



# Informed Prostate Cancer Support Group Inc.

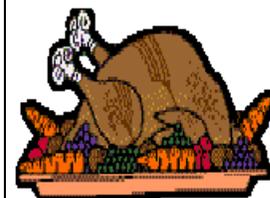
"A 501 C 3 CORPORATION ID # 54-2141691"



## 2013 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142  
Phone: 619-890-8447 Web: [www.ipcsg.org](http://www.ipcsg.org)

We Meet Every Third Saturday (except December)



### Officers

Lyle LaRosh  
President

Gene Van Vleet  
Chief Operating Officer

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John Tassi  
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### Table of Contents

- Pg.
- #1 What We Are About
- #1 Video DVD's
- #1,2 Sep. Meeting Recap
- #2, 3 Future Meetings
- #3 On the Lighter Side
- #4-7 Noteworthy Articles
- #8 Networking, We Need Help, Finances
- #9 Directions and Map to Where We Meet

Editor: Gene Van Vleet

**HAPPY  
THANKSGIVING!!**

**Next Meeting  
Nov 16, 2013  
10:00AM to Noon**

Meeting at  
Sanford-Burnham  
Auditorium  
10905 Road to the  
Cure, San Diego CA  
92121  
**SEE MAP ON THE  
LAST PAGE**

Tuesday, November 12, 2013

Volume 6 Issue 10

### 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

At our October meeting, 80 people were in attendance to hear Dr. Robert Rosenthal, President, Rolling Oaks Radiology Medical Group present information about multiparametric prostate MRI as a useful technique for analyzing prostate cancer.

He opened with comments about how little prostate cancer is promoted in relation to breast cancer. The NFL teams were wearing pink shoe covers, gloves and towels to promote breast cancer. September was Prostate Cancer Awareness Month and it was never mentioned. Prostate cancer (PCa) is the second most frequent cause of death in men. 208,000 were diagnosed last year and

### 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 DVD's' button.

(Continued from page 1)

28,000 died from it. One in six men will be diagnosed in their lifetime. We are showing reduction in mortality rates and survival rates are at an all time high. The National Cancer Institute spends twice as much for breast cancer research as for PCa. Thirty million men will eventually be diagnosed but at a horrible cost because there will be a million benign biopsies which cost the health care society \$2 billion. In 2010, 70,000 had treatment failure and 40,000 were over-treated for low grade disease. All this shows the need to improve awareness and for better algorithms to improve outcomes. The main challenges for PCa is to have good treatment and good management. To do that we need diagnostic accuracy and risk stratification to determine who has low, intermediate or high risk disease. How can we better apply Active Surveillance as appropriate treatment management? What do we do for men who have had a PSA relapse after radiation or surgery and how do we assess responsive therapy for advanced disease? The problem with PSA relapse is that none of the imaging standards are very useful with a PSA of less than one. Often these men have gone from undetectable PSA to a slope of .2, .4 and upward and standard imaging may not be useful.

The standard strategy is the digital rectal exam plus the PSA blood test for which the cut-off is 4 and above—which has a sensitivity of 80% but is not specific and 15% of men with a PSA of up to 4 will never have cancer. Seventy percent of men with a PSA greater than 4 never develop prostate cancer. The problem is that by protocol for primary care doctors, if your PSA is greater than 4, you will be referred to urology. Urologists only get paid for doing an ultrasound if they do a biopsy at the same time. Ultrasound suffers from low specificity in identifying tumors. Further, an ultrasound guided biopsy using a matrix pattern of 10 to 12 needles is inaccurate 30% of the time and resulting Gleason scores may be inaccurate because a tumor may have been only partially hit or even missed. All this leads to men selecting inappropriate therapies.

Why should you do a multiparametric MR? The negative predictive value for a significant tumor defined as a Gleason 4+3=7 is 97% and for a Gleason 3+4=7 is 90%. What is better about it? Endorectal coils have improved accuracy. Functional imaging in different pulse sequences allow it to be more specific. It doesn't show insignificant indolent cancers or non-cancers which are those of Gleason 3+3=6 or a size 1 to 2mm. Thus, the need for unnecessary biopsies is reduced. Many low risk men can be managed with active surveillance which commonly requires a Gleason of 3+3=6, getting a PSA twice a year and having an annual biopsy. A study showed that 41% of such men refused to go back for a biopsy, so a multiparametric MR would be a good alternative. The question that follows, then is why not do a multiparametric MR before doing any biopsy? Studies are under way to justify this and more and more men are doing it which have resulted in reducing the need for unnecessary biopsies.

