Informed Prostate Cancer Support Group Inc.

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

October 2011 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Thursday, October 06, 2011 Volume 4, Issue 10

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
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Bill Manning
E. Walter Miles
Jerry Steffen
Robert Werve, Treasurer

Next Meeting October 15th 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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The September meeting was well attended by 90 including 15 newcomers.

The speakers were Dr. A.J. Mundt, Professor and Chairman, Dept. of Radiation Oncology, and Dr. John Einck, Associate Clinical Professor of Radiation Oncology, both of Moores Cancer Center, UCSD.

Dr. Mundt spoke about external methods of radiation oncology. He described radiation as the use of high energy x-rays or beams of energy which was first discovered in 1895 with the first patient being treated in 1896. CAT scans and radiation treatments come from that methodology. Two thirds of all cancer patients receive radiation therapy in their lifetime. There are 2 ways to give radiation: teletherapy (external) and brachytherapy

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://www.ipcsg.org. Click on the 'Purchase DVDs" button.

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(internal) where radioactive sources are put into a tumor either temporarily or permanently. It was first used for prostate cancer in 1909 which was brachytherapy at that time. Interest in this type of therapy waned after WWII because many patients were not cured, or because the mainstay of treatment became radical surgery and the discovery of the ability to treat with hormone therapy. Interest returned in the 1960's with the discovery of megavoltage (high energy) machines that could project highly penetrating beams which could treat the prostate without skin toxicity.

Today, the National Cancer Institute recognizes that for men with early stage cancer (those with a PSA less than 10 and a Gleason of 6 or less) cure rates are the same between surgery and radiation. Radiation therapy is now commonplace in the treatment of both early and more advanced prostate cancer. It is often thought that the treatment for prostate cancer is a contest between surgery and radiation. Assuming equal cure rates the choice needs to be based on potential toxicities: for surgery they are urinary incontinence and impotency; for radiation they are rectal bleeding and impotency. Often, surgery and radiation are used together, Multiple studies have demonstrated that men who undergo surgery who have positive margins and/or extracapsular disease should also receive radiation therapy.

There are essentially two types of conventional external radiation therapy:

1.Intensity Modulated Radiation Therapy (IMRT). This was developed in the early 1990's and uses computers to conform the radiation dose in 3 dimensions to the shape of the prostate ("shrink wrap") which reduces the dose to the bladder and the rectum and allows higher doses in to improve cure rates.

2.Image Guided Radiation Therapy (IGRT). This is a method to use images in the treatment room to improve the delivery of IMRT. IMRT focuses the radiation on the prostate while IGRT ensures that it is aimed correctly every day. There are two approaches. Non-radioactive seeds are implanted in the prostate or a daily CT scans are taken of the position of the prostate. Both methods allow the treatment beams to be re-adjusted based on the prostate location.

In today's world there is a lot of marketing hype directed at the patient relating to new machines and "new" types of therapy. All the machines deliver exactly the same thing—-x-rays. They differ in how they do it but they may not be relevant to prostate cancer. Some are directed at shorter treatment times. In shorter treatment times about the same total dosage is given over a shorter time period. It is too early to tell if these treatments fare as well over time.

Dr. Einck spoke about internal radiation therapy (Brachytherapy). This treatment uses radioactive isotopes inserted directly or in close proximity to the tumor or organ at risk. It was developed in Seattle in the 1980's. Some of its advantages are: it does work for prostate cancer; it is convenient for patients; there is low risk of long term side effects.

There are two types:

1. Low Dose Rate. Permanent radioactive seeds are inserted into the prostate which give off radiation for a period of time – weeks to months.

2.High Dose Rate. Non-radioactive needles or catheters are inserted into the prostate and the radiation is given by a high intensity radioisotope connected to the catheters. The radiation is not left in the patient.

To determine which dose rate is used it must be determined what level of risk for disease progress the patient has:

1.Low Risk. The patient has no tumor that can be felt during a DRE or the tumor involves less than one half of one of the lobes. The PSA is less than 10. The Gleason Score is 6 or less.

2.Intermediate Risk. The tumor can be felt and involves more than one half of a lobe. The PSA is 10-20. The Gleason Score is 7.

3.High Risk. There are large tumors in the prostate. The PSA is more than 20 and the Gleason Score

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is 8-10.

