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

Aug 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)

Saturday, August 10, 2013 Volume 6 Issue 7

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Editor: Gene Van Vleet

Next Meeting
Aug 17
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

Please note the revised listing of persons active in making our support group highly successful. We welcome Bill Manning as a new Director.

Meeting Facilitator George Johnson kindly prepared the following recap of our July meeting:

FORUM ON PROSTATE CANCER TREATMENTS

A lively discussion was conducted July 20, 2013 at the IPCSG monthly meeting attended by 65 men and women on a beautiful sunny day in La Jolla. This is a summary of the results:

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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MEMBER PROFILE

Our goal was to have the group participate in an open exchange of experiences and results. More than twenty two men attended the meeting for the first time. The median duration of prostate cancer was about seven years. Our leading survivor had 23 years followed by another meeting enthusiast of 21 years.

TREATMENT EXPERIENCE

A growing number our members are delaying immediate invasive treatment and are instead participating in Active Surveillance which involves changes in diet and increased exercise while closely monitoring PSA levels. Results are very favorable. Only a small number have had follow up invasive treatment. One of our members gave a good example of his four years of successfully delaying treatment and his plans for continued monitoring with frequent PSA tests and occasional biopsies.

There appears to be a decline in the selection of the surgery treatment option. A majority in this treatment had the newer Robotic Surgery. There were no marked differences between this approach and the standard open Prostatectomy. Three members reported successful recovery with no recurrence. The majority experienced a recurrence of their prostate cancer. We recognize that many of the other patients who have successful treatment results do not continue to participate in our support activities, and therefore the surgery results in our membership may not be representative of the statistical norm for this mode of treatment.

Radiation Therapy is the choice of about one third of the attendees, primarily IMRT and one each for Cyberknife and Proton, Two had seeds implanted or brachytherapy. An attendee described his successful treatment with IMRT. This positive result was supported by several others. At least three experienced a recurrence.

Androgen Deprivation Therapy (ADT/Hormone Therapy) was used by the remaining third of the members, primarily as a result of recurrence from the above series of treatments. Three members spoke in support of the rather rapid effectiveness of Casodex. Side effects were common for ADT but positive results were achieved by most in this group. Possibly for this reason no one indicated use of the newer, more advanced drugs, Zytiga and Xtandi, that recently passed FDA clinical trials.

Four in the group were undergoing Chemotherapy. A member described the process and his current remission. There was considerable interest in new technology for diagnostic imaging and testing. One member provided positive experience with the new Provenge immunization treatment. He will keep us informed on his progress.

All members were encouraged to ask questions and discuss issues and concerns. We had good interaction and positive participation. We received several compliments about the breadth of coverage and the opportunity to exchange lessons learned and treatment insights. Ideas for new meeting subjects were developed and potential speakers were suggested. After the conclusion of the meeting, a significant majority stayed in the hall for more than 30 minutes to continue further networking. It was also noteworthy that an increased number of spouses attended this meeting and participated in the question session.

We plan to conduct a similar forum next year.

FUTURE MEETINGS

August 17. Annette Conway, Annette Conway, Psy.D., Licensed Clinical Psychologist and Director of HELP Mental Health & Counseling Services. Subject: Successful Ways to Manage Stress

September 21. Patricia DeLeo, Independent Insurance Agent. Subject: Health Insurance—Changes and Options

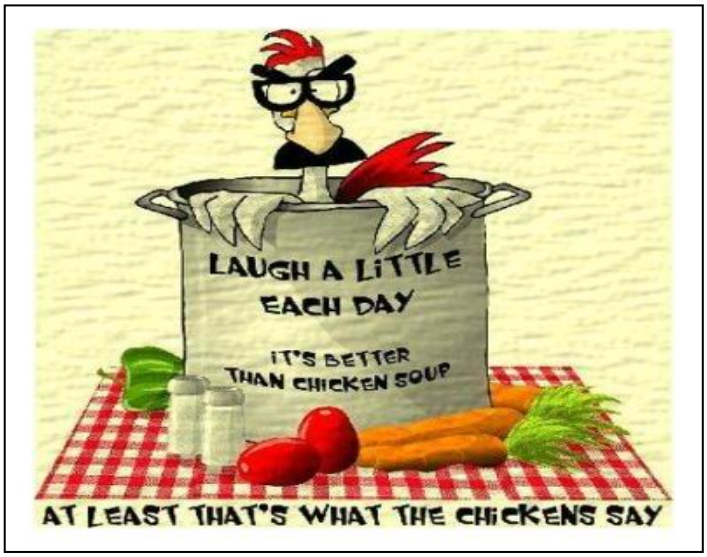
October 19. Dr. Robert Princenthal, Director of Prostate Imaging, and President, Rolling Oaks Radiology Medical Group. Subject: Multiparametric prostate MRI; how to best utilize this functional information for patient management.

