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

October 2014 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, October 11, 2014

Volume 7 Issue 10

Next Meeting
October 18, 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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PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

The September meeting began with President Lyle LaRosh presenting to Gene Van Vleet the national award for prostate advocacy bestowed by the Prostate Cancer Research Institute at its annual conference in early September. The annual award is given in recognition of a lay person for their accomplishments and personal attributes that show excellence in prostate cancer education, research, advocacy, and community support . Lyle LaRosh won this same award in 2009. The recognition of our leaders confirm that our support group is one

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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.

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of the most progressive in the nation.

The agenda of the meeting was for two men to tell of their experiences in dealing with prostate cancer (PCa) after which the group was divided into sections by treatment type for networking.

Leonard is 61 years old and has been dealing with PCa for 13 years. His last PSA was 0.03 and he feels good, works at a full-time job and visits a gym regularly. Shortly after the 9/11/2001 attacks, he took his 4 year old daughter to LEGOLAND for the day, carrying her around much of the day. Afterwards he experienced back pain which he mentioned to his family doctor during his physical the next day. He took a PSA test which came back 5.8, re-took the test which was 6.3 followed by another which was 6.9. Because of the rapid rise he was referred to a Urologist who did a biopsy which returned a Gleason score of 4+4 (pathology later rated it as 5+4). Treatment options were discussed and Len spoke of his feelings of uncertainty and fear at this time. He asked if had metastasized and was told there was a 20% change that it had. He asked how long he might expect to live and was told 1-2 years!! He was told that chemotherapy wouldn't help and surgery was the answer. He did the surgery and recovered reasonably well, removing the catheter after 3 weeks. He did experience incontinence. 4 weeks after surgery his PSA had only gone down to 1.1 indicating the surgery was not totally successful. He then went to an Oncologist who helped develop a treatment plan. It started with a 4 course treatment of Taxotere. This was in 2002. After the second treatment his PSA began climbing slowly so he started androgen deprivation therapy (ADT) using Zolodex injections every 3 months for the next 2 years during which his PSA remained about 0.0. He then took a 2 year "vacation" from Zolodex at the end of which the PSA began to climb again. Disappointed, he wanted another opinion and went to Sloan Kettering in New York. They found metastasis in lymph nodes and raised his staging from T2 to T3. He went back on ADT for the next 6 years and his PSA stayed near 0.0. Then in 2012 his PSA began to rise again and in September 2013 it had risen to 14.91. His doctor recommended starting a new drug Zytiga which a regimen of 4 pills per day plus 2 pills per day of prednisone to help overcome steroid loss. After 2 months, his PSA dove and in December he started Provenge immunotherapy which is a treatment to help your own immune system to fight cancer cells. It is comprised of 3 treatments 2 weeks apart. Each treatment starts with a 3 hour session to remove white blood cells which are couriered to a Dendreon processing factory in Seal Beach, where dendritic cells are added. Within 3 days, the treated white cells are infused. He had no reaction following the 1st infusion, experienced a high fever following the 2nd treatment and had only a minor fever following the 3rd treatment. The issue with this treatment is that there is no measurement of how well it works but the clinical trials showed it did extend life. Currently his PSA is around 0.0, he is still using Zytiga and his daughter is now 17---an age that in the beginning he never thought he would see!!!

Paul is 68 years old. He was first diagnosed 3 years ago. He uses no prescription drugs, blood pressure is always good, he is physically active and eats well. 14 years ago his wife dealt successfully with breast cancer. He doesn't like doctors and put off PSA testing. 3 years ago during a physical his PSA was a little high at 5.4 and he was directed to a Urologist. He was told he should do a biopsy but he decided to put it off and began doing research. He and his Urologist agreed to watch it for a while by doing PSA tests every 3 months. Three months later his PSA had moved up to 6.0, then 6.6 so the urologist suggested a biopsy again. He was still reluctant to do a biopsy, so a pca3 test was suggested which is a urine test which indicates a percentage chance of having PCa. The test results showed he had a 65% chance of having PCa so he agreed to do a biopsy which was about a year and a half after the first PSA test. They took 12 cores with a resulting score of Gleason 3+3=6. He was advised of treatment possibilities which included surgery, radiation and active surveillance (AS). He chose AS and did PSA tests every 3 months.

