



Informed Prostate Cancer Support Group Inc.

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



MARCH 2016 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142
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We Meet Every Third Saturday (except December)

Friday, March 11, 2016

Volume 9 Issue 3

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Next Meeting

March 19, 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

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

PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

The February meeting was well attended by 110 men and women gathering to participate in a roundtable meeting where 3 men spoke of their experiences in dealing with prostate cancer (PCa) after which the audience was segregated by treatment type for networking.

Joe Duffy spoke about his journey in dealing with PCa. In May, 2005 his PSA was 2.4, taken during a physical exam. He noted that his PSA has never been above 4. Further, at that point in time he had no record of what his PSA had been over previous years. In June 2005 he noticed some blood in his urine. His GP gave him some antibiot-

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://ipcs.org> Click on the 'Purchase DVDs' button.

The DVD of each meeting is available by the next meeting date.

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ics but it didn't clear up so he was sent to a Urologist. He had a biopsy in September 2005 which gave a result of 3+3=6 in the left side. A seminal vesicle biopsy was negative. He brought his wife into his consultation and it was decided to start Lupron and Casodex as a precursor to radiation treatment. He was then referred to a radiation oncologist. At that time, ten years ago, a radiation treatment called Calypso was recommended. He felt uncomfortable with his association with that doctor, so he began seeking alternatives. After consulting with friends and others who had gotten prostatectomy treatment, he researched many noted sources, mostly outside San Diego, but ultimately asked himself why not see what was available here. Through doctor contacts he was led to the Chief of Surgery, Dr. Kane, at UCSD with whom he and his wife consulted. Another biopsy was performed with a result of 3+4=7. In February 2006, he had a radical prostatectomy. He had check-ups every 6 months and after almost 3 years was experiencing no incontinence or other side effects. Discussions with his Urologist included the word "Cured". But, in January 2009, his PSA jumped up to 0.12 and in June it was 0.23. During a physical exam a digital rectal exam was performed and a nodule was felt in the area where the prostate had been. Another biopsy was performed with the result this time of 4+3=7 which is higher risk than 3+4=7. He considered options and decided that radiation would be a good choice. In September 2009 he consulted with Dr. A.J. Mundt, Chief of Radiation Oncology at UCSD and they developed a program of salvation IMRT which was administered over 34 treatments. His PSA nadir in March 2010 was 0.05. His PSA began rising again and got up to 2.74 in February 2012. He then started Androgen Deprivation Therapy (ADT) with Lupron injections every 3 months. His PSA dropped to 0.01 or undetectable. In April 2012 he stopped the ADT treatment. His side effects from Lupron have been hot flashes, weight gain, fatigue and swelling of joints. In May 2013, his PSA rose to 0.3 then up to 1.2 in August. A CT and bone scan in September revealed an enlarged lymph node in the pelvic area so he resumed ADT. His sister lives in Houston and through contacts he decided to have an analysis performed at MD Anderson. He mentioned at that point the importance of keeping thorough records of your medical history, These were thoroughly reviewed at MD Anderson who concurred with the treatment path he had taken and sent their reports to the doctors here in San Diego. His PSA continued to climb and further CT and bone scans showed metastases in the spine and left shoulder. Through information he got from attending IPCSG, he learned of Dr. Lam of Prostate Oncology Specialists, who they went to see for an additional opinion as well as going to see Dr. Fabio Almeida at Phoenix Molecular Imaging in Phoenix to get the Carbon 11-acetate scan. Dr. Lam reviewed this as well as his prior history and recommended a course of action. He started Xtandi in August, 2015 as well as Zometa infusions every three months for aiding bone health. He changed his diet and began an exercise program 6 days a week which has improved how he feels, his enthusiasm and his outlook. His PSA has dropped from 1.94 to 1.6 the week of this meeting.

