Informed Prostate Cancer Support Group Inc.
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July 2017 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Monday, July 10, 2017

Volume 10 Issue 7

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Editor: Stephen Pendergast

Next Meeting
July 15,2017
10:00AM to Noon

Meeting at

Sanford-Burnham-Prebys Auditorium

10905 Road to the Cure, San Diego CA 92121

SEE MAP ON THE LAST PAGE

PROSTATE CANCER - 2 WORDS NOT A SENTENCE

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 PCa 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!!

RECAP OF LAST MEETING

By Bill Lewis

George Johnson -- Hormone Therapy (also called ADT, Androgen Deprivation Therapy)

"We are not medical professionals but a group of experienced participants and any sharing by anyone at this meeting should not be a substitute for your medical counsel." You may develop questions you may want to ask your medical counsel.

His personal story: Current age is 84. Member of the IPCSG since 2009. First PSA test result was 9.0 in 1998. His doctor wrote on the test report "I think you have cancer. Go see a urologist," and mailed it to him. Then his doctor never returned his calls. The urologist he went to, as this group would expect, recommended surgery. He visited four other doctors, and chose to

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.

The DVD of each meeting is available by the next meeting date. They now include the slides.

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get EBRT (external beam radiation treatment) in 1999. It was very successful. Not much side effects, and the treatment lasted for 10 years, but then his PSA went to 14. Two years before, it was still only 0.7. The doubling rate for the PSA was very high: 3 months to double. Anything two years or less is of concern.

He has had several ADT drugs over the years since then: Trelstar (a version of Lupron), Avodart, Casodex, and is now receiving Firmagon (which gives him a big red mark at the monthly abdominal injection site). He has had many adverse side effects (being Swedish, he is particularly prone to these): atrial fibrillation and a stroke due to Lupron, a fall that broke his leg, constipation, diarrhea, and all the others listed below. Use of ADT for the past 8 years, with some periods of intermittent treatment, has been effective for him.

An overview of ADT, its causes, perspective of urologists, controversies, and member experiences.

It is often called hormone therapy, which is a bit of a misnomer. It's designed to reduce or suppress levels of male hormones called androgens (mainly, testosterone and dihydrotestosterone) in the body, or to stop them from promoting the growth of prostate cancer cells. In the slides, information from the American Cancer Society is shown in black type, and his own opinions are shown in blue and italicized. He chose the ACS as source for this talk, because they are more open to presenting controversy when it has occurred, compared to the National Cancer Institute.

Types of ADT

1. Treatments to lower androgen levels in the body.

a. Surgery (**orchiectomy** -- removal of testicles -- it's permanent! Rarely done any more. No one present at the talk has had a double orchiectomy.)

b. Chemical castration using LHRH (luteinizing hormone-releasing hormone) **agonists** or **antagonists**, which reduce the amount of testosterone made by the testicles (and cause them to shrink over time). Costs more than surgical castration, and requires frequent doctor visits, but the effects are mostly reversible if/when treatment is stopped, and most men choose this method.

About 25-30 men present at the talk are currently using such drugs, mostly agonists. About 20 are on Lupron. A half-dozen are on Trelstar. Very few other agonists being used. Only George is on an antagonist, Firmagon. One other had it briefly, then went on Lupron. This is sometimes done, because it reduces the flare in the testosterone level (and possible tumor growth) that can occur with Lupron. (The other alternative is to give a short course of Casodex or the like to avoid the flare).

Some advantages of Firmagon over Lupron are that it lowers testosterone levels much more quickly, doesn't cause tumor flare like agonists do, and reduces by 50% the likelihood of cardiac or stroke side effects. George had heart arrhythmia and a stroke on Lupron, so is using Firmagon. The official Lupron website doesn't point out this side effect problem, only mentioning "chest pain." The clinical trial report for Lupron, which George searched out, showed that 8% of the participants in the trial had side effects that were heart-related. A disadvantage is that it requires monthly abdominal injections, which can be painful.