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His PSA had remained around 6.0 but about a year ago the test came in at 22.5. He was not able to get to see his Urologist for about a week which gave him time to assess possibilities. The new Proton Beam center at Scripps had just opened up so he investigated that alternative by seeing Dr. Rossi who spent over 2 hours discussing it with him. He became dubious when he noticed the facility had large empty rooms. So he read more about it and concluded it had potential issues. When he finally got to see his Urologist about the high PSA score, he was told it was probably an anomaly so he re-checked it 4 weeks later and it was back down to 6. Later it went down to 4.4. Through a friend, he was introduced to Lyle LaRosh, IPCSG's President. Lyle spent 3 hours with him and changed his life about the direction he was headed. Lyle gave him specific information about the disease and invited him to the support group meetings to share knowledge. He made some dietary changes. He learned that as many as 85% of men are over-treated which fortified his decision to continue with AS. He believes he has benefitted by chi gung, a method of exercising, breathing, and meditation to boost and use what is called 'life energy". He cautioned that you must be able to cope with the knowledge that you have cancer in order to be successful in staying with AS over time. Have faith that the longer you are able to stay with AS, studies and research will continue to improve survival rates.

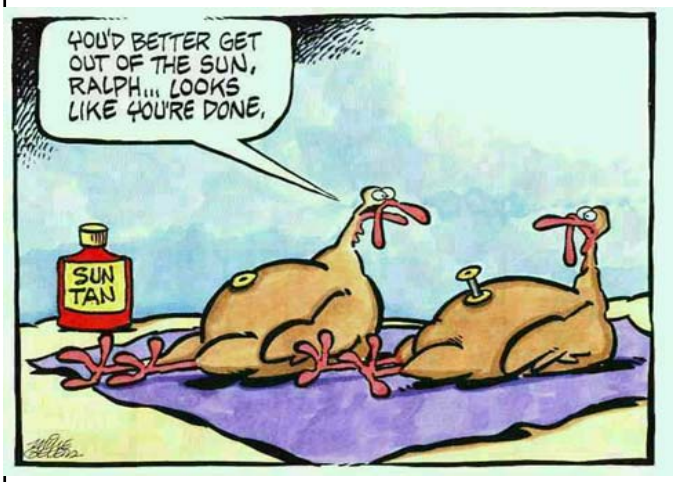
FUTURE MEETINGS

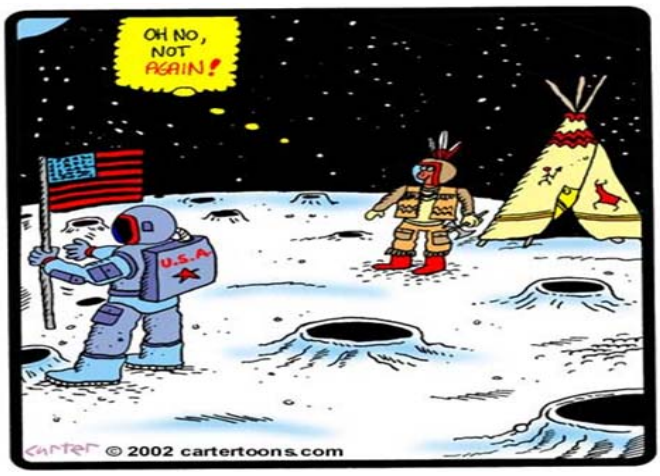
October 18, 2014 - A.J. Mundt, M.D., Professor and Chair, Department of Radiation Oncology UCSD, John P. Einck, M.D., Associate Clinical Professor Radiation Oncology UCSD: New radiation treatment modalities and current evidence to help you understand radiation options available

November 15, 2014 - Richard Lam, M.D. Research Director, Prostate Oncology Specialists: Androgen Deprivation Therapy and recent treatment developments.

