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

JULY 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)

Sunday, July 12, 2015 Volume 8 Issue 6

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Next Meeting
JULY 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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Editor: Gene Van Vleet

PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

The June meeting was a very good presentation by Dr. Mike Hsieh on the subject of sexual side effects of prostate cancer and treatment possibilities before and after treatment.

Dr. Mike recognizes the sensitivity of the subject of sexual dysfunction and offered to speak with individuals privately by filling out a request form. Our group was very forthcoming with their issues during Q&A, likely because he established a comfortable atmosphere.

He talked about the priorities of doctors treat-

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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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ing PCA. Job 1 is to treat the cancer by whatever means the doctor and patient agree upon. Job 2 is to preserver urinary control, Job 3 is to preserve your sexual function. This is commonly called the "Trifecta" of treatment..

He first talked of issues of low testosterone. It is experienced by 1 in 5 men in their 60's and 1 in 4 men in their 70's. Symptoms include low sex drive, poor erections, fatigue, poor concentration, reduced muscle mass and increased body fat. Treatments include injections, topical patches, topical gels and slow-release implants. The most popular are topical gels applied on upper arms in the shoulder area, inner thighs or in the axillary region. After one year of use 60% of men had improvement in their sexual desire and 76% had improvement in sexual performance. Further there was a gain of 5 lbs of muscle and a loss of 4 lbs of fat. He cautioned about going to widely advertised "Low T" clinics or physical trainers because they do not monitor other body functions that may be detrimental to your health, such as stroke, heart attack and blood clots.

So what about PCa? Similarly, as you get older your testosterone (T) count goes down and your chances for PCa goes up. There are recent studies, mostly on men who have treated PCa, that show that by increasing T to the 180-496 range the PSA remained less than 0.1. Since this is a relatively new concept UCSD has developed a policy that men with high risk PCa, Gleason 8,9 or even certain Gleason 7's are not given T treatment until their cancer has been taken care of. For men on Active Surveillance having Gleason scores of 6 or low-volume 7 they believe T treatment is okay as long you are being properly monitored.

Similar to an injured athlete, they now know that you have a better chance of sexual recovery by starting during the treatment process. Their protocol for patients before they have any PCa treatment is to put them on a low dose oral medication such as Cialis or Viagra. At about 1 month after treatment, they introduce either a vacuum device or a larger dose of the oral medication. If after 3 months after treatment you are not able to achieve an erection, they introduce an injection. At 6 months after treatment they start checking T levels along with the PSA. If your T level is low and you are systematic from it, they feel comfortable in giving T within the first year after PCa treatment because they are keeping an eye on your PCa. In 12 to 16 months after treatment, if you are not having adequate sexual functions, they then consider in implant.

Dr. Hsieh continued with an update about what treatments are available today for sexual dysfunction. One in five men is experiencing sexual problems---all men, not just those with PCa. It effects over 30 million men. It was originally thought that 90% of the problems were psychological and 10% physical. It is now known that the reverse is true. Some things that cause sexual dysfunction are diabetes, heart disease, medications, spinal chord injuries, hormonal imbalance, thyroid imbalance and cancer treatment of many kinds of cancer not just PCa. Lifestyle issues that can affect sexual function are depression, obesity, sedentary life style, heavy drinking, use of recreational drugs, and smoking. Loss of sexual function can often be a precursory sign of these problems. Often patients come to him wanting a Viagra prescription and end up with a referral to a cardiologist because they have vascular problems. Some things available to help treat sexual dysfunction are testosterone to treat imbalance as mentioned earlier. Usually the first step is to try oral therapy (pills) such as Viagra, Cialis or Levitra, which help increase the blood flow to the penis, but can cause discomfort including flushing, headaches, stomach pain, backache. Unfortunately these are the most expensive and generally not covered by insurance.

