Informed Prostate Cancer Support Group Inc.

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

February 2013 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142
Phone: 619-890-8447 Web: www.ipcsg.org

We Meet Every Third Saturday (except December)

Friday, February 08, 2013 Volume 6 Issue 1

Officers

President: Lyle La Rosh,
Vice President : Gene Van Vleet

Additional Directors

Dr. Dick Gilbert
John Tassi
George Johnson

Steering Committee

Judge Robert Coates
Victor Reed
Robert Keck, Librarian
Bill Manning
E. Walter Miles
Jerry Steffen

Next Meeting February 16th 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 PC 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

During the January meeting three men told of their experiences:

Frank Wuerfel could be the poster boy for our group. He is 87 years old and is a 22 year survivor. His father died of PCa at the age of 79 and his grandfather died of PCa at the age of 82. During a physical exam in 1990 he decided to have his prostate checked. The results were a PSA of 6.4 and a Gleason score of 2+2=4. When he asked what he should do the doctor replied "There is only one thing to do—-have a radical prostatectomy". His wife, Penny, is a nurse and advised that he should seek other opinions. Her involvement

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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throughout his experience has been of great help and comfort. Through research he learned of Dr. Israel Barken, now the principal of Prostate Cancer Research and Education Foundation (PCREF) who was in the forefront at that time on newer ways to approach PCa. He advised Frank tp take charge and do what he wanted to do. He was against surgery because there had been too many mistakes and too little was known about the resulting side affects. He then started on a combination of Lupron and Flutamide and an arbitrary PSA maximum level of under 2.0 was set. His PSA went down to zero quickly. He and Dr. Barken were considering other treatment options, but decided after a year on doing nothing (then called Watchful Waiting) to see what happened. He did this for 18 years! He never had another biopsy. Along the way Dr. Barken retired and he learned of Drs. Scholz and Lam by attending the first PCRI conference in 1999. He became a patient of Dr. Lam. Rather than do more biopsies, he had Color Doppler Ultrasounds performed by Dr. Bahn to assist in monitoring his condition. They continued monitoring his progress until the PSA became a concern at which time he was referred to Dr. Mundt of UCSD to consider radiation. Although initially against radiation, after carefully considering the positive case history results of Dr. Mundt, he decided on IMRT and was treated 4 years ago. He has had no treatment since and as of his last test taken this January his PSA was 0.04!!! Our best wishes go out to Frank and Penny for continued good health.

Bobby Turner was diagnosed with PCa in September 2011 at the age of 62. He is a diabetic which requires frequent blood analyses. From one of the tests it was determined that he had a PSA of 17. He has a family history of PCa which included his father and grandfather. He first saw a urologist who performed a biopsy. He was driving when the call came with the results advising that he had PCa. He pulled over and stopped while the rush of emotions hit him. His Gleason score was 3+4=7 and Stage 2. The urologist did not recommend surgery but rather recommended hormone treatment and radiation. He began attending our support group meetings and learned how to become his own case manager. He armed himself with questions to ask when talking with doctors. He decided to consult Dr. Mundt of UCSD about radiation, but his urologist refused the referral. He finally was able to get one from his primary care physician. Dr. Mundt recommended hormone treatment and radiation. From his own research he had decided against hormone treatment because it was not suitable to his lifestyle. By this time his PSA had risen to 28 over a six month period. From Dr. Mundt he learned about IMRT and IGRT and was further referred to his colleague Dr. Einck who specializes in brachytherapy. He first had 25 treatments of IGRT which dropped his PSA to 20 after 30 days. He then did two sessions of the type of brachytherapy in which radiation is delivered via 19 needles inserted into the prostate through the perineum. 30 days after this treatment his PSA dropped to 3.4, 60 days afterward it dropped to 1.4 and as of this January, it was 0.9. Bobby is grateful to our group for the information he developed to become his own case manager in order to reach a successful conclusion suitable to his lifestyle.