2. Anti-androgens, such as Casodex: They can be thought of as being like "duct tape on the cells" or a stopper in the drain. Sometimes used in combination with Lupron, or the like, but this is not done very often in the United States, and its effectiveness is debated. In Europe, use of Casodex instead of Lupron is very common, and is highly regarded. In the USA, testing Casodex alone has never been reported, although there is apparently a test (finally) in progress now.

3. "Advanced" ADT. Here in the IPCSG we refer to these drugs as "Super Lupron" and "Super Casodex." These are Zytiga and Xtandi, respectively, taken as pills daily. The costs are extremely high: $8-10,000 per month. To qualify for insurance coverage, a patient needs to have both "failed" prior treatment (that is, the cancer began to grow again despite continuing treatment), and have metastasized cancer. The earlier drugs are continued (presumably in the hope they will continue to provide some slight benefit) and the new drug is added. For example, Gene Van Vleet in the group has received Xtandi, as have four others. One group member has been taking it

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for two years, but it is now losing its effectiveness for him. Only one member has received Zytiga. A former member of the group had a PSA of 2200, which dropped to 2 over 6 months on Xtandi. It worked for two years, but then became ineffective, and he has passed on.

"Side effects" of LHRH Agonists (according to the ACS website): Hot flashes -- these may diminish or go away eventually. Breast tenderness and breast tissue growth. Osteoporosis (bone thinning), which can lead to broken bones. Shrinkage of testicles and penis. Loss of muscle mass. Increased cholesterol levels. Not mentioned by the ACS are several more common and devastating effects: depression, fatigue, memory loss, erectile dysfunction and libido loss. As noted above, George has had all these side effects.

"Serious side effects:" Risk of high blood pressure, strokes, diabetes, and even death from heart disease is reported by some researchers (but is not mentioned on the Lupron website!). George again noted that Firmagon has half the cardiac side effects vs. Lupron.

Side effects of anti-androgens: Casodex is said to have similar side effects as Lupron, BUT it has only been tested (in this country) in combination with Lupron. Casodex may have fewer negative sexual side effects vs. Lupron. When used alone, sexual desire and erections can often be maintained.

The cause of cancer: The ACS doesn't know! Only vague speculation is discussed in the ACS literature.

Who prescribes ADT? Typically, a urologist. The average urologist only has 20% of his business in prostate cancer. 80% of urologists in the US only do 8 or fewer prostate surgeries per year. Biopsies are normally done by urologists. Prostate cancer is the only type of cancer, where the initial referral from a general practitioner is to a surgeon (a urologist), rather than to an oncologist!

Most urologists seem to prefer prescribing injections for ADT, instead of pills. You need to go to them for the injection and they get about $1000 each time! A pill, by contrast, is much cheaper, and the monies paid for it go to a pharmacy, not to the urologist. George is not suggesting that urologists are greedy, but this is a way for them to maintain their business.

Intermittent ADT (not very popular among doctors in the San Diego area -- George was even advised to stop it, while being on it): the ACS mentions that it "may" prolong the time to drug resistance, and that it does reduce side effects during the time off the drugs. (Men feel better when they go off the drugs!)

An example from a recent IPCSG newsletter: Bob Keck, a member of the group, has 24 years of ADT experience, using Casodex and Avodart (more recently adding Metformin, which really helps to slow the rise in his PSA). He cycles between using and not using the ADT drugs. It takes about 1-1/2 years for his PSA to rise to about 1.5, and then he goes back on the drugs. When off the drugs, the side effects go away. This wouldn't work for everyone, but it works for him.

Testosterone vs. DHT. Dihydrotestosterone is present in men at 5-10% of the level of testosterone, but it also has 5-10 times the stimulating effect on prostate cancer growth, according to the ACS. So George concludes that it is DHT, not testosterone, that really stimulates prostate cancer growth.

His question: "Why not focus on DHT? Is there an anti-DHT pill?" The answer to this is that finasteride (Proscar) and dutasteride (Avodart) <u>are</u> anti-DHT pills. Avodart is more effective. Most urologists in San Diego do not prescribe these, despite the potential benefit of their anti-DHT effects! A half dozen members of the group are taking Avodart, typically having learned about it in the group.

