattern that makes up most of the cancer seen in the biopsy. The 2nd pattern that is assigned is the one showing the next most common pattern. These two different grades are then added together to yield the Gleason score (also called the Gleason grade). For example, if the Gleason score is written as “3+4=7”, it means most of the tumor is primarily pattern 3 and to a lesser amount pattern 4. These two numbers are then added together to create a Gleason score of 7. If the tumor has only one pattern throughout the whole tumor, the same pattern is counted twice in order to keep the grade in scale. For example, a biopsy core that is involved by only Gleason pattern 4 would have a Gleason score of 4+4=8.

2. WHAT DOES A GLEASON SCORE OF 6 MEAN?

Gleason scores 2-5 tumors are very rare because they cannot be identified accurately on needle biopsy. So even though it is technically correct to say that the Gleason score can range from 2-10 suggesting that 6 would be “in the middle,” in actual practice, the Gleason score only ranges between 6 and 10. Therefore, a Gleason 6 actually represents the lowest grade (the most favorable) possible. Assigning the number 6 can lead to potential misinterpretation by patients. For example, Gleason score 6 cancer is almost always cured (see Table 1). Gleason score 6 cancers are so indolent that many men with these tumors are candidates for active surveillance. For this reason, I have proposed a modification of the Gleason score that more accurately transmits the favorable message about Gleason 6. On the other hand, most men with higher grade tumors will be recommended to undergo some type of treatment. Question #5 below expounds further on this proposal to revamp the way we report Gleason score. Full details of the proposal have been published in the medical journal called *European Urology* in September 2015.

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Table 1: Risk of PSA Relapse 5 Years Following Radical Prostatectomy, Based on Various Biopsy Gleason Scores.

Group 1	Gleason Score 6	5%
Group 2	Gleason Score 3+4=7	17%
Group 3	Gleason Score 4+3=7	35%
Group 4	Gleason Score 4+4=8	37%
Group 5	Gleason Score 9-10	76%

3. WHAT DOES IT MEAN TO HAVE A GLEASON SCORE OF 7?

A Gleason score of 7 can be made up of either 3+4=7 or 4+3=7, depending on whether the pattern 3 or pattern 4 is predominant. There is a big difference between these two grades. Table 1 shows the substantial difference in five-year cure rates. The biggest therapeutic difference between these grades is that more aggressive radiation therapy protocols are often given for Gleason score 4+3=7 and above.

4. WHAT DOES IT MEAN TO HAVE GLEASON SCORES OF 8-10?

Although Gleason score 8 cancers are aggressive, they are not as concerning as Gleason scores 9-10 tumors (Table 1). However, some patients with Gleason scores 9-10 patients can still be cured.

5. WHAT IS THE BEST WAY TO PUT ALL THESE DIFFERENT GLEASON SCORES INTO A CLINICAL CONTEXT?

The best and simplest way to get a sense of what the Gleason score is predicting about the future behavior of the tumor is by grouping them from 1 to 5 with group 1 having the best outlook and 5 having the worst. For example, Table 1 shows how these Gleason groupings predict cure rates with surgical treatment at a center of excellence. As can be seen, cure rates decline as the group number increases.

6. WHAT DOES IT MEAN WHEN THERE ARE DIFFERENT BIOPSY CORES WITH DIFFERENT GLEASON SCORES?

Different cores may sample different areas of the same tumor, or the cores may sample different tumors in the prostate (it is fairly common for men to have more than one tumor). Because the grade may vary within the same tumor or between different tumors, different cores taken from the prostate may have different Gleason scores. The highest Gleason score observed in a particular patient is selected for predicting prognosis and deciding therapy.

7. CAN THE GLEASON SCORE FROM A RANDOM BIOPSY REALLY TELL WHAT THE CANCER GRADE IS IN THE ENTIRE PROSTATE?

The Gleason score on biopsy usually reflects the cancer's true grade. However, in about 20% of cases, the biopsy underestimates the true grade, resulting in under-grading. This can occur because randomly directed biopsy needles occasionally miss a higher grade (more aggressive) area of the cancer. Under-grading is statistically more likely to occur in men with: 1) larger tumors, 2) higher PSA levels, and 3) smaller prostates.

Somewhat less commonly, the true grade of the tumor is lower than what is seen on the biopsy, resulting in over-grading. For example, studies show that 16% of cases with a Gleason score of 3+4=7 on biopsy, will end up having Gleason score 6 when the surgically removed prostate is examined. Discrepancies between the biopsy Gleason and the final Gleason after surgery may be caused by inaccurate over-grading of the biopsy specimen by an inexperienced pathologist, or because the actual quantity of pattern

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4 originally detected in the biopsy core turned out to be so small that it could not be found by the pathologist who examines the surgically removed prostate.

8. WHAT DOES IT MEAN IF MY BIOPSY REPORT MENTIONS SPECIAL STUDIES SUCH AS HIGH MOLECULAR WEIGHT CYTOKERATIN (HMWCK), CK903, CK5/6, P63, AMACR (RACEMASE), 34BE12, OR PIN4 COCKTAIL?