December, 2014. NO MEETING

ON THE LIGHTER SIDE





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Ponderings:

Why is abbreviation such a long word?

How do you KNOW it's new and improved dog food?

What do they use to ship styrofoam?

What was the best thing before sliced bread?

We are born naked, wet, and hungry. Then things get worse.

Real advertisements:

Illiterate? Write today for free help.

Wanted: Hair-cutter. Excellent growth potential.

Auto Repair Service. Free pick-up and delivery. Try us once, you'll never go anywhere again.

One day a policeman stopped a motorist who had just gone through a four way stop sign and was about to give him a ticket when the motorist said. "Officer you can't give me a ticket for that!' "Why not" said the officer. "Because although I did not stop I slowed right down and its almost the same." "But you did not stop" replied the officer, "and the sign says STOP." "But the way was clear and it was safe" replied the motorist. The officer then pulls out his batton and starts hitting the motorist. "What are you doing!" yells the motorist in surprise. "Do you want me to slow down or stop" says the officer.

A red neck walks into a hardware store and asks for a chain saw that will cut 6 trees in one hour. The salesman recommends the top of the line model. The red neck is suitably impressed, and buys it. The next day he brings it back and says, "This chainsaw is defective. It would only cut down 1 tree and it took ALL DAMN DAY!" The salesman takes the chain saw, starts it up to see what's wrong, and the red neck asks, "What's that noise?

A successful man is one who makes more money than his wife can spend. A successful woman is one who can find such a man. - Lana Turner

For every action there is an equal and opposite government program.

INTERESTING ARTICLES

How to Cope with a Prostate Cancer Diagnosis

Posted: 07 Oct 2014 05:50 PM PDT Prostate Snatchers Blog

BY RALPH BLUM

There is no easy way to receive the news that you have cancer of any kind, but—and I cannot say this too often —it is important to realize that prostate cancer is typically not a death sentence. The majority of men diagnosed with prostate cancer have Low-Risk disease and will live a normal life span. And even more aggressive High-Risk type is now being successfully treated with a combination of therapies.

Having said that, a diagnosis of prostate cancer is daunting, and once you join the ranks of the newly diagnosed, you enter into what Mark calls "a medical minefield." While you are still reeling from shock you are required to make treatment decisions that can permanently affect your quality of life, and there are no easy answers. There are, however, a few basic things to bear in mind while you navigate the prostate cancer minefield.

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1) Don't waste energy asking yourself, "How did this happen? Did I bring this on myself?" Because regardless of your lifestyle—eating habits, exercise regime, or anything else that might contribute to getting this disease—you did not cause it. Prostate cancer is incredibly common. Like diminished sight and hearing, it comes with advancing age. In the words of one prostate oncologist, "If you are over seventy, and you don't have prostate cancer, chances are you're a woman."
2) Stay as calm as possible. The very process of gathering the information necessary to make an informed decision can be scary. But do not be panicked by all the numerical tables, statistics and graphs. Statistics measure populations. You are not a statistic. You're a person. And statistics and pathology reports do not take into account all the variables and intangibles that make you an individual.
3) Be proactive. The days of the passive patient with a "Whatever-you-say-Doc" attitude are over. The single most influential decision maker when it comes to obtaining the best care and treatment is you. Do your own research, and become actively involved with your doctor in the decision-making process. Ask your doctor about all your treatment options, and make sure you understand their short-term and long-term side effects.
4) Recognize and resist your natural desire to rush into radical treatment. Be aware that a combination of the urologist's preference for surgery and most men's "just get it out" attitude, leads to tens of thousands of unnecessary radical prostatectomies every year. These men would have lived just as long without surgery, without the risk of losing both potency and normal urinary function and greatly compromising their quality of life.
5) Even if you are satisfied with your urologist, it is critically important to get a second opinion, preferably from an independent board-certified medical oncologist—a cancer specialist—and if possible, an oncologist with a specialty in prostate cancer. Obtaining a second opinion doesn't imply that you don't trust your doctor. On a decision this important, you owe yourself the benefit of more than one person's thinking. Be prepared for conflicting opinions, and remember to trust your instincts about which doctor is right for you. Finding the right doctor may require traveling to a major cancer center to talk with a leading edge specialist.