Dr. Princenthal showed slides of what the process looks like—which were strikingly clear definitions of the location of cancers and they showed the ability to measure density in order to establish aggressiveness. At this stage of development, they prefer to confirm their findings with a biopsy. Such imaging can be use by urologists for targeted biopsies OR his facilities can perform targeted biopsies. Be aware that CT and Bone Scans generally are not valuable for PCa!

See website: <http://rollingoaksradiology.com/> for specific locations and appointments. Facilities in Temecula are expected to open by the end of this year.

**Our group has long been promoting effective imaging before biopsy. This helps ratify our position.**

Much more definitive and valuable information is available in the DVD of this meeting including specific answers to specific questions of members. Improve your understanding by obtaining a copy from our library at the next meeting or through our website: [www.ipcsg.org](http://www.ipcsg.org). Click on the "Purchase DVDs" button.

## FUTURE MEETINGS

**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** - Dr. Michael Kipper, Director of PET/CT Imaging, Genesis Healthcare, San Diego. Subject : Xofigo (radium 223) treatment. Followed by roundtable & 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.

**April 19, 2014** - Roundtable & 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.

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

## ON THE LIGHTER SIDE

### Bumper stickers:

If you can read this, I can hit my brakes and sue you.  
Life is too complicated in the morning.  
Nobody's perfect. I'm a Nobody.  
He who laughs last thinks slowest!

### Good Questions:

What do people in China call their good plates?  
What do you call a male ladybug?  
Why don't they call mustaches "mouthbrows?"

### Crazy things to do in an elevator:

Crack open your briefcase or purse, and while peering inside ask: "Got enough air in there?"  
When at least 8 people have boarded, moan from the back: "Oh, not now, damn motion sickness!"  
Meow occasionally.

*(Continued on page 4)*

(Continued from page 3)

Say "Ding!" at each floor.  
Blow spit bubbles.

A man and his wife were having some problems at home and were giving each other the silent treatment. The next week the man realized that he would need his wife to wake him at 5.00 am for an early morning business flight to Chicago. Not wanting to be the first to break the silence, he finally wrote on a piece of paper, "Please wake me at 5.00 am."

The next morning the man woke up, only to discover it was 9.00am, and that he had missed his flight. Furious, he was about to go and see why his wife hadn't woken him when he noticed a piece of paper by the bed ... it said... "It is 5.00am; wake up."



#### INTERESTING ARTICLES & INFORMATION

Editorial

Those who regularly attend our meetings may recall that our President, Lyle LaRosh, informed us that the American Cancer Society was cancelling support of the national Man To Man prostate cancer support groups. He has been in close contact with a friend and member from New York who is vigorously opposing this action. The following is a response to a question about why they are discontinuing their support:

“While ongoing patient support groups offer a wonderful service to some patients, they are not a strategy that will allow us to help the most people, end the most suffering and save the most lives.

Although the Society costs for the program are not as high as other programs, we must focus all of our energy and resources into those strategies that will finish the fight against cancer by helping the most people, ending the most suffering and saving the most lives.

Additionally, today's cancer patients have many options for ongoing patient support groups, including more programs offered by health care facilities. As a result fewer prostate cancer survivors are utilizing Man to Man as they have identified alternative programs.

We will continue to connect all cancer patients – including those battling prostate cancer – with others going through similar experiences through our online Cancer Survivors Network and other resources, including referring patients to resources in their community.

(Continued on page 5)

(Continued from page 4)

The Society currently has 100 grants in effect worth over \$56 million\* that will impact the fight against prostate cancers. “

**Vanessa Moos** | Senior Representative, Community Engagement

American Cancer Society, Inc.

2655 Camino del Rio North Suite 100

San Diego, CA 92108

Phone: 619-682-7425

[cancer.org](http://cancer.org) | 1.800.117.2345

\* It is notable that according to this grant listing as of March 1, 2013 prostate cancer is far behind breast cancer!

