Informed Prostate Cancer Support Group Inc.
"A 501 C 3 CORPORATION ID # 54-2141691"

OCTOBER 2015 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Sunday, October 11, 2015 Volume 8 Issue 10

Next Meeting
October 17, 2015
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

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.

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Editor: Gene Van Vleet

PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

A few days before the September meeting we had our first Fundraiser Cruise for Prostate Cancer Awareness which was a very successful event. We hope to sponsor this annually. If you didn't see the blurb on the cover e-mail, check it out.

Our speaker for the September meeting was Dr. Franklin Gaylis, Chief Scientific Officer Genesis Healthcare Research Center, who spoke about genomic technologies and advances for active surveillance. To understand genomics, he gave some ba-

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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.

The DVD of each meeting is available by the next meeting date.

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sics of biology. A cell has a membrane on its periphery, the cytoplasm is the inside and the brains of the cell reside in the nucleus which is where the DNA is housed that controls the activity of the cells and who we are. The DNA is a complex strand which incorporates chromosomes and DNA into the double helix of a gene. The human body cells contain 46 chromosomes in 23 pairs-one of each pair is inherited from each parent. Each chromosome contains genes in a linear order. Genes are codes for cells to make protein. PSA is a protein. Alterations in genes or chromosomes alter the protein produced and hence can cause disease. He showed an example of BRCA1 and BRCA2 mutations which can lead to breast or ovarian cancer. It was well publicized that Angelina Jolie had these mutations and sought treatment before any disease developed.

Prostate cancer (PCa) is a heterogeneous disease which means its is not uniform but all different. We know that there is lethal prostate cancer and non-lethal prostate cancer. One in six men or 16-17% will develop prostate cancer but only 3% will die from it

Each individual has a unique cancer biology. Each year about 240,000 men will be diagnosed with PCa and 27-30,000 will die from it. The issue is to find out how to determine who needs aggressive treatment and who does not. He discussed the Prostate Intervention Versus Observation Trial (PIVOT Trial). It looked at if all men experience the same benefit or risk from radical prostatectomy (RP) as compared with those on active surveillance. It concluded that those with low risk PCa do not benefit from surgery--the mortality rate was the same. For high risk patients having RP there was a reduction in death rate.

He talked about the recommendation in May, 2012 of the U.S. Preventative Services Task Force which recommended discontinuing PSA screening. His Genesis Health Care group has gathered statistics since that ruling which shows that the percentage of low risk patients has decreased and the number of intermediate and high risk patients has increased. Also the PSA values at the time of first visit has gone up from 17 to 27. The worry is that more men will be presenting with metastatic disease. His recommendation is, of course, to ask your doctor to be screened.

A man diagnosed with low risk PCa has the dilemma of choosing surgery, radiation, hormonal (ADP), other treatments such as cryotherapy and HIFU all of which have certain negative side effects--or active surveillance (AS).

Dr. Gaylis then focused on genomic testing. A genomic test is based on the tissue. It helps the physician and the patient decide, with more information about the biology seen in the genes, whether they have aggressive or indolent (slow growing non-aggressive) disease. It can help the patient decide if they can opt for AS or should seek treatment.

Genetics vs genomics. Genetics examines the function of a single gene. Genomics looks at a group of genes and their relationships in order to identify their combined influence on an organism or person. The National Comprehensive Cancer Network (NCCN) has come out with guidelines for risk stratification into:

- Very low risk=PSA<10, Gleason 6, Stage T1c, less than 3 positive cores positive <50% cancer in any core
- Low Risk=PSA <10, Gleason 6, Stage T1-T2a
- Intermediate=PSA 10-20, Gleason 7, Stage T2b-T2c
- High Risk=PSA >20, Gleason 8-10, Stage T3a
- Very High=T3b-T4 Tumor extends through the capsule
- Metastatic=Fixed to or invades adjacent structures.

He mentioned that he does not favor any particular genomic test. Prolaris, Oncotype DX, Decipher & ConfirmMDX all provide varying versions.