These are special tests that the pathologist sometimes uses to help make the diagnosis of prostate cancer. Not all cases need these tests. Whether or not the report mentions these tests, there is no effect on the accuracy of the diagnosis.

9. WHAT DOES IT MEAN IF MY BIOPSY MENTIONS THAT THERE IS “PERINEURAL INVASION”?

“Perineural invasion” means that cancer cells were seen surrounding or tracking along a nerve fiber within the prostate. When this is found on a biopsy, it means that there is a slightly higher chance that the cancer has spread along the nerves outside the prostate. Still, perineural invasion doesn’t necessarily mean that the cancer has spread outside the gland. Actually, other factors, such as the Gleason score and amount of cancer in the cores, are better indicators of cancer spread outside the gland. And even when tumor has microscopically spread out of the edge of the prostate, the majority of men are still cured.

10. WHAT DOES IT MEAN IF, IN ADDITION TO CANCER, MY BIOPSY REPORT ALSO SAYS “HIGH-GRADE PROSTATIC INTRAEPITHELIAL NEOPLASIA” OR “HIGH-GRADE PIN”?

“High-grade prostatic intraepithelial neoplasia” (or “high-grade PIN”) is a pre-cancer of the prostate. It has no importance whatsoever in someone who already has been diagnosed with cancer. In this case, the word “high-grade” refers to prostatic intraepithelial neoplasia and not the cancer, so it has nothing to do with the Gleason score or how aggressive the cancer is.

11. WHAT DOES IT MEAN IF MY BIOPSY REPORT ALSO SAYS “ATROPHY” OR “ADENOSIS” OR “ATYPICAL ADENOMATOUS HYPERPLASIA” OR “SEMINAL VESICLE?”

All of these terms are things that the pathologist sees under the microscope that are benign (not cancer). They are mentioned merely for completeness in the report because sometimes, to a physician with a less experienced eye, they might be misinterpreted as cancer. They are of no concern for the patient.

12. WHAT DOES IT MEAN IF IN ADDITION TO CANCER MY BIOPSY REPORT ALSO SAYS “ATYPICAL GLANDS” OR “ATYPICAL SMALL ACINAR PROLIFERATION (ASAP)” OR “GLANDULAR ATYPIA” OR “ATYPICAL GLANDULAR PROLIFERATION?”

All these terms mean that the pathologist saw something under the microscope that suggests cancer may be present. However, the actual evidence for cancer is insufficient to be conclusive. Finding any of these is of no relevance to the overall outlook if cancer has already been diagnosed in another part of the biopsy.

13. HOW DO PATHOLOGISTS MEASURE THE AMOUNT OF CANCER IN THE CORE?

There are multiple techniques used to quantify the amount of cancer found on needle biopsy. The most common are: (a) number of positive cores, (b) total millimeters of cancer amongst all cores, (c) percentage of each core occupied by cancer, and (d) total percent of cancer in the entire specimen. All of these different methods of measuring cancer volume on needle biopsy are tightly related with each other, such that it is difficult to demonstrate the superiority of one technique of measuring over the other. In general, a report which has the number of positive cores along with one of the other measurements is

sufficient.

14. HOW CAN I BE SURE THAT THE GLEASON GRADE IN THE REPORT IS ACCURATE?

Assigning the correct Gleason score is a skill just like any other that is developed through experience and practice. **It is often prudent to have the biopsy material referred for a second opinion at a reference center to confirm the accuracy of the initial Gleason score that was assigned.**

(Editor's note: There is none better than Dr. Epstein)

15. DOES GENETIC TESTING WITH PROLARIS AND ONCOTYPE PROVIDE ADDITIONAL USEFUL INFORMATION?

Preliminary studies seem to indicate that these tests can provide additional information about a cancer's future behavior in a minority of patients who are tested. It is possible that these tests may also have some value in "cross checking" the accuracy of the Gleason score that has been assigned, though, at this time, testing for this purpose has yet to be evaluated in a clinical trial.

CONCLUDING THOUGHTS

A few years ago, there was a news story about a polar bear attacking a man in Canada. Shockingly, the bystanders did nothing to help the poor man. Upon further review, however, it turned out that the reporter had neglected to report that the "bear" was only a cub, whose reach was lower than the man's knees.

When facing a monstrous behemoth like "cancer," the most important question to ask is "What kind of cancer am I dealing with?" With the currently available medical knowledge and technology, there can be no excuse for not knowing the exact grade of the cancer in order to make an informed treatment (or non-treatment) decision. Men facing a new diagnosis of prostate cancer should carefully scrutinize the pathology report and reflect carefully on its implications before rushing or being urged to make hasty treatment decisions.

