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

SEPTEMBER 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)

Wednesday, September 09, 2015 Volume 8 Issue 8

Next Meeting
Sept. 19, 2015
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

The August meeting was well attended by 88 people to hear members speak of their experiences followed by break-out groupings to facilitate information gathering by networking with others.

In February 2011, Gary found that his PSA had risen to 4.5 from 3.6 so his doctor referred him to a urologist who performed a digital rectal exam and told him he needed a biopsy. He waited a while before doing the biopsy because he had read about prostate cancer being an indolent disease. He scheduled the biopsy in January, 2012. Prior to

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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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performing the biopsy, the doctor told him 80% of the people undergoing biopsy do not have prostate cancer. Three days later he was called about the biopsy and was told he had prostate cancer with a Gleason score of 3+4=7, putting him in an intermediate risk category. He first set up an appointment with a robotic surgeon who proposed they "go wide" (like in football?) meaning taking out the nerves and seminal vesicles as well as the prostate. This sounded unacceptable to him so he decided to get more information. His wife had been invaluable to him in his process thus far. She mentioned that her brother had prostate cancer and was a member of IPCSG. The first meeting he attended was a round table like this one from which he gathered much meaningful information including the need for additional testing. He went back to his doctor and asked about further testing such as Color Doppler Ultrasound. He was told that was not in the standards of care at Kaiser. Having had discussions with Gene following his first meeting he had learned of alternatives for medical care. He changed to Medicare Supplementary coverage through AARP which allowed him to see doctors of choice. He first saw Dr. Carol Salem, a prominent robotic surgeon and then went to Dr. Lam at Prostate Oncology Specialists. Dr. Lam ordered a bone density test, an MRI and a re-read of his biopsy results. Unfortunately the biopsy re-read came back as a 4+5=9--quite aggressive! This indicated immediate attention and Dr. Lam recommended he start on androgen deprivation therapy (ADT) right away. He started with a Firmagon injection, used to alleviate the testosterone spike usually experienced with the beginning of ADT using Lupron. That was followed a month later with a 90-day Lupron shot and he was taking Casodex daily. He spoke of the unfavorable side effects of ADT which included low libido, but recognized this was needed to contain the disease while on the path to determining the treatment best suited for him.

Dr. Lam explained the relative advantages/disadvantages of the different treatments and Gary chose to first do brachytherapy high dose rate (HDR) at UCLA which consisted of inserting radioactive seeds in the affected area through tubes penetrating the perineum. He spent the night there and the process was repeated the next day. This total process was then repeated one week later. A week after that, he saw Dr. Mundt at UCSD, had a stabilization mold made to stabilize him during IMRT. He began the treatment a week later. before each treatment he had to drink 16oz. of water to ensure the bladder was full and he had to make sure the rectum was empty. The treatment cycle took only about 1/2 hour and was repeated each week day for five weeks. Dr. Lam recommended that he continue ADT for 18 months afterward, but he decided to stop after 15 months on the theory that it would take some time for the medicines to work their way out of his system. For the first year after radiation he said his PSA was next to zero which he expected because of the ADT, but it has remained at that level for the next 2 years. Gary closed by recommending reading The China Study and changing your diet accordingly in order to give your body the best advantages to deal the disease.

Next up was Tom who spoke about his experience in deciding on Proton Beam treatment. He found he had an enlarged prostate early in 2014. With medication, he reduced the size somewhat but in early 2015 his doctor performed an ultrasound, a biopsy and a nuclear bone scan. In April he joined IPCSG and began to improve his knowledge of the disease. His doctor told him his Gleason was 4+3=7 and recommended that he do watchful waiting. After seeing an ad in the newspaper about Proton Beam therapy at Scripps, he decided to make an appointment to see what that was about. He was impressed with the facility and the friendliness of the people he met with. A week later he met with Dr. Carl Rossi (who spoke to our group-- March 2013 DVD). Dr. Rossi first recommended a CAT scan and an MRI, after which he drew out a plan and started the treatment sessions. There are to be 40 sessions done Monday through Friday. He had to drink 16oz. of water 45 minutes before his scheduled treatment. Each day they scanned the bladder to ensure is was more than 50% full. He had difficulty holding the 16oz, so Dr. Rossi

