Informed Prostate Cancer Support Group Inc.

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

July 2012 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Wednesday, July 11, 2012 Volume 5, Issue 6

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
Carlos Richardson
Robert Keck, Librarian
Bill Manning
E. Walter Miles
Jerry Steffen
Robert Werve, Treasurer

Next Meeting July 21st 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

Gene Van Vleet accepts donation from Valarie Garza. She selects charities at random via Google. Our website presence helped get us selected.

THANK YOU VALERIE!!!

The June meeting focused on sharing experiences and networking.

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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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Gene Van Vleet summarized his 9 year survival experience that runs the gamut from BPH, to retropubic prostatectomy, to salvation external beam radiation, to hormone therapy. He highlighted choices that might have been altered had he had the benefit of knowledge gained through our support group. His complete story is posted on our website. Go to www.ipcsg.org and click on the blue Personal Experiences button.

George Johnson monitored an audience survey of experiences. A summary of the results follows:

Informed Prostate Cancer Support Group
MEMBER SURVEY

A survey was conducted during the June 16, 2012 IPCSG monthly meeting attended by 75 men on a beautiful sunny day in La Jolla during our Father's Day weekend. This is a summary of the results:

MEMBER PROFILE

The total exceeds 100% because some members had more than one type of treatment due to recurrence, and a few chose not to respond fully. All results mentioned are estimates from our members based upon quick counts of raised hands.

TREATMENT*	DISTRIBUTION
Active Surveillance	**20%**
Surgery	**28**
Radiation	**30**
ADT/Hormone Therapy	**17**
Chemotherapy	**12**
Other-Cryotherapy, HIFU, Provenge	**5**

*Highlights of the discussion and comments are provided for each treatment category as follows:

ACTIVE SURVEILLANCE

The 20% member involvement represents those whom choose this treatment before having any other invasive procedure. Many members have included this program after other treatments, but their comments were not included here.

Participants selected this option on the advice of doctors and through attendance at IPCSG and discussion of the book, The China Study.

Diet: A majority are on a vegan diet

Exercise: Many have a scheduled activity, many more think they could increase their exercise efforts

PSA Test Frequency: 6 months

Results: Very positive, only 3 members later needed more aggressive treatment

SURGERY

A majority had the advanced Robotic Treatment over the standard Retropubic Prostatectomy. No differences in results were noted between these two treatments.

Decision Factors: A majority selected surgery within weeks of their biopsy while a lesser number took more time, months, for second opinions and study of alternatives. One person was advised by his urologist to start with active surveillance before surgery.

Initial Treatment Response: Most patients had only minor, short- term concerns.

Degree of Satisfaction: A significant majority had a low degree of satisfaction. Only one person showed a highly positive result. Many had second thoughts about their decision. All but two had recur-

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rence of their prostate cancer; a majority of these occurred within the first two years. Almost half had the so-called nerve sparing procedure, all with unsatisfactory results.

Lessons Learned: Take more time and get a second opinion

(It should be noted that half of our support group members have experienced a recurrence in their prostate cancer following failed treatments. We recognize that many patients who have successful treatment results do not continue to participate in our support activities.)

RADIATION

Almost all members have had IMRT or EBRT. Only two members have had Brachytherapy seed implants, and one each for the newer proton and Cyberknife treatments.

Decision Factors: A majority selected radiation after months of study and second opinions. Several selected this treatment after Active Surveillance.

Treatment Response: Members did not show any negative concerns during their treatment program.

Degree of Satisfaction: A majority had a high degree of satisfaction. Only 3 members showed a low level of satisfaction. Side effects were minor. No one had second thoughts about their decision. Slightly less than half had recurrence of their prostate cancer and a majority of these occurred after several years.

ANDROGEN DEPRPIVATION THERAPY - ADT (Hormone Therapy)

LHRH Injections - Lupron, Trelstar, Zoladex, etc.

Pills - Avodart , Proscar – dutasteride, finasteride

Casodex - bicalutamide

Most members had a combination of the above.

