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

November 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)

Thursday, November 08, 2012

Volume 5, Issue 10

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
November 17th
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

October 2012 Meeting Notes

Our President, Lyle LaRosh, gave an interesting presentation "A Patient's Opinion of Today's Medical Practices". In case you missed it, his PowerPoint presentation follows. The presentation was followed by an informative Q&A session which can be viewed on the DVD of the meeting available in the library or through our website: http://ipcsg.org

◊ Process from elevated PSA by normal annual blood test. Your PSA should have gone up by

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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50% in a 12 month interval.

- ◊ GP sends you to Urologist who recommends a biopsy. No one tells you what they are going to do to you and the trauma it will cause. You go home and bleed.
- ◊ If you are 60 or older, biopsy will probably be positive 70% of the time. Most Urologists do a very poor job of explaining Gleason score. You are scared and confused. Doctor says he can operate next week and that you will be cured and have no problems. He does not tell you of incontinence, impotence, and reoccurring cancer. Or that your dick will be 1 inch shorter. If you ask for a 2nd opinion, they send you to another Urologist who tells you the same thing.
- ◊ If you have surgery and it is successful, you will probably be incontinent to some degree. Same with erection. About 55% of the time within 5 years you will have recurring cancer.
- ◊ Welcome to IPCSG
- ◊ Why didn't the doctor tell me?
  - ◊ Old doctors don't like to be questioned.
  - ◊ Young doctors don't have time. Student loans have to be paid.
  - ◊ Medical school does not teach Prostate Cancer. Traditional medicine only refers men to Urologists who are only taught surgery.

◊ Charles Huggins was awarded the Nobel Prize in medicine 1966. In 1941 Dr. Huggins was studying the effects of hormones on the growth of cancer. He was using mice and dogs as his subjects. Common legend has it that he cut the testicles off of 3 men and made the conclusion that Testosterone was the cause of their cancer. Recently, a researcher located the original notes and found that the surgery had only been performed on one man. So, the common idea that Testosterone causes PCa is about 60 years old and is still being taught in Medical School. Most of the new emerging drugs are used for what we now call Androgen Deprivation Therapy. The old common term is Hormonal Therapy. This therapy is based on removing a man's Testosterone by Chemical Castration. Same effect as removing your testicles.

◊ Current state of referral is the same as above in most cases. General Practioner to Urologist to surgery or if you are lucky you get sent to a Radiation Oncologist for an opinion. Almost never will you be referred to a Medical Oncologist . The fact is that there is no Medical Oncologist that specializes in ONLY PCa in San Diego County. We refer ALL of our members to "Prostate Oncology Specialists" in Marine Del Rey. Those doctors are partnered with other MDs for specific treatments. In particular, for all radiation therapy, they are partnered with the John Moores Cancer Center in LaJolla with Dr. AJ Mundt.

◊ Urologists vs. Men. This is the problem with today's medical practice for treating PCa. Urologists are

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traditionally the first line of a rising PSA. This absolutely should be stopped, banned or made illegal. Urologists have a vested interest in keeping you as a patient. When I am asked what the diagnostic process should be, my opinion is this:

- ◊ Family doctors should be trained at Medical School to follow a different referral policy. Men with an abnormally rising PSA should be referred to a Medical Doctor or facility specializing in the diagnosis of the Prostate including BPH. Prior to biopsy, it should be determined if the PSA increase is due to other factors than cancer. This is can be done by imaging using Color Doppler Ultrasound, Spectroscopy MRI, or several new types that are becoming available. This is still not being followed by most Urologists.
- ◊ If during these imaging tests it is decided that a biopsy is justified, a targeted biopsy can be taken from the suspected tumor and reduce the number of specimens taken. This results in a dramatic reduction of trauma to the patient. Those of you fortunate enough to have used Dr. Duke Bahn can testify to the proper way to do a biopsy

◊ Doctors that specialize say my way is the BEST way. Several of our members have spent a huge amount of time doing research, visiting many doctors, and come back just as confused as when they started.

- ◊ Finally we are discovering new methods that show the Biology of PCa is very different and that there are different strains that react differently to different treatments. We are learning that the different genetic makeup of PCa reacts to different treatments. Soon we will learn that we will be able to know what treatment might really cure PCa.
- ◊ Most of you know that current medicine treats us with a variety of drugs, surgery, radiation, freezing, heating, etc. Almost all doctors will try to treat us with something, wait to see if it works. When it fails, they try something else, ad nauseum. Many of our members have gone through many years of tried and failed therapies. The practice of medicine is "lets try this and see if it works". Every treatment comes with side effects, many of which are irreversible.