John Tassi was in his forties when he first became aware he had prostate cancer. In 2007 he got the dreaded words "you have cancer". He went backwards in his mind trying to figure out how he got it. All along his doctors had been telling him his PSA was fine, he was young and did not have PCa. BUT he learned his PSA was 19. He later learned his Gleason score was 5+4=9! John advised us not to be bashful about firing your doctor which is what he did. He saw 2 other urologists both of whom recommended surgery. One had done 12 surgeries, the other over 300—obviously choosing the later. He advised finding out the qualifications of the surgeon including references—which he did. This happened before he became acquainted with our group so he was influenced by the surgeons and had the surgery. Things were really good for seven months. Then his PSA started doubling again. He was suffering relapse. No one told him this could or would happen nor did anyone tell him about the side effects. He then saw more doctors to help analyze his situation and still has 6 on his team. He has become his own case manager. He listens to what the doctors have to say and then forms his own conclusion. He has also done a lot of research to learn about the disease. He advised that when you have a disease that is trying to kill you, you need to learn as much about it as you can and what treatments are possible. John also noted that another important factor in his case was the involvement of his wife who has been a strong partner with him through the whole process. His next step was radiation, followed by chemotherapy followed by hormone treatment (ADT). He was doing everything he thought possible to aggressively knock down the disease. His PSA is currently zero. His final advise was to not put too much of your thoughts into the bad aspects of the word "cancer" but rather learn how to deal with

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it. You Can Live With It!

The forgoing personal experiences are recaps of their presentations. For further detail you can get a copy of the DVD of this meeting from our library or through our website: www.ipcsg.org and clicking on the button, Purchase DVD's.

Future Meetings

February 16.Networking. Presentations by a few members' experiences followed by break-out sessions by treatment type.

March 16. Dr. Carl Rossi, Medical Director of the Scripps Proton Therapy Center. New Scripps facility for proton beam therapy in relation to prostate cancer.

April 20 - Not yet confirmed.

On The Lighter Side

It is OK to keep an open mind as long as you do not let your brain fall out

DRE Comments:

"You know, in Arkansas, we're now legally married."
"Any sign of the trapped miners, Chief?"
"Hey Doc, let me know if you find my dignity."
"You used to be an executive at Enron, didn't you?"
"Could you write a note for my wife saying that my head is not up there?

Q. Can I get coverage for my preexisting conditions?
A. Certainly, as long as they don't require any treatment.

The published statistics on prostate cancer show that single men are diagnosed much less frequently than married men. On the other hand, married men diagnosed with prostate cancer live longer than single men with the disease. The conclusion that can be drawn from this is that men should stay single, but should get married if diagnosed with prostate cancer.

A driver was stuck in a traffic jam on the highway outside Washington, DC. Nothing was moving. Suddenly, a man knocks on the window. The driver rolls down the window and asks, "What's going on?" "Terrorists have kidnapped the entire US Congress, and they're asking for a $100 million dollar ransom. Otherwise, they are going to douse them all in gasoline and set them on fire. We are going from car to car, collecting donations." "How much is everyone giving, on an average?" the driver asks. The man replies, "Roughly a gallon."

Never forget that the goal of the doctor and the patient are not always identical. You must take charge of your treatment as the doctor has a different agenda than you do. Dr Charles 'Snuffy' Myers

NOTEWORTHY ARTICLES

Long-Term Urinary, Sexual And Bowel Function Side Effects Tracked In Prostate Cancer

From Medical News Today Article Date: 01 Feb 2013 - 1:00 PST

A new study comparing outcomes among prostate cancer patients treated with surgery versus radiotherapy found differences in urinary, bowel and sexual function after short-term follow-up, but those differences were no longer significant 15 years after initial treatment.

The study, led by first author Matthew Resnick, M.D., instructor in Urologic Surgery, Vanderbilt University Medical Center, was published in the New England Journal of Medicine.

From Oct. 1, 1994, through Oct. 31, 1995, investigators enrolled men who had been diagnosed with localized prostate cancer in the Prostate Cancer Outcomes Study (PCOS).

For the current study, investigators followed 1,655 men between the ages of 55 and 74 from the PCOS group, of whom 1,164 (70.3 percent) had undergone prostatectomy, while 491 (29.7 percent) had undergone radiotherapy. At the time of enrollment, the patients were asked to complete a survey about clinical and demographic issues and health-related quality of life. The men were contacted again at set times following treatment and were asked about clinical outcomes and disease-specific quality of life issues.

Men whose prostates had been surgically removed were significantly more likely than those who received radiation therapy to report urinary leakage at two years and five years. However, at 15 years, the investigators found no significant difference in the adjusted odds of urinary incontinence. Nonetheless, patients in the surgery group were more likely to wear incontinence pads throughout the 15-year follow-up period.

Men in the prostatectomy group were also significantly more likely than those in the radiotherapy group to report having problems with erectile dysfunction two years and five years after surgery.

"At the two- and five-year time points, men who underwent prostatectomy were more likely to suffer from urinary incontinence and erectile dysfunction than men who received radiation therapy," explained Resnick. "While treatment-related differences were significant in the early years following treatment, those differences became far less pronounced over time."

Despite early and intermediate-term data revealing treatment-dependent differences in patterns of sexual dysfunction, after five years both groups had a gradual decline in sexual function.

