Informed Prostate Cancer Support Group Inc.

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

May 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, May 10, 2013 Volume 6 Issue 3

Officers

President: Lyle La Rosh,

Vice President : Gene Van Vleet

Additional Directors

Dr. Dick Gilbert

John Tassi

George Johnson

Steering Committee

Judge Robert Coates
Victor Reed
Robert Keck, Librarian
Bill Manning
E. Walter Miles
Jerry Steffen

Next Meeting May 18th 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

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

During the April Meeting two men told of their experiences:

Dick Balsam is a long time member of our support group who had proton beam therapy 18 years ago at Loma Linda University Medical Center. His treating doctor was Dr. Carl Rossi now Medical Director of Scripps Proton Therapy Center who spoke to our group in February. Dick had his first PSA test in 1990 which was 4.4 and a biopsy was negative. Through 1994 his PSA had risen to 6.4 and, again, a biopsy was negative. In early 1995 his PSA had risen to 8.4 and his Gleason score from

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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biopsy was 8. He had several verifications tests of the biopsy three of which confirmed the 8 score and two others were 6. The pathology revealed that 3 samples on one side were clear and 3 samples on the other side were cancerous—one showed 30% involvement, the other two 80%. After much research, and consultation with many doctors, Dick decided on radiation therapy. Starting in October, 1995 he had 3 weeks of proton beam therapy followed by 5 weeks of external beam therapy. His PSA currently is .08 and his lowest point was .0017. He used double hormonal blockade (Zolodex and Flutamide) for 14 years. About 5 years after radiation he developed issues of incontinence requiring catheterization beginning twice a day and increasing to 4 times most recently. Dick reinforced the recommendations of our group in learning to become your own case manager in order to find suitable treatments for your lifestyle.

Harvey Lyons, 57, had his first biopsy 4 years ago after his PSA level had risen from the low 4's to the high 4's. The results of his biopsy were negative. Two years ago he had a TURP procedure to clear the urethra pathway which helped reduce frequent urination from four to five times a night to only once a night. His PSA levels remained at high 4's for about 18 months. He was testing PSA levels every 6 months. In October 2012 his PSA rose to the mid 5's and 1 month later it was 5.9. In December it had risen to 6.4—too much of a rise. He had a biopsy the first week of December and the result was that 2 of 12 cores were malignant and 1 was borderline. His Gleason score was 3+4=7. He began developing stomach pains and in January 2013 he had an endoscopy and colonoscopy both of which were clear. He then had a CT scan which showed involvement of lymph nodes and one of concern to him was behind the heart. He knew he needed to take action. His personal choice was surgery---he just wanted it out. He didn't want radiation. Because of the CT findings about lymph node involvement he chose to see Dr. Almeida in Phoenix to have the carbon 11-acetate PET/CET scan which showed that the lymph nodes he was most concerned about were benign. He researched the most qualified surgeons, both robotic and retropubic, and opted for a highly qualified surgeon, Dr. Gary Lieskovsky of USC. He had performed over 3,000 retropubic surgeries. He had surgery in April 11, 2013. He was assured that the doctor had preserved the erectile function nerves, but it is too early to know for sure. During the surgery 29 enlarged lymph nodes were removed from his pelvic area. He remained in the hospital for 5 days. The catheter installed after surgery was removed after 2 weeks. All 29 lymph nodes were benign when tested. He is doing Kegel exercises 5-6 times a day to strengthen the muscles that stop urination, which has been successful in stopping any significant leakage. He hasn't found it necessary to wear a pad. He was advised that to test PSA every 3 months and if it starts to rise he can consider adjuvant radiation. He has decided to do the radiation after he heals as a precaution.

The forgoing personal experiences are recaps of their presentations. For further detail you can get a copy of the DVD of this meeting from our library or through our website: http://ipcsg.org and clicking on the button, Purchase DVD's. If you wish to speak with them, contact Gene Van Vleet at 619-890-8447.