◊ There have been two incidents in Southern California where patients were told by their surgeons that they would be "Strong as a bull" and be able to have sex like a young man. Both stories followed the same pattern. Following surgery here in San Diego, the patient made an appointment to visit his doctor. When the doctor entered the room, the patient pulled out a pistol and shot the doctor in the penis 3 times. The patient was tried and when on the stand called the doctor a "Butcher". He was convicted, sent to prison, and a few years after his release he committed suicide. The doctor is still practicing here in San Diego. The second patient committed suicide in front of a Denny's after the police followed him

◊ The near future of care. Support groups like ours, The Prostate Cancer Research Institute, PAACT (Publisher of "Choices"), and the Prostate Cancer Foundation are forming lobbying groups to pursue a change in the way the business of PCa is being done. The success of the leadership of PCRI through their Annual National Convention are bring the different segments of the business together to work towards a better future. Men like Dr. Mark Scholz deserve the praise of the world for their work in making this happen.

◊ The long term view of the future holds great promise. As men are exposed to the long term causes of PCa they might start early in life to be more careful of their diets. Ask yourself this question:

"Why don't men in Asia have Prostate Cancer?"

Future Meetings

November 17. Robert Louie of Medivation will speak about the recently FDA approved Xtandi (formerly MDV3100.

December. NO MEETING

January 19, 2013. To be announced

February 16. Roundtable discussions

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.

ON THE LIGHTER SIDE!!!!!!!!

The Manogram

If women controlled medicine, one of the tests the men might have to undergo could look like this:

Unfortunately, we appear to be living in a time when physician income is more important than patient outcome.

Dr Stephen Strum

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Cockroach Analogy

Prostate cancer is similar to finding a cockroach in the middle of your kitchen table. You panic, knowing that where there is one there are probably more and they do multiply. You call several exterminators. The surgeon recommends removal. He'll use a chain saw and remove the kitchen from the rest of the house and repair the plumbing as best he can with what remains.

The external beam radiation exterminator wants to stand out side the kitchen and blast away with a twelve gauge shot gun hoping he will miss the plumbing.

The seed implant exterminator is really slick. He just wants to drill holes in the wall and toss in grenades.

The cryosurgery exterminator wants to drill holes in the walls and pump in liquid nitrogen, hoping he doesn't freeze the plumbing.

The hormone guys.. well they just want to pump in sleeping gas. Knowing all too well that in a couple of years the cockroaches will wake up pissed off and hungry.

Chemotherapy boys will offer to poison everything in the kitchen and will promise you that if you eat the poison they will give you an antidote which may or may not work.

The alternative medicine people will give you a bit of eye of newt and toe of frog plus a couple of other exotic ingredients and hope to hell that chases the cockroaches away.

And then there are the watchful waiting folks, some of whom are not real sure that there was a cockroach and some of whom think it may have been just an old bachelor 'roach with no kids that they saw.

The active surveillance men are a little different - they set up their equipment color dopplers, infra-red cameras - ready to pounce on those pesky cockroaches if they ever show themselves again.

Now if there is only the one cockroach the odds are good - you can get rid of the infestation. However if the little bugger laid eggs elsewhere or more of his buddies are lurking about in other places... well you get the picture. In any case, life in the kitchen will never be the same. One of these days an exterminator will come along who just swats the cockroach and puts out poison bait for the others!! You'll never know he was there. Until then good luck on your choice of exterminators, and low or non-existent PSA's to you all.

And remember - Don't take life too seriously. You won't get out of it alive anyway!

NOTEWORTHY ARTICLES

The Un-Cancer

Posted: 23 Oct 2012 0800 AM PDT Prostate Snatchers

By Mark Scholz, MD

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It's easier to teach a proper golf swing to a true beginner than to someone who has previously developed bad habits that are now ingrained. The young mind of a child learns a new language much more easily than the cluttered mind of the adult. Good first impressions are valued so highly because we all know how hard it is to undo a bad first impression. The biggest challenge of educating people about prostate cancer is overcoming their preconceived notions—what they already think they know about *cancer*.

What is prostate cancer? Many say it's harmless, that "you die with it, not from it." But how does that jibe with 28,000 deaths annually? One reasonable conclusion is that prostate cancer occurs and acts in a variety of different ways. **The Prostate Cancer Research Institute (pcri.org)** recommends dividing prostate cancer up into five categories or *Shades of Blue*. This is helpful both for understanding the varieties of prostate cancer and for guiding the choice of treatment.