A vacuum device can be utilized to achieve an erection, but to maintain it requires the use of a very tight ring to be placed at the base of the penis which can be very uncomfortable. However, in the first year after treatment this is a good way to rehab yourself by using the vacuum device without using the

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ring. It will help re-establish some of the loss of length. There is a urethral suppository called MUSE, but it has the limitation of a burning sensation which is usually unsatisfactory.

Injections are the cheapest method of achieving an erection, but it has the drawbacks of mood inconvenience to inject and the fear of pain even though it does not hurt that much. Some cases of priapism (unhealthy time of erection of 4 hours or more) have been experienced. This is dangerous because blood clotting in the penis may occur.

If all else fails a penile implant is an important consideration. The ones he uses most commonly consist of three parts. An inflatable tube is put in the penis, there is a water reservoir put in the belly and a small pump put in the scrotum. These are all done surgically. When intercourse is desired, the pump in the scrotum is pressed to push water from the reservoir to inflate the tube in the penis causing an erection. When finished an internal button is pushed to release the water back into the reservoir. Interestingly penile implants are covered by insurance because they require surgery. The other methods are not.

He summarized by stating that nearly any man can be successfully treated, but options should be discussed thoroughly with you doctor and your partner.

As usual, this is a recap of the presentation and more thorough information can be derived from the DVD of the meeting which will be available by our next meeting on our website www.ipcsg.org/shop/ and from our library at the meeting.

FUTURE MEETINGS

July 18th - Donna Hansel MD, PhD, Division Chief of Anatomic Pathology UCSD and an expert in genitourinary pathology. Gleason Test. Why and what it means.

Aug 15th - Round Table. Some members talk of their experiences followed by Q&A, then break-out sessions by treatment type for networking.

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

From T-Shirts:
If I was meant to pop out of bed, I would sleep in a toaster.
I did not slap you, I simply high-fived your face.
People are like music. Some speak the truth while others are just noise.
Sometimes my greatest accomplishment is just keeping my mouth shut.
The easiest way to please a woman: Put the toilet seat down.
If God wanted me to touch my toes, he would have put them on my knees.
I wonder if clouds ever look down on us and say "Hey look! That one is shaped like an idiot!"

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"If you try to fail, and succeed, which have you done?" — George Carlin
"I think I've discovered the secret of life -- you just hang around until you get used to it." — Charles M. Schulz
"One morning I shot an elephant in my pajamas. How he got in my pajamas I'll never know." --Groucho Marx
"Who was the guy who first looked at a cow and said 'I think I'll drink whatever comes out of these when I squeeze 'em?" — Bill Watterson
"Sometimes the road less traveled is less traveled for a reason" — Jerry Seinfeld

"What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?"

INTERESTING ARTICLES

Xtandi and Zytiga, The Future is Now

Posted: 23 Jun 2015 Prostate Snatchers Blog
MARK SCHOLZ, MD

There are two new kids on the block, Xtandi and Zytiga. Both medications are real game changers. They are special because they can induce cancer remissions in men whose prostate cancer has become resistant to Lupron. These pills are so effective that protocols for managing hormone resistant prostate cancer have been completely revamped. Previously, men with hormone resistance were first treated with Taxotere chemotherapy, typically with undesirable side effects and frequent doctor's visits. When men on Xtandi and Zytiga are responding well, since they no longer need an intravenous infusion of Taxotere every three weeks, they only have to come in for a doctor's visit every three months.

While Xtandi and Zytiga are now FDA approved for hormone resistant prostate cancer, there is no reason to believe they won't also show enhanced effectiveness against earlier-stage, hormone-sensitive disease as well. This rationale is based on a long established fact about anticancer treatments in general: "Any treatment that is effective against advanced cancer generally proves to be more effective against earlier-stage cancer." This assumption is so logical one might wonder why the academic medical world insists on doing studies to prove it. Honestly, the biggest barrier is probably cost. Insurance companies that pay for these expensive medications demand ironclad proof of a beneficial effect before being willing

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to cover their expanded use.