Since the prostate is not removed in this kind of treatment, there will be PSA scores after the treatment. When the PSA reaches its lowest point (nadir) following treatment and if it remains within 2 points of that nadir, it is a successful treatment. This is different than in surgery, because when the prostate is removed PSA should be undetectable.

The low dose rate (implanted seeds) is most commonly used for patients with low risk and the high dose rate (given by a high intensity radioisotope connected to catheters) is more commonly used for intermediate and high risk patients. For higher risk patients 5 weeks of IMRT are added to the treatment.

Some studies show that brachytherapy is more successful likely because a higher dosage is delivered with less danger to the bladder and rectum.

As usual with excellent presentations such as these you can get a more thorough understanding by getting the DVD of this meeting. Since the projector was not working well during their presentations, we obtained a copy of their slides which will be incorporated into the DVD. Copies of the DVD will be available by the October 15th meeting and can be purchased from the library or through our website: www.ipcsg.org by clicking on the "Purchase DVDs" button on the home page.

Future Meetings

October 15, 2011. Mr. David Weil from HICAP, a non-profit organization. Helping you understand your specific rights and health care options. www.cahealthadvocates.org . Roundtable networking will follow after the speaker.

November 20, 2011. Open date , waiting on speaker confirmation..

January 21, 2012. Dr. Richard Lam, Prostate Oncology Specialists-Review and update on prostate cancer treatment.

February 18, 2012. Dr. Richard Safrin, Head of Pathology at Alvarado Hospital, will speak about Gleason testing.

March 17, 2012. Dr. Irwin Goldstein and Dr. Brian Dicks will speak about sexual medicine. Dr. Andrew Goldstein will speak about his research in understanding stem cells in relation to prostate cancer.

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

NOTEWORTHY ARTICLES

Making Sense of the TNM Staging System

(From Prostate Snatchers Blog Posted: 27 Sep 2011)

By Ralph Blum

In my last Blog I described the Gleason *grading* system, which urologists use to establish the aggressiveness of your cancer based on the pathologist's analysis of your biopsy. If you are requesting copies of all your medical records (as you should) you may come across a tumor staging code called the Tumor Node Metastasis (TNM) *staging* system. This code is used to describe to doctors information about whether your prostate cancer is localized, regional, or advanced.

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The letter "T" in the TNM system refers to the tumor. Your doctor "stages" the tumor based on how big the tumor nodule feels when he does a digital rectal examination. For example, information about size, on whether it is in one or both sides of the prostate, and on whether it has gone outside the prostate is communicated by the four categories—T1, T2, T3, and T4.

Subtypes of T1 (T1, T1a, T1b, T1c) or T2 (T2, T2a, T2b, T2c) refer to localized cancer, meaning the cancer has not spread beyond the prostate. Any of the T3 subtypes (T3a, T3b) refer to regional cancer, which means that the cancer extends just outside the prostate and may have gone into the seminal vesicles. T4 has only one category, and refers to cancer that has spread to the bladder and/or to other adjacent areas of the pelvis.

The "N" in the TNM code refers to whether the cancer has spread to the lymph nodes in the pelvis. N0 means it has not spread to the pelvic nodes; N1 indicates that it has spread. If the cancer *has* spread to the pelvic nodes, it is more likely to move beyond the nodes and into other parts of the body, making it harder to treat.

The "M" in the TNM staging system refers to whether the tumor has spread or metastasized beyond the lymph nodes in the pelvis. M0 means zero metastasis. M1a means the cancer has spread into the lymph nodes beyond the pelvic area. M1b refers to cancer that has spread to the bones. M1c means the cancer has spread beyond the lymph nodes and bones to other parts of the body.

At the initial staging of the cancer, your urologist first performs a digital rectal examination to determine the presence and status of the tumor. If he determines that the cancer is at a very low level perhaps he will not order further tests. But if he suspects that the cancer may have spread outside the prostate gland, he will order a CT scan, an MRI, or bone scan. Cautious or conservative doctors are likely to order all three of these imaging tests regardless of their findings in the DRE. So don't assume that you may have advanced cancer just because your doctor sends you for a CT scan or MRI.

I realize that all this information is somewhat confusing (It begins to sound like loony runaway variations on the British Secret Service MI5, MI6, SIS and Lord knows what else). However, the fact remains that, by grouping your PSA level, Gleason grade, and TNM stage, your urologist can determine your prostate cancer's risk level and advise you on your best treatment options.