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

ON THE LIGHTER SIDE

Are Chickens Always Right?



We should always consider any vested interests when given advice by anyone, from chickens to doctors!!

"The statistics on sanity are that one out of every four people is crazy. Look at your 3 best friends. If they're ok, then it's you." — Rita Mae Brown

A man was invited for dinner at a friend's house. Every time the host needed something, he preceded his

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request to his wife by calling her "My Love", "Darling", "Sweetheart", etc., etc. His friend looked at him and said, "That's really nice after all of these years you've been married to keep saying those little pet names." The host said, "Well, honestly, I've forgotten her name."

EVER WONDER Why??

Why doctors call what they do "practice"?

Why you have to click on "Start" to stop Windows?

Why the man who invests all your money is called a broker?

Why they don't make the whole plane out of the material used for the indestructible black box ?

Why sheep don't shrink when it rains?

If con is the opposite of pro, is Congress the opposite of progress?

Q. How many men does it take to change a roll of toilet paper?

A. We don't know; it has never happened.

NOTEWORTHY ARTICLES

Hormone Blockade for Early-Stage Prostate Cancer

From Prostate Snatchers Posted: 30 Jul 2013 03:22 PM PDT

MARK SCHOLZ, MD

Being medical oncologists rather than surgeons—and being more impressed by the toxicity of surgery than by its effectiveness—my partners and I hypothesized back in the early 1990s that since testosterone inactivating pharmaceuticals (TIP) are powerful enough to reverse metastatic disease, they should be even more effective against early-stage disease.

Clinical Experience with TIP for Early Stage

In 2011, we published a scientific article in the Clinical Genitourinary Cancer detailing the twelve-year outcome for 73 men who embarked on TIP as primary therapy. In this group of men the average PSA was 9 and the average Gleason score was 7 (intermediate grade). Most of the men had tumors in their prostate large enough to be felt by digital rectal examination. Twenty-one of them maintained a low PSA indefinitely with a single course of TIP—they never needed a second cycle.

Another group of 24 men required periodic repeat cycles of TIP to keep their PSA less than five. In the remaining 28 men, after one or more cycles of TIP, the decision was made to undergo treatment with surgery, seeds or radiation. However, the average time to treatment was 6.2 years after the first cycle of TIP. Only three of those 28 men ever relapsed after treatment. In summary, this study showed that initial remissions with TIP were universal and that even if the remission was not permanent, treatment with more radical therapy was delayed many years.

In 2012, we published another scientific study in The Prostate, in which we evaluated the effect of 12 months of TIP in 102 men. Twenty-two men were in the Low-Risk category, 30 were Intermediate-Risk and 50 were High-Risk. The median PSA was 7.8 and the median Gleason score was 3 + 4 = 7. The at-

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tainment of a clear biopsy after TIP followed by a sustained 7- year remission occurred in forty-five men. The likelihood of durable remission was dependent on the risk category: 82% of Low-Risk, 47% of Intermediate-Risk and 25% of men with High-Risk required no further treatment.

Monitoring TIP's Effectiveness

One of the beauties of TIP is how easily its anti-cancer effects can be monitored with PSA. Although there is much debate about using PSA for cancer screening, PSA is an amazingly accurate tool for monitoring treatment response. In a study we published in Urology in 2007, we showed that more than 95% of men with newly-diagnosed disease drop their PSA to less than 0.05 within eight months of starting therapy. It's a rare for cancers to continue producing PSAs above a threshold of 0.05 after six months of TIP therapy. However, when these rare cancers occur, i.e. when an elevated PSA nadir occurs, it is a flashing sign that aggressive multi-modality therapy should be instituted.

What about Side Effects?