Decision Factors: This treatment was prescribed by urologists shortly after surgery/radiation failure.

Treatment Response: Members did not show any negative concerns during their treatment program.

Degree of Satisfaction: Most men had a high degree of satisfaction. Many had the standard side effects of hot flashes and fatigue but did not express major concerns. Only one person had major side effects involving heart and bone problems. Slightly less than half have current intermittent treatments.

Lessons Learned: No comments. The responses were generally positive for this later-stage treatment. In part, the lack of negative responses may have been a result of the closing time pressures for this survey.

CHEMOTHREAPY

Because this treatment is highly individualized, it is not possible to summarize specific aspects of the seven members. All were positive about their treatments and hopeful for their continued participation.

OTHER TREATMENTS

Three members are participants in the FDA trials of the new and unique immunization Provenge Program. Two are in the early stages where results are not yet available. One member had a severe setback and viewed the treatment as a failure.

Another member had a successful Cryoablation Treatment. No one has participated in the HIFU trial

MEMBER COMMENTS

Most appreciated the opportunity to participate and found the results encouraging. Many were surprised by the unfortunate results of surgical treatments. The growth in Active Surveillance is striking and is now expected to increase.

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Future Meetings

July 21. Dr. Franklin Gaylis, MD FACS. Subject: Advances in Prostate Cancer Management from Active Surveillance to Management of Recurrence.

August 18 . Dr. John Grimaldi, DO. Subject: Newest techniques in treating impotence and incontinence. http://www.grimaldiurology.com

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

NOTEWORTHY ARTICLES

Loss of Protein SPDEF Allows Prostate Cancer Cells to Gain Foothold at Possible Sites of Metastasis

ScienceDaily (July 6, 2012) — Prostate cancer doesn't kill in the prostate -- it's the disease's metastasis to other tissues that can be fatal. A University of Colorado Cancer Center study published this week in the *Journal of Biological Chemistry* shows that prostate cancer cells containing the protein SPDEF continue to grow at the same pace as their SPDEF- cousins, but that these SPDEF+ cells are unable to survive at possible sites of metastasis.

"It's as if these cancer cells with SPDEF can't chew into distant tissue and so are unable to make new homes," says Hari Koul, PhD, investigator at the CU Cancer Center and director of urology research at the University of Colorado School of Medicine, the study's senior author.

Koul and his group discovered the homesteading power of cancer cells that have lost SPDEF by introducing a gene into cells that makes them glow in the presence of a dye, and then introducing them into the bloodstream of animal models. Cells without SPDEF traveled through the blood and successfully attached to tissue, surviving and so fluorescing many weeks later when dye was introduced. However, cells with SPDEF flowed through the blood but were unable to successfully establish new colonies and so soon died out.

In fact, the protein SPDEF doesn't act directly to allow cells to attach at possible metastasis sites, but is a transcription factor that controls the production (or lack thereof) of two other proteins MMP9 and MMP13. These two downstream proteins work to break down tissue, like a dissolving agent -- they are the cleaning crew that clears space for new and different growth, and in the case of prostate cancer metastasis they chip the tissue footholds that cancer cells need to create micrometastases.

"Given that MMP9 and perhaps MMP13 are also involved in metastasis of several other cancers including lung, ovarian, breast and colon to name a few, our findings could potentially have far-reaching consequences outside prostate cancer," adds Koul

The group's continuing work points in two directions.

"First, we hope that the presence of SPDEF could help doctors recognize prostate cancers that don't require treatment." If future studies confirm the group's initial findings, the presence of SPDEF could predict prostate cancers that are unable to metastasize and so unable to kill. These cancers could be left

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to run their course without the use of treatments that sometimes carry difficult side effects.

"And second," Koul says, "we hope to regulate expression of this protein to *remove* prostate cancers' ability to metastasize."

Koul points to small molecules, gene therapy or nanodelivery as possible mechanisms for introducing SPDEF into cells that lack the protein.

"With this discovery we have opened a hopeful door into a future in which prostate and potentially other cancers are unable to metastasize," Koul says.