Bottom line, the more you know the better. Yours is really the decision that counts so you have to understand what is going on. You can obtain more information about staging on the PCRI's blue community website at **www.pcribc.org**.

5-GENE SIGNATURE IDENTIFIES LETHAL VARIETIES OF PROSTATE CANCER AND MAY BETTER DIRECT PATIENTS TO APPROPRIATE LEVELS OF TREATMENT

(Reprinted from Prostate Cancer Foundation News Pulse)

Discovery enabled by collaborative effort of scientists at more than a dozen institutes in U.S. and Sweden

In treating prostate cancer patients, clinicians agree: no one size of treatment fits all. With more than 25 genetic subtypes of this cancer already identified by PCF-associated researchers at the University of Michigan, we not only know that there are indeed varieties that a man might die with and not of while, while other varieties require immediate aggressive treatment, but we are zeroing on which genotypes require aggressive treatment. For decades, our inability to differentiate definitively between the two groups, as well as those in between, has resulted is an estimated $2 billion in overtreatment each year. Not only is this an unnecessary burden on the U.S. healthcare system, such overtreatment can needlessly subject many men to the numerous life-changing side effects that treating this disease can impart.

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We may now be steps closer to alleviating this problem and improving treatment for the more than 240,000 men in the U.S. alone who will be diagnosed with prostate cancer this year.

Janet L. Stanford, Ph.D. at the Fred Hutchinson Cancer Research Center is a PCF-funded investigator. She and a team of scientists from Seattle to Sweden have identified a 5-gene signature for lethal prostate cancer. The findings, published online ahead of the September issue of *Cancer Epidemiology, Biomarkers and Prevention*, might serve as the basis for a new blood test that could be given on initial diagnosis in order to determine which patients need aggressive treatment versus watchful waiting.

"Being able to accurately stratify a patient's disease, predict outcome and direct them to the appropriate treatment would empower us to cure more and overtreat less," explains Jonathan W. Simons, MD, president and CEO of the Prostate Cancer Foundation. "What's more, bringing more assurance to the diagnostic, staging and treatment process may also bring more confidence and clarity to patients and their families as they are force to navigate through a very difficult time.

To discover the five "disease genes" implicated in lethal prostate cancers, Dr. Stanford and her colleagues looked for genetic variants that men with prostate cancer share in common. Called single-nucleotide polymorphisms, or SNPs (pronounced "snips"), these inherited genetic variants are certain genes in the whole prostate cancer human genome that may code—or signal—the development of fatal varieties of the disease. The five SNPs Dr. Stanford identified were linked to five genes that may affect prostate cancer progression: namely, LEPR, RNASEL, IL4, CRY1, and ARVCF.

Dr. Stanford explains that her team "chose to study SNPs in genes that potentially play a key role in biological pathways that may contribute to prostate cancer progression such as inflammation, steroid-hormone production and metabolism, DNA repair, circadian rhythm and vitamin D activity." With approximately 20% of all human cancers linked to chronic infections and chronic inflammation, the finding associating two of the five genes studied (IL4 and RNASEL) with prostate inflammation may play a part in better understanding whether there is an infectious agent that triggers early prostate cancer. The identification of *Helicobacter pylori* as an unrecognized infectious cause for stomach ulcers and stomach cancer transformed the entire direction of research around early diagnosis and prevention of gastric cancer.

To find the panel of markers associated with lethal prostate cancer, the scientists studied a population-based group of 1,309 Seattle-area prostate cancer patients who were age 35 to 74 at the time of diagnosis. They investigated 937 SNPs in 156 candidate genes. Of these, 22 SNPs stood out as being associated with more fatal forms of prostate cancer. This result, found through analysis of DNA in blood samples, was compared to a validation study conducted in another population-based group of 2,875 prostate cancer patients in Sweden who were age 35 to 74 at diagnosis. Five of the 22 SNPs were identified in this Swedish study as being implicated in prostate cancer mortality.