Lessons learned: Get annual PSA tests including DRE's; spread the word about the importance of getting PSA tests; be aware that all Urologist and Oncologists are not well qualified--find those that specialize in PCa; Biopsies are important, MRI guided are the best; take advantage of PPO insurance so you can see doctors of choice; keep detailed records; get involved with a support group; arm yourself with knowledge but beware of computer information which can cause overload and confusion; get second opinions; be your own case manager; bring someone with you to your appointments; remain positive and focus on the good things--don't let PCa ruin your life; maintain a good diet and exercise; understand that as you go along, you are taking your family and friends with you.

Next up, Jerry Ohlin told of a history of PCa in his family. His father was diagnosed at age 65 and died at the age of 72 after experiencing very painful bone metastasis. Jerry has been dealing with PCa for 12 years. In 2003 his PSA was at 3.3 and in mid-year 2004 it was 4.5. During a physical exam, his PCP de-

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tected a lump on his prostate and he was sent to see a urologist who performed a transrectal ultrasound with biopsy. The biopsy result was Gleason 3+4=7. Perineural invasion was also noted in the pathology report which indicates that through nerve paths the cancer had a way out of the gland. There was a high probability of seminal vesical and lymph node involvement. Thus in July, 2004 he formally found out he had PCa. He discussed options with his Urologist and his PCP recommended seeing another Urologist for a second opinion both of which agreed he was at high risk. He opted for a radical prostatectomy, being somewhat influenced by his father's experience and by research he had done. Also he felt that radiation could be performed after surgery if necessary, but not in the reverse order. In September 2004 he underwent a bilateral pelvic lymph node dissection and radical prostatectomy. The pathology of the removed prostate showed he had a Gleason 4+3=7 and it involved both the left and right sides of the prostate, but no positive margins were found. However he did have a tumor in the right seminal vesical. The lymph nodes that were removed were benign. He was released from the hospital after 5 days and used a Foley catheter for several weeks. He wore a pad until he gained confidence that he did have bladder control. He does have some incidents when he sneezes or when working out. He showed a PowerPoint slide that showed his tracking since his surgery. It showed his Gleason at 4+3=7 and PSA of 4.73 at time of surgery, dropping to near zero afterwards and then rising over the years to its highest point in September 2011 of 3.7. He then went to see Dr. Lam of Prostate Oncology Specialists who reviewed his records and gave him a color doppler ultrasound test, had him get a heart screening, full body bone scan, chest x-ray, and CT scan of the abdomen and pelvis. An indeterminate mass was found in his left seminal vesical so a CT guided needle biopsy was ordered which confirmed he had metastatic PCa there. The tumor was measured at 2.8cm in size. In June 2012 he began ADT which consisted of 3 injections of Lupron of 30 days duration followed by two 90 day injections and included Casodex and Avodart pills. He also did a six month injection of Prolia to counteract osteoporosis. Dr. Lam also recommended getting involved in a weight-bearing exercise program to also help reduce osteoporosis and he continues this program to date. His tumor reduced by one half and his PSA neared zero. After a year he took a "holiday" from Lupron and his PSA rose back up in a year to 3.1, his tumor increased to 2cm so he began the ADT treatment again in July 2014 which this time included 2 six month injections of Prolia. His PSA again went down to near zero and the tumor size got down to about 1cm. During the second round of ADT he began discussing the possibility of radiation with Dr. Lam. He considered IMRT and then met with Dr. Rossi about Proton therapy and decided to get that treatment in May 2015. His PSA has been tracking at 0.05 since that treatment and his last reading just before the meeting was 0.04. His insurance company paid most of the Proton therapy charges leaving him with minimal co-pays. He continues to have hope and should he experience recurrence, he plans to visit Dr. Almeida at Phoenix Molecular Imaging in Phoenix for the carbon 11 acetate scan to help identify treatment possibilities.