Future Meetings

May 18. Dr. Richard Lam, Research Director, Prostate Oncology Specialists. Subject: Newly Diagnosed Prostate Cancer - From Screening to Treatment

June 15. Dr. Jay Cohen, author, Prostate Cancer Breakthroughs.

Important guides to life

If it doesn't look right it probably isn't
Don't eat anything bigger than your head
It can always get worse
Speak less and say more
Old age and treachery can always overcome youth and skill

The male's prostate (after the child bearing days are over) provides no necessary function, much like an appendix. All it does is cause trouble for the aging male. It is something the male does not need, yet it continues to enlarge. The very part of the male anatomy he cannot see and does not need grows, while another part of his anatomy that he would prefer to grow, not only doesn't, but slowly loses the ability to function.

It has recently been discovered that research causes cancer in rats.

A large dark horse walks into a bar and orders a whisky. The bartender says, "do you know we have a whisky named after you? “

The horse, quite surprised, replies, "you have one called Eric ? "

An old prospector shuffled into the town of El Indio, Texas leading an old tired mule. The old man headed straight for the only saloon in town, to clear his parched throat. He walked up to the saloon and tied his old mule to the hitch rail. As he stood there, brushing some of the dust from his face and clothes, a young gunslinger stepped out of the saloon with a gun in one hand and a bottle of whiskey in the other.

The young gunslinger looked at the old man and laughed, saying, "Hey old man, have you ever danced?" The old man looked up at the gunslinger and said, "No, I never did dance... never really wanted to."

A crowd had gathered as the gunslinger grinned and said, "Well, you old fool, you're gonna' dance now," and started shooting at the old man's feet. The old prospector, not wanting to get a toe blown off, started hopping around like a flea on a hot skillet. Everybody was laughing, fit to be tied.

When his last bullet had been fired, the young gunslinger, still laughing, holstered his gun and turned around to go back into the saloon. The old man turned to his pack mule, pulled out a double-barreled shotgun, and cocked both hammers. The loud clicks carried clearly through the desert air.

The crowd stopped laughing immediately. The young gunslinger heard the sounds too, and he turned around very slowly. The silence was almost deafening. The crowd watched as the young gunman stared at the old timer and the large gaping holes of those twin barrels. The barrels of the shotgun never wavered in the old man's hands, as he quietly said, "Son, have you ever kissed a mule's ass?"

The gunslinger swallowed hard and said, "No sir..... but..... I've always wanted to."

There are a few lessons for us all here:

* Never be arrogant.
* Don't waste ammunition.
* Whiskey makes you think you're smarter than you are.
* Don't mess with old men, they didn't get old by being stupid.

NOTEWORTHY ARTICLES

Why Is There So Much Resistance to Active Surveillance?

Posted: 15 Apr 2013 05:16 PM PDT in Prostate Snatchers blog

BY RALPH BLUM

Multiple studies have shown that the survival rate of men with early stage low-risk prostate cancer who choose Active Surveillance, matches that of men who choose immediate surgery, and without all of the attendant risks. Men who choose Active Surveillance are enthusiastic about having dodged the double bullets of erectile dysfunction and loss of urinary control. So if the virtues of active surveillance are so obvious, and major medical centers like Johns Hopkins are reporting excellent results with their active surveillance program, why are prostates still being removed at a record pace?

One reason is the pressure on for-profit private hospitals to boost the volume of procedures in a bid to hold onto huge annual profit margins. And the 2,900 non-profit hospitals across the country, which are exempt from income taxes, actually end up averaging higher profit margins than the 1,000 for-profit hospitals—in one case more than $500 million in the fiscal year 2010.

I'm not suggesting that these jaw-dropping profit margins are solely the result of the drastic overtreatment of men with prostate cancer. However, there is also no doubt that prostate cancer is a multibillion dollar industry.