The FDA has approved these drugs for BPH (enlarged prostate), but not for prostate cancer. An editor about 10 years ago in the New England Medical Journal wrote several negative statements that George feels are wrong. What urologists don't mention is that it really knocks down DHT. For example, in George, the DHT level went from 30 to less than one.

Combined therapy (e.g., Lupron + Casodex): The ACS reports that some say it's helpful and others not. George believes that the best doctors favor it. A new study, published in February, showed that Casodex after radiotherapy was helpful for survival and for fewer metastases. Again this is a combined therapy, not stand-alone Casodex therapy. George would really like to see data for Casodex used alone.

Triple androgen blockage (adding Proscar or Avodart): The ACS says there is very little evidence to support

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this. Dr. Strum, author of a primer on prostate cancer, reaffirmed recently to George that he is a strong advocate of Avodart use.

Other ADT variations: Avodart alone. Avodart + Casodex. Casodex alone (not FDA approved, but what George did). Lupron. Lupron + Casodex. Lupron + Casodex + Avodart. Or, sequential use of these.

Bipolar androgen therapy: Alternate suppression of testosterone with supplementation to above-normal levels in the body. Very controversial as to whether there is a benefit.

How many members had their testosterone level tested before they went on ADT? Thirteen of us had, which is higher by far than when George surveyed some years ago. He feels it's important to know what the level is, before you start. A somewhat larger number of members are getting testosterone checked while on ADT. He feels all should. Only six have ever had their DHT level measured. And yet, George says that is the primary agent that stimulates prostate cancer growth. You have to ask for the test, or doctors don't do it. His insurance will only cover the test cost every six months.

Typical testosterone levels in men: 200-500. After ADT is in progress, the level should be 50 or lower. George's went from 550 to 30 in two months with a single shot of Firmagon. That produces a significant shock to the cancer. The typical DHT level is around 30. With Avodart, it should drop below 5. George's is below 1.

A graph of George's PSA level over the past 18 years was shown. After EBRT, his PSA dropped to below 0.5, then gradually rose over the next ten years. He had to ask his doctor to run the PSA test, and then had to ask what the results were. His doctor said the result was "low," not realizing that after EBRT, any small rise was significant. Since the result was "low," George wasn't tested again for two years. His next test showed his PSA had risen to 14. That was devastating. He had thought he was cured. He went to a urologist, who immediately gave him a shot of Trelstar, and recommended against his joining a support group, saying that they are "a bunch of whiners." (This group is full of enthusiasts, with no whiners!) From the group, he learned that Casodex + Avodart might help him.

The Trelstar made his PSA drop very low, but gave terrible side effects: hot flashes that made sweat just pour off him, and gave him terrible fatigue. He should have been given a 1-month shot, to see what the side effects might be. Instead, he had to wait out the full three months. He also got atrial fibrillation and a stroke. He came to the IPCSG, and also went to see Dr. Duke Bahn, then went on Casodex + Lupron for six months. After that, George was not willing to have more Lupron, and Dr. Bahn wouldn't give him Avodart instead of Lupron. So he had his general practitioner prescribe it. His PSA went to undetectable. No Lupron used. Then he had intermittent dosing, which allowed him to reduce the side effects and feel great. His testosterone, after the Lupron wore off, went from 30 to 700, then gradually went back to 550 and has stayed there ever since. His DHT level went down to 1, and stayed there.

A group member mentioned a European study that showed a benefit from Casodex, but not further benefit from adding Avodart. George's response was to point out that many studies are poorly structured, and that results vary for different people. Note: Casodex tends to cause a slight increase in testosterone, but blocks the receptor for it on the cell membrane.

A side note: "When Breath Becomes Air: -- a book by a doctor who found he had very aggressive lung cancer at age 37. He had been a brain surgeon. Well-written, interesting and poignant book. This doctor's doctor refused to show him Kaplan-Meyers charts ("time to death" probability charts) for his disease!