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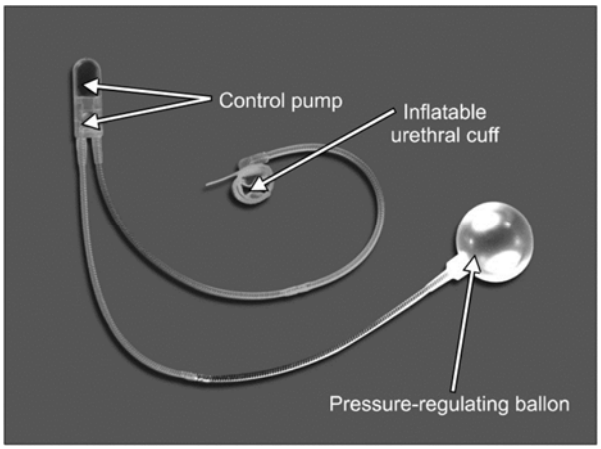
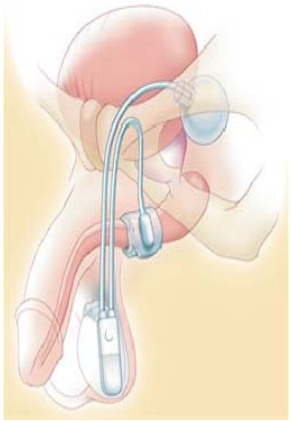
OK'd cutting back to 12oz. The treatments were covered by Medicare. He noted his wife had worked at Scripps which helped in the process. At the time of our meeting he had completed treatment number 27. He made note of the modern capability of the Scripps center which uses the "pencil beam" therapy which reduces the exposure to proton beams. He has not had any significant side effects--maybe a little bit tired on occasion. He read the advantages of Proton Beam therapy at Scripps which is "precise targeting, of cancerous and benign tumors, reduced radiation to vital organs and reduced radiation to healthy tissue". We hope to hear from Tom the results of the therapy once completed.

Next up was Chuck who spoke about the artificial sphincter. He had surgery in June 2010 which left him with incontinence issues. About three months later, he started physical therapy which reduced the problem to a level acceptable to him. He wore a pad to contain any leakage. About a year later, he had a recurrence of PCa so he did radiation therapy which he tolerated well, but about six months after that the incontinence returned very strongly. He tried physical therapy again and had some success in reducing the problem to about half of what it was but it was still more than acceptable. He pondered for quite some time about whether or where to do the sphincter implant surgery.





He described how it works. The control pump is in your scrotum. To urinate you press on the end of the pump which takes the pressure out of the inflatable urethral cuff allowing the urine to flow and it takes about two minutes for it to close down and go back into the reservoir or pressure-regulating balloon. He said it takes a while to get used to pressing the pump, taking two hands to do it initially, but after about a week he learned to use just one hand. He is too impatient to wait for the dripping to stop so he still wears a pad to catch the few drips that come out. He said you have to be a little careful if you sit on a chair with a hard edge because it may slightly activate the pump causing a small leak. Likewise you have to learn to be careful getting in and out of a car. After about a week he learned to overcome those issues. He was referred by Dr. Lam to Dr. Gary Leach in West Los Angeles who specializes in incontinence and Chuck is very pleased with the results. He and his wife spent the night before in a motel near Cedars Sinai Hospital, where the surgery was performed. He spent the night following the surgery in the hospital, and stayed in the motel the following night to continue recuperating and drove home the next day. Based on the success he has had with the device, he wishes he had done the procedure sooner. The procedure is covered by Medicare.