Above all remember: if you are diagnosed with Low-Risk disease you do not require any immediate radical treatment. You can be safely monitored with "Active Surveillance." When you are watched closely, treatment can be safely delayed until there is some sign of progression.

Even then, the cancer will still be manageable. Multiple studies clearly show that survival rates of men on Active Surveillance match those of men getting immediate surgery. Also, be particularly careful if you are in your 70s or 80s. Men in this age group are rarely at risk of disease that will be clinically significant in their lifetime, and these men have the highest incidence of overtreatment. As you start out on your prostate cancer journey, be very aware that overtreatment of this disease is rampant, and do not become a needless victim of unnecessary treatment.

Blood test could identify when cancer treatment has become detrimental

From Science Daily September 17, 2014

Some treatments for prostate cancer, while initially effective at controlling the disease, not only stop working over time but actually start driving tumor growth, a major new study shows.

Researchers identified the emergence of drug-resistant cancer cells by testing repeated blood samples from patients with advanced prostate cancer.

They set out a new 'treatment paradigm' -- the constant monitoring of patients using a blood test for signs that therapy is becoming counter-productive.

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The study was conducted at The Institute of Cancer Research, London, The Royal Marsden NHS Foundation Trust and the University of Trento in Italy.

It was mainly funded by Prostate Cancer UK with support from the Movember Foundation and Cancer Research UK, and is published in Science Translational Medicine.

The research showed use of glucocorticoids -- steroid drugs often given alongside hormonal therapy -- coincided with the emergence of mutations that resulted in the drug becoming an activator of the disease rather than an inhibitor.

The results also provide robust evidence that 'liquid biopsies' analyzing tumor DNA circulating in blood could give an accurate picture of cancer development in individual patients.

The findings suggest that in future, men with advanced prostate cancer could be carefully monitored for circulating tumor DNA, allowing doctors to spot the emergence of dangerous mutations and alter treatments before they drive the disease into more aggressive forms.

The study, based on complex genetic analysis of biopsies and blood samples from 16 patients with advanced prostate cancer, shows that treatments can act as an evolutionary force on the population of cancer cells in a tumor.

Researchers were looking in particular for clues that glucocorticoids could favor the survival of cells containing androgen receptor mutations -- affecting how cells respond to hormones. They used repeat biopsies from tumors and analyzed circulating tumor DNA over time, monitoring the emergence of cancer cell clones containing each mutation.

In several patients, use of glucocorticoids coincided with the emergence of androgen receptor mutations and the progression of cancer into more advanced forms.

The study also showed that measuring circulating tumor DNA levels -- which is less expensive and invasive than taking repeated samples of tumors with needle biopsies -- could be used to monitor the emergence of treatment-resistant prostate cancer.

Study leader Dr Gerhardt Attard, Cancer Research UK Clinician Scientist at The Institute of Cancer Research, London, and Honorary Consultant at The Royal Marsden NHS Foundation Trust, said: "Our study showed that a steroid treatment given to patients with advanced prostate cancer and often initially very effective started to activate harmful mutations and coincided with the cancer starting to grow again."

"Our results introduce a new paradigm for the management of patients with advanced prostate cancer. In the future, we hope to routinely monitor genetic mutations in patients with advanced disease using just a blood test -- enabling us to stop treatments when they become disease drivers and select the next best treatment option. We need to confirm these findings in larger numbers of patients but using these types of blood tests could allow true personalization of treatment for prostate cancer patients, based on the cancer mutations we detect."