<i>Cancer Type</i>	<i>Number of Grants involving Cancer Type**</i>	<i>Funded Amount(\$)</i>	<i>Specific Amount(\$)</i>
Brain Tumor	47	24,048,000	16,525,200
Breast Cancer	220	117,769,325	86,039,922
Cervical Cancer	26	14,319,000	7,928,840
Colon and Rectal Cancer	108	61,900,000	37,754,700
Head and Neck Cancer	22	13,226,550	6,556,987
Kidney Cancer	18	9,399,000	4,844,470
Leukemia/Leukaemia	97	47,070,683	30,637,383
Liver Cancer	41	26,198,000	12,875,210
Lung Cancer	109	56,615,487	30,793,647
Melanoma	56	27,767,000	17,515,520
Non-Hodgkin's Lymphoma	52	25,723,750	14,324,125
Ovarian Cancer	58	30,613,000	16,369,370
Pancreatic Cancer	27	16,343,000	8,412,050
Prostate Cancer	82	47,036,500	27,642,780
Thyroid Cancer	19	13,997,000	11,903,900
<u>Other Cancer Types</u>	199	98,770,500	45,134,508
<i>Applies to all cancers ≠</i>	243	87,369,887	87,369,887
<b>Grand Total</b>	<b>923</b>		<b>462,628,499</b>

(Continued on page 6)

## Enzalutamide (Xtandi) First-Line in Prostate Cancer: Trial Stopped

Article suggested by member Ron Abbott—from Medscape October 22, 2013

The road ahead for first-line use in prostate cancer seems clear now for enzalutamide (*Xtandi*, Medivation/Astellas), after a pivotal phase 3 trial exploring this use of the drug was **stopped early because of benefit.**

After an interim analysis showed significantly better overall survival with enzalutamide compared with placebo, the Independent Data Monitoring Committee recommended that the trial be stopped, and that patients who were receiving placebo should be offered the active drug.

Enzalutamide is already approved for use in prostate cancer, but its current indication is for second-line therapy in men with metastatic castration-resistant prostate cancer who had previously received docetaxel. This indication was approved by the US Food and Drug Administration in August 2012, and was recently approved in the European Union. In addition, last week in the United Kingdom, the National Institute for Clinical Excellence announced that this use of enzalutamide in prostate cancer would be covered by the National Health Service.

The approval of enzalutamide for second-line use was based on results from the AFFIRM study, which showed a survival benefit in men with postdocetaxel prostate cancer, reducing the risk for death by 37% relative to placebo, extending survival by more than 4 months. At the time, enzalutamide, a first-in-class androgen-receptor inhibitor, was hailed by experts as a "game changer" in the treatment of prostate cancer.

### New Results for First-Line Use

The new results for first-line use come from the PREVAIL trial, conducted in 1715 men with metastatic prostate cancer that had progressed, despite androgen-deprivation therapy, and who have not yet received chemotherapy. Patients were randomized to receive either enzalutamide (160 mg orally once daily) or placebo.

The manufacturers released top-line results from the study in a press release. The companies said that the results will be presented at an upcoming medical conference. The companies also said that they will talk to regulatory authorities about these data in early 2014.

The results show that patients treated with enzalutamide had significantly longer overall survival, showing a 30% reduction in risk for death compared with placebo ( $P < .0001$ ), according to the companies.

At the time of the interim analysis, 72% of patients in the enzalutamide group and 65% in the placebo group were still alive, and the calculated point estimate for median overall survival was 32.4 months (95% confidence interval [CI], 31.5 months - upper limit not yet reached) for enzalutamide versus 30.2 months (95% CI, 28.0 months - upper limit not yet reached) for patients receiving placebo.

Enzalutamide also showed a significantly improved radiographic progression-free survival, showing an 81% reduction in risk for radiographic progression or death compared with placebo.

The median radiographic progression-free survival was not yet reached (95% CI, 13.8 months - upper limit not yet reached) in the enzalutamide group and was 3.9 months (95% CI, 3.7 - 5.4) in the placebo group.

Two patients were reported by investigators to have had a seizure event.

(Continued on page 7)

"To my knowledge, the benefits in overall survival and radiographic progression-free survival reported in today's PREVAIL trial results are unprecedented in this patient population," said Tomasz M. Beer, MD, FACP, professor of medicine and deputy director of the Knight Cancer Institute at Oregon Health & Science University in Portland, and the coprincipal investigator of the PREVAIL study.

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### **Self-Referral for Radiation Treatment Skyrockets**

Published: 10/25/13 in MedPage Today, Article by David Pittman, Washington Correspondent

WASHINGTON -- Efforts to close the self-referral loophole for certain in-office services gained ammunition this week as more research showed a dramatic increase in prostate cancer radiation therapy for providers who self-refer.