At 15 years, erectile dysfunction was nearly universal with 87 percent in the prostatectomy group and 93.9 percent in the radiotherapy group reporting sexual difficulties.

The authors noted that age may have played a role in the patients' waning sexual function, as shown in unrelated studies.

Some patients also experienced problems with bowel function in the years following treatment. Those who were treated with radiotherapy had more problems in the short term. Men in the radiotherapy group reported significantly higher rates of bowel urgency than those in the prostatectomy group at two years and five years. However, at 15 years, despite absolute differences in the prevalence of bowel urgency between the two groups, the researchers found no significant difference in the odds of bowel urgency. Men who had been treated with radiotherapy were significantly more likely to report being bothered by bowel symptoms at both the two-year and 15-year points.

"This study of 15-year outcomes represents a mature portrait of quality of life issues following prostate cancer treatment," said David Penson, M.D., MPH, Ingram Professor of Cancer Research, professor of Urologic Surgery and Medicine, and director of the Vanderbilt Center for Surgical Quality and

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Outcomes Research, the senior study author.

"Regardless of the form of initial treatment, patients in this study had significant declines in sexual and urinary function over the duration of the study. The causes of these declines probably include advancing age and additional cancer therapies, in addition to the original therapy," Penson said. "Patients need to be aware that all aggressive therapies for prostate cancer have significant side effects and perhaps these data make an argument for active surveillance (avoiding aggressive treatment and closely following the cancer) in certain cases."

Since the median life expectancy after treatment for prostate cancer is 13.8 years, the authors suggested that these data may be used by physicians to counsel men who are considering treatment for localized disease.

A Prostate Biopsy Can be Dangerous

Prostatesnatchers Blog Posted: 15 Jan 2013 04:51 PM PST

BY MARK SCHOLZ, MD

Last August, I railed against too many biopsies. However, my experience at a recent prostate cancer meeting prompted me to revisit the topic for today's blog. There is now general agreement among experts that prostate cancer is over-diagnosed. I believe this results from the excessive use of random prostate biopsy and, all too often, leads to radical over-treatment.

More than a million men in the United States have prostate tissue extracted by transrectal needle biopsy every year. Of all those biopsied, one-fourth, about 240,000 men, are diagnosed with prostate cancer. Of these 240,000, between one-third and one-half—that is, from 80,000 to 120,000—are diagnosed with a harmless condition destined to remain dormant for life. And yet, despite the innocuous nature of low-grade prostate cancer, the great majority of these unfortunate men still undergo radical treatment with decidedly negative impact on their quality of life.

The unwillingness of surgeons and radiation therapists to withhold treatment for low-grade prostate cancer is not entirely surprising given that doctors are specifically trained to treat cancer. Understandably, patient enthusiasm for treatment is also a major contributing factor, considering how dangerous it would be to withhold treatment of most any other type of cancer.

The overtreatment of prostate cancer is giving experts sufficient concern that editorials are appearing in prestigious scientific journals, such at the Journal of Clinical Oncology and Lancet Oncology, discussing the possibility of renaming low-grade prostate cancer something besides "cancer." Everyone seems to agree that it's unreasonable to name a condition cancer when we know this low-grade form doesn't usually metastasize.

Given these daunting issues, I was interested to survey a group of twenty male experts at a prostate cancer meeting last month about their attitudes toward biopsy. Because the average age of the group was around sixty, everyone in the group readily agreed that if all of us underwent a standard random biopsy at least five would be diagnosed with prostate cancer. With such a high statistical risk of finding cancer, I then asked by a show of hands if anyone was interested in having a biopsy.

While an unnecessary cancer diagnosis is one risk of biopsy, there is one other significant risk: the possibility of toxic effects of biopsy itself. The Journal of Urology this month reports that with prostate biopsy the rate of infections serious enough to require hospitalization has quadrupled to approximately one in fifty. One out every twenty of these infected men admitted to the hospital actually dies—making the risk of death from biopsy is one in a thousand.

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Not a single doctor raised his hand.

Fortunately there is an excellent alternative to random biopsy. Modern prostate imaging with 3-Tesla MRI or color Doppler ultrasound, is just as accurate for detecting high-grade disease. When an abnormality is detected through imaging, it can be targeted with just one or two biopsy cores instead of randomly shooting a dozen cores throughout the gland. And yet, despite the obvious advantages of imaging and targeted biopsy, practically all biopsies done in the United States are being performed randomly.