So what is the catch? To this point TIP sounds like a very logical way to initiate treatment. Even if the disease is not arrested altogether, it delays progression for many years. And men who select TIP as initial therapy can always "jump ship" and undergo radiation or surgery. Delaying surgery or radiation with their potentially irreversible side effects makes sense considering the accelerating pace of medical progress. In this rapidly changing environment, postponing irreversible treatment for even five years is unquestionably an attractive proposition.

The catch is that while TIP side-effects are manageable, they are not trivial. Without attention to diet, notable weight gain occurs. Without regular resistance training and weight lifting, significant muscle weakness will ensue. While on treatment, the majority men lose their sex drive. A loss of sex drive is, however, different than impotence. With medications such as Viagra and Cialis most men on TIP can have erections sufficient for intercourse. Sex can be enjoyed, but it is not sought after with the usual male verve. There is also the potential for additional side effects such as breast enlargement, osteoporosis and hot flashes. As dire as these sound, they are preventable with common medications such as Femara, Prolia and progesterone. However, the side effects are cumulative and become more prominent the longer TIP treatment is continued.

Final Thoughts

Some men are concerned that their cancer will progress if "real treatment" like surgery or radiation is delayed. They forget that surgery and radiation only eradicate the "friendly types" of prostate cancer, the ones that remain contained in the gland. The real danger lies in the possibility of microscopic metastasis. Radiation and surgery have no effect whatsoever on cancer that has already spread. Only TIP circulates throughout the entire body attacking early-stage micro-metastasis in the lymph nodes or bones.

In my next blog, I will be discussing a new, more powerful type of TIP that has recently been approved by the FDA. The enhanced effectiveness of this new drug may enable a shorter course of treatment. And since testosterone levels in the blood remain normal throughout, the risk of lingering side effects should be eliminated.

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Thanks to member Dennis Walker for sending this article

New Cancer Imaging Technology Shows Promise

From University of Rochester Medical Center July 18, 2013

A new imaging technology that combines ultrasound and laser technologies has been shown to be highly effective in identifying prostate cancer. The system, which was developed by University of Rochester Medical Center (URMC) researchers, could also ultimately be deployed to detect and track breast, kidney, liver, skin and thyroid cancers.

The new medical imaging technology – called multispectral photo acoustic imaging – was created by Vikram Dogra, M.D., a professor in URMC's Department of Imaging Sciences, in collaboration with Naval Rao, Ph.D. from the Rochester Institute of Technology's Chester F. Carlson Center for Imaging Technology.

Physicians currently have a suite of tools at their disposal to test for prostate cancer. Monitoring PSA levels, digital rectal examinations, and transrectal ultrasound are all used as frontline screening tools. The current gold standard for a definitive diagnosis of an aggressive vs. slow growing prostate cancer is a prostate biopsy. But even this method – which is invasive, uncomfortable, and carries a risk of side effects – has its limitations; cancers are only successfully detected 70 percent of the time.

Seeing the need for a noninvasive and effective imaging technology to detect cancerous tissue, Dogra and his colleagues began to explore the use of a hybrid technology that combines ultrasound and laser irradiation.

The system uses nanosecond long bursts of light from a laser to bombard the target tissue. This heats the tissue and creates thermal waves that can be detected by ultrasound. These signals are then used to recreate an image of the target tissue and – because different wave lengths elicit different responses – observe variations in light absorption. To accomplish this, the researchers used an acoustic lens to focus the image, a method that is more cost effective than the alternative electronic focusing system.

The system enables researchers to track the level of lipids (fat), water, and forms of hemoglobin found in the blood, all of which respond to different wave lengths from the laser. Fluctuations in these compounds can indicate a tumor's status. Hemoglobin, the protein in red blood cells responsible for transporting oxygen, is of particular interest. Increases in the level of deoxyhemoglobin – the form hemoglobin without the bound oxygen – significantly raises the odds that the tissue is malignant.

"By observing increases and decreases in these things, particularly deoxyhemoglobin levels, we can tell if the tissue is malignant or benign," said Dogra.

Earlier this year, the researchers presented the findings of the first study using multispectral photoacoustic imaging to evaluate prostate cancer specimens at a meeting of the meeting of the American Roentgen Ray Society. The system was able to identify 25 or 26 healthy prostates, and 12 of 16 cancerous prostates, a 96 percent and 81 percent success rate.

