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

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, October 11, 2013 Volume 6 Issue 9

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Editor: Gene Van Vleet

Next Meeting
Oct. 19
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!!

PROSTATE CANCER IT'S ONLY 2 WORDS, NOT A SENTENCE

Our guest speakers for the September meeting were Patricia (Trish) DeLeo and Diane Waggoner, both independent insurance professionals. Their purpose was not to represent any insurance company but rather to inform about Medicare coverage and changes—although some changes would not be known until October. They are both specialists in the Medicare field. Medicare Part A covers hospitalization, Part B covers doctors, outpatient and home care, and Part C is an Advantage plan, also called Complete Plan or Plan P which is a managed care plan. There is also a Supplemental, sometimes called a Medigap plan, which offers more flexibility

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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for freedom of choice of doctors.

Diane spoke about the Medicare Advantage plans which are HMO or PPO plans where you pick your primary doctor and all needed specialists must be in the same network in the hospital of your choice. The only qualifiers are that you must be domiciled in the areal of the plan for 6 months and whether you have in stage renal disease (kidney failure). If you have cancer you would still qualify. Different copays and deductibles are available. Some cover ancillary benefits that Medicare does not—such as out of country expenses, vision, hearing , dental, chiropractic and acupuncture. You can easily move from one plan to another during the open enrollment period from October 15th through December 7th with the same qualifier of kidney failure. The Advantage plans also include Part D prescription drug coverage. This covers the first $2,970 of drug costs which is the total of the cost including what you pay. After that the coverage gap or "donut hole" goes into effect wherein you must pay the cost of generic drugs and others your doctors may require if they are approved by Medicare. It is always wise to go to Medicare.gov website and check on approved drugs.

Trish spoke about Supplemental or Medigap plans. They offer coverage of unexpected costs of Medicare Parts A & B as well as the flexibility to see any doctor who takes Medicare—without a referral. The plans are scaled by degree of coverage up to Plan F. Plan F covers unpredictable costs and offers great flexibility. Premiums are somewhat higher. It is wise to asses your costs of an Advantage Plan relative to copays and deductibles versus the higher premiums of Supplemental plans. It may not be more costly. Coverage is not plan specific in that you can access doctors and services in other areas of the state and country. Also, additional drug coverage is available as a supplement to Medicare Part D that is billed separately. It is beneficial to discuss the different levels of Supplemental plans with a professional to find the one most suited to your needs.

The two ladies fielded extensive questions from the group and further stayed after the general session to talk with individuals about their needs. A DVD of the meeting will be available by the October meeting in our library or from our website: ipcsg.org. Click on the "Purchase DVDs" button.

FUTURE MEETINGS

October 19 - Dr. Robert Princenthal, Director of Prostate Imaging, and President, Rolling Oaks Radiology Medical Group. Subject: Multiparametric prostate MRI; how to best utilize this functional information for patient management.

November 16 - Dr. Fabio Almeida, Medical Director, Southwest PET/CT Institute-Arizona Molecular Imaging Center. Subject: Updated information on Carbon-11-Acetate PET/CT imaging for Prostate Cancer

December - NO MEETING

January 18, 2014 - Roundtable meeting. Networking among members.

February 15, 2014 - Dr. Christopher Kane, Professor and Interim Chair, Department of Surgery Chair, Department of Urology, University of California San Diego Health System. Imaging for targeted biopsies. Robotic surgery.

March 15, 2014 - Dr. Russell Low, Medical Director of Sharp and Children's MRI Center. DCE MRI Techniques for Prostate Cancer Diagnosis and Surveillance.

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April 19, 2014 - Roundtable meeting. Networking among members.

May 17, 2014 - Not yet committed.

June 21, 2014 - Dr. Irwin Goldstein, Director of Sexual Medicine, Alvarado Hospital speaks about the effects of PCa treatments on sexuality and Dr. Andrew Goldstein updates his work in stem cell research in relation to PCa.

ON THE LIGHTER SIDE

How did this happen?

The aspiring psychiatrists were attending their first class on emotional extremes. "Just to establish some parameters," said the professor to the student from Arkansas, "What is the opposite of joy?"
"Sadness," said the student.
And the opposite of depression?" he asked of the young lady from Oklahoma.
"Elation," said she.
"And you sir," he said to the young man from Texas, "how about the opposite of woe?"
The Texan replied, "Sir, I believe that would be giddy-up."