Herman Persaud has been observing Active Surveillance. He is 67 years old and has a family history of PCa and other cancers. He admitted he had a low confidence in PSA scores. At age 64 although his PCP recommended a PSA test, he did not do one because of insurance issues. At age 65 he did the PSA and it was 10.5. His PCP recommended that he see a Urologist to get a biopsy but he chose not to. A year later his PSA tested 11.2. He had just come off a cruise where "they tried to poison me" and his doctor gave him Cipro for infection. He decided that was the reason for the rise and did not go for a biopsy. At age 66 he did another PSA test which was 31. That got his attention. His PCP again wanted to refer him for a biopsy. He again refused but he began doing a lot of research as well as joining the IPCSG group. One meeting he attended was the presentation by Dr. Schwartzberg of Imaging Healthcare Specialists

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about Multi-parametric MRI imaging. He decided to call him and was told the procedure would cost \$600 if insurance did not cover it. He did the MP-MRI on October 20, 2015 after which his PCP called to advise he has a tumor on the right front apex of his prostate and this time told him to let him know what he wanted to do about it. Now he knows he has a tumor, so he wants to know if it is slow growing or not. After doing more research he decided to do an MRI guided biopsy and had it performed October 23rd, also at Imaging Healthcare Specialists by Dr. Cooper who works with Dr. Schwarzberg. The procedure was to do the MP-MRI procedure again and use it to guide the biopsy. He had no discomfort during the procedure and only had a little bleeding for a couple of days from the rectum and in the urine. The Gleason result was 4+3=7. In order to visualize the tumor he made a mock-up on a walnut where it was located. He did another PSA about the 1st of February this year which was 45.3 compared to the 31 of six months ago. When the biopsy was performed he asked for samples to be sent for genomic testing, but didn't think that was done, Some time later results did come back that 2 genes that are present in 65% of aggressive tumors were tested and the result was negative. He wants to know more and asked tissue samples be sent to Genomics Health in San Francisco from which he hopes to get a Genomic Prostate Score for 17 genes. After gathering all this information he will make his treatment decision. At this time he is leaning toward Proton Beam therapy and will consult with Dr. Rossi about that.

The foregoing is the Editor's recap of the meeting presentations. More specific information can be derived from the DVD of the meeting which will be available from the library or from the website: www.ipcsg.org/shop by the next meeting on March 19th. If you wish to communicate with any of the men, contact Gene--Ph. 619-890-8447, or genevanvleet@outlook.com.

FUTURE MEETINGS

March 29. James Rucks,, Regional Sales Manager, GenPath Diagnostics / BioReference Laboratories. Subject: Opco 4K test. The only test to assess a patient's risk for aggressive prostate cancer prior to a prostate biopsy. www.opko.com/

Apr 16. Bernadette Greenwood, BSc, RT(R)(MR) from Desert Medical Imaging. Update on Focal Laser treatment and MP-MRI Biopsy.

May 16. TENTATIVE Michael Kipper, MD. Director of PET/CT Imaging, Genesis Healthcare. Update on Xofigo treatments for bone metastasis and new imaging possibility.

Jun 16. Roundtable. A panel of members talk of their experiences followed by Q&A, then break-out sessions by treatment type for networking.

ON THE LIGHTER SIDE



Things to ponder:

Suburbia: where they tear out the trees & then name streets after them.

Adults are just kids who owe money.

A closed mouth gathers no feet.

Any small object when dropped will hide under a larger object.

Seen it all, done it all, can't remember most of it.

I wonder how much deeper the ocean would be without sponges.

Few women admit their age, Few men act it!

3 kinds of people: those who can count & those who can't.

Why don't sheep shrink in the rain?

Did I read that right?

Juvenile Court to Try Shooting Defendant

If Strike Isn't Settled Quickly, It May Last a While

Man Struck By Lightning Faces Battery Charge

Police Begin Campaign to Run Down Jaywalkers

Survivor of Siamese Twins Joins Parents

INTERESTING ARTICLES

When Prostate Cancer Spreads Where It Goes Matters - A Lot

Prostate cancer tends to be the tortoise of tumors, growing and spreading slowly. When cancerous cells escape the golf ball-sized prostate, they can lodge in various places throughout the body. New research shows that where these cells go can affect how long a man survives.

