Informed Prostate Cancer Support Group Inc.

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

February 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)

Monday, February 06, 2012 Volume 5, Issue 1

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 February 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

Our first meeting of the new year was a resounding success. We overflowed the 140 seat auditorium with standing room only. Ten newcomers were welcomed.

George Johnson did his usual great job as facilitator of the meeting. He opened by asking those men directly involved in the organization to give a quick summary of their experiences in dealing with the disease and then greeted the newcomers.

Gene Van Vleet gave a statistical summary of last year's meetings. Most importantly, we operated at a virtual cash flow break-even without a major fund raiser other than the yearly mailing in November. The average attendance at our meetings was 93, a significant improvement. There was an average of 13 newcomers at each meeting, proof

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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that our outreach efforts are working.

This month's guest speaker was Dr. Richard Lam of Prostate Oncology Specialists in Marina del Rey. The subject of his presentation was Androgen Deprivation Therapy (ADT). ADT is also known by other names: Hormone Blockade (HB), Androgen Suppression Therapy (AST), and Testosterone Inactive Pharmaceuticals (TIP). The testicles create testosterone (TES) as well as dihydrotestosterone (DHT). A cancer cell receptor is stimulated by TES and by DHT which leads to DNA and RNA synthesis which then leads to cell replication that may become visible tumors. There are many ways to stop production of TES: Injections such as Lupron, Trelstar, Zoladex, or Firmagon cause the testicles to stop making TES.

There is misunderstanding about the benefits of ADT. As men age the testicles stop producing TES gradually over time. It is sometimes believed that ADT does not cure cancer. For some, adding ADT along with radiation treatment improves the cure rate. ADT is mostly used for men with higher grade cancers-a Gleason of 8,9, or 10, with Stage T3 meaning cancer has extended beyond the capsule, perhaps invading the seminal vesicles and their PSA is over 20 (PSA of 10 or above if already on Proscar & Avodart, because those drugs falsely lower the PSA reading).

ADT is not recommended after surgery unless cancer has spread to the lymph nodes. If it has spread and ADT is added after surgery, the likelihood of survival improves dramatically. Candidates for seed implants, when the cancer is contained, or if the prostate is large and needs to be shrunk, may benefit by ADT. Another myth Dr. Lam discussed was that if you relapse after treatment such as surgery or radiation your life expectancy is short. ADT works to extend life expectancy about 10 years on average.

ADT treatment after relapse prolongs life and decreases painful complications of advancing disease. ADT does have side effects and judgment is needed to balance the benefits against side effects. Among the side effects discussed were osteoporosis, hot flashes, loss of sex drive, muscle loss and fatigue. There are drugs that help overcome bone loss which he discussed in detail. Exercise especially including weight training helps overcome muscle loss, fatigue and even depression.

Another myth about ADT is that once you go on it, you are stuck on it for life. Studies are now showing that being on ADT intermittently is as effective as staying on it all the time. Further, the 10 year extended life expectancy was the same.

An alternative to ADT is Antiandrogen monotherapy. Rather than taking away TES it prevents it from reaching the cancer in order to feed it. Studies of those on AAM showed that survival rates were the same, they had more energy, a better sex life, less bone loss, and less hot flashes but did have more breast growth. However, with AAM the period of time between cycles of treatment is shorter. AAM is used mostly for relapse patients whose cancer is less aggressive and for men who have bad osteoporosis and those with a keen interest in preserving their sexual function.

The next myth discussed was that when ADT stops working, the next step is chemotherapy. Today there are more options. Abiraterone cuts down any excessive hormone production produced elsewhere in the body that the traditional ADT did not block---mainly in the adrenal glands. Another new drug in the pipeline include MDV3100 which is also a hormonal related medication for men who have failed ADT. Several others were discussed. It is hoped these drugs will overcome the need for moving to chemotherapy.

This presentation is intended to be only a summary of Dr. Lam's presentation. You can gain more specific knowledge by obtaining the DVD of this meeting through the website: www.ipcsg.org and clicking on the blue "Purchase DVDs" button, through the library that is available at each meeting or by contacting Gene Van Vleet: e-mail gene@ipcsg.org or phone 619-890-8447.