Take surgical robots: The so-called Da Vinci Robotic system, broadly acclaimed as "state of the art" for prostate surgery, costs more than $1 million to acquire and install. Roughly $1,500 worth of parts must be replaced after every procedure. The Da Vinci System is now in use in more than 1,000 hospitals and clinics across the country. When a hospital invests that much money in a surgical robot and trains surgeons to use it, the pressure is huge to sell surgery over other treatments.

So the advent of robot-assisted prostatectomies has significantly increased the number of surgeries performed each year. Nationally, 80% of men over age 70 with low-risk disease are either undergoing radiation or having their prostates removed unnecessarily. Yet there is a confluence of new evidence that men with a PSA of less than 10 who had surgery gained no benefit from the procedure; that in many cases, no treatment is the best treatment.

Of course what Ted Turner calls "serious cash money" is not the only reason for the radical overtreatment of prostate cancer. Even though 91% of men with this disease will have a normal life expectancy, a diagnosis of prostate cancer leaves most men reeling and, in many cases, with an overwhelming desire to "just cut it out"—despite the risks and life disrupting side effects one can expect if the delicate nerve-sparing surgery doesn't go as planned. Yet according to prostate experts at Johns Hopkins, if urologists separated out men with low-risk disease and entered them in an Active Surveillance program, prostatectomies would dramatically decline and patients would be better off.

Research is currently underway at Johns Hopkins to further refine the protocols for separating out low-risk, slow-growing prostate cancers from the high-risk, aggressive cancers. And it is worth noting that, in the meantime, of the hundreds of men who have been enrolled in Hopkins' Active Surveillance program, not a single patient has died of prostate cancer.

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Decoded: Molecular Messages That Tell Prostate and Breast Cancers to Spread

From Science Daily Apr. 30, 2013

Cancer cells are wily, well-traveled adversaries, constantly side-stepping treatments to stop their spread. But for the first time, scientists at the University of Michigan have decoded the molecular chatter that ramps certain cancer cells into overdrive and can cause tumors to metastasize throughout the body.

Researchers have long known that tumors recruit healing cells, which is a major reason why cancer is so difficult to thwart. This is the first known study to explain the molecular behavior behind the series of changes that happen in the healing cells that result in metastasis.

Russell Taichman, a professor at the U-M School of Dentistry and research associate Younghun Jung looked at prostate and breast tumors. Their study, "Recruitment of mesenchymal stem cells into prostate tumors promotes metastasis," appears April 30 in the online journal *Nature Communications*.

Consider that a tumor is a wound that won't heal. To that end, both cancerous and benign tumors emit distress signals and messages to recruit healing-type cells, called mesenchymal stem cells, or MSCs, Taichman said.

"Now we know what messages (tumors) send to recruit and alter those healing cells, and we can take steps to block those messages," said Taichman, the study's principal investigator.

With this information, researchers can now try to develop drugs to pharmaceutically derail tumor formation earlier. This is especially important because this particular molecular signaling involves reactions among proteins that actually make cancer cells more migratory, more aggressive and more likely to spread.

To that end, Taichman said he was surprised at the large role played by the protein CXCL16 in altering the healing type cells in such a way that they revved the cancer cells into overdrive.

"Think of giving a bunch of kids sugar, and they all go nuts," he said.

On a personal level, the way the results emerged also delighted Taichman. Half of the researchers in Taichman's lab work on tumor development and half on wound healing. The research of Jung, the first author on the study, straddles both.

"It was her idea to put these together," Taichman said. "She sorted it all out, came up with the idea and finally came to me."

