Informed Prostate Cancer Support Group Inc.

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

August 2016 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: http://ipcsg.org

We Meet Every Third Saturday (except December)

Tuesday, August 09, 2016

Volume 9 Issue 8

Next Meeting
August 20, 2016
10:00AM to Noon

Meeting at

Sanford-Burnham-Prebys Auditorium

10905 Road to the Cure, San Diego CA 92121

SEE MAP ON THE

PROSTATE CANCER - 2 WORDS NOT A SENTENCE

What We Are About

Our Group offers the complete spectrum of information on prevention and treatment. We provide a forum where you can get all your questions answered in one place by men that have lived through the experience. Prostate cancer is very personal. Our goal is to make you more aware of your options before you begin a treatment that has serious side effects that were not properly explained. Impotence, incontinence, and a high rate of recurrence are very common side effects and may be for life. Men who are newly diagnosed with PCa are often overwhelmed by the frightening magnitude of their condition. Networking with our members will help identify what options are best suited for your life style.

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SPECIAL NOTE

Gene Van Vleet has resigned most of his duties as Chief Operating Officer of IPCSG effective Aug. 24th. One of those duties included being editor of this newsletter. <u>A volunteer replacement is urgently needed.</u> This is the last newsletter that will be published until a replacement comes forward. Gene will work with whomever may volunteer to familiarize them with the publisher program and the processes he utilized to create the newsletter.

He will retain involvement in the Hotline, accounting and annual Cruise for Awareness.

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

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

NOTES FROM THE JULY MEETING

Dr. John Grimaldi was our guest speaker for this meeting. http://www.grimaldiurology.com/en/ He spoke about options for dealing with impotence and incontinence as well as making decisions on treatment options. It became very apparent that he is not your usual urologist who may have protocol restrictions to being candid or may not be able to take time to deal with you. Dr. Grimaldi is genuinely interested in your situation. Rather than trying to do a recap of this straightforward presentation, I think you would be better served to get a copy of the DVD of the meeting because Dr. Grimaldi graciously spent a long time fielding questions that are pertinent to the subjects he spoke about. Copies of the DVD will be available at the next meeting on September 17th or from our website: http://ipcsg.org/shop/ For those of you that don't use the internet, Call: Gene 619-890-8447 or Bill Manning 619-980-0769 to arrange for a copy.

FUTURE MEETINGS

August 20. Wolfgang Fendler, MD. Department of Molecular and Medical Pharmacology and David Geffen School of Medicine at UCLA. Diagnosing and treating prostate cancer with radioactive drugs directed at the prostate-specific membrane antigen (PSMA).

September 17. Round Table. A panel of members talk of their experiences followed by Q&A, then break-out sessions by treatment type for networking.

October 15. - Fabio Almeida, M.D. Medical Director, Phoenix Molecular Imaging - Southwest PET/CT Institute, Yuma. Updates on Molecular Imaging and new clinical trials.

Nov 19. Richard Lam, M.D., Research Director, Prostate Oncology Specialists: Updates and recent treatment developments.

December. No Meeting.

FYI

Our President, Lyle LaRosh has been focusing on increasing prostate cancer awareness. He recently was interviewed on KFMB radio. Swipe this link to your browser to listen to it. Lyle's part is about 10 minutes into the broadcast. http://www.760kfmb.com/story/15884059/its-your-money-and-your-life

Those of you needing Crestor (rosuvastatin) or Avodart (Dutasteride) RX it should be generic now. Check with your pharmacy.

2016 PROSTATE CANCER CONFERENCE. Los Angeles Airport Marriott. September 9-11. http://pcri.org/2016-prostate-cancer-conference

2ND ANNUAL FUNDRAISER CRUISE FOR PROSTATE CANCER AWARENESS. September 15. Special rates for IPCSG members. Contact: gene@outlook.com or 619-890-8447

ON THE LIGHTER SIDE

Never, under any circumstances, take a sleeping pill and a laxative on the same night.

You do not need a parachute to skydive. You only need a parachute to skydive twice.

Just remember...if the world didn't suck, we'd all fall off.

When tempted to fight fire with fire, remember that the Fire Department usually uses water.

Do not argue with an idiot. He will drag you down to his level and beat you with experience.

A bank is a place that will lend you money, if you can prove that you don't need it

Knowledge is knowing a tomato is a fruit; Wisdom is not putting it in a fruit salad.