Dennis, a long-time member that provides valuable technical research information, informed us about issues he encountered in getting proper imaging for his son-in-law. He is 56 years old and had a progressing PSA for several years to 4.4 when he was referred to a Urologist. The Urologist said he needed

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to do a systematic (we call it random) biopsy which is firing 12 needles as follows: 2 in the top left, 2 in the top right, 2 in the center left, 2 in the center right, 2 in the lower left and 2 in the lower right. With this method they can sometimes hit the cancer, sometimes they can nick the margin of the cancer or the cancer can be missed. This procedure has been done for 25 years. New technology has come into use, called a multiparametric MRI (MP-MRI). With this technology they can image the prostate, find the suspected area(s) and target that area with the needle going right through the middle so that pathology can get a more exact determination of the cancer status. Dennis did not want his son-in-law to go through the "poke and hope" biopsy procedure and he finally got permission to go to another Urologist. The second Urologist checked his computer and found the information his son-in-law had gotten from the first urologist. He said he should do the biopsy right away because his PSA had jumped from 4.2 to 8.4 causing him great alarm. Dennis advised that he for sure needed to do the MP-MRI first. To do this he had to go outside his insurance system. He found a doctor (Dusing) that would give him a referral to Dr. Schwartzberg (DVD May 2015). Dr. Schwartzberg told him that with his procedures he could get a very accurate analysis of his condition and might find that he didn't even need a biopsy but could go on active surveillance (AS). The procedure was very much like a standard MRI. Dr. Dusing read the MP-MRI report and told him that all that was detected was some BPH, a little enlargement of the prostate and some prostatitis which likely explained the PSA rise. He said he didn't need a biopsy!! Henow had a baseline from which to compare future images to determine if his condition is changing.

Unfortunately the MP-MRI system is new and expensive, therefore not available through many Urologists. It becomes necessary to be very insistent to get a referral to get the MP-MRI.

Here is the list of DVD's in our library of doctors that do this type of imaging:

Dr Schwartzberg - May 2015
Dr. Princenthal - Oct 2013
Dr. Low - Mar 2014
Dr. David Karow - Jul 2014

Dennis also recommended Dr. Feller of Desert Imaging in Palm Desert under whom Drs. Schwartzberg, Princenthal and Low studied.

As always, be reminded that the foregoing is a recap of presentations. Should you wish to speak to any of the presenters, contact Gene at 619-890-8447 genevanvleet@outlook.com. DVD's of this meeting will be available by the September 19th meeting from our library and our website: www.ipcsg.org/shop/

FUTURE MEETINGS

Sep 19th - Franklin Gaylis, MD, FACS, Chief Scientific Officer, Genesis Healthcare Partners. Perspective on Active Surveillance and Genomics.

Oct 17th - Fabio Almeida, M.D. Medical Director, Phoenix Molecular Imaging - Southwest PET/CT Institute, Yuma. "Advances in Detecting Prostate Cancer in Bone and Soft Tissue." Dr. Almeida returns to speak about updates on Molecular Imaging and new clinical trials.

Nov 21st - Richard Lam, M.D., Research Director, Prostate Oncology Specialists: : Updates and recent treatment developments

December - No Meeting

ON THE LIGHTER SIDE

Better than rubbing sticks together!

What's the penalty for bigamy? Two mothers-in-law!

I found out why cats drink out of the toilet. My mother told me it's because the water is cold in there. And I'm like, how did she know that?--Wendy Liebman.

I told my psychiatrist I have suicidal tendencies. He told me to pay in advance--Rodney Dangerfield

GOLF BALLS THE SIZE OF HAIL--sign in front of a golf shop

PULL. If that doesn't work, PUSH. If that doesn't work, we're closed. Come again. On a post office door.

What's the shelf life of a shelf?--Jason Love

Actual items gleaned from resumes.

Wholly responsible for two failed financial institutions.

It's best for employers that I not work with people.

The company made me a scapegoat. Just like my previous three employers.

INTERESTING ARTICLES

High Cost of Pharmaceutical Agents

Posted: 18 Aug 2015 12:02 Prostate Snatchers Blog

MARK SCHOLZ, MD

In the last five years the prostate cancer world has been blessed with some incredible pharmaceutical breakthroughs--Zytiga, Xofigo, Xtandi, Provenge and Jevtana, just to name a few. All these new medications are proven to prolong life and improve quality of life. In my day to day life practicing as a prostate oncologist, I have seen with my own eyes how these new medications have transformed "hopeless" situations into genuine cancer remissions.