However, even though there are many forms of prostate cancer, this fact fails to convey how differently prostate cancer as a whole acts, compared to other cancers. Why is it so important to understand this difference? First of all, surgery—which is everyone's first thought when they hear the word "cancer"—can have dire consequences. For example, surgery almost always causes partial or complete impotence. Second, new research published by Dr. Timothy Wilt in the July issue of this year's *New England Journal of Medicine,* shows that forgoing immediate treatment and embarking on a program of close monitoring known as "active surveillance," *has exactly the same survival rate as immediate surgery.* Bottom line: For far too many men, immediate treatment for prostate cancer is not only damaging, it is often unnecessary.

Forgoing treatment with something called *cancer* is certainly counterintuitive. In order to support the case for monitoring, let's compare the statistics for prostate cancer with those of colon cancer.

	Prostate Cancer: The "Un-Cancer"	Colon Cancer: A "Typical" Cancer	Difference Factor
Deaths Annually	28,000	26,000	1 : 1
New Cases Diagnosed	241,000	73,000	3.5 : 1
Mortality Rate	8.5%	35.5%	4.2 : 1
Average Survival if Relapse Occurs	13 Years	13 Months	12 : 1

As the table shows, men diagnosed with colon cancer are not only three and a half times more likely to die from the disease, they die *twelve times more quickly*. Unfortunately, almost all cancers—lung, pancreas, stomach, gallbladder, kidney, brain, bone, etcetera—approximate the behavior of colon cancer rather than prostate cancer.

The fact remains that it is logical for the general population to be terrified by the very idea of cancer. When you consider all the different types combined, cancer is the second most common cause of death, just below heart disease. The risk of death from most cancers is high and if a cure is not obtained, death follows all too quickly. The unfortunate men who die from prostate cancer make the "news," even though it may not be generally understood that it took 13 years for those men to succumb. However, the fact remains that there are *2.8 million* prostate cancer survivors presently living in the U.S. That should be news too.

Ninety-one and a half percent of men diagnosed with prostate cancer will have a normal life expectancy, and will die of natural causes. The eight and a half percent who die from prostate cancer will live an average of 13 years, with this number expected to increase dramatically over the next ten years, thanks to continuing improvements in medical technology. Treatment can definitely improve survival in selected cases. However, it would seem that only men in the high-grade category are likely to benefit consistently.

The encouraging facts about prostate cancer outlined in this blog have been compiled to help men realize that survival rates with prostate cancer are extremely favorable compared to other types of cancer. Now that studies show that survival with active surveillance matches that of immediate surgery, a great many men should take heart, and resist all efforts to rush into a treatment with such uncertain rewards but such predictable and devastating side effects.

Sensitive New Sensor Detects Prostate Cancer in Early Stages

PostsWebsite By Vonda J. Sines | Yahoo! Contributor Network – Tue, Oct 30, 2012

British scientists have designed a prototype of a highly sensitive scanner that can detect diseases such as prostate cancer and HIV in very early stages. They consider their discovery extremely useful in countries where high-tech detection equipment is scarce.

The researchers, from Imperial College London, reported that their new visual sensor technology is 10 times more sensitive than traditional disease detectors that measure biomarkers in the body, according to Medical News Today.

The team tested the sensor's accuracy in looking for a biomarker known as p24 that's associated with HIV in human blood samples. They tested other samples for the Prostate Specific Antigen (PSA) marker, one indicator of prostate cancer.

The National Cancer Institute predicts that more than 240,000 men in the United States will be diagnosed with prostate cancer in 2012 and that more than 28,000 of them will die. A male newborn has a one in six chance of developing this disease.

The two standard ways of detecting this cancer are a digital rectal exam and a PSA test. In early stages, many cases have no symptoms. According to the Mayo Clinic, use of the PSA test is debatable because studies have never proven that the blood test saves lives. It can yield suspicious results even when the patient merely has an infection.

The new sensor detects prostate cancer by looking for PSA in a blood sample. With a positive result, irregular clumps of nanoparticles form and emit a specific blue shade inside the disposable container. For a negative test, the nanoparticles separate and form shapes that resemble a ball. The process creates a red hue. Both colors are visible to the naked eye.

The ultra-sensitive sensor could detect certain diseases at much earlier stages than current technology can find. It found miniscule levels of p24 in samples from patients with low HIV viral loads, a result impossible with standard tests like the Enzyme-Linked Immunosorbent Assay (ELISA).

The next step toward implementation is finding a sponsor among not-for-profit global health organizations to oversee the strategy for development, funding, and distribution of the technology.

While use of the sensor in the United States might be years away, the device is of special interest to my family. After years of lower-than-average PSA results, the numbers for my husband, who has a family history of prostate cancer, shot up last year. A test six months later showed even higher numbers.