Evening news is where they begin with 'Good evening', and then proceed to tell you why it isn't.

If you think nobody cares if you're alive, try missing a couple of payments.

Some people say "If you can't beat them, join them". I say "If you can't beat them, beat them" because they will be expecting you to join them, so you will have the element of surprise.

INTERESTING ARTICLES

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Patients with low risk prostate cancer on active surveillance experience good quality of life

From Science Daily July 25, 2016

Active surveillance (AS) has become an increasingly important alternative to surgery, chemotherapy, or radiation treatment for men diagnosed with low risk prostate cancer. However, what is the impact of AS on health related quality of life (HRQoL) in patients selected or opting for this conservative form of disease management? New research published in *The Journal of Urology*® found that patients on AS who were

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tracked for three years experienced similar HRQoL as men without prostate cancer, both clinically and psychologically.

The majority of men diagnosed with prostate cancer have low risk disease and face a difficult decision between having the disease managed conservatively through AS or undergoing definitive therapy. These results can help guide physicians and patients through this decision-making process.

"To our knowledge this is the first report of HRQoL outcomes of men on AS for prostate cancer compared to men without prostate cancer in a prospective, multi-institutional study," explained lead investigator Christopher R. Porter, MD, FACS, Virginia Mason Medical Center, Seattle, WA. "The potential clinical impact of these results is significant and will allow clinicians to counsel patients effectively in regard to the potential HRQoL outcomes associated with AS."

Although the lifetime risk of a prostate cancer diagnosis is about 1 in 6, the lifetime risk of death from the disease is 1 in 30. Management of low risk prostate cancer with AS appears feasible and safe, yet most men in the U.S. with low risk disease still undergo definitive therapies such as radical prostatectomy, which carry the burden of urinary, bowel, and sexual dysfunction that can be avoided, or at the very least postponed, with management on AS.

Using data compiled from four military medical centers participating in the Center for Prostate Disease Research Multicenter National Database, researchers analyzed patient-reported HRQoL using validated metrics derived from two questionnaires, one dealing specifically with prostate cancer related outcomes and a second focusing on general health assessment. The racially diverse study sample consisted of two groups: 89 patients diagnosed with low risk prostate cancer (clinical stage T1-T2a, biopsy Gleason score 6 or less, and prostate specific antigen less than 10 ng/ml), who initially underwent AS, and 420 patients without cancer who had a negative prostate needle biopsy.

With the exception of a slight difference in bowel function, investigators found that HRQoL outcomes for patients on AS were no different than those in men without prostate cancer during the three years of follow-up.

"Our results suggest that for at least three years, men selecting AS do not experience a substantial psychological burden or clinically significant problems due to untreated disease. This study provides important data that can be used to inform comparable patients when considering management options for low risk prostate cancer," noted Dr. Porter.

Prostate cancer breakthrough could lead to new diagnostic tests and treatments

From Science Daily July 28, 2016

Prostate cancer patients have been offered hope after scientists at Newcastle University, UK, have identified a new group of molecules that could be targeted to slow tumor growth.

Experts used an advanced screening technique which found hundreds of genes were affected by the male hormone testosterone. It is believed this could lead to new diagnostic tests and treatments.

Among the 700 genes identified was an important set that add sugar groups -- known as glycans -- to the surface of prostate cancer cells. This group has never been investigated before.

Results of the research, published in *Biomedicine*, suggest that testosterone changes glycans to make cancer cells more likely to survive, grow and spread to other parts of the body.

Scientists say there is the potential to target these glycans which could stop the growth and spread of tumors and save lives.

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Dr Jennifer Munkley, Research Associate at the Institute of Genetic Medicine, Newcastle University, co-led the three-year research project with Professor David Elliott.

She said: "Our findings are very significant for future treatments as they identify a new group of molecules in prostate cancer which could be targeted therapeutically.

"Now we have identified these glycans we will be able to develop strategies to inhibit them and help patients with this condition.

"Treatments targeting glycan sugar groups have been developed for other types of the illness, such as breast cancer. Our results mean these treatments could also be used for prostate cancer."

Glycans have the potential to be used as part of a diagnostic test to help doctors decide which prostate cancers need treatment.

One in eight will be diagnosed with the condition. It is the most common cancer in UK males, and there is a need to identify how the disease progresses and for treatment options to be established.

