



Informed Prostate Cancer Support Group Inc.

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



October 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)

Tuesday, October 09, 2012

Volume 5, Issue 9

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

October 20th

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

September 2012 Meeting Notes

The agenda for the meeting was for three men to speak of their experiences, each followed by a few questions, after which the group divided up into sub-groups by treatment type for networking.

Gene Van Vleet spoke for Bobby Turner, age 62, who could not make the meeting because of a sudden health issue but relayed his experience by phone message. He had experienced a rising PSA and after attending our meetings, began researching the best treatment for his preferred lifestyle. He had concerns about impotence and incontinence. His PSA had reached 20 and his biopsy reading was 3+4=7, so he knew he should seek

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 DVD's' button.

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treatment. He attended the IPCSG meeting at which Dr. A.J. Mundt and Dr. John Einck spoke about radiation therapy. After consultations with both, he opted for their treatment recommendations. He had 6 treatments of IMRT (Intensity Modified Radiation Therapy) followed by 2 treatments of Brachytherapy which is the implantation of radioactive seeds. His PSA went from 20 to 3.4 in 30 days. He is highly satisfied with the results, with the only troublesome side effect being slight incontinence which he has controlled with Flomax. Should anyone wish to speak with Bobby about his experience, please see Gene and he will put you in contact.

John Jonas, 61 years old, had been monitoring his PSA which had stayed in the 2.3 to 2.5 range. Last January his PSA score jumped to 6.7. He consulted an urologist who performed a digital rectal exam and recommended a biopsy. He chose to do some research before submitting to the biopsy. He had a biopsy in April and soon after attended his first IPCSG meeting through which he expanded his knowledge and learned from the experiences of others. His biopsy result was 3+4=7 and of the 12 cores taken, 3 were positive---one from the left side of his prostate had 8% involvement and 2 from the right side were 60% and 50% involved. These two were worrisome because they were near the outer edge of the prostate. He and his doctor decided to do an MRI and a bone scan. While waiting on those results, he attended his second IPCSG meeting which included Dr. Almeida speaking about C-11 Acetate imaging which is a highly enhance version of PET/CT scan. Based on the MRI and bone scan results, his doctor recommended doing some surgical biopsies. Rather than do this, John contacted Dr. Almeida and explained his case to see if he thought the C-11-Acetate imaging would be beneficial. Although the clinical trial Dr. Almeida is involved with is for those with recurrent cancer, he agreed to do it. The imaging results were devastating, yet amazing in that they showed he had significant cancer involvement outside the prostate including lymph nodes and the abdomen. Dr. Almeida suggested that he have an ultrasound guided biopsy on one of the lymph nodes and thought perhaps lymphoma might be involved. He had the biopsy done and it was determined that he had non-Hodgkins lymphoma. Although this was terrible news, he was informed that the positive news was that the lymphoma was treatable and, further, its existence was masking the true condition of his prostate cancer which was probably less serious than first thought and likely to respond to treatment as well. On further study the lymphoma was determined to be in the early stages and easily treatable with Rituxsan. He began the first of 4 treatments the week of our September meeting and then met Dr. Mundt, Chief of Radiation Oncology at UCSD. They put together a program for treatment with IMRT after the lymphoma treatment is complete. By becoming his own case manager, John is confident he is on his way to effective treatment of his two diseases.

Charles Lops, 71, spoke about his unusual journey in the diagnosis and treatment of his PCa. He has been dealing with his cancer for over 2 ½ years. To develop an understanding of the unusual circumstances of diagnosing his PCa, he chronicled his experiences in dealing with ulcerative colitis and other related issues for more than 25 years. He has had 7 surgeries to deal with those issues which included closing his rectum. He later contracted a serious bacterial blood infection which caused him to have blood tests every week. During these tests it was discovered that his PSA was escalating. Having no rectum presented an issue of how to accomplish a biopsy. An urologist at UCSD tried unsuccessfully to accomplish the biopsy and referred him to Dr. Shinohara at UCSF who was able to accomplish a biopsy by going through the perineum. By chance, he was discussing his cancer situation with his dentist who brought him to an IPCSG meeting where he learned from others and began to become his own case manager. He did extensive research to decide on his treatment. He became a patient of Dr. Lam of Prostate Oncology Specialists and opted for IMRT treatment with Dr. A.J. Mundt at UCSD. All during

