Informed Prostate Cancer Support Group Inc.

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April 2012 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Tuesday, April 03, 2012 Volume 5, Issue 3

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
Carlos Richardson
Robert Keck, Librarian
Bill Manning
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Jerry Steffen
Robert Werve, Treasurer

Next Meeting April 21st 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!!

Table of Contents

Editor: Gene Van Vleet

The March meeting was well attended in spite of the inclement weather with 100 in attendance and 8 newcomers.

Dr. Irwin Goldstein moderated the presentations of Dr. Andrew Goldstein and Dr. Brian Dicks. Dr. Andrew Goldstein's expertise is in stem cell research as it relates to prostate cancer. There are two types of stem cells. A cluster of cells can be grown on a plastic dish and are known as embryonic stem cells. They never exist in a human body. They have an unusual capacity to make different kinds of cells. The other kind are defined as "adult stem cells" or "tissue specific stem cells" which exist in human bodies in about every organ. These were the subject of his pres-

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.

(Continued from page 1)

entation. Each organ has its own resident stem cells. The job of those stem cells is to re-make the cells in that organ. Adult stem cells can make more of themselves and they can make more of other kinds of cells that are in that organ in order to replenish that organ throughout your life. For example, if given a bone marrow transplant, these stem cells have the ability to replenish themselves to create healthy blood cells of all kinds. The need, in the arena of prostate cancer, is to find better ways to diagnose the severity of the disease to determine the need for treatment vs active surveillance. In the prostate, there are only two kinds of stem cells--Basal cells and Luminal cells. Through a complicated process utilizing microbiology they can identify these cells. Through experimentation with mice it was discovered that only Basal cells have the ability to re-grow prostate tissue within the mouse. More importantly, it was discovered that only the Basal cells could be induced to form cancer. The importance of this discovery is that it leads science to look for the source of the cancer, which are the adult stem cells, in order to stop the cancer rather than treating the result.

Dr. Brian Dicks spoke about the clinical consequences of prostate cancer and prostate cancer treatment. He talked about preserving erectile function from before you get treatment as opposed to recovery after treatment. Sexual problems are not just biologic, but they also involve the brain and the sexual partner. He indicated that nerve sparing surgery is not the determining factor for erectile dysfunction (ED), but rather what happens to the penis. The erection nerves that affect the penis are alongside and in the prostate and are so small that they cannot be seen therefore they cannot all be spared. In an erection, blood comes in, the valve turns off to hold the blood and the penis becomes hard. Problems come about if nerves are injured, blood inflow is interrupted by the surgical process and the penis just won't hold the blood anymore. Problems with holding the blood can occur six months to a year after the surgery or later because the cells just won't hold the blood anymore. Their practice recommends starting treatment before treatment for prostate cancer in order to maximize function beforehand which can include low-dose pills such as Viagra or Cialis, self-injections or vacuum therapy. In some cases where low testosterone is a problem, patients may be started on supplemental testosterone. It is important that both sex partners become involved in the process. Dr. Dicks presented several studies verifying the positive benefits of their recommended therapies.

The foregoing is intended to be only a summary of the presentations. You can gain more valuable and specific knowledge by obtaining the DVD of this meeting through the website: http://ipcsg.org by clicking on the blue "Purchase DVDs" button; through the library that is available at each meeting, or by contacting Gene Van Vleet: e-mail gene@ipcsg.org or phone 619-890-8447.

Future Meetings

April 21, 2012. Round Table. Hear member experiences, then participate in break-out networking sessions by treatment type. Learn about treatment options from others' experiences.

May 19th, 2012. Dr. Fabio Almeida, Medical Director, Southwest PET/CT Institute-Arizona Molecular Imaging Center. Subject: An ongoing clinical trial for Carbon-11-Acetate PET/CT imaging for Prostate Cancer.