Researchers at Newcastle University used a technique, called RNA-sequencing, to identify the new set of genes that are important.

The genes identified may provide novel ways the disease can be monitored in patients to predict the most aggressive prostate cancers that need to be treated.

The research was funded in partnership between Prostate Cancer UK and the Movember Foundation.

Simon Grieveson, Head of Research Funding at Prostate Cancer UK, said: "There's a desperate need for more treatments for men with advanced prostate cancer, who currently have too few options available to them.

"However, in order to develop new, effective treatments, we need to understand more about the genetic makeup of aggressive prostate cancers and identify what makes them tick.

"This promising research has unearthed a new group of genes which could play a part in cancer cell survival and development, and could pave the way for new treatments in the future.

"Although this work is still in its infancy, and there is a long way to go before we could have a potential new treatment, we will be watching its progression with great interest."

Dr Munkley has been awarded a Newcastle University Faculty of Medical Sciences Fellowship to continue her research.

As each prostate tumor is unique, future studies will look at how to use glycans as therapeutic targets in personalized treatment.

Case study

One man who knows first-hand the importance of this research is David Forrester, who was diagnosed with prostate cancer four years ago.

The 62-year-old experienced some episodes of what he thought to be urinary infections. His brother had been diagnosed with the illness in 2004 and, therefore, Mr Forrester was monitored by doctors.

He had annual PSA tests -- a blood test that can detect the early signs of an enlarged prostate -- and his PAS doubled in a short space of time. Mr Forrester was referred to a urologist and underwent a biopsy which confirmed he had prostate cancer.

As a former operating theatre manager, the grandfather-of-three decided to have surgery to remove his prostate. Although he did experience side-effects, he has recovered well and is enjoying life.

Mr Forrester, of West Denton, Newcastle, said: "It is absolutely vital that research is done into prostate cancer and experts gain as good an understanding of the condition as possible.

"With two sons and two grandsons, who are at higher risk of developing the disease, I am especially interested in this research.

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"The results of this study offers hope to patients affected by prostate cancer and their families that improved diagnostics and treatment options will be developed in the years ahead.

"It is exciting that Newcastle University is leading the way and it shows what world-class research is going on."

NEW CLINICAL TRIAL ENDPOINT MAY SPEED THE DEVELOPMENT OF NEW THERAPIES FOR PATIENTS WITH LOCALIZED PROSTATE CANCER

From Prostate Cancer Foundation

Prostate cancer can be slow to progress, frustrating the development of new therapies for patients with early, high-risk disease. A new clinical trial endpoint has been identified that will shorten the time taken to conduct trials, enabling the development of novel therapies that can be administered at the earliest — and potentially curative — stage possible.

At the 2016 American Society of Clinical Oncology (ASCO) Annual Conference, Dr. Christopher Sweeney presented results from ICECaP (Intermediate Clinical Endpoints in Cancer of the Prostate), a Prostate Cancer Foundation (PCF)-supported initiative, that will halve the time required to assess new therapies for aggressive prostate cancer.

"We need to move trials for new therapies earlier, as this is the time when patients with lethal but potentially curable cancer have the best chance of being cured," said Sweeney, principal investigator of the ICECaP project, medical oncologist at the Dana-Farber Cancer Institute, and Associate Professor in Medicine at Harvard Medical School. "We already have many new treatments that extend the lives of patients in the late stage metastatic setting but aren't curative. If we can use them earlier, it is likely we can improve upon proven successes in the adjuvant setting."

"These findings will make a huge impact on prostate cancer drug development," said Dr. Howard Soule, executive vice president and chief science officer of PCF. "Using intermediate clinical endpoints in clinical trials will shorten the time to approval for new treatments and will motivate development of therapies in early disease settings where prostate cancer might be curable. We applaud the ICECaP team, and especially Dr. Sweeney's leadership, for coordinating this huge data collection and analysis program."

When diagnosed early, prostate cancer is highly treatable, but approximately 20% of patients will experience disease recurrence. However, due to the slow nature of prostate cancer progression, it can take up to 10-15 years before patients who relapse succumb to the disease. Of the approximate 29,000 deaths per year in the U.S. resulting from prostate cancer, an estimated 17,000 are patients initially diagnosed with localized disease, but who ultimately experience progression.