Author Biography

Jonathan I. Epstein, MD, obtained a combined BA-MD degree from Boston University's 6-Year Medical Program (1975–1981). Following his residency in anatomic pathology at The Johns Hopkins Hospital in Baltimore, Maryland and a fellowship in oncologic pathology at Memorial Sloan Kettering Cancer Center in New York, he joined the staff at The Johns Hopkins Hospital and has been there his entire career. At The Johns Hopkins Medical Institutions, he is Professor of Pathology, Urology, and Oncology; the recipient of the Reinhard Chair of Urological Pathology; and Director of Surgical Pathology. He is the past President of the International Society of Urological Pathology. Dr. Epstein has over 800 publications in peer-reviewed literature and has authored 51 book chapters. He is the author or coauthor of 7 books including "Interpretation of Prostate Biopsies" which is in its 5th edition. More recently, he authored or co-authored "The Gleason Grading System: A Complete Guide for Pathologists and Clinicians" and "Differential Diagnoses in Surgical Pathology: Genitourinary System." Dr. Epstein has one of the largest surgical pathology consulting services in the world with approximately 12,000 cases per year, covering the full range of urologic pathology. He has lectured 349 times outside of his institution including 40 different countries.

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.

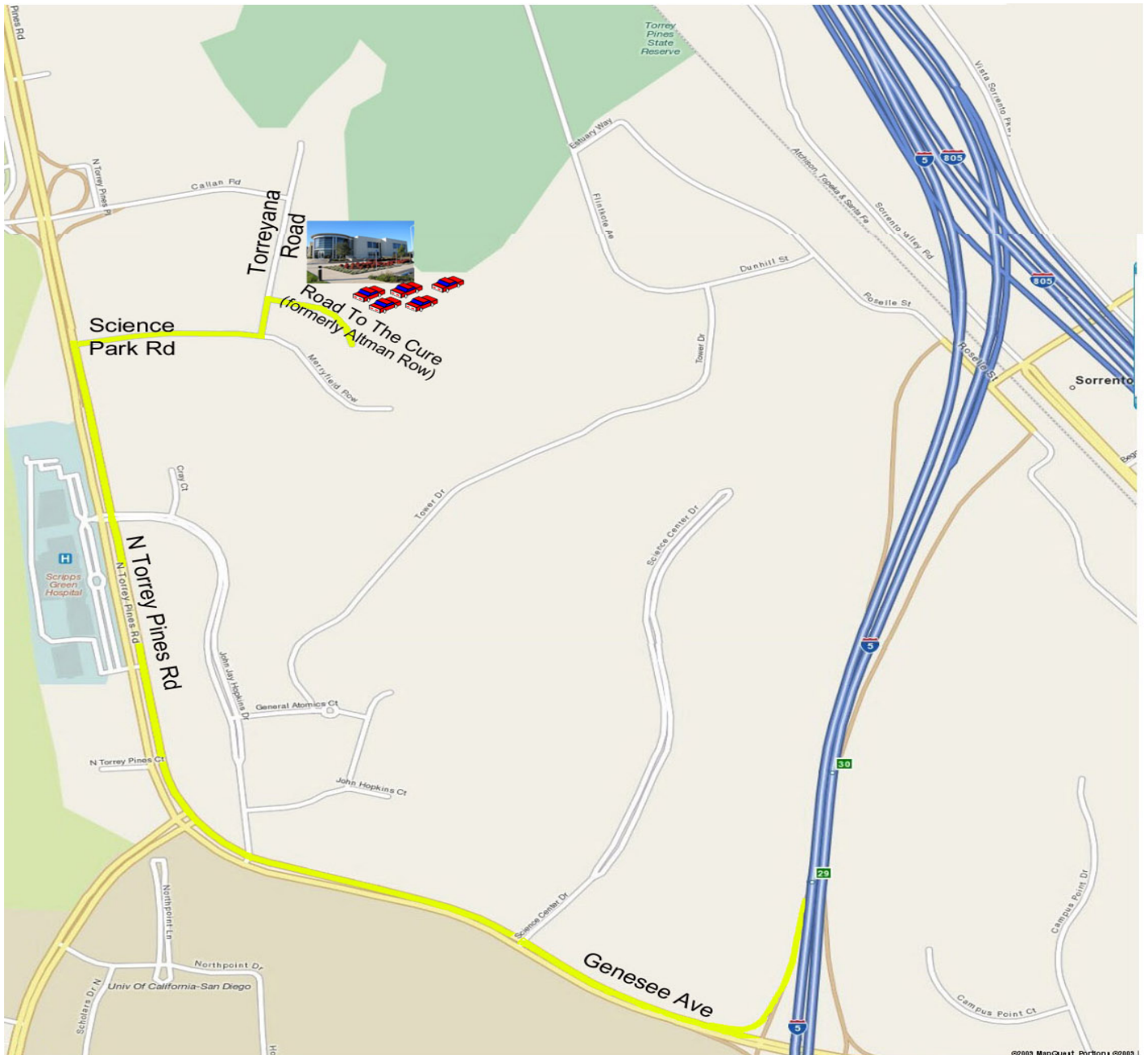
Ads about our Group are in the Union Tribune 2-3 times prior to a meeting. Watch for them.

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.