New Drugs, New Ways to Target Androgens in Prostate Cancer Therapy

ScienceDaily (June 20, 2012) — Prostate cancer cells require androgens including testosterone to grow. A recent review in the *British Journal of Urology* International describes new classes of drugs that target androgens in novel ways, providing alternatives to the traditional methods that frequently carry high side effects.

"In many ways, therapies for prostate cancer have led the way in the fight against the disease," says E. David Crawford, MD, investigator at the University of Colorado Cancer Center and review co-author. "The first effective oral therapy for any cancer was estrogen which was described in 1941. The first cancer biomarker that allowed diagnosis and staging was prostatic acid phosphatase back in 1938. Then there was little progress for over four decades."

During those 40 years, in which early work in prostate cancer led to Nobel prizes for researchers Charles Huggins and Andrew Schally, other cancer types capitalized on this research, notably developing hormone therapies targeting estrogen in breast cancer. But work in prostate cancer stalled.

"What we realized is that production of androgens like testosterone depends on an intact system in which the brain recognizes hormone levels, signals the pituitary to increase or decrease production, and the pituitary in turn sets the testes in motion. Additionally, by targeting the production of androgens by the testes, we could break that system at many other points," Crawford says.

For example, estrogen is similar enough to testosterone that administering estrogen to patients tricked the brain into thinking testosterone hormone levels were high -- with high presumed hormone levels, the brain sent no production signal to the pituitary. But estrogen therapy led to side effects including breast enlargement.

The next class of drugs, known as luteinizing hormone releasing hormones or LHRHs, intervened in this signaling chain at the level of the pituitary. Just as estrogen keeps the brain from signaling for more testosterone, LHRHs keep the pituitary from passing messages to the testes.

"Because the effects of LHRHs are reversible, this allowed us to use hormone-targeting therapies much earlier in the disease," Crawford says. "But LHRHs lead to an initial spike in testosterone, before it decreases." Most patients can withstand this spike, but for some, for example those with bone metastasis in the back, a spike in testosterone could flare the disease and lead to spinal complications.

"It was only about ten years ago that somebody was able to make a usable *antagonist*," Crawford says. Instead of first spiking and then lowering testosterone, these LHRH antagonists lead to an immediate drop.

And instead of targeting the signaling pathway that leads to the production of androgens including testosterone, androgen antagonists like Enzalutamide (formerly known as MDV3100), currently in phase III clinical trials, target cells' ability to *trap* testosterone that exists in the body -- it doesn't matter how

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much testosterone is floating around, as long as prostate cancer cells are unable to grab it. Specifically, Enzalutamide and other androgen antagonists are easier to "catch" than the androgens themselves, and so cells grab Enzalutamide and are then unable to grab testosterone.

Also new to the field are drugs that block the production of androgens from all sources which of course includes the testes, but also includes blocking the smaller amounts produced by the adrenals and even by the cancer itself. This class of drugs is called androgen biosynthesis inhibitors, and the first approved is a drug called abiraterone or Zytiga.

"Targeting cells' androgen receptors is a new and exciting development in the field of prostate cancer therapy," Crawford says. "As these new drugs make their way from the lab to clinic, we expect the ability to offer androgen antagonists to patients whose cancers have resisted other treatments."

Dr. Crawford wishes to disclose that he is an advisor to the company Medivation, which manufactures the drug Enzolutamide.

Prostate Cancer: The Stress Factor

BY RALPH BLUM

Posted: 10 Jul 2012 02:00 PM PDT www.prostatesnatchers.blogspot.com/

It's no secret: Men are considerably less likely to seek medical help than women. The reluctance starts with a superficial cut or a bellyache. And when it gets to what's happening "down there," given half a chance, we go into "ostrich" mode.

There was an informative article some years ago in *Psychiatric Times* in which the authors, William F. Piri, MD, and Jeffrey Mello, MSW, focused on some of the factors that keep men from going to a doctor. In seeking care, men may fear being viewed as weak, appearing "unmanly," feeling that they must live up to society's image of them as strong and independent by "dealing with it" on their own. So we find ourselves in a bind and resort to denial: When we are questioned about this neglect, we offer excuses such as "I just don't have the time because of . . ." and give reasons like our work, family obligations, and just plain preferring to "wait and see how things go."