American Society of Clinical Oncology Genitourinary Cancers Symposium Report

TRIPLE-HITTER FOR ALPHARADIN: NOVEL DRUG IMPROVES QUALITY OF LIFE, LENGTHENS TIME TO CANCER-RELATED BONE COMPLICATIONS AND IMPROVES SURVIVAL IN MEN WITH ADVANCED PROSTATE CANCER

Radium-223, also known as by its trade name, Alpharadin, is a first-in-class injectable radiopharmaceutical that has undergone late-phase clinical testing. The drug targets radioactive alpha particles to cancer cells that have formed bone metastases in order to eliminate the lesions. Alpharadin is being developed

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jointly by Bayer Healthcare Pharmaceuticals and Algeta ASA, a Norwegian pharmaceutical company. The ALSYMPCA (ALpharadin in SYMptomatic Prostate CAncer) study was a multinational, double-blind, randomized, placebo-controlled Phase III clinical trial evaluating Alpharadin in men with treatment-resistant prostate cancer (also known as castration resistant prostate cancer (CRPC) who have established bone metastases. (The study was successfully finalized this past summer.) In the study, men meeting the above criteria were either given best standard medical care and placebo or best standard medical care and Alpharadin. Interim results of this study were reported earlier this year, finding that men treated with Alpharadin had a 31 percent reduction in risk of death during the trial period compared to men receiving placebo.

Prior data from the study were presented this past fall at the European Society of Medical Oncology (ESMO) Congress in Vienna, highlights of that presentation included:

- Men given Alpharadin had a median overall survival benefit of 3.6 months.
- Men given Alpharadin experienced a six month longer timeframe to first skeletal related event, which are defined as complications such as fractures or spinal cord compressions that are caused by metastatic lesions in bone.

Men given Alpharadin reported significantly better quality of life measures, such as emotional and functional well-being, as compared to men on placebo.

Overall, the men given Alpharadin tolerated the medication well, with low rates of side effects such as depressed white blood cell or low platelet counts.

This past week at the 2013 Genitourinary Cancers Symposium in Orlando, Florida researchers on the study presented further sub-analysis data on Alpharadin from the phase III ALSYMPCA study.

From the abstract listed above the findings showed that in addition to prolonging overall survival, Alpharadin reduced pain and the need for pain-reducing opioid drugs in men with bone-metastatic treatment-resistant prostate cancer. For men who received Alpharadin, 36% required opioid use for pain control compared to 50% of men receiving placebo. (Baseline pain was similar in both cohorts of men prior to receiving Alpharadin.) Also, the time period before the need for external beam radiotherapy for palliative (pain-reducing) reasons was significantly extended in men who received the investigational drug vs. men given placebo.

Because bone metastases are present in greater than 90% of men with metastatic, treatment-resistant prostate cancer, this finding has broad implications for quality of life for men living with this disease. Alpharadin is the first bone-targeted drug to improve survival in prostate cancer, say experts.

Read the Abstract here:

http://www.asco.org/ASCOv2/Meetings/Abstracts?&vmview=abst_detail_view&confID=134&abstractID=107297

Surgery vs. Seeds vs. IMRT

Posted: 07 May 2013 08:00 AM PDT Prostate Snatchers blog

BY MARK SCHOLZ, MD

Many men with *Intermediate-Risk* prostate cancer consider treatment with radiation or surgery. Treatment selection is influenced by age and preexisting status, especially as regards baseline sexual and urinary function. These days "surgery" usually means *robotic* surgery rather than the older, "open" procedure. Brachytherapy (radioactive seeds), and intensity modulated radiation (IMRT) are the most widely used types of radiation.

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Cure Rates

All treatment options result in similar cure rates assuming the best physicians and technology are used. If any single treatment can be considered to have a slight advantage, it is brachytherapy. Seed implants deliver a somewhat higher dose of radiation, possibly with slightly better accuracy. All types of radiation have a slight cure-rate advantage over surgery because radiation treats a small *margin around the gland.* Surgery, especially when extra-capsular disease is present, may leave cancer behind, an unfortunate situation called "a positive margin."

Quality of Life

Since cure rates are equivalent, the main criteria for selecting treatment are side effects. Table 1 lists the risks faced by a 65-year-old with good erectile function and without preexisting prostate problems. Risks are adjusted up or down based on a man's age and his sexual and urinary function prior to treatment.