The rate of intensity-modulated radiation therapy (IMRT) use by self-referring urologists more than doubled, from 13.1% to 32.3%, from 2005 to 2010 ( $P < 0.001$ ), the study published in the New England Journal of Medicine found. Meanwhile, the rate of IMRT use among non-self-referring urologists increased by just over a percentage point -- from 14.3% to 15.6% -- in that same time period ( $P = 0.05$ ).

However, self-referral was associated with a 3-day decline in the time to initiation of treatment for urologists in private practice ( $P < 0.001$ ) and a 6.4-day drop for urologists employed by cancer centers ( $P < 0.001$ ), author Jean Mitchell, PhD, economist at Georgetown Public Policy Institute in Washington, found. Those numbers were unadjusted for group practice, treatment age, health status, and year of diagnosis.

"Allowing urologists to self-refer for IMRT may contribute to increased use of this expensive therapy," Mitchell concluded in the special article.

She compared the use of IMRT before and during ownership of the therapy equipment to evaluate rates of use. The study compared 35 self-referring urology groups with 35 non-self-referring groups, as well as 11 employed, non-self-referring urologists with 11 self-referring urologists in private practice.

The Stark law prohibits physicians from making self-referrals for most services but allows self-referral for advanced diagnostic imaging, radiation therapy, anatomic pathology, and physical therapy under an "in-office ancillary services" exemption. It remains to be seen whether Mitchell's work will have an impact on efforts to close that self-referral loophole.

The Government Accountability Office (GAO) has reported use of costly services such as IMRT, anatomic pathology services, and MRIs and CTs have increased greatly after physicians began to self-refer for those services. The GAO in August said doctors who began self-referring increased IMRT referrals by 46.6% while those who didn't self-refer increased their use of IMRT by 5.5% from 2006 to 2010.

Mitchell said the Stark law's exemption was for services such as blood tests or urinalysis. "It wasn't meant for tests or procedures that were never going to be performed on the same day as the office visit," Mitchell told MedPage Today in a telephone interview.

The GAO's findings prompted Reps. Jim McDermott, MD (D-Wash.), and Jackie Speier (D-Calif.) to propose the Promoting Integrity in Medicare Act (H.R. 2914), which would remove the exemptions.

(Continued on page 8)

"Self-referral is bad for healthcare, it is bad for the patient, and it creates a perverse incentive," Speier said at an event in Washington Thursday sponsored by the American Society for Radiation Oncology (ASTRO). "That's why there is a ban on self-referral."

She called the current exceptions "troubling" and said physician's greed is driving use of IMRT.

But the bill is being fought by multiple medical groups. More than 30 national medical societies -- including the American Medical Association, the American College of Surgeons, and the American Urological Association -- wrote a letter to all members of Congress in August opposing Speier's bill. They argued that the Stark exemptions encourage care coordination and that removing them would create barriers to more integrated delivery.

ASTRO, however, supports widening the ban. If the loophole was closed, urologists would have to refer patients out to radiation oncologists for treatment.

The Large Urology Group Practice Association denounced Mitchell's study, calling it an attempt by ASTRO "to persuade lawmakers to legislate a monopoly for its members."

The research was funded through an educational grant from ASTRO that went to Georgetown University. ASTRO said it had no role in the design or outcome of the work and did not see the results until just before the study was published in the *New England Journal of Medicine*.

Mitchell, who received no financial gain from this week's study, has previously published several articles related to self-referral arrangements, including for pathology services for urologists.

Deepak Kapoor, MD, president of the Large Urology Group Practice Association, said Mitchell's study was riddled with selection bias in the comparison and control groups in terms of patient demographics, practice size, and severity of illness.

For example, he said the study compared a urology practice in inner-city Baltimore to that of suburban Maryland, even though such patients respond differently to the varying cancer treatments.

The Medicare Payment Advisory Commission and GAO have each declined to endorse closing the self-referral loophole for IMRT, noting that the service would move from physician services to more costly inpatient settings such as hospitals.

Closing the Stark loophole is a "zero-sum game" as the overall use of IMRT has remained steady, Kapoor said.

"Hospitals are more expensive than urology offices," he told *MedPage Today* in a telephone interview. "They get paid more than urologists do in a hospital setting to go ahead and do radiation -- not a little more, but a lot more."