If you have leads to speakers related to the interests of our group please contact: lyle@ipcsg.org or gene@ipsg.org

NOTEWORTHY ARTICLES

Biopsy, Biopsy Everywhere

Reprinted from Prostatesnatchers
http://prostatesnatchers.blogspot.com/
Posted: 27 Mar 2012 01:32 PM PDT

BY MARK SCHOLZ

A month ago I promised to expound more concerning our national passion for prostate biopsy. A million men are biopsied every year. Two hundred thousand will be diagnosed, the majority with *Low-Risk* disease, a condition that can be safely monitored without immediate treatment. Even so, most will undergo prompt radical treatment. Irrational fears drive most men into taking immediate action.

Since diagnosis overwhelmingly portends overtreatment, some experts have suggested that we put a stop to PSA testing. Practically speaking this will never happen. Patients and doctors alike are unwilling to forgo the information that PSA provides, imperfect as it may be.

Realistically speaking, PSA testing per se is not the real problem. The problem is doctors and patients *overreacting* to the information PSA supplies. The solution is not less frequent PSA testing, but rather convincing physicians to slow down the rush to immediately biopsy men with slight PSA increases. Diagnosing every single case of prostate cancer is of highly questionable value. Many men would rather be spared the unnecessary knowledge that they have a non-threatening *Low-Risk* prostate cancer.

Rushing into an immediate biopsy only makes sense when aggressive cancer is present and that is much less common.

So where is the middle ground between immediate biopsy of every PSA elevation and forgoing PSA testing and biopsy altogether?

Before deciding to do a biopsy, the prostate gland should be measured with an ultrasound scan to determine whether it is abnormally enlarged. If the amount of PSA elevation is proportionate to the degree of prostate enlargement, then the PSA elevation is due to benign cause. Rather than proceeding with an immediate biopsy, additional PSA monitoring and a urine test called PCA-3 may be helpful.

PCA-3 is a relatively new test that measures ribonucleic acid (RNA) secreted by the cancer cells into the urine following manual massage of the prostate. Studies show that the amount of PCA-3 in the urine increases in proportion to both the size and aggressiveness of a man's prostate cancer. Unlike PSA, PCA-3 is unaffected by the size of the prostate. Low amounts of PCA-3 in the urine, say less than 40, indicate that the presence of an underlying aggressive cancer is less likely.

If the PCA-3 and PSA density are favorable, further monitoring with some form of imaging offers additional insurance against missing the diagnosis of aggressive cancer. Modern 3-Tesla endorectal MRI and high-resolution color Doppler ultrasound, while not perfect, are reasonably accurate methods for detecting aggressive cancers.

So in summary, biopsy should be reserved for men with elevated PSA levels that can't be explained by a prostate infection, laboratory error or recent sexual activity. Here are some signs that a biopsy may be needed:

1. A PSA elevation out of proportion to the size of their gland or
2. Abnormally elevated PCA-3 levels or
3. An abnormality felt on digital rectal examination or
4. Imaging studies suggestive of underlying aggressive cancer.

PSA is a remarkable tool that has transformed the management of prostate cancer over the last 20 years. Rather than triggering an immediate biopsy, an elevated PSA should lead to further investigation. Rushing to a biopsy simply because PSA is elevated frequently leads to unnecessary radical treatment with

(Continued on page 4)

(Continued from page 3)

detrimental lifelong consequences

PRICEY NEW TOOL FOR PROSTATE CANCER: PROTON BEAM

Robert Langreth

Reprinted from San Francisco Chronicle, Wednesday March 20112

Imagine a prostate cancer therapy that has almost no side effects. Hospitals say it exists and they're vying to be among the first to offer it. Too bad the treatment may not work as well as advertised and could boost America's already spiraling health care costs.

The technology uses narrowly focused proton beams to deliver precisely targeted blasts of radiation. The particle beams are delivered by 500-ton machines in facilities that cost from $100 million to $200 million, and can require a football-field sized building to house. A typical treatment costs about $50,000, twice as much as traditional radiation therapy though it is usually covered by Medicare or private insurance.

For U.S. taxpayers and employers facing spiraling health care costs, that's a worry.