Dogra and his team are now in the process of developing a prototype version of their scanner and hope to begin clinical evaluation of the device within two years. They believe that the system will ultimately be significantly less expensive – both in terms of equipment cost and cost per test – than biopsies and that the underlying technology could ultimately be applied to several other forms of cancer.

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Media Madness: Fish Oil Supplements and Prostate Cancer

By Jonny Bowden, PhD, CNS

Jonny Bowden, PhD, CNS, (aka "The Rogue Nutritionist") is a nationally known expert on weight loss, nutrition and health. Dr. Bowden has a Master's Degree in psychology and counseling and a PhD in nutrition, and has earned six national certifications in personal training and exercise. He is board certified by the American College of Nutrition, a member of the prestigious American Society for Nutrition, and a much in-demand speaker at conferences and events across the country.

A frequent guest on television and radio, Dr. Bowden has appeared on Fox News, CNN, MSNBC, ABC, NBC, and CBS as an expert on nutrition, weight loss, and longevity. He is a past member of the Editorial Advisory Board for Men's Health magazine, is the Nutrition Editor for Pilates Style, and is a regular contributor to AOL, Vanity Fair Online, Clean Eating Magazine, Better Nutrition, and Total Health Online.

Dr. Jonny has contributed to articles for dozens of national publications (print and online) including The New York Times, The Wall Street Journal, Forbes, The Daily Beast, The Huffington Post, Vanity Fair Online, Time, Oxygen, Marie Claire, Diabetes Focus, GQ, US Weekly, Cosmopolitan, Self, Fitness, Family Circle, Allure, Men's Heath, Prevention, In Style, Natural Health, and many other publications. He appears regularly as an expert on ABC-TV Los Angeles.

Reviewing the new study http://aje.oxfordjournals.org/content/173/12/1429 .full that's been widely reported as showing fish oil supplements increase the risk of prostate cancer puts me in mind of a recent review of a Kenny G album:

"There's a lot to criticize in the music of Kenny G. For example, everything." I found that pretty amusing. This study? Not so much.

There's nothing amusing about this study, and what the media has done with it is—to paraphrase Samuel Jackson in Pulp Fiction—"very (blank)-ing far from funny".

Before we get to the study itself—and we will—let's talk about the media, whose reporting here is disgraceful, incompetent, and scientifically illiterate. Here's an example of some of the headlines, the idiocy of which will become clear in just a moment.

- "Omega-3 supplements linked to prostate cancer" (Fox News)
- "Omega-3 supplements 'could raise prostate risk" (Telegraph)
- "Fish oil supplements linked to prostate cancer" (Health News)
- "Men who take omega-3 supplements at 71% higher risk of prostate cancer" (NY Daily News)
- "Omega-3 supplements may trigger prostate cancer" (Nursing Times)
- "Hold the salmon: Omega-3 fatty acids linked to higher risk of cancer" (CNN)

So, reading this, you might well think that researchers divided a population of men into two groups, gave one group fish oil supplements and the other a placebo, and found that the ones who took the fish oil supplements got way more prostate cancer than the ones who didn't. Right?

Wrong.

The first thing you need to know is that no fish oil supplements—or any other kind of supplements, for that matter—were given in this study. None. This study looked at blood levels of long-chain fatty acids such as those found in fish (EPA and DHA). And even there, the association between higher blood levels and prostate cancer—which we'll get to in a minute—was only found for DHA. No association was found between EPA and prostate cancer, nor between prostate cancer and ALA (the omega-3 found in

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flax and chia).

How do you explain the fact that reporter after reporter and news outlet after news outlet conveniently equated higher blood levels of DHA with "fish oil supplement taking"? There's almost no other explanation other than a strong anti-supplement bias and a desire for shocking headlines. And any doubt about the objectivity of the researchers should have been abandoned after one of them—Dr. Alan Kristy—told reporters, "We've shown once again that use of nutritional supplements may be harmful". http://www.huffingtonpost.co.uk/2013/07/11/supplement-linked-to-aggressive-cancer_n_3577523.html

So let's be clear. Supplements weren't a part of the study and weren't given to the participants. Period.

No, like so many studies these days, this was an observational study (based on nested data from participants in the Prostate Cancer Prevention Trail from 1994-2003). There was no experiment, just an observation about what things were found together in this particular population.

Stranger than Fiction: Trans Fats Protective!