George showed a Kaplan-Meyers probability chart for Lupron and Casodex. Shows days to death, vs. proportion surviving. Half of the men died at about 3-1/2 years, with Lupron + Casodex, versus about 3 years with Lupron and a less-effective anti-androgen. Among those surviving, the benefit for the Casodex group gradually stretched out to about two years. But where is the data for Lupron alone? George hasn't been able to find that anywhere! Not readily available.

Looking at the Kaplan-Meyers chart, George started to say to himself, "you have 3 years." But some of the men lived much longer! He doesn't take Lupron, but he has started to take Firmagon. He's doing really well.

How many in attendance are on Casodex alone? A few. Lupron + Casodex: a half dozen or more. Some problems with side effects. One member reported being on Lupron 3 years, with Casodex added after the first

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year, and the combination has recently begun to lose its effectiveness. He may start Xtandi. How many on Avodart? 3.

One member's report: He had radiation (81 Greys, 45 treatments) 6 years ago. PSA crept up to 1, leveled off, bounced a little, then up to 1.9. Dr. Lam had him get an Axumin scan (radioactive fluorine), and one hot spot was found. Dr. Mundt at UCSD will treat it with SBRT (Cyberknife) in a couple of months, now that Dr. Lam has started him on a triple dose of Casodex (150 mg daily). Also taking Proscar daily, and a medicine to prevent breast enlargement. Expects to be on Casodex for two years. No significant side effects so far.

Current situation among attendees: Degree of satisfaction High: "some." Low: "a few." Second thoughts: "some." (One member mentioned concerns whether surgery and radiation had really helped him).

George's Gleason is 9. His cells are very undifferentiated. They don't produce much PSA. He's had two TURPs (trans-urethral resection of the prostate), the last one very painful. He would like an Axumin test, but can't get it because the last TURP dropped his PSA below the qualifying level for insurance to cover the test.

Intermittent ADT? 8 have tried it. Chuck Grim had radiation + chemo + ADT for a year. Off for two years. 9 months on 12 off, triple blockage each time. After 9 back on. Then began to fail, but that was five years total, vs. typical ADT benefit for only 3 years. It did reduce his cancer. After the first PSA rise, a scan at Dr. Almeida's office in Phoenix showed 5 lymph nodes involved. After the next rise, another scan showed only 2 nodes still had "some" cancer (but with one new node showing positive). Bill Lewis reported that triple ADT for 6 months gave a 90% reduction in what had been over a hundred metastases to the bones.

Side effects: memory loss and fatigue were severe for George, perhaps partially due to age. Hot flashes can be helped by medications -- ask your doctor. Breast enlargement: drugs or radiation therapy (to prevent further growth; does not reduce existing enlargement; the procedure failed to help George, and instead gave him shingles on his breasts. It did work for Gene Van Vleet). Femara may stop growth, or may only stop the pain. Drugs can help with bone loss, or with depression.

Different degrees of seriousness of prostate cancer: Gleason 6 is really like "pre-cancer" or not cancer. It seems not to metastasize into more aggressive cancer. But Gleason 3+4 or 4+3 or higher needs treatment.

Second opinion on biopsy? Highly recommended. Johns Hopkins is a good place to send the samples.

Value of exercise: Per Gene Van Vleet, "It works!" He hated gyms, but now is addicted to it, going 6 days a week for an hour. With all the drugs he has taken, the exercise has greatly helped him with side effects, and has also allowed him to discard his blood pressure medication. Similar report from Chuck Grim.

Reduction of testosterone affects many things across the board. George feels avoiding reducing it is a good thing. Member comment by Ron: Dr. Strum's book, "Prostate Cancer: Essential Concepts for Survival 2013" lists the many negative effects of reduced androgens. Dr. Strum has left the L.A. area, and does limited practice in Oregon. He's a co-founder of the Prostate Cancer Research Institute. Recurrence doesn't really occur in prostate cancer-- it was there all along, according to Dr. Strum.