When prostate cancer spreads, or metastasizes, about three-quarters of the time it takes up residence in the bones. Less common locations are the lungs, liver, and lymph nodes. An international team of researchers pooled information from nine clinical trials to estimate the average survival times for men

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with prostate cancer that had spread to four different tissues. Metastasis to the lymph nodes was linked to the longest survival; metastasis to the liver led to the shortest.

"This important study confirms that one size does not fit all when it comes to metastatic prostate cancer," said Dr. Marc Garnick, a prostate cancer specialist at Beth Israel Deaconess Medical Center in Boston.

The new study, led by Susan Halabi, a professor of biostatistics at Duke University School of Medicine, suggests that prostate cancer that skips the bones and spreads to the liver and lungs may represent a different disease than prostate cancer that invades bones or lymph nodes. The results were published Monday in the *Journal of Clinical Oncology*.

"A better understanding of how metastatic prostate cancer behaves in different locations is letting us tailor diagnostic approaches and treatments that we hope will improve outcomes," Garnick said.

Prostate cancer survivors' risk of heart disease studied

From Medical News Today February 10, 2016

The 3 million prostate cancer survivors in the United States are likely to die from something other than cancer, thanks to early detection, effective treatment and the disease's slow progression.

What survivors need to be more concerned with is heart disease, the most common non-cancer cause of death for men with prostate cancer, according to a paper published in *Circulation*, authored by Vanderbilt physicians.

For this reason, Vanderbilt's Cardio-oncology program is focusing on modulating the risk factors for cardiovascular disease in men, especially those receiving androgen deprivation therapy (ADT) to treat their prostate cancer.

"While ADT therapy is of great benefit to many patients with prostate cancer, it may also increase the risk of developing diabetes or having a heart attack or stroke. By collaborating with urology, medical oncology and the cardio-oncology program, we are better able to determine which patients are most likely to benefit from hormones, and in those who do get hormones, how to better protect their cardiovascular system," said Eric Shinohara, M.D., MSCI, associate professor of Medicine and medical director of the Vanderbilt Radiation Oncology Clinic.

ADT reduces serum testosterone levels, which can make prostate cancers shrink or grow more slowly. In 2010 the American Heart Association released a statement about the possible association between ADT and adverse cardiovascular events.

Specifically, there appears to be an association between ADT and increased low-density lipoprotein and triglyceride levels, increased fat and decreased lean body mass, increased insulin resistance and decreased glucose tolerance, and a general metabolic state similar to metabolic syndrome, according to the *Circulation* paper.

"Aggressive treatment of these altered cardiovascular risk factors can be an important step to decrease the risk of heart attack and stroke in patients treated with ADT," said senior author Javid Moslehi, M.D., assistant professor of Medicine and director of Vanderbilt's Cardio-oncology program.

"In general, cardiovascular wellness is an important aspect of care for all of the nearly 230,000 men newly diagnosed with prostate cancer each year in the U.S."

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Cardiovascular disease is the No. 1 killer of all men in the United States whether they have prostate cancer or not, so it's important for men to understand the elevated risk associated with ADT, said David Penson, M.D., MPH, who is also an author of the paper.

"Frankly, all men need to be cognizant of the cardiovascular risk. After all, a lot more men die of heart disease than prostate cancer every year in this country. It is particularly important for men on ADT since anything that affects the hormonal balance will impact cardiovascular risk," said Penson, the Paul V. Hamilton, M.D. and Virginia E. Howd Professor of Urologic Oncology.

Vanderbilt's Cardio-oncology program is rare in its collaborative, multi-specialty care of men with prostate cancer, said Moslehi, who helped develop the Vanderbilt ABCDE paradigm for cardiovascular health in cancer survivors, an algorithm that is now being adapted as part of national cancer survivorship guidelines by National Comprehensive Cancer Network (NCCN).