"Proton-beam therapy is like the death star of American medical technology; nothing so big and complicated has ever been confronted by the system," said Amitabh Chandra, a health economist at Harvard University's John F. Kennedy School of Government. "It's a metaphor for all the problems we have in American medicine."

Yet even though the machines are breathtakingly expensive, hospitals and for-profit clinics are in a race to build proton-beam facilities for their prestige, perceived benefits and potential revenue. With one machine able to generate as much as $50 million in annual revenue, new facilities are sprouting up around the country.

Like an 'arms race'

"It's like a nuclear arms race now, everyone wants one," said Anthony Zietman, a radiation oncologist at Boston's Massachusetts General Hospital, which has had a proton-beam accelerator since 2001.

Proponents of the technology say it can zap cancerous tumors without damage to surrounding tissue. That's a major benefit for the relatively small number of people who suffer from tumors of the spine, brain and eyes, where stray radiation may blind or paralyze, or in children who are more sensitive to radiation.

The therapy has even wider appeal for treating prostate cancer, a much more common disease, since existing treatment often causes rectal bleeding as well as impotence. More than 240,000 American men were diagnosed with prostate cancer in 2011, making it the nation's most-diagnosed tumor, according to the American Cancer Society. Most of those men are potential candidates for proton-beam therapy.

"The easiest group to market to in the country is a group of men worrying about the functioning of their penis," said Paul Levy, former head of Beth Israel Deaconess Medical Center in Boston.

(Continued on page 5)

(Continued from page 4)

Is it better?

The problem is that despite the push to build proton-beam facilities and the groundswell of enthusiasm for the treatments, it remains unclear whether the therapy does a better job of shrinking tumors or avoiding side effects than the far less costly traditional therapy. Clinical trials haven't yet provided a clear picture proving the treatment's worth for common tumors such as prostate cancer.

Lower rates of impotence, for one, are unlikely from the use of proton therapy because proton and traditional treatments deliver high doses of radiation to the nerves to the penis, Zietman said. So whether the pricey treatments will do a better job managing prostate cancer while also preserving sexual function is an open question.

Proton-beam therapy and traditional X-rays are equally effective at killing tumor cells. The debate is over side effects. Proton-beam therapy works by shooting intense, narrow beams into targeted areas of the body. Protons slow down as they travel deep in the body. Doctors can manipulate the speed of the atomic particles, allowing them to deposit most of their radiation as they come to a stop inside a tumor.

X-rays used in conventional radiation therapy are made up of photon beams that zip through a patient, exposing tissues along the way to excess radiation. While modern machines use multiple beams sculpted to intersect and concentrate high doses on a tumor, lower doses are spread over a much larger region.

The proton technology isn't new, but only in recent years has it caught on. Loma Linda University Medical Center in Loma Linda (San Bernardino County) built the nation's first hospital proton-beam accelerator in 1990, but the treatment became more viable after the American Medical Association granted proton therapy an insurance billing code in 2000, making reimbursement easier, said Allan Thornton, a radiation oncologist at Hampton University's proton-beam center, which opened in August 2010.

"That brought proton therapy out of the closet," he said.

UPDATED STUDY UNDERSCORES PROSTATE CANCER SCREENING SAVES LIVES

By Large Urology Group Practice Association

Posted: 1:27pm on Mar 15, 2012; Modified: 1;31pm on Mar 15, 2012

Reprinted from Bradenton Herald

TALLAHASSEE, Fla., March 15, 2012 — /PRNewswire/ -- In a comprehensive study published today in the New England Journal of Medicine, PSA screening was shown to reduce the mortality rate of prostate cancer by 29 percent. The Large Urology Group Practice Association (LUGPA), representing more than 1,800 urologists, stated that today's study confirmed what urologists and other healthcare providers have known for years — that PSA-based screening is a critical, valuable life-saving tool. The study "Prostate-Cancer Mortality at 11 Years of Follow-up" underscored the power of PSA-

(Continued on page 6)

(Continued from page 5)

based screenings in saving lives from prostate cancer.