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his ordeals, doctors did not approach the subject of sexuality. After hearing Dr. Grimaldi speak to IPCSG at its August meeting, he made an appointment to assess his possibilities. To his surprise, Dr. Grimaldi spent a great deal of time educating him about the psychology, intimacy and spirituality of male sexuality. They developed a plan to start him on a path to recovery. He has learned that Dr. Grimaldi is widely recognized in the U.S. as an expert on impotence and incontinence and emphatically recommended that those with such issues should avail themselves of his expertise.

The foregoing are summaries of the individuals' presentations. You can get the DVD of the meeting from the library or through the website in order to see the specifics of the presentations. Should you wish to talk privately with any of these men call Gene at 619-890-8447 who will get you in contact with them.

Future Meetings

October 20. Lyle LaRosh, Winner of National Award for Prostate Cancer Patients' Advocacy. A Patient's Opinion of Today's Medical Practices.

November 17. Robert Louie of Medivation will speak about the recently FDA approved Xtandi (formerly MDV3100).

December. NO MEETING

January 19, 2013. Speaker to be announced.

February 16. Roundtable discussions

March 16. Dr. Carl Rossi, Medical Director of the Scripps Proton Therapy Center. New Scripps facility

NOTEWORTHY ARTICLES

On the Lighter Side

IDIOT SIGHTINGS

I handed the teller at my bank a withdrawal slip for \$400 and I said "May I have large bills, please?" She looked at me and said "I'm sorry sir, all the bills are the same size."

My daughter and I went through the McDonald's take-out window and I gave the clerk a \$5 bill. Our total was \$4.25, so I also handed her a quarter. She said, 'you gave me too much money.' I said, 'Yes I know, but this way you can just give me a dollar bill back. She sighed and went to get the manager, who asked me to repeat my request. I did so, and he handed me back the quarter, and said 'We're sorry but we could not do that kind of thing.' The clerk then proceeded to give me back \$1 and 75 cents in change.

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I was at the airport, checking in at the gate when an airport employee asked, 'Has anyone put anything in your baggage without your knowledge?' To which I replied, 'If it was without my knowledge, how would I know?' He smiled knowingly and nodded, 'That's why we ask.'

On The Serious Side

Prostate Cancer Study Shows New Test May Reduce Biopsies

Prostate cancer check-ups aren't pleasant, but prostate cancer biopsies are downright horrible, and can lead to infection or urinary troubles.

Now, researchers have found a method of detecting prostate cancer that may reduce the number of repeat biopsies performed on men each year. According to a Bloomberg report, a study, published in the Journal of Urology, used biopsies from 498 men who had undergone second biopsies and predicted with 90% accuracy which of those men did not have prostate cancer.

Often, doctors will repeat biopsies to be sure there isn't cancer that was missed during a previous test. Bloomberg cites a Nomura Code Securities analyst as stating an estimated 1.5 million men get abnormal results from current screening tests.

The method of detection used in the study looks for genes that suppress tumors, and determines whether they are "on" or "off." Being "off" is an indication of cancer. The test, marketed as ConfirmMDx by MDxHealth SA, could help lower the number of repeat biopsies patients must undergo to make sure nothing has been missed.

Bloomberg also quotes the Nomura Code Securities analyst as stating that ConfirmMDx can help reduce medical costs. A biopsy, according to the analyst, can cost as much as \$2,500, while the MDxHealth test costs only \$146 per tissue sample. According to Bloomberg, MDxHealth, a Belgian company, is competing to get its test into the hand of urologists ahead of competing tests, while its stock is up 34% this year.