Testosterone therapy: Dr. Charles Huggins (who later won the Nobel Prize) reported in 1941 that lowering testosterone caused prostate cancer to regress, and that injecting testosterone caused its growth. More than 60 years later, Harvard-based Dr. Abraham Morgentaler found the original article actually showed that the conclusion about increased testosterone was based on a single patient, and used a test that was later abandoned because of unreliable results! Dr. Morgentaler's fascinating article, "Destroying the Myth About Testosterone Replacement and Prostate Cancer," is on the IPCSG website. A member had injections for low testosterone for 4 years, and then his PSA jumped up. George's reply: "It varies." Jim Kilduff, of the group, had low testosterone after coming off Lupron, and was dragging. He now has a testosterone patch, and feels much better. Lyle LaRosh (president of IPCSG) is also an advocate of testosterone supplementation. A PCRI talk two years ago (the video is available in our library) talked about benefits of testosterone supplementation.

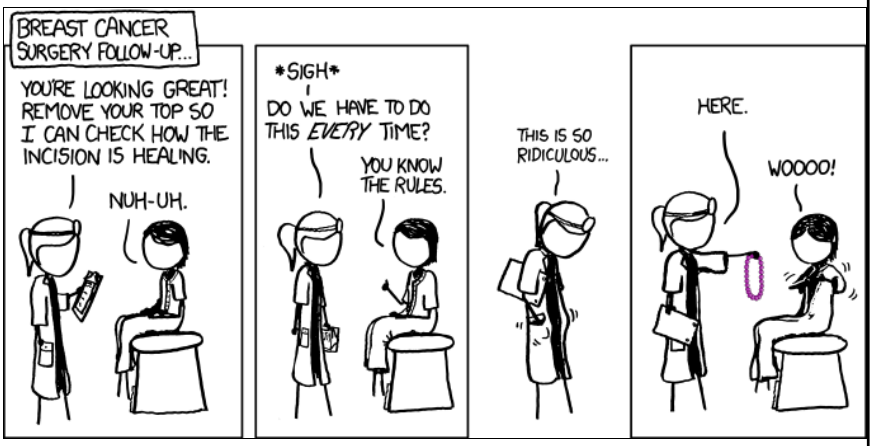
When you get to be a certain age, doctors don't want to see you. It's hard to deal with the many problems, and many of us are hard to talk to, hard of hearing, forgetful, etc.

Questions to ask your doctor: What is my testosterone level? What is my dihydrotestosterone level? Would Avodart be a good start for my ADT? Would Casodex also be a good start? What are the side effects of Lupron? What are the remedies? How long will I take Lupron? What are the options?

FUTURE MEETINGS

- July 15. Bernadette Greenwood - Director Clinical Services at Desert Medical Imaging Oncologic imaging and prostate MRI and MR-guided intervention.
- August 19—to be determined.

ON THE LIGHTER SIDE



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INTERESTING ARTICLES

10 Ways Exercise Is Beneficial When Going Through Cancer Treatment

Cancer is tough and so is the treatment. There will be times when you are so devoid of energy you may find it difficult to lift your head off the pillow but equally, there will be times when you have more energy and want to get out and get active.

As the American Physical Therapy Association explains, there are many reasons why exercising while going through cancer treatment is good for you. These include:

Reduces Fatigue -Although it sounds counterproductive, exercise can actually help you feel less fatigued and give you more energy, helping you to get through that next round of treatment.

Increases Muscle Strength - Exercising regularly will help to maintain and increase muscle strength which will help you look and feel stronger.

Reduces Stress -Exercise has been proven to help alleviate stress, ease depression and anxiety, and release happy, feel-good hormones.

Prevents Swelling - Swelling and water retention (lymphedema) can be a major concern when going through cancer treatment. Regular exercise can help prevent or reduce swelling.

Relieves Pain - So long as you don't overdo it and injure yourself, exercising at a comfortable pace can help relieve pain.