The extremely high cost of these new pharmaceutical agents, however, is a hot topic that I have addressed in previous blogs. A recent editorial from the Wall Street Journal addresses this issue with uncommon wisdom and aptly points out how potentially dangerous seemingly well-intentioned efforts to control costs can end up snuffing out the new drug development process.

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Please click on the link HERE to read this short and extremely well-written editorial: http://goo.gl/F7pG8w >>>>>

Be Careful What You Wish For
Blog | August 13, 2015
By Craig R. Hildreth, MD
"Doctors Object to High Cancer-Drug Prices"
— Wall Street Journal headline, July 23, 2015

"We economists don't know much, but we do know how to create a shortage. If you want to create a shortage of tomatoes, for example, just pass a law that retailers can't sell tomatoes for more than two cents per pound. Instantly you'll have a tomato shortage."

— Milton Friedman, Nobel Laureate in Economics

I read with interest a recent editorial[1] in Mayo Clinic Proceedings that called for a grassroots movement to lower cancer drug costs, signed by over 100 academic oncologists. The authors stated that "simple and measured incremental actions can improve the situation and allow market forces to work better." I was hoping they were going to call for simplifying and accelerating the approval process for new drugs, forcing companies with competing products to consider price when vying for market share. The first solution proffered, however, was to establish a "mechanism" to set a "fair price" for new treatments, a rather vague statement with minatory overtones. Letting a central committee determine the price of goods brings to mind the command economies of countries like Venezuela—not exactly a shining example of success.[2] It behooves us to recall how a free market adjusts to products marked down by fiat. The economist Thomas Sowell put it succinctly:

"A shortage is a sign that somebody is keeping the price artificially lower than it would be if supply and demand were allowed to operate freely."

Another idea floated by the editorialists is to pass legislation permitting Medicare to negotiate with pharmaceutical companies for lower drug prices. This power is currently used in the United Kingdom to deny coverage for treatments deemed too expensive to benefit the entire population; costly drugs are impeached for siphoning too much money away from too many to benefit too few.[3] If we take this line of reasoning to the absurd, having no product at all guarantees less expenditure on healthcare but how does this advance our quest toward the ultimate control and cure of cancer?

On the other hand, what would happen if pharmaceutical companies capitulate and lower the price of cancer drugs in return for allowing them on the market? This is the question that concerns me. As previously implied, establishing price controls whether by diktat or law subjects the transaction to one of the foundations of economics—the Law of Supply and Demand. Those who lived through President Nixon's wage and price freezes in the early 1970s can recall the meat and gasoline shortages they produced. If a company is forced to drop the price of a cancer drug, according to the law, the demand for the drug increases and the supply of the product decreases, leading to a shortage. If there no longer is any incentive to make the product, why go through the effort? Again, to quote Milton Friedman:

"The most important single central fact about a free market is that no exchange takes place unless both parties benefit."

I don't think we're about to dissolve the free market in this country, so it might be wise to consider the interests of both producer and purchaser—lest no exchange occur.

The editorialists are to be applauded for pushing for the right to purchase cancer medications from other countries, which would undoubtedly lead to lower prices for American product. Why not let cancer patients reap the benefits of competition in our global economy? Also, the concept of determining "the overall value of drugs and treatments in formulating treatment guidelines" is in my opinion the cor-

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nerstone of managing the rapidly expanding and costly armamentarium of cancer treatments. The value of a new drug should be obvious to all within 10 seconds of perusal—and not because it adds another measly 5 weeks of life. If this was baseball, "We only pay for extra base hits, not walks."

The high cost of new cancer treatments is both ridiculous and unsustainable, and kudos to the oncologists who have taken the lead on solving this problem. Just be careful when fighting "greed" by calls for regulation and price controls. I don't ever want to read about drug shortages or, even worse, pharmaceutical companies calling it quits (Atlas Shrugged, qv).

References:

1. Tefferi A, Kantarjian H, Rajkumar SV, et al. In support of a patient-driven initiative and petition to lower the high price of cancer drugs. Mayo Clin Proc. 2015;90:996-1000.