Physicians, particularly urologists, who are unfamiliar with these potent new agents, are another barrier to the expanded use of Xtandi and Zytiga in earlier-stage prostate cancer. Urologists, the surgeons who over the last 20 years have only slowly become familiar with how the standard medications Lupron and Casodex function, are often uncomfortable using new agents that can be associated with rare side effects such as high blood pressure, seizures, liver problems and potassium depletion. To urologists, the doctors who are managing the men with early-stage prostate cancer, Xtandi and Zytiga are relative unknowns.

In spite of all these barriers, the logical place to consider using Xtandi and Zytiga is in earlier-stage, "high-risk" situations which have suboptimal cure rates with Lupron alone. The situations where this might apply are listed below:

- Newly-diagnosed men with a PSA over 20 and a Gleason score over 8
- Newly-diagnosed men with seminal vesicle invasion or pelvic lymph node metastases
- Relapsed men after surgery with a PSA doubling < 3 months having salvage radiation
- Newly-diagnosed oligometastatic disease undergoing radiation to all sites of disease

In all these situations, Lupron is known to be beneficial. In some cases, the addition of Casodex to Lupron further increases the anticancer effect over Lupron alone. This is an important observation because compared to Xtandi or Zytiga, Casodex is a very weak anticancer agent. Substituting these far more potent agents for Casodex is very likely to result in substantial improvement of the anticancer benefit and is a logical consideration for men who want to optimize their cure rates.

Vanderbilt-led study finds significant drop in new prostate cancer diagnoses

Decline follows USPSTF recommendation against PSA testing

Published: Friday 19 June 2015 Medical News Today

A new study led by Vanderbilt University Medical Center investigators found new diagnoses of prostate cancer in the U.S. declined 28 percent in the year following the draft recommendation from the United States Preventive Services Task Force (USPSTF) against routine PSA screening for men. The new research, led by first author Daniel Barocas, M.D., MPH, assistant professor of urological surgery and medicine, was posted online in the June 15 issue of The Journal of Urology in advance of publication.

In October 2011, the USPSTF issued a draft guideline discouraging the use of prostate-specific antigen (PSA)-based screenings for prostate cancer after concluding the harms outweigh potential benefits. Harmful side effects of treatment may include incontinence, erectile dysfunction and radiation cystitis.

However, the 'grade D' recommendation was considered controversial because of uncertainty about the risk-benefit ratio of screening since prostate cancer is the second leading cause of cancer death among men in the U.S., with nearly 30,000 deaths annually, and some studies show that screening saves lives.

To assess the effects of this recommendation, the investigators identified new cancers diagnosed between January 2010 and December 2012 in the National Cancer Database. They studied the trend of prostate cancers diagnosed each month before and after the draft guideline, compared with new colon cancer cases.

The research revealed that 12 months after the draft USPSTF guidelines were published diagnoses of new low-risk cancers had fallen by 37.9 percent while colon cancer cases remained stable.

New prostate cancer diagnoses also declined by 23 to 29.3 percent among men over age 70 and 26 percent among men considered infirm. The authors note these are populations who are unlikely to live long enough to benefit from early detection and are at risk of harms of treatment.

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However, the investigators suggest that withholding screening may also result in failure to detect higher-risk cancers during the window of curability. Timely treatment of intermediate and high-risk localized disease is associated with superior overall survival, disease-specific survival and decreased spread of the disease to other locations in the body.

The study identified a drop of 28.1 percent in diagnoses of intermediate-risk disease and 23.1 percent in high-risk prostate cancer one year after the draft guideline. The decline did not vary across age or comorbidity features.

'These findings suggest that reduced screening may result in missed opportunities to spare these men from progressive disease and cancer death,' said Barocas.

While the observation period was too limited to determine the impact on the diagnosis of metastatic prostate cancer, which is associated with a high treatment burden, decrease in quality of life and increased mortality, the authors did observe a small upward trend in diagnoses of non-localized disease.