Future Meetings

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.

April 21, 2012. Round Table. Hear member experiences, then break-out networking sessions by treatment type.

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

NOTEWORTHY ARTICLES

Scripps Invents Way To Spot Spread of Cancer

From the Union-Tribune Feb. 2, 2012

The Scripps Research Institute has invented an experimental way to spot and analyze cells that break away from solid tumors, possibly giving doctors a faster and better way to treat a variety of cancers.

The blood test could supplement and, in some cases, replace, surgical biopsies, which can be costly, painful and difficult to conduct, says Peter Kuhn, the Scripps Research investigator who developed the test with pathologists and oncologists from across the country.

The test involves taking a blood sample from a cancer patient and adding a chemical that illuminates circulating tumor cells (CTCs), the name for cells that break off from tumors that cause such diseases as breast, prostate, pancreatic, ovarian and lung cancer. The CTCs also can spread to distant sites in the body, causing metastatic cancer.

"We have a brand new way of doing a biopsy. Instead of sticking a needle in your chest wall, we can see disease-derived cells in the blood," said Kuhn, co-founder of Epic Science, Inc., a new La Jolla company that's working to refine the high-definition test, known as HD-CTC. The test will require FDA approval before it can move beyond clinical testing.

Pathologists and oncologists already have a test, called CellSearch, that's used to look for CTCs. But Kuhn says physicians need a test that is far more sensitive, and thus more useful for a wide array of cancer patients. The alternative option, a surgical biopsy, can collapse a person's lung, and there is concern that cancerous cells can be spread in the body when the needle is being removed.

The new HD-CTC tests addresses part of that problem by taking 40,000 images of the cells in each blood sample. It identifies and labels abnormal cells, and offers up a small number of photos for review by pathologists and oncologists.

"The types of biopsy that could potentially be replaced are ones that would occur further down the line as the disease evolves," said Kelly Bethel, a Scripps Health diagnostic pathologist who contributed to the HD-CTC research.

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"We're trying to tailor your therapy. We trying to see if you have new mutations that have arisen in your cancer that has made it more resistant to the chemotherapy we're trying to give. We can then see which other therapy might be better suited."

"This is not going to cure cancer. But it is going to help us understand the evolution of disease. You can use the test right after someone has gone through treatment to see if they still have disease in their body, and whether there are circulating cells that put you at risk for metastasis

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The Baltimore Sun

January 17, 2012

After urologists got machine, cancer treatments soared

By Jay Hancock

Brought to our attention by Dr. Geoffrey Gordon

Four years ago, doctors at Chesapeake Urology Associates started ordering the most expensive kind of prostate-cancer therapy for many more of their patients.

Before 2007, the large, multi-office practice was prescribing the treatment, known as intensity modulated radiation therapy, for 12 percent of its prostate-cancer patients covered by Medicare, according to data compiled by a Georgetown University researcher. But starting in mid-2007, Chesapeake Urology's referral rate for IMRT more than tripled, rising to 43 percent of the Medicare cases.

What could have caused such a sharp change?

It couldn't have been because IMRT, which costs about $40,000 per treatment, was new. Maryland hospitals had been offering it for years.It couldn't have been because IMRT was better."No randomized clinical trials show that prostate cancer patients receiving IMRT live longer or experience fewer long-term side effects than those getting the alternatives" of radiation-seed therapy or surgery, said Dr. James Mohler, a urologist at Roswell Park Cancer Institute in Buffalo, N.Y., and chairman of the national committee that sets standards for prostate-cancer care.

Chesapeake Urology tripled its percentage of prescriptions for IMRT after the practice acquired its own IMRT machine in 2007. The more patients the Baltimore-area urologists referred for that expensive therapy alternative, the more revenue and profits they would generate.