2. Gupta G. Business Insider. A clear sign that Venezuela's economy is decaying. Available at: http://www.businessinsider.com/headhunters-are-taking-advantage-of-venezuelas-decaying-economy-2015-8. Accessed August 13, 2015.

3. University of York. Research says approval of new drugs by NICE is 'doing more harm than good.' Available at: http://www.york.ac.uk/news-and-events/news/2015/research/nice-drugs-research/. Accessed August 13, 2015.

- See more at: http://www.cancernetwork.com/blog/be-careful-what-you-wish?GUID=4C4EB483-F403-4D85-828C-09018A51F759&XGUID=&rememberme=1&ts=14082015#sthash.yO9V7uCD.dpuf

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Study identifies five different types of prostate cancer

Published: Thursday 30 July 2015 Medical News Today

For the first time, scientists have discovered prostate cancer can be categorized into five different types - a finding that may prove to be "game-changing," according to a new study.

Prostate cancer only affects men and targets the prostate gland.

Prostate cancer is one of the most common types of cancer among men.

The findings, published in the journal EBioMedicine, may have important clinical implication for the future. Doctors can now hope to identify which tumors are present in patient's body and if they are likely to spread aggressively and grow.

This new knowledge could open up the path to more tailored cancer treatments.

Previously, prostate cancer could not be separated into subgroups. Due to this, treatments for the disease can often be inconsistent in effectiveness due to the wide range of reactions from patients.

Prof. Malcolm Mason, from Cancer Research UK, describes the difficulties of treating prostate cancer. He explains:

"The challenge in treating prostate cancer is that it can either behave like a pussycat - growing slowly and unlikely to cause problems in a man's lifetime - or a tiger - spreading aggressively and requiring urgent treatment. But at the moment we have no reliable way to distinguish them."

"This means that some men may get treatment they do not need," he continues, "causing unnecessary side effects, while others might benefit from more intensive treatment."

Prof. Mason says the findings could be "game-changing" if the same results are achieved in larger clinical trials. He explains:

"Ultimately this could mean more effective treatment for the men who need it, helping to save more lives and improve the quality of life for many thousands of men with prostate cancer."

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Prostate cancer is the most common non-skin cancer in American men and is the second leading cause of cancer death among white, African-American and Hispanic men in the US.

The American Cancer Society predict 220,800 new cases of prostate cancer and 27,540 deaths from the disease this year.

Treatment could be tailored based on a specific tumor

In 2010, scientists discovered breast cancer to be at least ten different diseases, each with its own unique genetic signature, using an integrated genomic approach in stratifying disease.

It was this landmark study that prompted researchers from the Cancer Research UK Cambridge Institute and Addenbrooke's Hospital in the UK to investigate if the same techniques can be applied to prostate cancer.

Fast facts about prostate cancer:

An estimated 220,800 new cases of prostate cancer will be diagnosed in the US this year

There are nearly 2.8 million American men living with the disease

The average age at the time of diagnosis is about 69.

The sample group consisted of 259 men, with samples of healthy and cancerous prostate tissue taken for examination. Scientists looked out for abnormal chromosomes and measured the activity of 100 different genes linked to the development of prostate cancer.

The study discovered five distinct types, each with a characteristic genetic fingerprint, much like the study in 2010 on breast cancer.

The method utilized by the study also proved to be more effective at predicting the most aggressive cancers, compared with the prostate-specific antigen (PSA) test and the Gleason grading system.

Study author Dr. Alastair Lamb, from the Cancer Research UK Cambridge Institute, hopes the findings here can be expanded to develop further our knowledge to treat the disease. He says:

"The next step is to confirm these results in bigger studies and drill down into the molecular 'nuts and bolts' of each specific prostate cancer type. By carrying out more research into how the different diseases behave, we might be able to develop more effective ways to treat prostate cancer patients in the future, saving more lives."

Medical News Today recently reported that management of the disease seems to have improved, according to a recent study. Health care professionals have encouraged a more "watchful waiting" approach as opposed to an aggressive treatment, such as surgery.