'The results raise concern that if this trend continues more men may be diagnosed at a point when their disease is advanced. Younger, healthier men with intermediate or high-risk disease would normally be candidates for aggressive local therapy and they may not be receiving a timely diagnosis under this policy,' said Barocas.

The authors suggest that future research should focus on screening regimens that minimize harms and maximize potential benefits of screening, while also considering patient preferences.

EDITOR'S NOTE: The foregoing is based on data gathered only 12 months after USPSTF's recommendation. But it already shows the negative effects of not testing. Add the knowledge of the task force recommendation to not require routine PSA testing to the basic reticence of too many men to not do any testing and we will for sure see an upswing in more high risk diagnoses. Do your part to encourage friends and relatives to ask for the PSA test. It is the closest thing we have to women's Mammogram.

Award-winning agent developed for prostate cancer diagnosis and treatment

From Medical Press June 8, 2015

Prostate-specific membrane antigen (PSMA) is a surface protein that is normally present on healthy prostate cells, but is found at much higher levels on prostate cancer cells. It is barely found in the rest of the body. "Therefore, PSMA is an ideal target for diagnostic purposes as well as targeted therapies against prostate cancer," says biotechnologist Dr. Matthias Eder of the German Cancer Research Center (Deutsches Krebsforschungszentrum, DKFZ).

Eder's group has developed a small molecule (PSMA-617) that is capable of specifically attaching to PSMA and can be labeled with various radioactive substances, called radionuclides.

When chemically bound to gallium-68, a weakly radioactive diagnostic radionuclide, PSMA-617 can be used to visualize even the smallest assemblies of prostate cancer cells in PET (positron emission tomography) scans. "In this way, physicians are able to detect small secondary tumors in other organs or closely monitor response to therapy. Diagnostic approaches that have been used in the clinic so far have not come close to this sensitivity," says Eder.

Alternatively, the researchers can also bind a therapeutic radionuclide called lutetium-177 to PSMA-617. This radiopharmaceutical is taken up by tumor cells that carry the PSMA target molecule and then destroys these cells from the inside. This might be a promising treatment option, particularly in cases of hormone-resistant prostate carcinoma, which is very difficult to treat.

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At Heidelberg University Hospital, a team led by nuclear medicine specialist Prof. Dr. Uwe Haberkorn has already used radioactively labeled PSMA-617 to treat individual patients with advanced prostate cancer. The physicians made use of the therapeutic nuclides lutetium-177 and actinium-225. After treatment with the lutetium-labeled radiopharmaceutical, levels of the prostate cancer marker PSA fell sharply in 70 percent of cases; after treatment with the actinium-labeled radiopharmaceutical, this effect was observed in all patients.

In addition, PET/CT images confirmed that metastases had shrunk or were no longer detectable. "The results were so promising that we plan to go ahead with a clinical trial as soon as possible to examine whether PSMA-617 is superior to other therapy methods," says Haberkorn.

"Other agents that target PSMA and can be coupled with strong or weak radiation emitters are already being developed," explains Prof. Dr. Klaus Kopka, a chemist and departmental head at the DKFZ. "However, only a few of these agents have turned out to be ideal. Most of them are too unstable, accumulate insufficiently in cancer cells and wash out too slowly from healthy organs. By contrast, PSMA-617 accumulates in large quantities in tumors and metastases and is stored well in cancer cells. As a result, prostate cancer can be irradiated from the inside, so to speak."