The Prostate Cancer Foundation laid the groundwork for genetic studies of this kind through its early work collecting blood from patients and families with prostate cancer for genetic studies in 1994. It provided key funding to help establish the family-based study called the Prostate Cancer Genetic Research Study--*PROGRESS*. Recognizing the lack of research findings on the causes of prostate cancer and the emerging evidence that a family history of the disease conveyed an increased risk, Dr. Stanford and colleagues Drs. Elaine Ostrander and Lee Hood tackled this problem by initiating the *PROGRESS* study.

The problem of little research addressing the issue of the inherited causes for prostate cancer was close to home for Dr. Stanford. Family ties led her to become a prostate cancer researcher. After learning her father had been diagnosed with the disease in 1984, she questioned what variable risk factors might have caused his prostate cancer. She realized quickly that there was little research to address this issue.

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"There was very little support for prostate cancer research during the 1970's and 80's—few investigators were doing it," says Dr. Stanford, co-Head of Program in Prostate Cancer Research at the Fred Hutchinson Cancer Research Center in Seattle. "Back then the assumption was that almost 100% of men would develop prostate cancer in their lifetime, but they wouldn't develop it until they were quite elderly and would die from some other cause."

In 1995, *PROGRESS* gained considerable momentum after PCF founder and Chairman Mike Milken made a public appeal to viewers on nationally-televised *Larry King Live*. With a 1-800 number scrolled at the bottom of television screens during the interview, Milken urged those who had a family history of prostate cancer to call and be a part of the study.

According to Dr. Stanford, Milken's appearance resulted in thousands of phone calls throughout the night of the broadcast. She and her staff had to forward calls to voicemail after inquiries about the study continued to pour in up until the wee hours of 2 a.m.

"The *Larry King Live Show* was the best recruitment tool ever," said Dr. Stanford. "The 1-800 number made it easy for people to contact us directly, and it didn't require them to get a physician's referral. PCF's funding was critical, absolutely critical for starting this research," said Dr. Stanford. "*PROGRESS* would have never happened if it weren't for that initial funding. That support went towards the first critical stages of collecting the families' information, collecting the blood samples and getting them processed, and making the DNA available to researchers for genotyping."

Sixteen years later, the impact of *PROGRESS* lives on in Dr. Stanford's work identifying the inherited genetic variants for lethal prostate cancer. It may forever change clinical decision-making and vastly improve the quality of life for prostate cancer patients and their families.

The next step is to conduct further studies evaluating the use of the 5-gene signature in other patient populations and continuing to characterize other genetic mutations that might be useful for stratifying patients for more effective and efficient clinical decision-making.

Moving More Biomarker Studies Forward with MOVEMBER

Extending on our commitment to global collaboration to find better diagnostic tools like the 5-gene signature, PCF is leading the U.S. team in the Movember Global Action Plan (GAP). The overall goal of the two-year GAP research program is to better predict aggressive disease and to characterize metastatic biology and treatment resistance by identifying clinical biomarkers that ultimately enhance treatment decisions. This will be achieved through analysis and correlation of patient materials (tissue, urine, circulating tumor cells, serum and exosomes). We hope to accelerate progress and the use of potentially novel biomarkers of early detection.

Movember will create a Wiki-type global docking page for all biomarker discovery scientists where the standard operating procedure is to verify published papers, bio-repository inventories are transparent for collaboration, and postdoctoral students can communicate with one another. Creating an on-line "knowledge exchange" between laboratories around biomarker discovery and validation will foster additional collaboration and accelerate more discovery in genetic biomarkers.

The Global Team: Collaborators on the study included researchers from the Karolinska Institutet in Stockholm; Umea University in Umea, Sweden; the National Human Genome Research Institute of the National Institutes of Health in Bethesda, Md.; Wake Forest University School of Medicine in Winston-Salem, N.C.; and Johns Hopkins University in Baltimore.

The research was conducted via the National Cancer Institute-funded Pacific Northwest Prostate Cancer Specialized Program in Research Excellence, which is co-led by Stanford and based at the Hutchinson Center. Additional support was provided by the Hutchinson Center, the National Human Genome

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Research Institute, the Cancer Risk Prediction Center, the Swedish Research Council, the Swedish Cancer Foundation, the Hedlund Foundation, the Soderberg Foundation, the Enqvist Foundation and the

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 much simpler and easier 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"

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

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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.

The medical insurance committee, comprised of Bill Pitts, Dennis Walker and Gene Van Vleet assists in making choices that provide them the best coverage suitable to their situation The committee cannot be expected to make recommendations for suitable medical coverage but rather should be a resource of information to help you determine what options are most suitable for your situation.