Light travels faster than sound. This is why some people appear bright until you hear them speak.

A fine is a tax for doing wrong. A tax is a fine for doing well.

Oxymorons: Pretty ugly Plastic glasses Sanitary landfill accurate estimate Found missing Good grief

EVER WONDER Why—
doctors call what they do "practice"?
you have to click on "Start" to stop Windows
women can't put on mascara with their mouth closed?
the sun lightens our hair, but darkens our skin?

Bumper stickers:
A closed mouth gathers no feet.
It's lonely at the top, but you eat better.
Ever stop to think, and forget to start again?
What happens if you get scared half to death twice?

NOTEWORTHY ARTICLES

ACA Implementation: How's It Going?

By John E. McDonough, DPH, MPA From Medscape Sep. 26, 2013

Nearly 3.5 years have passed since President Barack Obama signed the Affordable Care Act (ACA) into law in March 2010. Although the law's biggest reforms will not take effect until January 1, 2014, already the changes wrought by the ACA have been the most substantial in the history of federal health policy-making. Let's take a look back and a look ahead.

From my experience in explaining the law to audiences all over the nation, a helpful way to view what is happening is to start by understanding the law itself. The ACA has 10 titles, and understanding these titles helps to see just how expansive it is:

1. Reform of private health insurance -- individual mandate, subsidies, guaranteed issue, employer responsibility
2. Expansion of Medicaid to all low-income Americans -- made a state option by the June 2012 US Supreme Court decision upholding the ACA
3. Reform of the US medical care delivery system and changes to Medicare
4. Prevention, wellness, and public health initiatives
5. Health workforce initiatives
6. Fraud and abuse prevention, transparency, and comparative effectiveness research
7. Creation of a regulatory pathway for marketing and sale of biosimilar drugs
8. Community Living Assistance Services and Support (CLASS -- repealed by Congress on January 1, 2013)
9. Revenue measures to pay for about one half the cost of the ACA
10. Amendments to titles 1-9, and the Indian Health Care Improvement Act

Each title should have ended with the words "and a lot more," because this thumbnail sketch is just that. By my measure, the ACA is the only federal law ever passed that seeks to achieve comprehensive health system reform; even its undisputed peer, the 1965 law creating Medicare and Medicaid, was modest by comparison. Hardly any part of the US healthcare system is left untouched by the ACA.

ACA Implementation: How's It Going?

I have been watching US federal and state health policy closely since 1985. Without reservation, this is the most dynamic period I have seen, at least on par with the creation of Medicare and Medicaid in the late 1960s, and so much more expansive. Much has been accomplished already, and much remains to be done; some elements have been repealed or delayed. Overall, the scope and pace of change in the past 3.5 years is astonishing.

On coverage, a host of early reforms were implemented in 2010-2011, including continued coverage for young adults up to age 26 years on their parents' insurance, elimination of lifetime and annual benefit caps, several billion dollars in insurance rebates to employers and consumers whose policies spend less than 80%-85% on pure medical costs, the closing of the Medicare Part D prescription drug "doughnut hole," and much more.

On delivery reform, a host of innovations involving Accountable Care Organizations (ACOs), patient-centered medical homes, hospital penalties for excessive readmissions and healthcare-acquired infections, comparative effectiveness research, and more are taking hold. When the ACA was signed, many observers dismissed the role of ACOs, none of which existed in March 2010; today, more than 250 of them are forming within Medicare. The movement toward accountable care and away from fee-for-service is proceeding.

On many of these reforms, flaws and shortcomings in the statutory language of the ACA should drive

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Congress to continuously assess and modify the law in a common practice that I call "continuous policy improvement." Unfortunately, the intensely partisan divide over the ACA in Washington, DC, has prevented Congress from fulfilling its normal function to correct, amend, and improve complex laws such as the ACA.

What's Coming?