The ABCDE algorithm for prostate cancer survivors includes awareness and aspirin; blood pressure monitoring; cholesterol management and cigarette avoidance; diet and diabetes; and exercise. Patient education is a shared responsibility of the multiple specialists who comprise the cardio-oncology program.

"Collaboration among subspecialties in medicine is critical to maintaining the health of our patients. No one is simply a prostate or a heart, and the treatments we use to treat one illness or another can dramatically affect the well-being of other parts of a patient. Bringing together a comprehensive team that addresses all facets of a patient's health allows us to provide the best medical care there is," said oncologist Alicia Morgans, M.D., MPH, assistant professor of Medicine, and also an author of the Circulation paper.

New milestone for device that can 'smell' prostate cancer

From Medical News, February 12, 2016

A research team from the University of Liverpool has reached an important milestone towards creating a urine diagnostic test for prostate cancer that could mean that invasive diagnostic procedures that men currently undergo eventually become a thing of the past.

'The use of a gas chromatography (GC)-sensor system combined with advanced statistical methods towards the diagnosis of urological malignancies', published today in the Journal of Breath Research, describes a diagnostic test using a special tool to 'smell' the cancer in men's urine.

Working in collaboration with the University of the West of England's (UWE Bristol) Urological Institute team at Southmead Hospital and Bristol Royal Infirmary, the pilot study included 155 men presenting to urology clinics. Of this group, 58 were diagnosed with prostate cancer, 24 with bladder cancer and 73 with haematuria or poor stream without cancer. The results of the pilot study using the GC sensor system indicate that it is able to successfully identify different patterns of volatile compounds that allow classification of urine samples from patients with urological cancers.

Urgent need for earlier diagnosis

Professor Chris Probert from the University of Liverpool's Institute of Translational Medicine began work on this project with UWE Bristol when he was working in Bristol as a gastroenterologist with clinical and research interest in inflammatory bowel disease.

The research team used a gas chromatography sensor system called Odoreader that was developed by a team led by Professor Probert and Professor Norman Ratcliffe at UWE Bristol. The test involves inserting urine samples into the Odoreader that are then measured using algorithms developed by the research team at the University of Liverpool and UWE Bristol.

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Professor Probert said: "There is an urgent need to identify these cancers at an earlier stage when they are more treatable as the earlier a person is diagnosed the better. After further sample testing the next step is to take this technology and put it into a user friendly format. With help from industry partners we will be able to further develop the Odoreader, which will enable it to be used where it is needed most; at a patient's bedside, in a doctor's surgery, in a clinic or Walk In Centre, providing fast, inexpensive, accurate results."

Like an electronic nose

Professor Norman Ratcliffe said, "There is currently no accurate test for prostate cancer, the vagaries of the PSA test indicators can sometimes result in unnecessary biopsies, resulting in psychological toll, risk of infection from the procedure and even sometimes missing cancer cases. Our aim is to create a test that avoids this procedure at initial diagnosis by detecting cancer in a non-invasive way by smelling the disease in men's urine. A few years ago we did similar work to detect bladder cancer following a discovery that dogs could sniff out cancer. We have been using the Odoreader, which is like an electronic nose to sense the cancer."

"The Odoreader has a 30 metre column that enables the compounds in the urine to travel through at different rates thus breaking the sample into a readable format. This is then translated into an algorithm enabling detection of cancer by reading the patterns presented. The positioning of the prostate gland which is very close to the bladder gives the urine profile a different algorithm if the man has cancer."

Mr Raj Prasad, Consultant Urologist at Southmead Hospital, North Bristol NHS Trust, said: "If this test succeeds at full medical trial it will revolutionize diagnostics. Even with detailed template biopsies there is a risk that we may fail to detect prostate cancer in some cases. Currently indicators such as diagnosed prostatomegaly (enlarged prostate) and unusually high PSA levels can lead to recommendations for biopsy if there is a concern that cancer may be prevalent. An accurate urine test would mean that many

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.