Sadly, the general public—including most primary care physicians and even perhaps the majority of urologists and radiation oncologists—remains uninformed about the advantages of modern imaging technology. For more information about biopsy and Imaging Technology see my March 27, 2012 blog, Biopsy, Biopsy Everywhere: http://prostatesnatchers.blogspot.com/2012/03/biopsy-biopsy-everywhere.html

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Targeted Prostate Cancer Biopsies Might Improve Care: Study

MONDAY, Dec. 10 (HealthDay News) -- A new, highly targeted form of biopsy could be an advance in prostate cancer care, a new study suggests.

Researchers at the University of California, Los Angeles, say prostate tumors can be diagnosed using "image-guided targeted biopsy" -- the direct sampling of tumors in tissue using both MRI and real-time ultrasound.

The UCLA team say this targeted form of biopsy is much more accurate than conventional "blind" biopsies that do not enable doctors to actually see the tumors. They suggested the new procedure may improve early detection of prostate cancer and result in fewer biopsies overall.

"Early prostate cancer is difficult to image because of the limited contrast between normal and malignant tissues within the prostate," study senior author Dr. Leonard Marks, a professor of urology and director of the UCLA Active Surveillance Program, said in a university news release. "Conventional biopsies are basically performed blindly, because we can't see what we're aiming for. Now, with this new method we have the potential to see the prostate cancer and aim for it in a much more refined and rational manner."

Almost all of the 1 million prostate biopsies performed in the United States every year are performed after a man tests positive for elevated blood levels of prostate-specific antigen (PSA), which can indicate prostate cancer.

One expert not connected to the new study said current biopsy methods have their pros and cons.

"Currently, the diagnosis of prostate cancer occurs through a transrectal ultrasound guided prostate biopsy," said Dr. Warren Bromberg, chief of urology at Northern Westchester Hospital in Mount Kisco, N.Y.

"The advantage of this procedure is that it can be performed with local anesthesia in a urologist's office in less than 10 minutes," he said. "The problem with this method is that approximately 75 percent of men have negative biopsies [and] the cancerous areas are usually not visible. So, multiple biopsies are taken to try to 'find' the cancer, the procedure is usually repeated at some point when the PSA test continues to rise, insignificant cancers are detected as often as significant ones, there is always the fear that a cancer was missed, and there are risks of infection, pain and bleeding."

The UCLA team sought to determine if more targeted biopsy methods could change that. In the study, they actively monitored 171 men with slow-growing prostate cancers or those who had re-

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ceived negative biopsies but maintained persistently high PSA levels, suggesting that a tumor might be present.

The participants first had an MRI to visualize their prostate. That image was sent to a device, called Artemis, that fuses the MRI pictures with real-time, three-dimensional ultrasound. This fusion process allows a urologist to see lesions during the biopsy.

"With the Artemis, we have a virtual map of the suspicious areas placed directly onto the ultrasound image during the biopsy," noted Marks. "When you can see a lesion, you've got a major advantage of knowing what's really going on in the prostate. The results have been very dramatic, and the rate of cancer detection in these targeted biopsies is very high. We're finding a lot of tumors that hadn't been found before using conventional biopsies."

Fifty-three percent of the men involved in the study had prostate cancer, according to the study published online Dec. 10 in The Journal of Urology. Marks and his colleagues also found that 38 percent of the cancers found using targeted biopsy were aggressive tumors -- meaning they more likely to spread and require treatment.

Unlike conventional blind biopsies which can be painful and require men to be placed under general anesthesia and undergo lengthy recoveries, the targeted UCLA biopsies were performed in about 20 minutes in an outpatient clinic setting under local anesthesia, the team said.

"Targeted prostate biopsy has the potential to improve the diagnosis of prostate cancer and may aid in the selection of patients for active surveillance and focal therapy," the study authors wrote.

Another expert said the the new technology has real promise.

"Prostate biopsies have been performed the same way for the past 30 years," said Dr. Louis Potters, chair of radiation medicine at North Shore-LIJ Health System in New Hyde Park, N.Y. "The study from UCLA is evaluating the next step in the evolution of the prostate biopsy. It combines the state-of-the-art MRI which allows clinicians to see inside the prostate with incredible detail."

Potters said the UCLA data matches those from his own institution "that reports improved cancer detection of this technique" compared to traditional biopsy.

"More importantly, the lesions seen on the MRI with a corresponding positive biopsy are associated with a higher grade cancer and increased amount of cancer sampled," he said. "This translates into improved information for the patient, as well as the clinician."

Bromberg agreed.

Besides allowing "better visualization" of tumors, "adding the MRI to the ultrasound seems to allow preferential detection of the more life-threatening type of cancer [high-grade], which could reduce the chances that a man would undergo unnecessary treatment," he said.