Want to know what else the researchers found? Participants who had the highest levels of trans fats in their blood also had the least risk for prostate cancer.

So, if you want to jump to conclusions and take action immediately, here are two things you should do right now to protect your health:

1) Stop eating fish
2) Start eating trans fats

No one in the media is dumb enough to tell us to do that. These same folks are, however, perfectly OK casting doubt about the safety of omega-3 supplements, which—in case you happened to miss this the first two times I mentioned it—were not used in the study.

If blood levels of omega-3's are the problem, fish should be just as "dangerous" as fish oil supplements. And-—so far, at least—I haven't heard any media pundits advise us to stop eating salmon and start scarfing down donuts and margarine—because they're so rich in "protective" trans fats.

Study Debunking 101: Why Were DHA Levels High?

The best study debunker in the business—Denise Minger— http://rawfoodsos.com/category/omega-3/ — points out that DHA levels in the blood do not necessarily track with dietary intake. The men with the higher levels of DHA weren't necessarily eating more fish, and we pretty much know that the majority weren't taking supplements (because the researchers said as much). Though DHA levels in the blood go up when you consume lots of omega-3's, they can also go up for other reasons, one of them being a low-fat diet http://jn.nutrition.org/content/131/2/231.full.

Think about that for a minute.

Minger also points out that the "highest levels of serum DHA" were based on percentage values, not absolute values. Let's just say that percentage-based measurements can be….well, misleading.

A higher percentage of DHA might mean a lower percentage of something that the researchers didn't investigate. (They only looked at 8 fatty acids.) "Expressing plasma phospholipid fatty acid composition as a percentage of the total is meaningful only when the total fatty acid content is identical for all subjects", writes Dr. Ching Kuang Chow in the American Journal of Nutrition. http://ajcn.nutrition.org/content/89/6/1946.1.full

Write One Hundred Times on the Blackboard: Correlation is not Causation

It's worth repeating—and repeating, and repeating- that correlation is not causation.

Observational studies like this one are not randomized controlled studies. They simply point to associations—like the fact that people who have "yellowish fingers" tend to have higher rates of lung cancer.

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But association studies like this never tell us why those associations exist. (Yellow finger syndrome is a "side-effect" of holding cigarettes in your hand all day long. Clearly, yellow fingers don't "cause" lung cancer, but there's a strong positive association between the two.)

In this study, we have no idea why higher blood levels of DHA were found to be associated with higher levels of risk for aggressive prostate cancer. DHA might be a marker for something else, just as "yellow fingers" are a "marker" for smoking. Researchers say they like to "control" for extraneous variables, but for reasons unknown, these researchers did not "control" for such variables as age and race and… oh yes, diet. God knows what else they didn't "control" for.

As Minger puts it:

"This is a classic case of correlation clashing with biological plausibility – and it highlights why observational studies, with their slew of undocumented variables and contradictory findings, can't tell us anything definitive about food and disease."

And while we're on the subject of confounding variables consider these statistics from the study, courtesy of my friend Bob Roundtree, MD, Medical Director for Thorne Research:

1. 53 percent of the subjects with prostate cancer were smokers.
2. 64 percent of the cancer subjects regularly consumed alcohol.
3. 30 percent of the cancer subjects had at least one first-degree relative with prostate cancer.
4. 80 percent of the cancer subjects were overweight or obese.

Context is Everything

Finally, let's put this study in context. There have been literally thousands of published studies on omega-3 fats, spanning the course of over three decades and including not just observational studies, but randomized controlled trials as well.

The overwhelming majority of them have been positive, so much so that when it comes to fish oil, even mainstream medicine has overcome its default bias against vitamin supplements. Major establishment health organizations now recommend fish eating and, often, fish oil supplementation. Even Big Pharma is getting in on the act, with pharmaceutical companies (GlaxoSmithKline) marketing prescription fish oil products (Lovaza).

Jumping to the opposite conclusion from one or two observational studies—particularly observational studies that contradict the bulk of the research, leave out a number of critical variables like diet, and postulate no biological mechanism that could explain the odd findings—certainly makes for good headlines.

It doesn't, however, make for good sense. http://www.JonnyBowden.com

Still Confused about Omega 3?

Below are some links to help you better understand Omega 3 and Fish Oil Supplements. These links along with your own research will better enable you to be your own case manager with it comes to Omega 3 Supplements.