The European Randomized Study of Screening for Prostate Cancer (ERSPC) studied 182,160 men between 50 and 74 years old, with a core age group of 162,388 men 55 to 69 years old. The trial was conducted in eight European countries. Men randomly assigned to the screening group were offered PSA screening. Men in the control group were not offered screening. The results showed that for all patients, there was a 21% survival advantage, and more importantly, for those with the longest follow-up (over 10 years) this increased to 38%.

"The ERSPC confirm what those caring for patients with prostate cancer have observed over the last two decades, that we are detecting cancer earlier and saving lives," said Dr. Kapoor, President of LUGPA and Chairman and CEO of Integrated Medical Professionals, PLLC. "The decision on how to screen and treat prostate cancer should be made by patients and their doctors, and no government agency should try and restrict men's ability to control their own health care."

Those at the greatest risk for prostate cancer — such as African-American men, the underinsured, men living in rural areas, and men with a family history of prostate cancer, need most urgently to hear about the value of PSA screening and know that it can save their lives.

Further evidence of the effectiveness of prostate cancer screening in the United States is the statistics relating to prostate cancer mortality: over the last two decades, the incidence of prostate cancer has remained stable, but the death rates from this disease have decreased by nearly 40 percent. Early detection is critical to the success of prostate cancer treatments.

Visit http://lugpa.org/about/press.aspx for more information about the value of PSA screening.

AboutLUGPA represents 98 large urology group practices in the United States, with more than 1,800 physicians who make up more than 20 percent of the nation's practicing urologists. LUGPA and its member practices are committed to best practices, research, data collection, and benchmarking to promote quality clinical outcomes. Visit http://lugpa.org/default.aspx for more information about LUGPA.

Announcements

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.

Our Steering Committee meets for lunch, usually at Baci's restaurant (preferred) at noon on the first Tuesday of each month. All members are welcome! Please call Lyle La Rosh at 619-892-3888, to make reservations and to verify location.

Library Announcement

"To all those who have borrowed books, tapes or DVD's please return them at the next meeting"

HEALTH INSURANCE NEWS

Affordable Care Act gives consumers new tools, makes health insurance market more transparent

Created under the Affordable Care Act, www.HealthCare.gov was launched July 1, 2010, and is the first website of its kind to bring information and links to health insurance plans into one place to make it easy for consumers to learn about and compare their insurance choices. HHS' Office of Consumer Information and Insurance Oversight (OCIIO) worked to define and collect detailed benefits and premium rating information from insurers across the country, and starting October 1, 2010, consumers will also be able to find information about health insurance options such as: Monthly premium estimates; Cost-sharing information, including annual deductibles and out-of-pocket limits; Major categories of services covered; Consumer's share of cost for these services; Percent of people in the plan who pay more than the base premium estimate due to their health status; Percent of people denied coverage from a health plan.

More than 225 insurance companies have provided information about their individual and family plans for more than 4,400 policies, including policies in every state and the District of Columbia. Consumers can search for and compare information on plans available based on age, gender, family size, tobacco use and location.

NOTE

California law requires that you have an annual 30-day period beginning on your birthday during which you may purchase any Medicare supplement coverage that offers benefits

(Continued on page 8)

(Continued from page 7)

equal to or lesser than, those of your current coverage. You are eligible to purchase such plans without regard to your health status, claims experience, receipt of health care or medical condition. This only applies if you currently are on Medicare.

Mr. David Weil from Health Insurance Counseling and Advocacy Program (HICAP) provided information about their free services in our October, 2011 meeting. HICAP is a non-profit program that assists with counseling about medicare coverage and billing issues, including appeals. They do not make recommendations but rather provide information to help individuals make decisions about available coverage. They also assist with Long Term Care Insurance. The local phone number is 858-565-8772 or, if calling from a cell phone outside of the San Diego Area, 800-434-0222. Website: http://www.cahealthadvocates.org/HICAP/sandiego.html

If you have particular knowledge that would be helpful to our goal of creating a base of information, please volunteer your efforts to the committee. Contact Gene Van Vleet, e-mail gene@ipcsg.org or cell phone 619-890-8447 who may redirect your inquiry to an appropriate person for response.