Professor Paul Workman, Interim Chief Executive at The Institute of Cancer Research, London, said: "Drug resistance is the single biggest challenge we face in cancer research and treatment, and we are just beginning to understand how its development is driven by evolutionary pressures on tumors. This important discovery reveals how some cancer treatments can actually favor the survival of the nastiest cancer cells, and sets out the rationale for repeated monitoring of patients using blood tests, in order to track and intervene in the evolution of their cancers."

Dr Matthew Hobbs, Deputy Director of Research at Prostate Cancer UK, said: "There are currently too few treatment options for men living with advanced stage prostate cancer. Not only do we desperately need to find more treatments for this group of men, we also need to understand more about when those that are available stop working and why. This research is important as it shows that there might be

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a new way to monitor how a man's cancer is changing during treatment and that could help us to pinpoint the stage at which some drugs stop being effective. In the future this could arm doctors with the knowledge they need to ensure that no time is wasted between a drug that stops working for a man and him moving on to another effective treatment.

"However, this is an early piece of research, carried out in very few men. We now need to see this tested in a bigger group of men to establish its true potential. Anyone currently taking medication for advanced prostate cancer should not stop doing so as a result of these findings, but should speak to their clinician or a Prostate Cancer UK Specialist Nurse if they have any concerns."

Nell Barrie, Science Information Manager at Cancer Research UK, said: "It's vital to understand the genetic twists and turns that offer tumor cells an escape route to become resistant to treatment. And this study provides an important first step towards working out how to use tumor DNA from blood samples as a way to monitor how prostate cancer evolves during treatment.

"Cancer Research UK scientists have played an important role in unravelling how groups of cancer cells can be genetically distinct, even within the same tumor. And these latest findings shed more light on how tumours evolve."

RNA biomarker may lead to urine test for prostate cancer

Last updated: Today at 8am PST Medical News Today

A new biomarker for prostate cancer has been identified that can be detected in tissue and urine samples. Researchers at Sanford-Burnham Medical Research Institute in Orlando, FL, have found a set of RNA molecules detectable in prostate cancer patients but not in men without this cancer. They publish their findings in The Journal of Molecular Diagnostics.

Currently, screening for prostate cancer consists of testing for high concentrations of prostate-specific antigen (PSA) in blood samples. These PSA tests are often followed by a biopsy to confirm the presence of cancer.

However, the PSA test is considered to be imperfect, and in 2013 the American Urological Association recommended against PSA tests being offered routinely.

Dr. Vipul Patel, medical director of the Global Robotics Institute at Florida Hospital in Orlando, explains:

"While elevated PSA can be an alert to a lethal cancer, it can also detect less aggressive cancers that may never do any harm.

Moreover, only 25% of men with raised PSA levels that have a biopsy actually have prostate cancer. Prostate cancer needs to be screened for; we just need to find a better marker."

The RNA molecules that the Sanford-Burnham researchers have identified are "long noncoding RNAs" (lncRNAs). Until recently, the usefulness of lncRNAs had not been appreciated by scientists, who dismissed the non-coding molecules as "non-functional noise in the genome."

lncRNAs are now believed to regulate cellular development. Evidence is also mounting that lncRNAs may contribute to a variety of diseases, including cancer.

ncRNAs were elevated in prostate cancer patient samples across three distinct groups:

- Human prostate cancer cell lines and normal prostate epithelial cells
- Prostate adenocarcinoma tissue samples and matched normal tissue samples
- Urine samples from patients with prostate cancer or benign prostate hypoplasia, and normal healthy individuals.

In each group, prostate cancer patients exhibited higher levels of lncRNAs compared with healthy

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control subjects.

"We have identified a set of lncRNAs that appear to have an important role in prostate cancer diagnostics," says Ranjan J. Perera, PhD, associate professor and scientific director of Analytical Genomics and Bioinformatics at Sanford-Burnham's Lake Nona campus in Orlando.

"The findings advance our understanding of the role of lncRNAs in cancer biology and, importantly, broaden the opportunity to use lncRNAs as biomarkers to detect prostate cancer," Perera adds.