Moreover, even providing that an annual checkup propels a man into the doctor's office, Piri and Mello point out that

…there is no guarantee he will receive prostate cancer screening. The idea of a digital rectal exam typically makes men anxious, provoking concerns about discomfort and the violation of their manhood. Primary care physicians often join their patients in avoiding this sometimes uncomfortable and socially awkward test, which typically lasts less than a minute.

This problem is even more challenging in the African-American community since black men have a prostate cancer mortality rate twice that of Caucasian men.

So what is the answer? Joining a support group is one good way to challenge the manly addiction to independence. However it depends on the group, and not all men find support groups beneficial. In which case counseling or psychotherapy—either individual or group—is a reasonable way to proceed.

In his last blog, Mark quoted a recent *New England Journal of Medicine* report stating that in the first three months after a diagnosis of prostate cancer, the rate of heart attack and suicides both increase by about 200%. So instead of ignoring, denying or trying to minimize the psychological effect of prostate cancer, know that all the feelings you have are normal, and that they are common among the more than 200,000 men diagnosed with this disease each year. Getting treatment for your fear, anxiety and depression is as necessary as facing and dealing with the disease itself—and ultimately just as beneficial in recovering your health.

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Announcements

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 continues to develop our new website that we believe is simple and easy to navigate. **Check out the Personal Experiences page and send us your story**. Go to: http://www.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.

Our Steering Committee meets for lunch, usually at Baci's restaurant (preferred) at noon on the first Tuesday of each month. All members are welcome! Please call Lyle La Rosh at 619-892-3888, to make reservations and to verify location.

Library Announcement "To all those who have borrowed books, tapes or DVD's please return them at the next meeting"

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

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HEALTH INSURANCE NEWS

Affordable Care Act gives consumers new tools, makes health insurance market more transparent

Created under the Affordable Care Act, www.HealthCare.gov was launched July 1, 2010, and is the first website of its kind to bring information and links to health insurance plans into one place to make it easy for consumers to learn about and compare their insurance choices. HHS' Office of Consumer Information and Insurance Oversight (OCIIO) worked to define and collect detailed benefits and premium rating information from insurers across the country, and starting October 1, 2010, consumers will also be able to find information about health insurance options such as: Monthly premium estimates; Cost-sharing information, including annual deductibles and out-of-pocket limits; Major categories of services covered; Consumer's share of cost for these services; Percent of people in the plan who pay more than the base premium estimate due to their health status; Percent of people denied coverage from a health plan.

More than 225 insurance companies have provided information about their individual and family plans for more than 4,400 policies, including policies in every state and the District of Columbia. Consumers can search for and compare information on plans available based on age, gender, family size, tobacco use and location.

NOTE

California law requires that you have an annual 30-day period beginning on your birthday during which you may purchase any Medicare supplement coverage that offers benefits equal to or lesser than, those of your current coverage. You are eligible to purchase such plans without regard to your health status, claims experience, receipt of health care or medical condition. This only applies if you currently are on Medicare.

Mr. David Weil from Health Insurance Counseling and Advocacy Program (HICAP) provided information about their free services in our October, 2011 meeting. HICAP is a non-profit program that assists with counseling about medicare coverage and billing issues, including appeals. They do not make recommendations but rather provide information to help individuals make decisions about available coverage. They also assist with Long Term Care Insurance. The local phone number is 858-565-8772 or, if calling from a cell phone outside of the San Diego Area, 800-434-0222. Website: http://www.cahealthadvocates.org/HICAP/sandiego.html

If you have particular knowledge that would be helpful to our goal of creating a base of information, please volunteer your efforts to the committee. Contact Gene Van Vleet, e-mail gene@ipcsg.org or cell phone 619-890-8447 who may redirect your inquiry to an appropriate person for response.