The work was supported by a grant from the American Society for Radiation Oncology.

## 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](mailto: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.

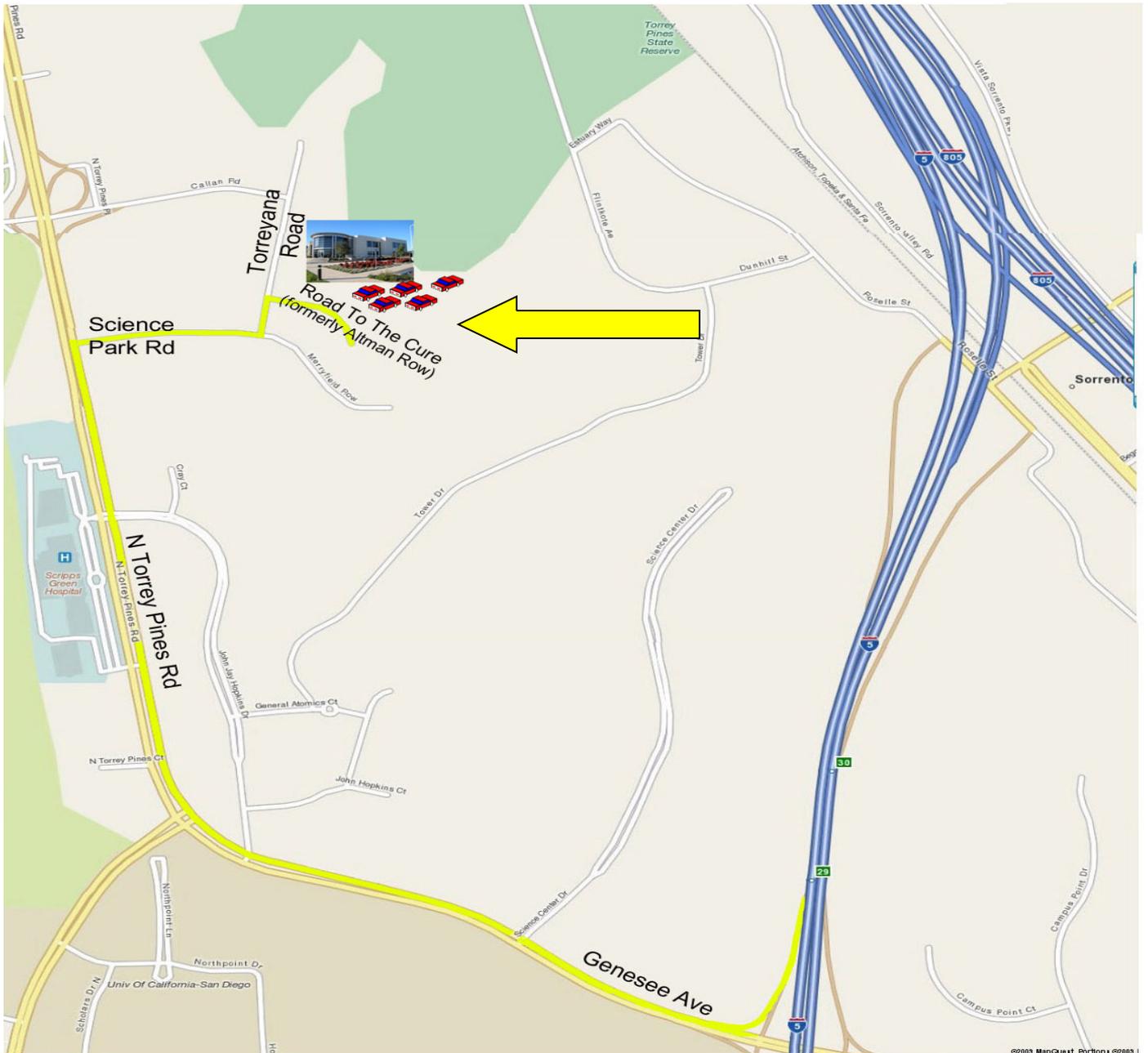
Anyone interested please contact: Gene Van Vleet, Vice President. 619-890-8447 [gene@ipcsg.org](mailto:gene@ipcsg.org) or Lyle LaRosh, President 619-892-3888 [lyle@ipcsg.org](mailto:lyle@ipcsg.org)

## 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).