Finding ways to prevent recurrence in these patients would pay enormous dividends toward reducing deaths from prostate cancer. Unfortunately, only a fraction of clinical trials for new therapies are conducted in patients presenting with localized disease. The overwhelming majority of trials are in recurrent or metastatic prostate cancer, when patients are essentially incurable.

The dearth of trials in early prostate cancer stems from the difficulty in conducting them. In order for international regulatory agencies such as the FDA to approve a new therapy, an improvement in length or quality of life due to the therapy must first be demonstrated in clinical trials. The "overall survival" (OS)

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endpoint, which measures the length of time from randomization to death from any cause, is the gold standard for measuring the impact of a treatment on length of life. In localized prostate cancer, reaching an OS endpoint can require 10-15 years — a prohibitive timeframe for pharmaceutical companies. This fact has translated into only limited improvements being made in the treatment of early, aggressive prostate cancer in the last decade.

PCF identified this issue as a critical unmet need, and in 2012, supported the establishment of the ICECaP Working Group, an international collaborative initiative led by Sweeney, and funded in partnership with Astellas/Medivation, Janssen, Millenium/Takeda, Sanofi and Sotio. The goal of ICECaP is to undertake the arduous task of identifying an intermediate clinical trial endpoint that functions as a "surrogate" for OS. A successful surrogate would accurately predict overall survival but could be obtained much earlier in the course of the disease. The information on the surrogate endpoint would then be forwarded to regulatory agencies and drug companies around the world in order to hasten clinical trials and regulatory approvals for new therapies for early prostate cancer patients.

To accomplish this goal, Sweeney and team assembled data from 21,140 patients from 24 randomized clinical trials in early stage prostate cancer for which long-term clinical follow-up information was available. A statistical analysis plan was created, in which a candidate surrogate endpoint was required to meet two conditions to be considered suitable: 1) the surrogate must correlate with the true endpoint (i.e., overall survival), and 2) the effects of the treatment on overall survival and on the surrogate endpoint must be correlated (i.e., the treatment must affect both endpoints to similar degrees).

The group found that "disease-free survival" (DFS) rates at 5-years (a measure of the length of time from randomization until local/regional progression, distant metastasis, or death from any cause) significantly correlated with overall survival rates at 8 years (correlation of 0.86). In addition, the treatments were found to similarly affect the OS and DFS endpoints (correlation of 0.73). (A correlation value of 0.70 or greater is considered a reliable surrogate.)

"We are providing the information which regulatory authorities will be able to use as documentation that **disease-free survival is a strong surrogate for overall survival**. We are currently also assessing the more refined endpoint of metastasis-free-survival as a surrogate for overall survival and will present the results of this analysis later in 2016," Sweeney said. "This project will inform drug developers on how to design their studies. They will then use this to petition regulatory authorities to see if it meets their metrics for approval."

To accelerate regulatory agency acceptance of the surrogate endpoint in lieu of overall survival, the ICECaP Working Group has solicited feedback and guidance from regulatory science experts from around the world including the U.S. (FDA), Canada, the U.K., mainland Europe, Ireland, Australia, and New Zealand.

"Although our work is not yet done, we have completed the most difficult task of collecting the data as part of a magnificent and inspiring data-sharing collaboration. I am confident the final product will be able to guide the next generation of clinical trials," said Sweeney. "This will help us to more expediently evaluate new therapies and apply all of the advancements we've been making in drug development to decreasing the death rate from prostate cancer."