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He summarized his take home points as:

- Prostate Cancer behaves in different ways according to the underlying biology
- The behavior of the disease relates to underlying genetic makeup of the tumor
- We now have a variety of genomic tests that improve our understanding and prediction of tumor behavior
- Many factors play an important role as to who should be screen tested and who should be treated
- Become informed and find a doctor who can help you make the best decision

He closed his presentation by talking more about Active Surveillance. He defined active surveillance as an alternative to immediate intervention that involves careful follow-up with the option of delayed treatment at a time when intervention will prevent harm from disease.

For men with low risk/non-threatening disease, it requires careful follow-up with DRE, PSA, imaging and biopsy tests. It may require delayed treatment in approximately 33% of men to prevent harm from the disease.

Research has shown that men on active surveillance results in a prostate specific mortality of less than 3% at 10 years. Most men who die during active surveillance die from other causes.

This is only a recap of the presentation. To get the full benefit of all the information provided, get a copy of the DVD of the meeting which will be available by the October 17th meeting date either at the meeting from the library or on the website at http://ipcsg.org/shop/

FUTURE MEETINGS

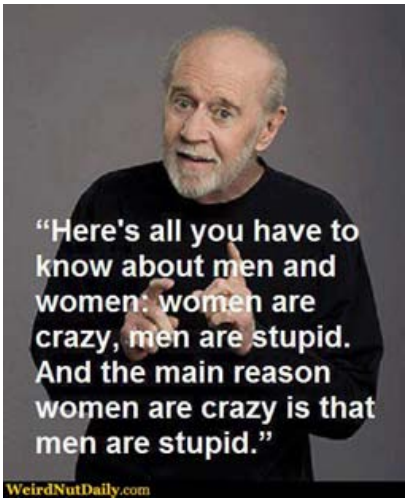
Oct 17th - Fabio Almeida, M.D. Medical Director, Phoenix Molecular Imaging, Phoenix, AZ. "Advances in Detecting Recurrent Prostate Cancer in Bone and Soft Tissue." Dr. Almeida returns to speak about updates on Molecular Imaging and new clinical trials.

Nov 21st - Richard Lam, M.D., Research Director, Prostate Oncology Specialists: : Updates and recent treatment developments.

December - No Meeting

Jan. 16, 2016 - AJ Mundt M.D., Professor and Chair, Department of Radiation Oncology, John Einck, Associate Clinical Professor, Radiation Oncology, both of UCSD & Carl Rossi Jr., M.D. Medical Director of the Scripps Proton Therapy Center, present facets of radiation and proton beam therapy.

ON THE LIGHTER SID



Inside every older person is a younger person wondering what the hell happened.

Politicians and diapers need to be changed often---for the same reason.

More Murphy's Laws

1. Light travels faster than sound. This is why some people appear bright until you hear them speak.
2. A fine is a tax for doing wrong. A tax is a fine for doing well.
3. He who laughs last thinks slowest.
4. A day without sunshine is like, well, night.
5. Change is inevitable, except from a vending machine.
6. Nothing is foolproof to a sufficiently talented fool.
7. It is said that if you line up all the cars in the world end to end, someone would be stupid enough to try to pass them.
8. If the shoe fits, get another one just like it.
9. The things that come to those who wait may be the things left by those who got there first.
10. God gave you toes as a device for finding furniture in the dark.
11. When you go into court, you are putting yourself in the hands of twelve people who weren't smart enough to get out of jury duty.

INTERESTING ARTICLES

Taking Charge of Your Prostate Cancer Recovery: Fast Forward From the Old Model

From Prostate Snatchers Blog Posted: 06 Oct 2015 By Ralph Blum

In the old model of prostate cancer care, you were rushed into radical treatment--usually surgery or radiation--often without fully understanding all your options, or the risks and side effects involved. The entire process was focused on the tumor; minimal attention was given to you as a person, and little effort was made to explore the benefits of healthy lifestyle choices, immune-enhancing treatments, reasonable delays, and emotional support.

The emerging new model of prostate cancer care recognizes the important role you can, and should,

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play in your recovery. The emerging model comprehends that simply attacking the cancer is not enough. Greg Anderson, who after surviving "terminal" lung cancer founded the *Cancer Recovery Foundation*, has said that "Retaining a medical team without doing everything you can to help yourself is like attempting to walk on one stilt."