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

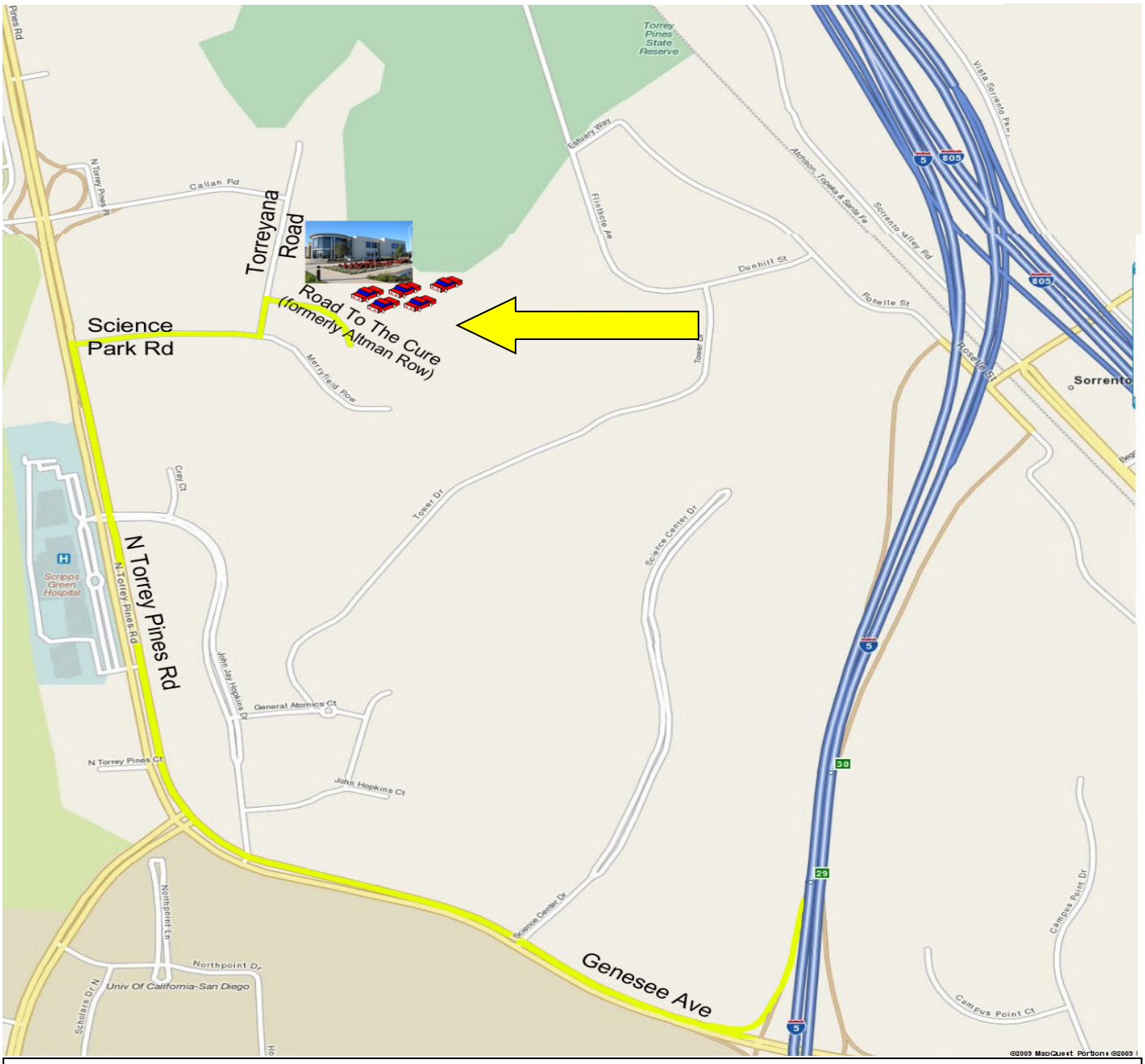
Our brochure provides the group philosophy and explains our goals. Copies may be obtained at our meetings. Please pass them along to friends and contacts.

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 <u>special donations</u> to IPCSG. Remember that your gifts are <u>tax deductible</u> 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. <u>Corporate donors are welcome!</u> If you have the internet you can contribute easily by going to our website, <u>http://ipcsg.org</u> 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).