The 2016 ASCO Annual Meeting was held from June 3-7, in Chicago, Illinois

NETWORKING

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

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

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

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

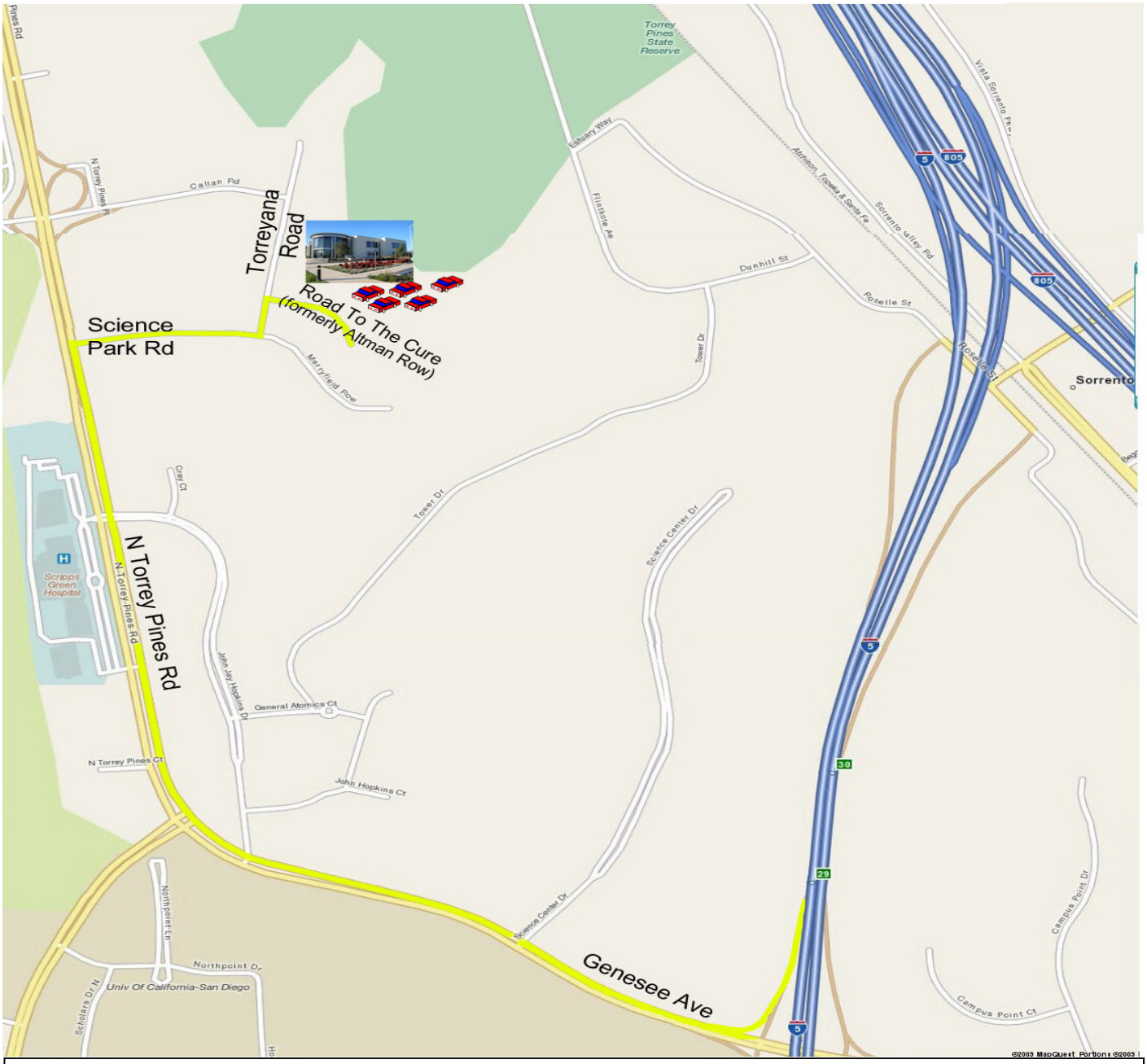
Ads about our Group are in the Union Tribune 2-3 times prior to a meeting. Watch for them.

FINANCES

We want to thank those of you who have made special donations to IPCSG. Remember that your gifts are tax deductible because we are a 501(c)(3) non-profit organization.

We again are reminding our members and friends to consider giving a large financial contribution to the IPCSG. This can include estate giving as well as giving in memory of a loved one. You can also have a distribution from your IRA made to our account. We need your support. We will, in turn, make contributions from our group to Prostate Cancer researchers and other groups as appropriate for a non-profit organization. Our group ID number is 54-2141691. Corporate donors are welcome!

If you have the internet you can contribute easily by going to our website, http://ipcsg.org and clicking on "Donate" Follow the instructions on that page. OR just mail a check to: IPCSG, P. O. Box 4201042, San Diego CA 92142



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

Take I-5 (north or south) to the Genesee exit (west).
Follow Genesee up the hill, staying right.
Genesee rounds right onto North Torrey Pines Road.
Do not turn into the Sanford-Burnham-Prebys Medical Discovery Institute or Fishman Auditorium
Turn right on Science Park Road. Watch for our sign here.
Turn Left on Torreyana Road. Watch for our sign here.
Turn Right on Road to the Cure (formerly Altman Row). Watch for our sign here.