"They're steering patients to IMRT because that's where they make their money," said Jean Mitchell, a professor and health care economist at Georgetown who's working on a national study about IMRT referrals. "They're making a ton of money out of this. There's no question about it. At the expense of the taxpayers" who finance Medicare.

http://www.baltimoresun.com/health/bs-bz-hancock-chesapeake-urology-20120114,0,670418.column

Comment: Technology that improves patient outcomes and reduces costs is great. Technology that increases costs, produces undesirable side effects, and provides no evidence of extended life expectancy is... well... not so great, except for meeting the financial goals of the entrepreneurial owners of the technology. And when the owners of the technology are the same trusted physicians who are prescribing it, that's reprehensible.

Theoretically a government-funded and government-administered health care financing program would have the power to prevent these abuses. Yet this diversion of radiation treatment fees to the referring physicians is occurring within the Medicare program. So simply expanding Medicare to everyone

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alone is not enough to fix our dysfunctional financing system.

A properly designed single payer national health program would do far more than simply remove private insurers from the system. In this instance the need for the radiation equipment would be determined by medical science confirming the value of the intervention. The decision to purchase the equipment would be made through regional planning based on need. The payment for the equipment would be through separate budgeting of capital improvements. The ownership would be public or non-profit and would have no investors to draw off profits.

Physicians would be paid appropriately for their professional services as urologists and radiation oncologists, but they would not receive extra dividends based on their insight as to the potential lucrative benefits of personally investing in the equipment.

So about that Medicare for all. We speak of an improved Medicare for all, but the improvements would have to be monumental.

The Radiation Round-Up

Posted: 24 Jan 2012 07:29 PM PST Prostate Snatchers

BY RALPH BLUM

Despite the significant advances in treatment options, there is still considerable uncertainty—even among doctors—about how or even whether to treat prostate cancer. The treatment controversy is the prostate cancer equivalent of a Dempsey-Firpo fight: the proponents of surgery slugging it out with those who favor some form of radiation.

In recent years we've seen the arrival of the elegant robotic surgery. Instead of cutting half-blind in a field of blood, with the da Vinci robot a surgeon can observe the anatomy blown up 100 times on a big TV screen and, with the aid of the robot, perform the complex and intricate surgery more precisely.

There are, however, two problems with this sophisticated new surgical procedure. First, it's hard to justify the significant additional cost of the robot because the results are not that much different from those obtained with traditional surgery.

The second problem is rather disquieting. I have observed the power of the robot as a selling tool—a blend of high visibility, big bucks, slick advertising—with the result that a considerable number of men who really do not (repeat, do not) need surgery in the first place are seduced, Pied Pipered into the O.R. by what one critic called the "bloodless glamor" guaranteed by the da Vinci robot. You might want to consider my earlier blog, **"The Robots Have Landed."**

My feeling —depending, of course, on your risk category—is that if you are going to opt for radical treatment you should be lining up for one of the state-of-the-art targeted radiation treatments: either radioactive seed implantation, or intensity modulated radiation therapy (IMRT).

So how do you determine which you should choose?

Not all men are candidates for radioactive seed implants, otherwise known as brachytherapy. It is not recommended for men with enlarged prostate glands, men with pre-existing urinary problems, or men with cancer outside the prostate. If, however, you are eligible, seeds have the advantage of a single hospital visit, whereas IMRT requires daily sessions at a specialized facility for two months. Also, with seeds, the radiation dose is minimally higher, giving you the possibility of slightly better cure rates.

Bottom line your decision to go for seeds versus IMRT is mainly influenced by your risk category. In my case, if, after all these years of "prostate cancer coexistence," if I decided on treatment, I would choose IMRT because it can be administered to a slightly broader field, thus creating a wider margin around the gland and even, if necessary, radiating the surrounding lymph nodes.

You will undoubtedly hear conflicting opinions about which treatment is best for you, and your decision will inevitably be complicated by multiple factors. With any prostate cancer treatment there is the risk of side effects, but with targeted radiation therapies the risk is significantly reduced. Moreover, both of these therapies—seeds and IMRT—are at least as effective as surgery at curing the disease without the additional risks of a major operation.