As for cost, "the overall added cost of the MRI may be offset by the reduced number of biopsy procedures," Bromberg said.

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 continues to develop our new website that we believe is simple and easy to navigate. Check out the Personal Experiences page and send us your story. Go to: http://www.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

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We Need Help

All services for our group are performed by volunteers. As is usual in our type of organization we have a few doing a lot for many. We need people to step up and help in the following areas:

1. Fund Raising. We need help from anyone with any knowledge or willingness to become involved in acquiring grants to support our organization. We need someone to organize fund raising activities.
2. Information Technology. Any techies out there that can help take advantage of the facilities available where we meet--such as live remote conferencing.

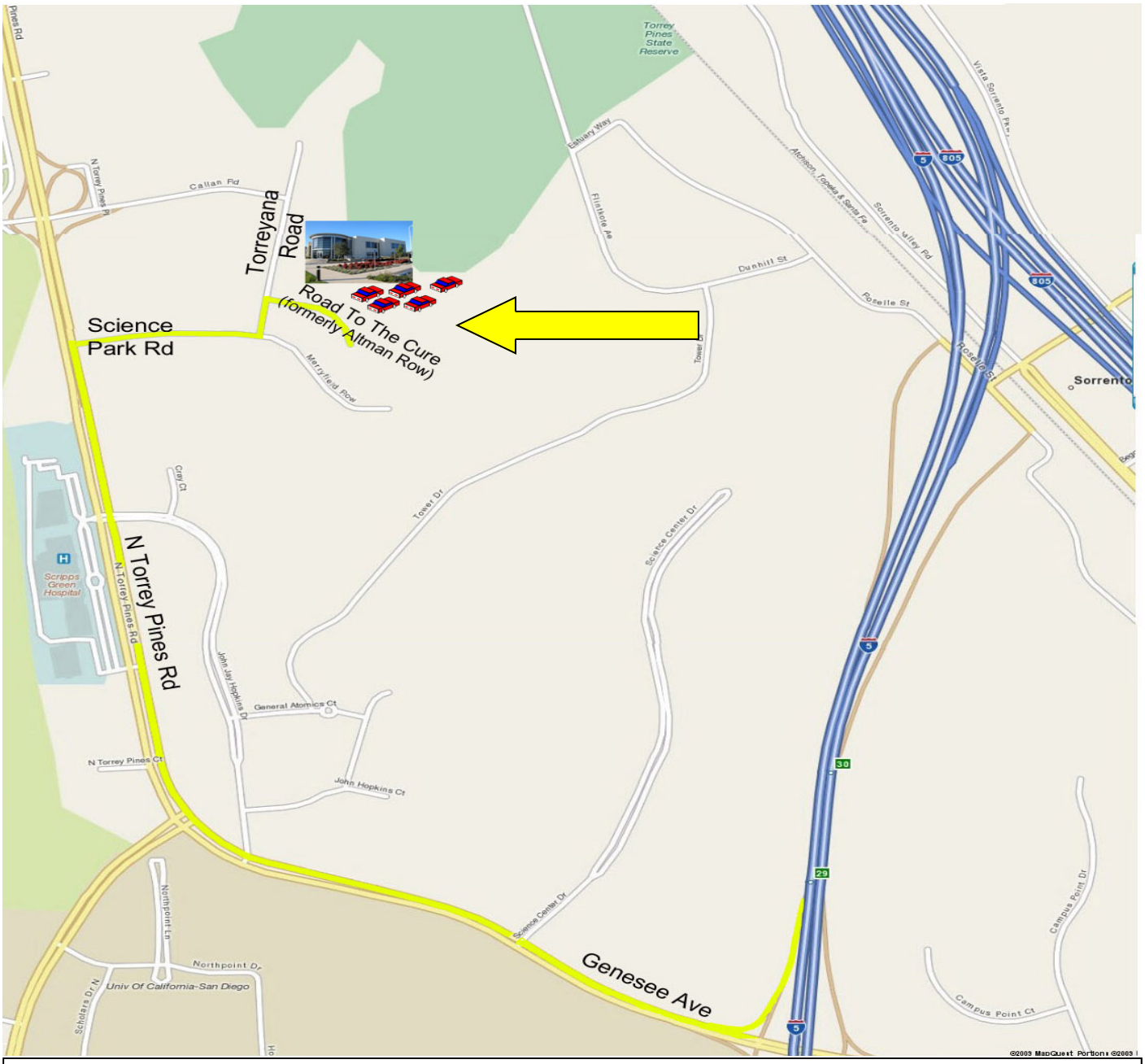
Anyone interested please contact:
Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org
Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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).