Helps Maintain a Healthy Body Weight - Some cancer treatments may make patients put on weight. Exercise can help to maintain a patient's natural healthy weight.

Reduces Brain Fog - Chemotherapy and radiation therapy can result in brain fog for many people going through cancer treatment. Exercise has been shown to lift the fog and improve cognitive skills.

Minimizes Bone Density Loss - Certain cancer treatments can result in the loss of bone density. Exercise can help to minimize bone density loss.

Improves Mood - If you love exercising, continuing to do so while going through cancer treatment will allow you to get out and do what you love and forget about your cancer for a while. It also means that when you're in remission and return full-time to your chosen exercise program, you won't have lost too much of your past progress.

Improves Outcomes - Studies have found that cancer patients who exercise are more likely to have a better outcome from their cancer treatment than those who don't exercise.

PSMA-Radioguided Surgery in Localized Recurrent Prostate Cancer: Current and Future Aspects: Beyond the Abstract

Salvage therapy might be considered as a valid treatment option in selected prostate cancer patients experiencing biochemical failure after primary treatment – especially when they present in good performance status. It is crucial, however, that in these cases recurrent disease is detected early and reliably. Anatomical imaging (CT or MRI), but also positron emission tomography (PET) with currently most widely used tracers like radiolabeled choline-derivatives show severe limitations in this regard and often underestimate the extent of metastatic spread.

Recently, 68Gallium-labelled ligands of the prostate-specific membrane antigen (PSMA) that exhibit a significant overexpression of PSMA at the cell surface of most prostate cancer cells have been introduced in PET imaging of prostate cancer. These tracers made it possible to detect recurrencies even at

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low PSA values. However, detected suspicious lymph nodes are often small-sized and located atypically hindering surgical resection.

Thus, based on PSMA PET imaging we developed a novel method (PSMA-radioguided surgery) to radioactively label prostate cancer cells for detection during surgery. After preoperative injection of PSMA tracers that were labelled with γ-emitting isotopes like 111Indium or 99mTechnetium a gamma probe is used intraoperatively to localize the small unobtrusive and/or atypically located metastatic lymph nodes and to guide resection. First results show that PSMA-radioguided surgery is a sensitive and specific method to track suspicious lesions and to facilitate complete removal.

Follow-up data from 55 consecutive patients show a PSA reduction >50% and >90% in 44 (80%) and 29 (53%) patients, respectively. In 34 (62%) patients a complete biochemical response (PSA drop below 0.2ng/mL) was observed. 15 of 55 (27%) patients received further prostate cancer-specific treatment after median 110 days after PSMA-radioguided surgery (range: 48 – 454 days), the remaining 40 (73%) patients remained treatment-free at a median follow-up of 195 days (range: 43 – 591 days).

In summary, PSMA-RGS seems to be of high value in patients with localised prostate cancer recurrence since it allows exact localisation and resection of metastatic tissue using intraoperative as well as ex vivo gamma-probe measurements. Thus, this new salvage method has the potential to influence further disease progression positively. However, prerequisite for preoperative patient selection is – apart from clinical parameters – a PSMA PET scan with preferably only solitary soft tissue or lymph node recurrency. Greater patient cohorts as well as long-term follow-up are needed to confirm these initial, but encouraging results.

Written By:

Tobias Maurer MD, Department of Urology, Technical University of Munich, Munich, Germany
Isabel Rauscher MD, Department of Nuclear Medicine, Technical University of Munich, Munich, Germany
Matthias Eiber MD, Department of Molecular and Medical Pharmacology, David Geffen School of Medicine, University of California Los Angeles, Los Angeles, CA, USA

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For Additional Reading go to: http://spendergast.blogspot.com/2017/07/prostatecancer-news-2017-07.html

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.