The fundamental structural components of Title I take full effect on January 1, 2014. These include:

• Establishment of "guaranteed issue" for all health insurance policies sold by insurers in the United States, with the accompanying elimination of the practices of "medical underwriting" and preexisting condition exclusions;

• Start of the individual responsibility provisions, which will impose annual tax penalties on citizens and legal residents who are able to afford to purchase health insurance and fail to do so;

• Initiation of subsidies to make the purchase of health insurance affordable for those with household incomes up to four times the federal poverty level (or about $84,000 for a family of 4);

• Launch of state health insurance exchanges/marketplaces to enable consumers and small businesses to purchase health insurance online; and

• Expansion of Medicaid eligibility to all US citizens with incomes below 138% of the federal poverty line (or about $15,000 for a single adult), although this expansion was made optional for states as part of the June 2012 US Supreme Court decision on the ACA.

Physicians need to understand these changes to be better able to counsel their patients on their coverage and care options. After January 1, health insurance in the United States will never be the same. Although many Americans applaud and many others jeer these reforms, they will be implemented and will take effect. We can only hope that Congress will soon be able to play its essential role in overseeing the improving the law as implementation unfolds.

John E. McDonough is the author of Inside National Health Reform (University of California Press, 2012).

18-Year Study Finds Drug Cut Prostate Cancer Risk

Follow-up focused on finasteride, the active ingredient in Proscar and hair-loss drug Propecia

By Dennis Thompson HealthDay Reporter

WEDNESDAY, Aug. 14 (HealthDay News) -- A drug used to treat enlarged prostate and male pattern baldness also reduces a man's risk of prostate cancer by nearly a third, according to a large new study.

The findings on nearly 19,000 men also overturn earlier concerns that treatment with finasteride -- the agent in the prostate drug Proscar and the hair-loss drug Propecia -- might promote the development of more virulent prostate cancers in men who contract the disease, researchers said.

Finasteride did not affect overall survival rates or survival rates after diagnosis with prostate cancer for men who did and did not receive the drug, said study lead author Dr. Ian Thompson, a urologist and professor at the University of Texas Health Science Center.

"If indeed the more high-grade cancers in the men taking finasteride were real, we would expect to find a higher death rate," Thompson said. "The survival of these men was exactly the same."

Continue reading below...

Published in the Aug. 15 issue of the New England Journal of Medicine, the study is an 18-year follow-up on the Prostate Cancer Prevention Trial, which took place in the late 1990s. Back then, the trial found that finasteride could reduce overall risk of prostate cancer by 25 percent -- but that it increased by 27

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percent the risk of high-grade prostate cancer in those men who did wind up with the disease.

The concern over the high-grade cancer findings led officials back then to decline recommending finasteride as a prostate cancer prevention tool. "Basically, this potential home-run prostate cancer intervention never happened," Thompson said.

When checking back with the men involved in the earlier trial, researchers behind the new study found that the drug actually worked better than earlier reported in reducing prostate cancer risk.

They also found that detection of high-grade cancers occurred in 3.5 percent of prostate cancer patients who took finasteride and 3 percent of patients given a placebo. There was no difference between the finasteride and placebo groups regarding overall long-term survival or survival following a prostate cancer diagnosis.

"It shows that the higher proportion of high-grade disease doesn't really matter, because it doesn't affect the risk of death," said Dr. Otis Brawley, chief medical officer for the American Cancer Society.

Brawley said the increased diagnosis of high-grade prostate cancer likely occurs due to finasteride's effectiveness in shrinking enlarged prostates.

"You take Proscar for six months to a year and it halves the size of your prostate, but the cancer inside your prostate does not shrink," Brawley said. "If I'm performing a biopsy on a smaller prostate, I'm more likely to hit that cancer than if I am sticking into a larger prostate. This drug wasn't causing more prostate cancer. It's causing more prostate cancer to be diagnosed."

Since finasteride does not affect survival rates, its true value may lie in reducing the diagnosis of minor prostate cancers that should not be treated, Thompson and Brawley said.

Prostate cancer is the most commonly detected form of cancer in men, found in one in six men during their lifetimes, Thompson said. Prostate cancer kills only 3 percent to 5 percent of men, however.

Most men "will get away with it, dying of causes other than prostate cancer," Thompson said.