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"

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

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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.

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

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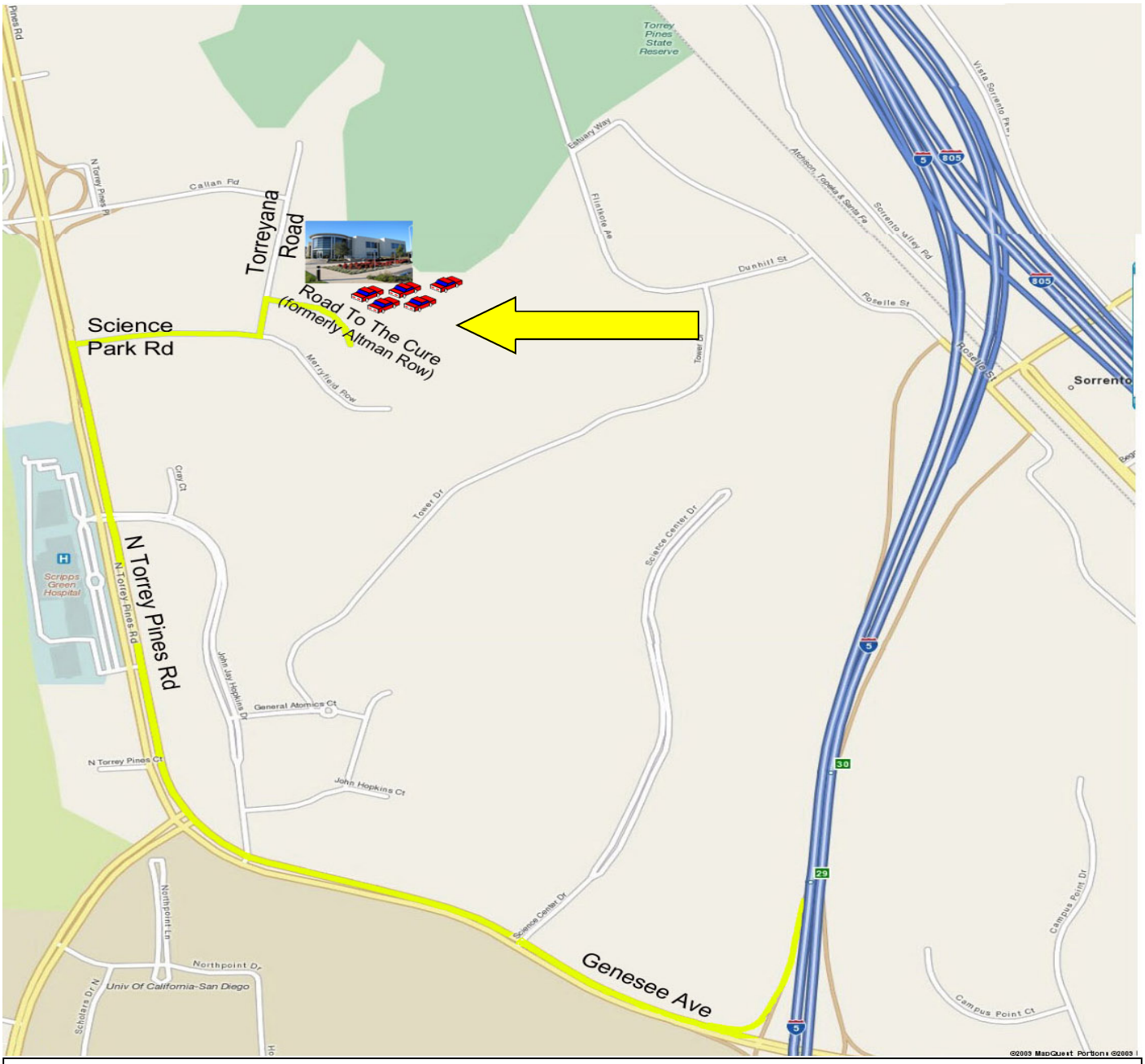
FINANCES

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).