Table 1 Long Term Side Effects

	Impotence	Incontinence	Climacturia*	Urethritis	Stricture**	Proctitis
Surgery	50%	8%	15%	-	5%	-
Seeds	30%	1%	-	10%	2%	1%
IMRT	30%	1%	-	4%	2%	2%

*Climacturia is the ejaculation of urine rather than sperm
**Stricture is a urethral scar

Short Term Side Effects

Some of the long-term effects noted in Table 1 also occur short term. All men are impotent after surgery though 50% eventually recover some functionality. Urinary symptoms, termed "urethritis," occur in two-thirds of men who undergo brachytherapy, usually lasting a couple months. Proctitis symptoms lasting one to two months occur in about half of the men who are treated with IMRT.

Treatment for Long Term Side Effects

Shrinkage and shortening of the penis due to surgery may be partially averted with early use of Viagra, Cialis or Levitra, and when necessary, the injection of prostaglandins. For treating impotence or incontinence, patient satisfaction is about 85% with a surgically implanted penile prosthesis and 60% with a surgically implanted artificial urinary sphincter. Chronic urethritis, a non-healing radiation burn of the urinary passage, manifests as pain, frequent urination, and a compelling urge to urinate *right now*. Proctitis side

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effects can be described similarly, but affecting the rectum. Palliative treatments for chronic urethritis and proctitis are only partially effective.

Further Aspects of Surgery and Radiation

Surgery: The surgical skill of urologists varies and is measured by how frequently cancer is left behind after the surgery, termed a *positive margin*. The best surgeons average a 10% rate. Studies show that many urologists, even at reputable centers, leave cancer behind up to 50% of the time. Prostate removal gives information about the size and grade of the cancer, helping to improve the accuracy of projections about future relapse. Surgery also simplifies PSA monitoring, since unlike radiation, there is no residual prostate gland producing PSA.

Seeds: Brachytherapy with permanent seeds is an outpatient procedure. Temporary, high-dose-rate (HDR) brachytherapy requires an overnight stay in the hospital. Men with preexisting urinary problems or glands over 60cc are more prone to develop urethritis from brachytherapy. A benign PSA rise after the implant, termed a "PSA Bump," occurs in 30% of men and can engender considerable anxiety.

IMRT treatment requires two months to deliver. Radiation beaming through surrounding organs may increase the risk of bladder and rectal tumors, though the risk is clearly less than one percent. The biggest risk besides impotence is proctitis. In the future, the injection of hydrogel between the prostate and the rectal wall may eliminate this risk (Hydrogel is pending FDA approval).

Cyberknife and Proton Therapy: Cyberknife is like IMRT but treatment is over one to two weeks rather than two months. Proton therapy is also similar to IMRT except it fires heavier subatomic particles (proton vs. photon). Proctitis rates are reported to be slightly higher with either of these two modalities.

Combination Radiation with Seeds and IMRT: Men with *High-Risk* disease and even some with *Intermediate-Risk* are treated with a combination of Seeds and IMRT. The side effects of Seed/IMRT combinations are similar to those of seeds alone.

The Outdated Sequencing Argument

As stated at the outset, cure rates are high with both radiation and surgery. Arguments touting surgery as the "Gold Standard" were true ten years ago when suboptimal radiation resulted in lower cure rates. Regrettably, to this day, many surgeons are still claiming that sequencing surgery before radiation is advantageous. This outdated thinking prioritizes planning for relapse, forgetting about the need to focus on quality of life. The goal is to be cured with the first treatment and be spared the side effects of additional rounds of therapy.

Taking Time to Decide

Prostate cancer is slow moving condition. There is no need rush to a decision. Radiation or surgery cures men with *Intermediate-Risk* prostate cancer 70-90% of the time. Even if a relapse occurs, salvage therapy usually gives a normal life expectancy. Additional options, besides surgery and radiation, can also be considered for men in the *Intermediate-Risk* category including active surveillance, focal therapy and intermittent hormone blockade. However, these treatments are outside the medical mainstream and beyond the scope of this short blog.

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

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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.