Because of this, prostate cancer has become an overtreated disease, with men suffering side effects such as impotence and incontinence because they received treatment for a cancer that wasn't likely to lead to their deaths, Brawley said.

"It does not affect a man's risk of death at all to take finasteride, but if he takes finasteride it will lower his risk of being diagnosed with prostate cancer," Brawley said. "Half to 60 percent of men who were diagnosed with localized prostate cancer, if it was never diagnosed, it would never have bothered them in their lifetimes. We cure some people who never need to be cured."

Can't NFL acknowledge prostate cancer too?

Submitted by Jon Mark Beilue, Amarillo News, on Mon, 10/07/2013 - 9:12am

For the millions watching NFL games on Sunday, pink was everywhere. There were pink ribbons on coaches polo shirts, pink arm bands, pink gloves, pink shoes and pink sweatbands on players. The officials even threw pink flags, which looked awfully weird.

This will be a common sight for the next four Thursdays and three Sundays. For any NFL game, pink will be the theme.

For the last few years, the NFL has taken a huge role in breast cancer awareness. Pink is the color of the campaign, and October is the month.

It's almost impossible not to miss the message. The idea behind the NFL's platform is for husbands, sons or fathers to encourage their wives, mothers and daughters to get regularly tested with a mammography, and/or to donate to credible organizations for continued research or to fund free testings for those women who can't afford it.

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And, yes, I know there are many women who watch the NFL too.

It's a worthy and important message being sent to a cancer that kills nearly 40,000 annually and has more than 230,000 new cases a year.

But why just limit the NFL's message to breast cancer? It would make sense if the NFL could find its way to acknowledge the men's version of breast cancer -- prostate cancer.

Prostate cancer and breast cancer have similiar numbers. According to cancer.org., prostate cancer kills nearly 30,000 men each year with more than 238,000 new cases.

For what it's worth, September -- the opening month of the NFL season -- is prostate cancer awareness month. Light blue is the color.

A month of games might be too much, but what about one week for players, officials and coaches to wear some light blue during games to highlight the importance of testing, especially for those men who are age 50 and older.

Talk about a captive audience. There's what, eleventy-billion men who watch the the NFL? It would be hard to find a bigger, more male-dominated audience to get the word out.

New Early Detection Test for Prostate Cancer

From Science Daily Sep. 25, 2013 — More than 1 million men will undergo a prostate biopsy this year, but only about one-fifth of those biopsies will result in a cancer diagnosis.

The reason is that the traditional prostate cancer screening test – a blood test to measure prostate specific antigen, or PSA – does not give doctors a complete picture.

Now, the University of Michigan Health System has begun offering a new urine test called Mi-Prostate Score to improve on PSA screening for prostate cancer. The test incorporates three specific markers that could indicate cancer and studies have shown that the combination is far more accurate than PSA alone.

"Many more men have elevated PSA than actually have cancer but it can be difficult to determine this without biopsy. We need new tools to help patients and doctors make better decisions about what to do if serum PSA is elevated. Mi-Prostate Score helps with this," says Scott Tomlins, M.D., Ph.D., assistant professor of pathology and urology at the University of Michigan.

Researchers validated the new test on nearly 2,000 urine samples. Mi-Prostate Score, or MiPS, was significantly more accurate than PSA alone for predicting cancer as well as predicting aggressive prostate cancer that is likely to grow and spread quickly.

Mi-Prostate Score developed from a discovery in the lab of Arul Chinnaiyan, M.D., Ph.D., in 2005 of a genetic anomaly that occurs in about half of all prostate cancers, an instance of two genes changing places and fusing together.

This gene fusion, T2:ERG, is believed to cause prostate cancer. Studies in prostate tissues show that the gene fusion almost always indicates cancer.

The new urine test looks for the T2:ERG fusion as well as another marker, PCA3. This is combined with serum PSA measure to produce a risk assessment for prostate cancer. The test also predicts risk for having an aggressive tumor, helping doctors and patients make decisions about whether to wait and monitor test levels or pursue immediate biopsy.

"This combination test is not designed to say definitively at diagnosis whether a man has aggressive prostate cancer, but it can provide a more accurate estimate of the likelihood of having cancer and the likelihood of that cancer being aggressive," Tomlins says.