So what do you need to know in order to take charge of your recovery?

There are three common misperceptions about prostate cancer:

- The assumption that the disease is as dangerous as other cancers.
- The assumption that the urologist who did your biopsy is a prostate cancer expert.
- The assumption that a quick treatment decision is necessary before the cancer spreads.

First of all, prostate cancer is unique among cancers because the mortality rate is so low. Around two hundred thousand men in the U.S. alone are diagnosed with the disease every year, and less than 15% will eventually die from it, usually over a decade down the line, while a majority of men who have the far more common low-risk, slow-growing prostate cancer can anticipate living a normal life span, or dying of something else.

Your local urologist has a busy medical practice that involves treating problems like impotence, infections, incontinence, and kidney stones. He also does biopsies. But the average urologist performs fewer than *five* prostate removals (prostatectomies) a year--far too few to be considered proficient. He may be a talented doctor, but he is unlikely to be a prostate cancer expert. So once you have your biopsy results, it is best to consult a prostate cancer specialist, either at a major medical center, or at a high-volume prostate cancer clinic.

As for the third misperception, it is essential, before committing to any form of treatment, that you do your own research, and are convinced the treatment you choose is the right one for you. Do not let anyone rush you into making a bad decision. Once your category of prostate cancer is identified (*Low, Intermediate, or High Risk*), get on the Internet and learn about every treatment option--including no treatment whatsoever--for your type of disease. If you are over 70, and have low-risk disease, my advice to you is to find a doctor who has experience monitoring an active surveillance protocol.

Your role in your recovery, however, doesn't end with choosing your treatment. The emphasis on lifestyle changes has been one of the most significant shifts in cancer care in the last decade. A study at UCSF showed that improving your nutrition, reducing stress and getting more exercise, can lower PSA levels. And according to a relatively new field of health psychology called "illness representation," your beliefs and expectations also impact the outcome of your disease. So take charge of your recovery, and have faith in your choice of treatment.

RELAXED GUIDELINES ON PSA TESTING MIGHT MISS AGGRESSIVE TUMORS: STUDY

From Health Day News Sept. 22, 2015

Relaxed guidelines on prostate cancer screening may delay diagnosis and treatment of aggressive tumors, a new study suggests.

In 2011, the U.S. Preventive Services Task Force recommended against routine prostate specific antigen (PSA) testing, to curb over-diagnosis and overtreatment of prostate cancer. Since then, PSA screening has dropped by 28 percent, the researchers report.

"On the positive side, there is a lot of prostate cancer that we don't need to know about," said lead researcher Dr. Daniel Barocas, an assistant professor of urologic surgery at Vanderbilt University, in

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Nashville, Tenn.

These are low-risk cancers that most men will not die of, and the treatment can be more harmful than the cancer, he explained. "To that extent, the guideline had a beneficial effect," Barocas said.

"On the negative side, we seem to be missing intermediate and high-risk cancers in men who would be eligible for treatment," he said. "Those are missed opportunities to identify disease and treat it."

The report will be published in the December issue of the Journal of Urology.

Dr. Kirsten Bibbins-Domingo, vice chair of the U.S. Preventive Services Task Force, said, "When the task force reviewed the evidence on PSA screening for prostate cancer in 2011, what we found is that there is a very small potential benefit and significant potential harms."

Most prostate cancers found by PSA screening are slow-growing and not life-threatening, she explained. "However, there is currently no way to determine which cancers are likely to threaten a man's health and which will not," she said.

Barocas disagreed.

"The policy of screening no one is throwing the baby out with the bathwater," he said.

Some men are at high risk for prostate cancer and should be screened, he said. These include men with a family history of prostate cancer, and black men.

In addition, screening should be combined with treatment. Low-risk cancer need not be treated but watched, while high-risk cancer should be treated, Barocas said. "That's the solution," he said.

Another expert made another point.

Since 2011, when the guideline was published, new techniques, including MRI and ultrasound, have been developed that can diagnose prostate cancer more accurately and distinguish between low- and high-risk cancers. These techniques may need to be taken into account in modifying the guideline, said Dr. Anthony D'Amico, chief of genitourinary radiation oncology at Brigham and Women's Hospital and Dana-Farber Cancer Institute in Boston.