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.

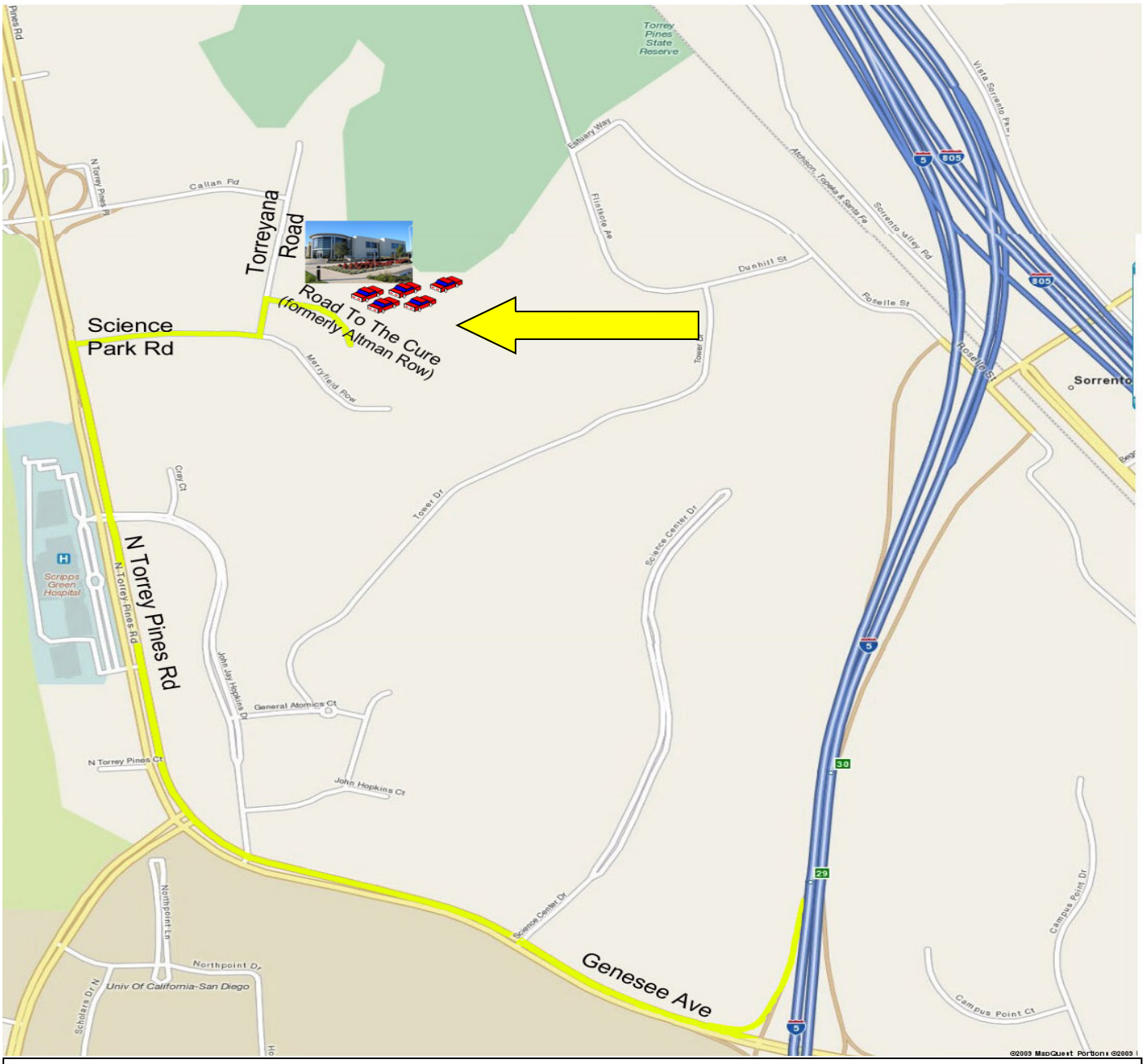
Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them

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).