Although prostate cancer has affected millions, treatments for the disease are more effective than ever before. According to American Cancer Society, the most recent data claims the relative 5-year survival rate for all stages of prostate cancer is almost 100%. The 10- and 15-year relative survival rates are around 99% and 94%, respectively.

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.

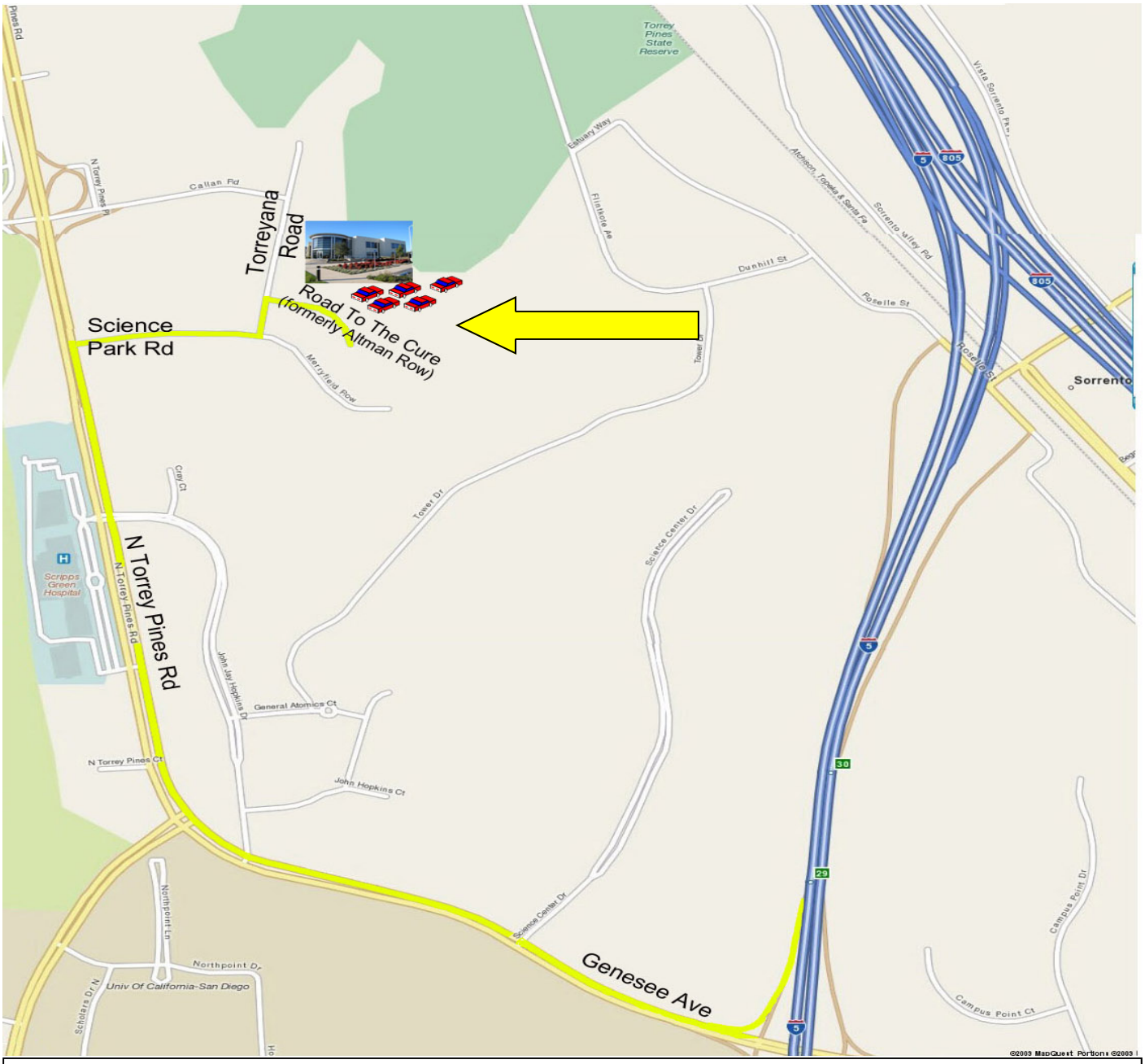
Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them.

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).