Our committee members are willing to provide you with education and resources.

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.

PLEASE, volunteer your effort to assist our cause.

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.
3. Assistance with editing and publishing monthly newsletter.

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

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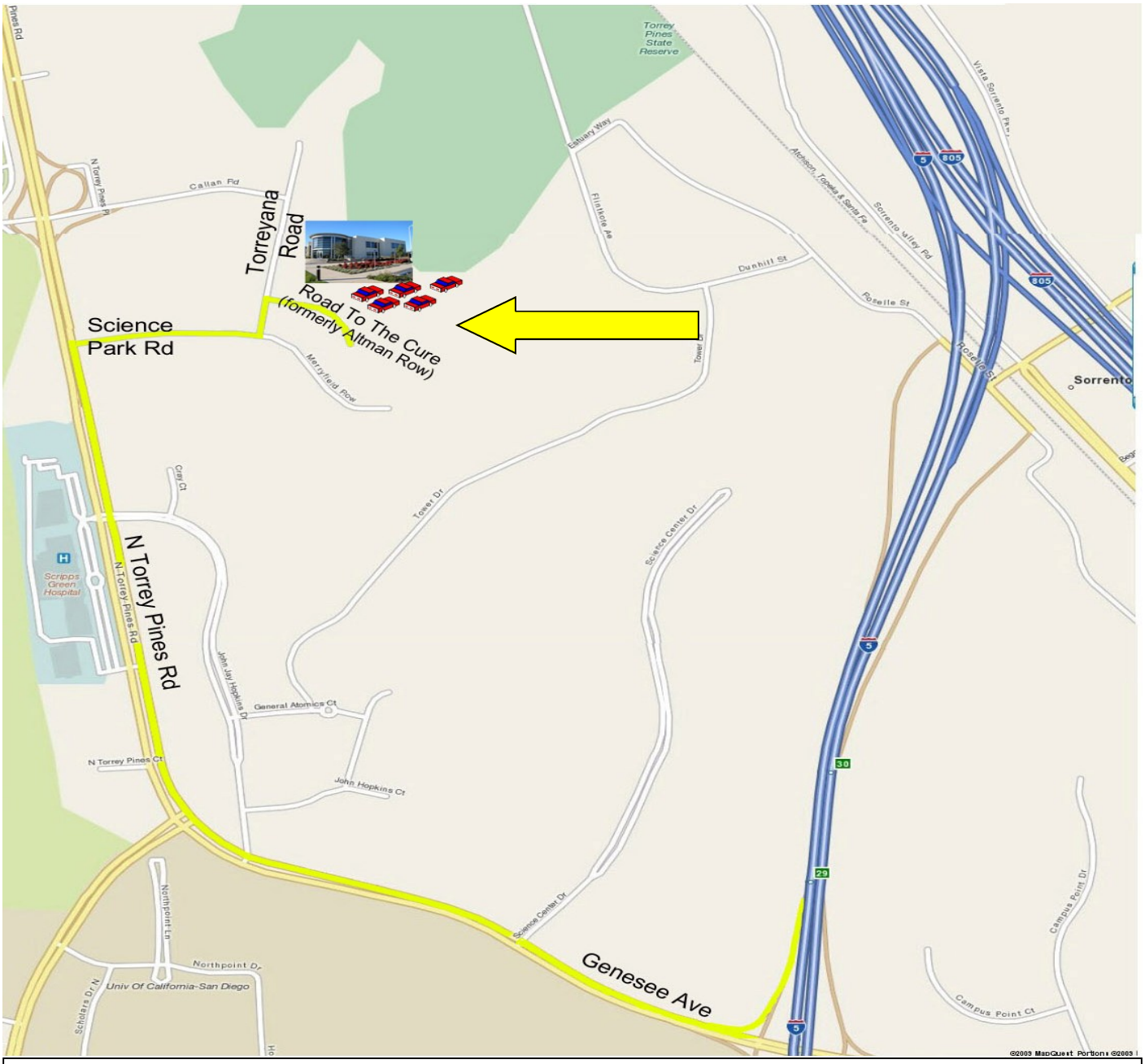

Directions to Sanford-Burnham Auditorium
10905 Road to the Cure, San Diego, CA 92121

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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