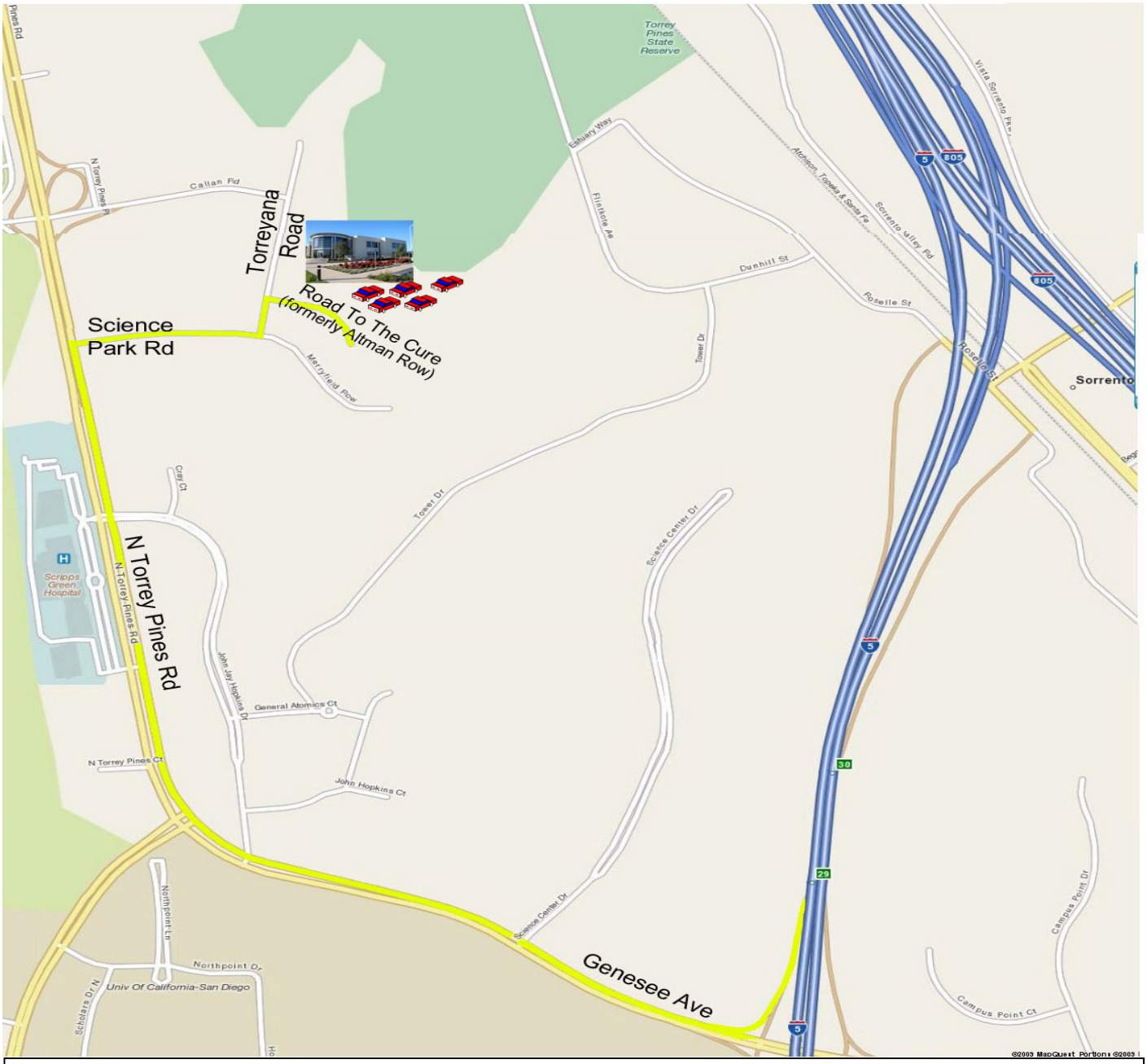
Ads about our Group are in the Union Tribune 2-3 times prior to a meeting. Watch for them.

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-Prebys 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-Prebys Medical Discovery Institute or Fishman Auditorium
Turn right on Science Park Road. Watch for our sign here.
Turn Left on Torreyana Road. Watch for our sign here.
Turn Right on Road to the Cure (formerly Altman Row). Watch for our sign here.