Using the U.S. National Cancer Database, Barocas and colleagues looked at the effect of the new guidelines on the number of new prostate cancer diagnoses between January 2010 and December 2012.

The researchers found that the number of prostate cancer diagnoses dropped more than 12 percent (1,363 cases) in the month after the draft guideline was issued. It continued to drop to an overall decline of 28 percent in the year after the draft guideline was issued.

The diagnoses of low, intermediate and high-risk prostate cancers all decreased significantly, but diagnoses of prostate cancer that had spread beyond the prostate did not change, they found. The decreases were similar for all ages, races, income and insurance.

In the year after the guidelines were published, diagnoses of new low-risk cancers dropped nearly 38 percent and continued to fall more rapidly than diagnoses of more aggressive cancer. This suggests that for low-risk cancer, the guideline had its intended effect, Barocas said.

In addition, prostate cancer diagnoses fell by 23 percent to 29 percent among men over 70 and by 26 percent among men who were not likely to live long enough to benefit from early diagnosis and treatment, the researchers found.

However, researchers also found a drop of 28 percent in diagnoses of intermediate-risk cancer and a 23 percent drop in diagnoses of high-risk cancer one year after the guideline was published.

"These findings are consistent with what we hoped would not happen," D'Amico said.

It is likely that men will develop more advanced prostate cancer before it is diagnosed and be less likely to be cured, he added. "This is a warning that we are not picking up patients who are curable," D'Amico said.

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New technology is taking the guesswork out of diagnosing prostate cancer

From Health Day News Oct 8, 2015

NEW YORK-- For decades, doctors have diagnosed prostate cancer using what's been called a 'blind' biopsy, removing and testing a dozen tiny tissue samples to see if cancer is present. Now, new technology is taking the guesswork out of the procedure by allowing doctors to precisely target suspicious areas where deadly cells may be lurking.

High-tech images and an electromagnetic tracking system, like GPS for the body, work together, giving doctors more information than ever before.

Arcenio Miller has prostate cancer. But he feels good knowing that doctors have a very clear picture of his condition. Miller told Ivanhoe, "More lesions came out and more spots were detected."

Doctors found cancer in an area of Miller's prostate that would not have been targeted by a traditional biopsy, using a system called UroNav.

UroNav fuses together a patient's MRI and ultrasound to create a highly-detailed 3D view of the prostate.

Art Rastinehad, D.O., Director of Focal Therapy and Interventional Urologic Oncology and Associate Professor of Urology and Radiology at Icahn School of Medicine at Mount Sinai said, "We're able to guide the needles in the treatmentarea and just focus on that specific spot."

Dr. Rastinehad inserts the needle precisely using this computerized grid. He does the biopsy by going through the skin.

"The infection rate is much lower in this approach because we are not going through the rectum," Dr. Rastinehad explained.

Miller suffered an infection after an earlier traditional biopsy. For him, this technique was a relief and may bring him one step closer to good health.

"Thanks to good doctors that I have been able to meet and that have been able to treat me, give me assurance that I will be cured from this disease," Miller said.

Dr. Rastinehad says between two and seven percent of all men who undergo traditional biopsies will get an infection. With the UroNav and a biopsy through the skin, the rate is less than half of a percent.

To read the full research summary, visit ivanhoe.com.

NETWORKING

The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is "networking". We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all. Many aspects of prostate cancer are complex and confusing. But by sharing our knowledge and experiences we learn the best means of prevention as well as the latest treatments for survival of this disease. So bring your concerns and join us.

Please help us in our outreach efforts. Our speakers bureau consisting of Lyle LaRosh, Gene Van Vleet and George Johnson are available to speak to organizations of which you might be a member. Contact Gene 619-890-8447 or gene@ipcsg.org to coordinate.

Member and Director, John Tassi is the webmaster of our website and welcomes any suggestions to make our website simple and easy to navigate. Check out the Personal Experiences page and send us your story. Go to: http://ipcsg.org

Our brochure provides the group philosophy and explains our goals. Copies may be obtained at our meetings. Please pass them along to friends and contacts.