The urologist performed prostate biopsies that caused bleeding and discomfort for weeks. The results showed no sign of malignancy, calling into question the validity of the two tests. A year later, the numbers mysteriously returned to the low end of the normal range. It would be reassuring to have access to this

Announcements

Medicare open enrollment began October 15th and ends December 7th. Research your options and what is changing in 2013.

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

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.

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

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 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.

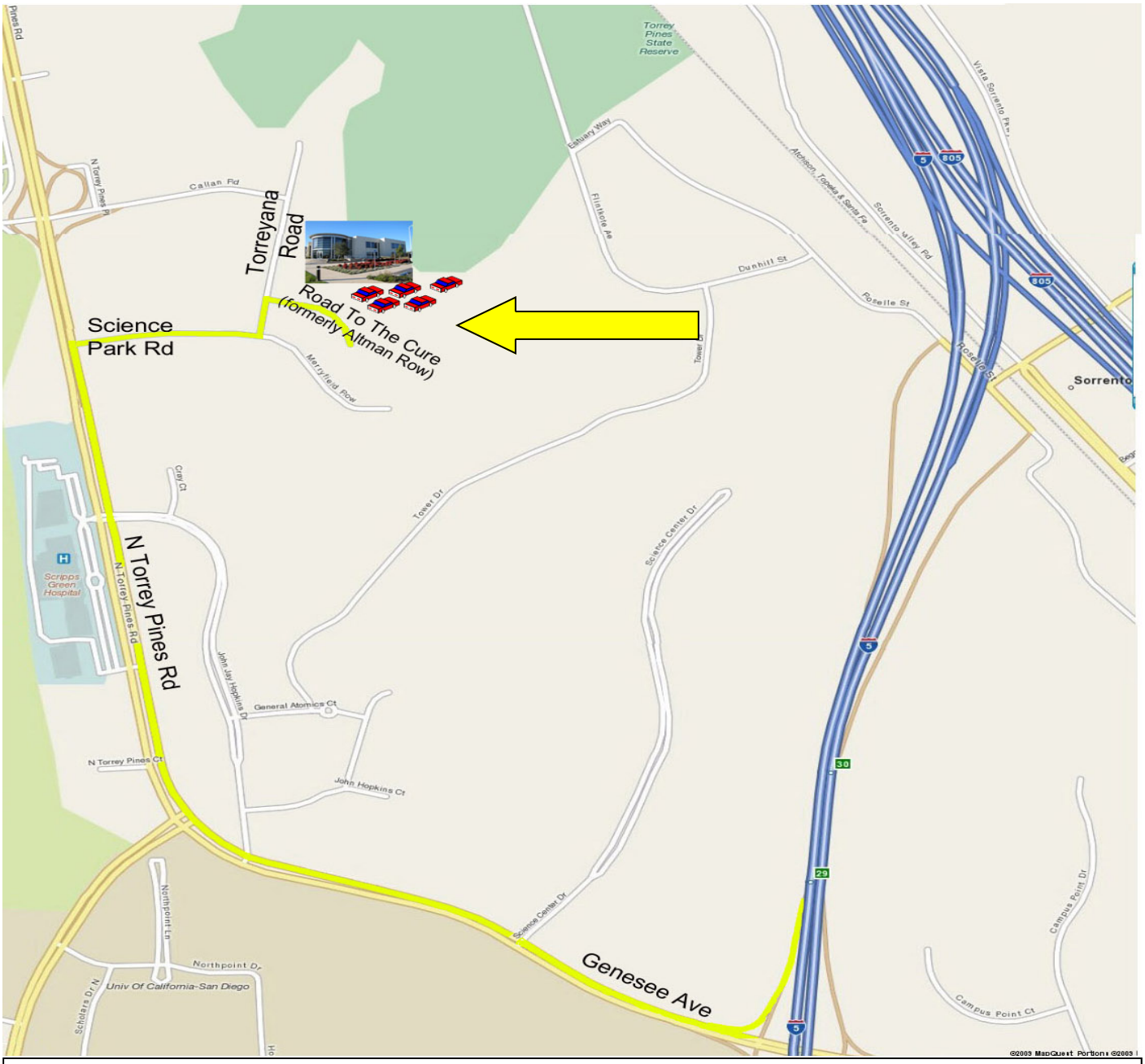
Mr. David Weil from Health Insurance Counseling and Advocacy Program (HICAP) provided information about their free services in our October, 2011 meeting. HICAP is a non-profit program that assists with counseling about medicare coverage and billing issues, including appeals. They do not make recommendations 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

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).