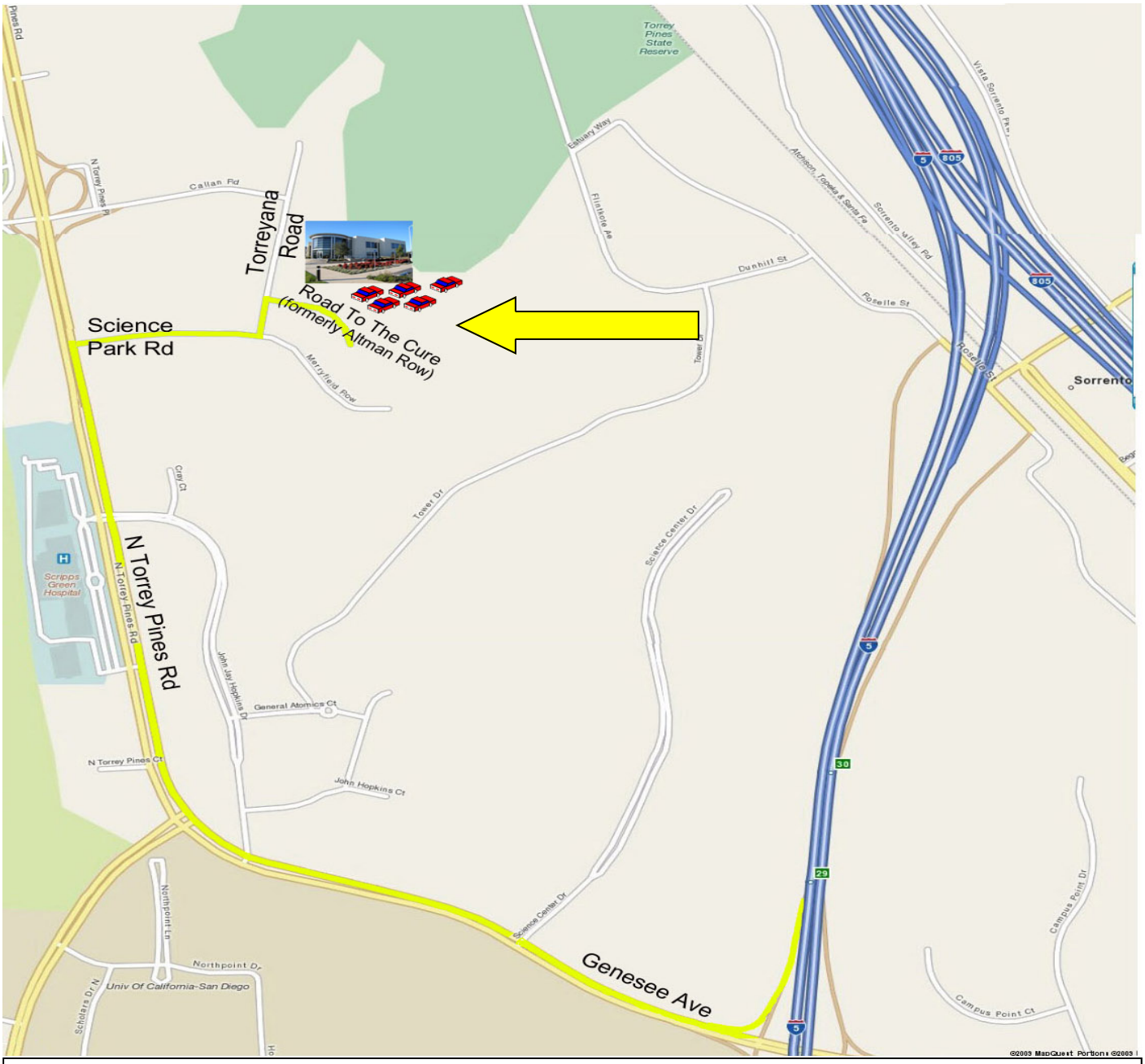
Anyone interested please contact:
Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org
Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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, 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).