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

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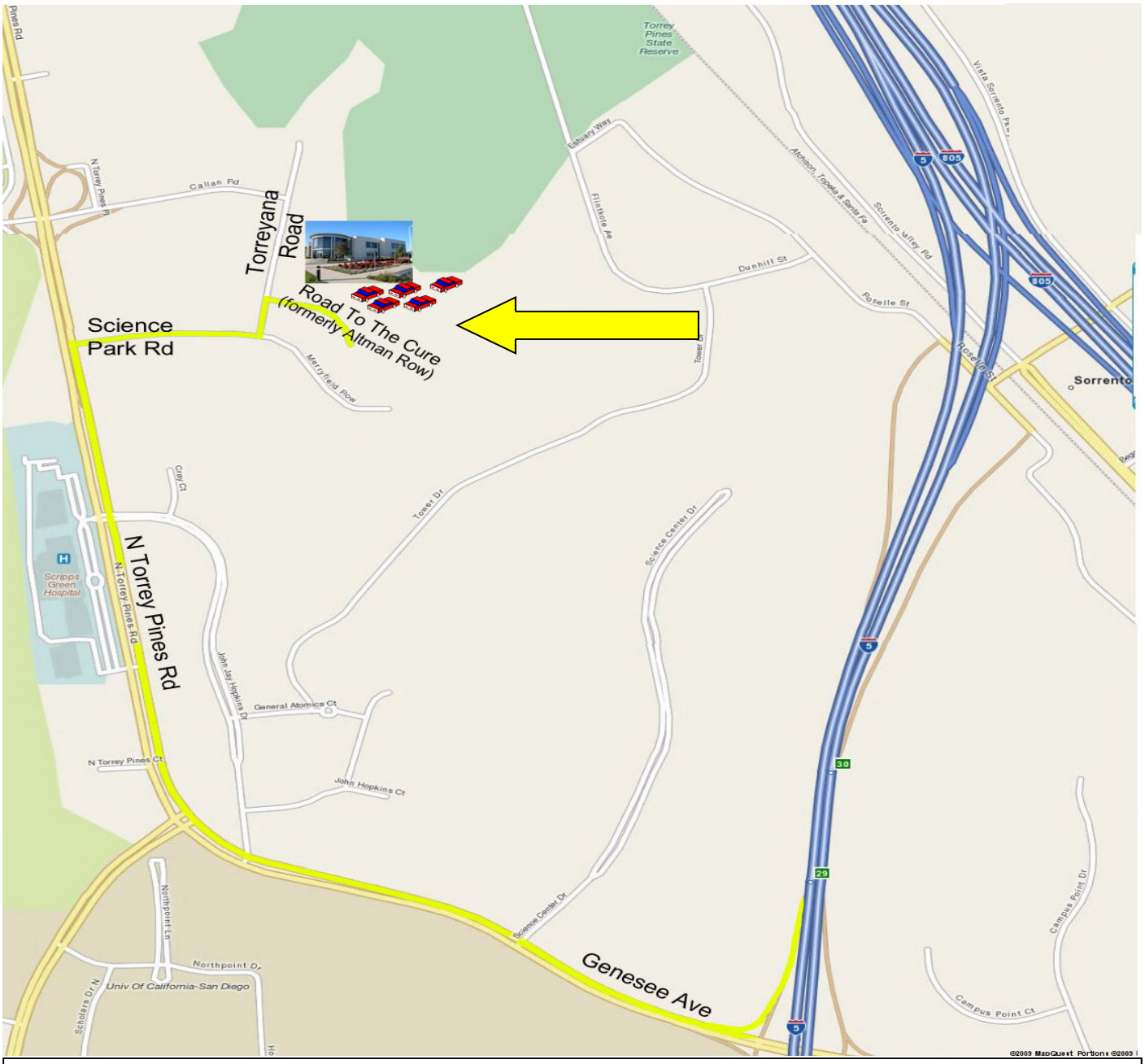

Directions to Sanford-Burnham Auditorium
10905 Road to the Cure, San Diego, CA 92121

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).

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