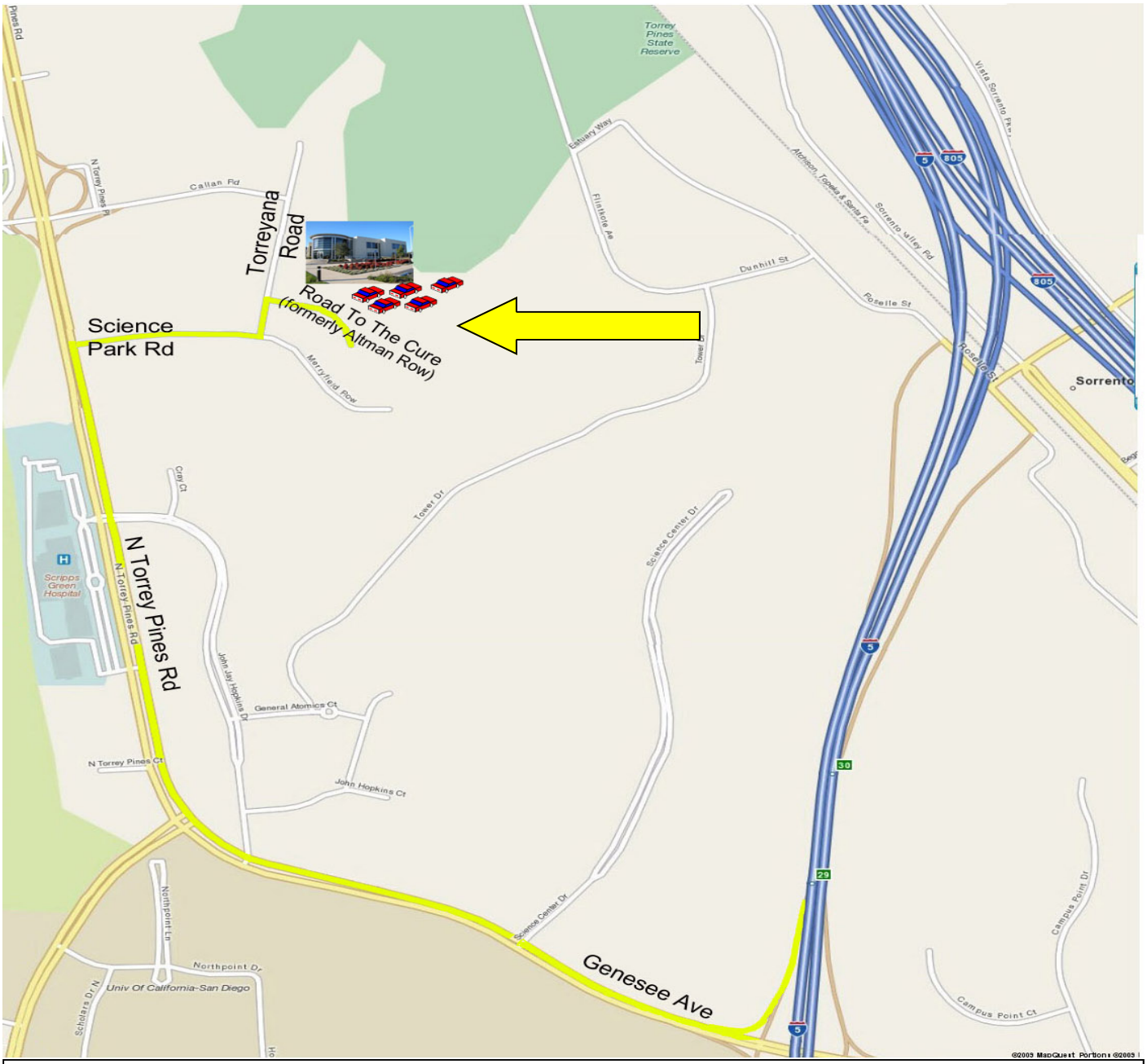
Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them.

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.
Turn Left on Torreyana Road.
Turn Right on Road to the Cure (formerly Altman Row).