Omega 3s + PCa - http://askdrmyers.wordpress.com/2013/07/24/omega-3s-pca/

Prescription Omega 3 Fatty Acids? - http://askdrmyers.wordpress.com/2013/07/31/prescription-omega-3-fatty-acids/

Experts Weigh In - http://e2.ma/message/efu8g/eb7zj

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:

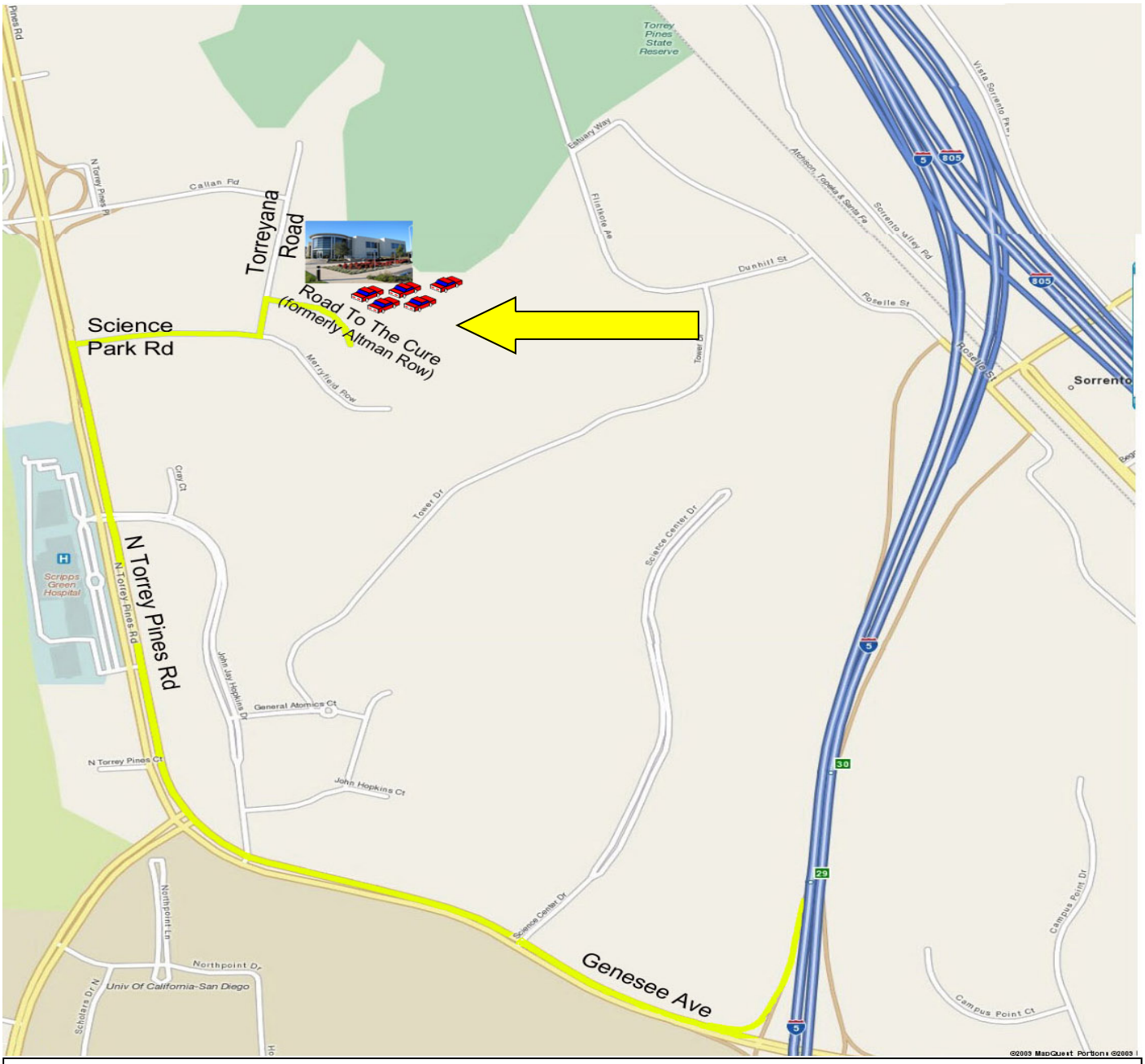
Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org
Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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



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).