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.
3. Assistance with editing and publishing monthly newsletter.

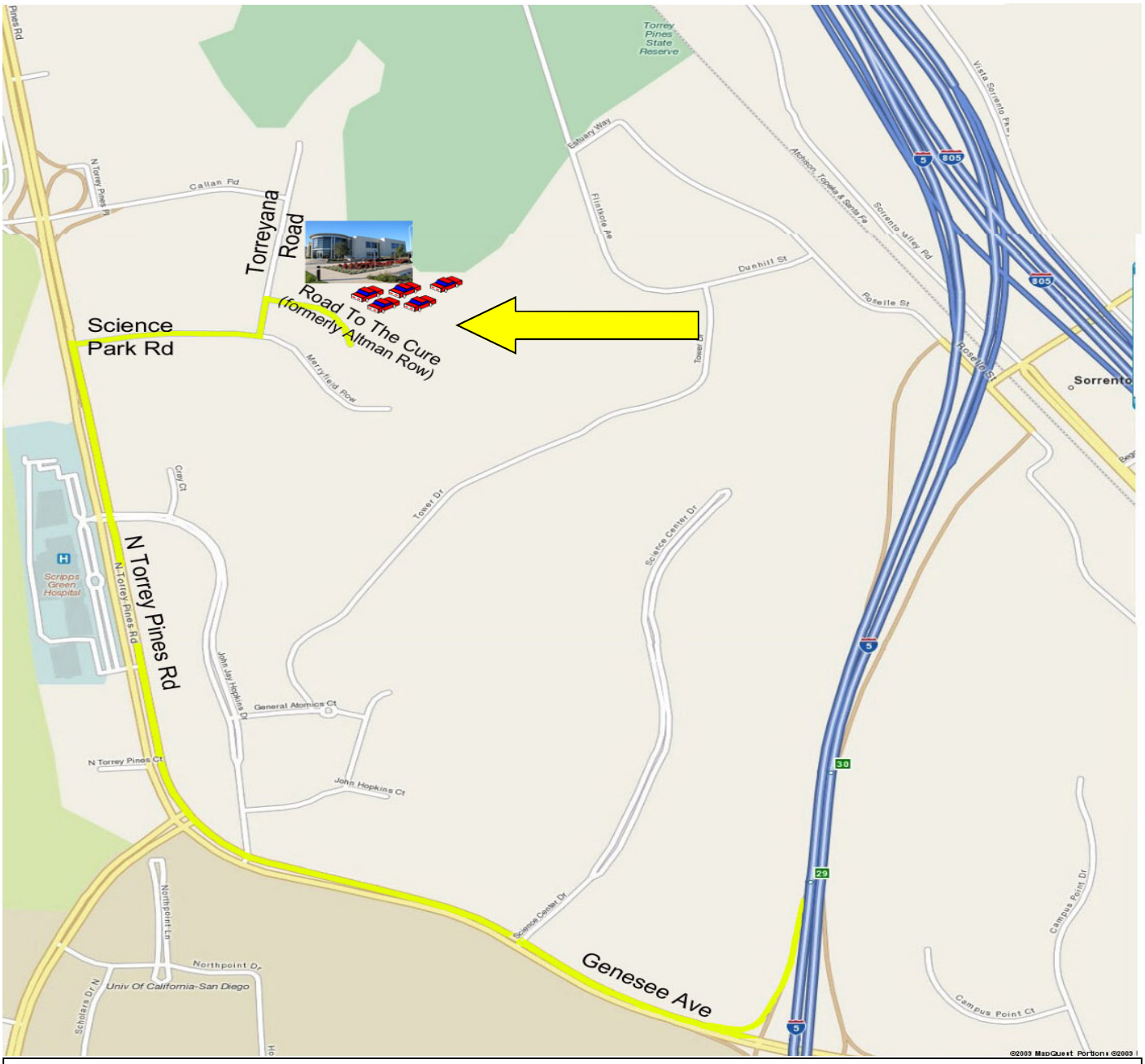
Anyone interested please contact:
Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org
Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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).