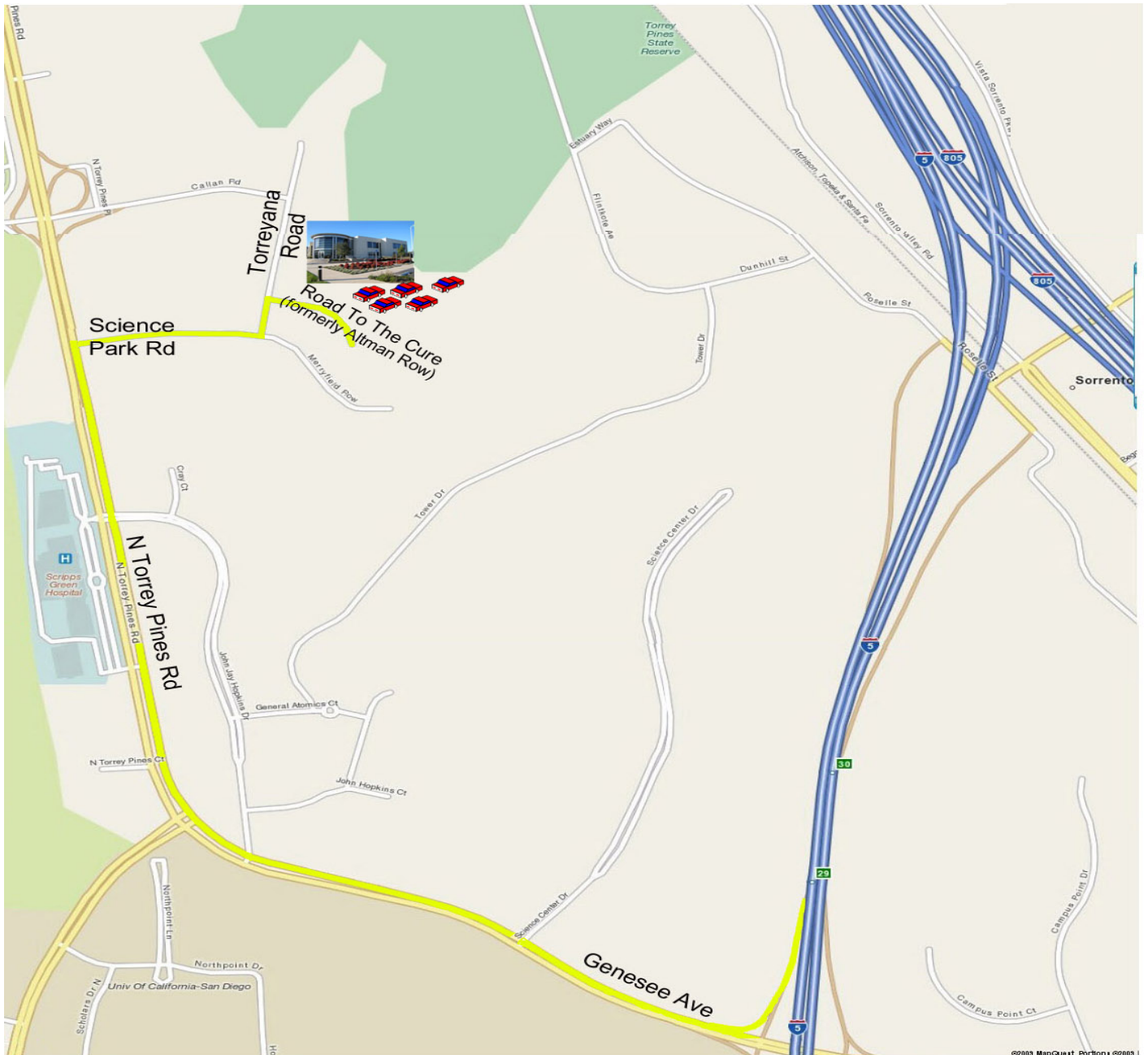
Ads about our Group are in the Union Tribune 2-3 times prior to a meeting. Watch for them.

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://ipcs.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.