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The test is available to anyone but requires a request from a doctor.

Prostate cancer statistics: 238,590 Americans will be diagnosed with prostate cancer this year and 29,720 will die from the disease, according to the American Cancer Society.

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

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.

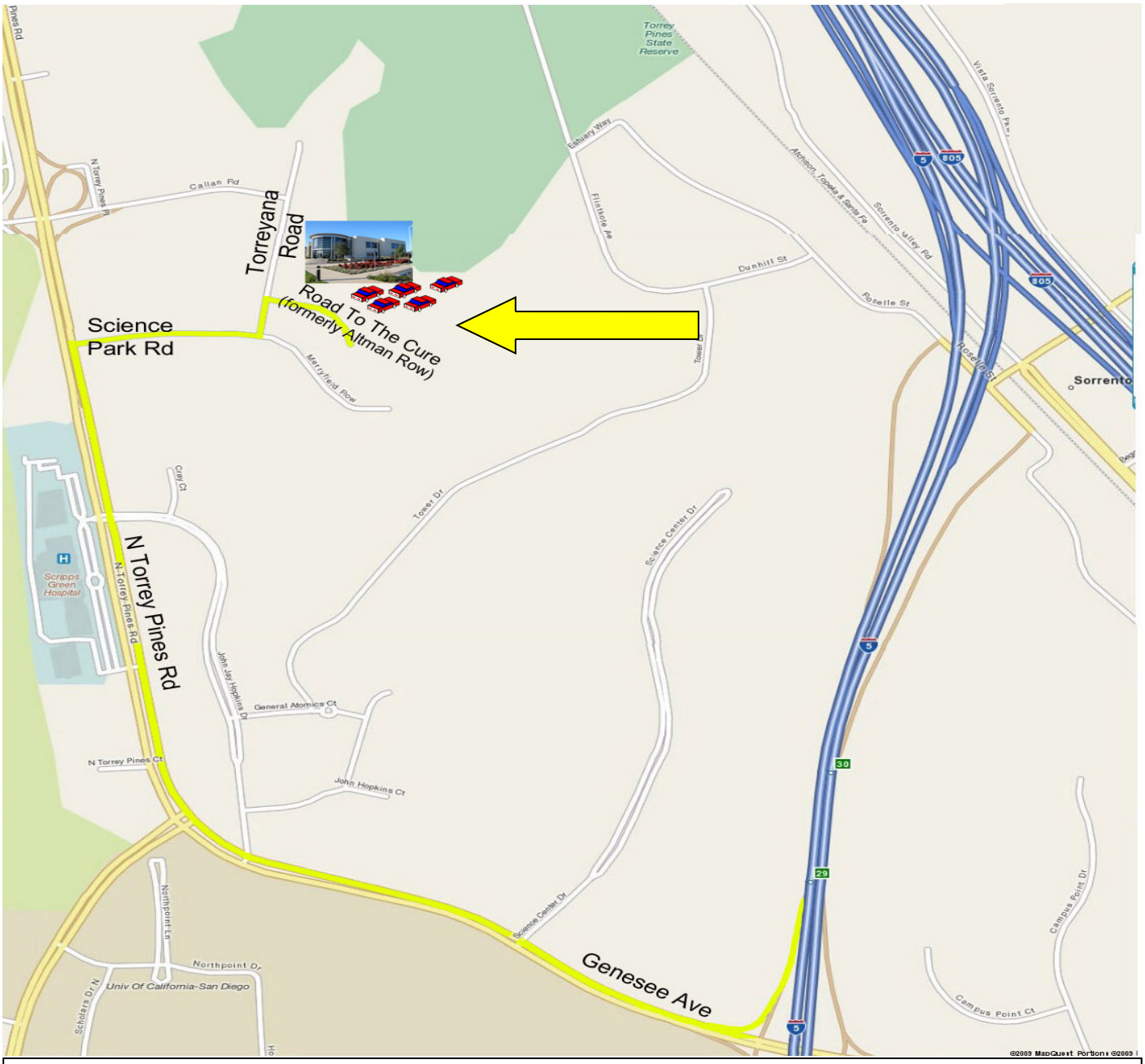
Anyone interested please contact: Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org or-Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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).