Better Detection Of High-Grade Prostate Cancers With Less Biopsies, With Contrast-Enhanced Ultrasound

From Medical News Today, October 1, 2012

Microbubble technique could serve as another monitoring tool for active surveillance in low-grade cancer patients, say Thomas Jefferson University researchers.

Contrast-enhanced ultrasound was found to better detect high-grade prostate cancer than conventional methods, making it a more appropriate approach for screening clinically important cancers and monitoring low-risk ones with less biopsies, researchers from Thomas Jefferson University and Hospitals conclude in a phase III study published online in the Journal of Urology.

Findings from the randomized, double-blind trial revealed the technique, which uses microbubbles to measure change in blood flow, found almost three times as many higher grade cancers using half as many needle biopsies compared to systematic biopsy methods.

"Today, a physician may sample 12 to 18 tissue cores from the prostate in order to help diagnose a patient. But with contrast-enhanced, that number drops to six or even less," says lead author Ethan Halpern, M.D. (insert link into full name: <http://www.jeffersonhospital.org/Healthcare%20Professionals/Ethan-J->

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Halpern.aspx), co-director of the Prostate Diagnostic Center Thomas Jefferson University Hospital and professor of Radiology and Urology at Thomas Jefferson University. "So it's less invasive, and a more effective guidance tool. We've found that with contrast-enhanced ultrasound, we are much more likely to detect cancers on the image, and in this case, the higher grades."

Results from the clinical trial of 311 men, 118 of which had positive prostate cancer biopsies, revealed that targeted biopsies using contrast-enhanced ultrasound with microbubbles detected significantly more higher volume/grade prostate cancers (clinically significant) in men (55 percent) compared to a conventional prostate biopsy technique (17 percent).

Ultrasound imaging of the prostate is commonly used to assess the size of the gland and for needle placement during systematic biopsy, but is limited by difficulty in distinguishing benign from malignant tissue. What's makes contrast-enhanced ultrasound different is the microbubble contrast agents, tiny bubbles of gas contained within a supporting shell that are injected into the patient to help better measure changes in blood flow.

Prostate cancer, like many cancers, harbors abnormal blood vessel flow. This change in flow in the prostate can be measured by ultrasound; the microbubbles enhance the reflection of those ultrasound waves. The technique has been used with success in Europe for some time, but researchers at Jefferson say it's ready for primetime in the United States. The U.S. Food and Drug Administration hasn't approved it for use for prostate screening, although it is used in other imaging applications.

In the clinical trial, researchers performed both targeted biopsies using contrast-enhanced ultrasound with flash replenishment maximum intensity projection MicroFlow Imaging on all patients, and a systematic 12-core biopsy protocol for comparison. The mean age of the patients was 62 years and a PSA level of 6.5ng/mL.

"Our ultimate goal is to perform a limited number of targeted biopsies and leave the rest of the prostate alone," says Dr. Halpern. "This will provide a safer, more cost-effective approach to diagnosing prostate cancer."

Subjects were also randomized to pretreatment with dutasteride, a drug used to treat an enlarged prostate, and placebo; however, no was significant difference in the proportion of positive biopsies for prostate cancer.

Dr. Halpern, who is principal investigator on the four-year, National Cancer Institute-supported trial, has been developing and refining techniques to enhance targeted biopsy of the prostate for more than a decade, along with his colleagues at Jefferson, Edouard J. Trabulsi, M.D., co-director of the Prostate Diagnostic Center and associate professor of urology, Flemming Forsberg, Ph.D., a professor of Radiology, Barry Goldberg, M.D., director of the Division of Diagnostic Ultrasound, and Leonard Gomella, M.D., F.A.C.S., director for Clinical Affairs at the Kimmel Cancer Center at Jefferson, and Chair of the Department of Urology. Peter A. McCue, M.D., a professor in the Department of Pathology, Anatomy and Cell Biology at Jefferson, was also part of this study.

Because prostate cancer often grows very slowly, some men, especially those who are older or have other serious health problems may never need treatment. Instead they may benefit from active surveillance where their cancers are carefully monitored with various tests to determine if the cancer is beginning to be more aggressive.

"It stands to reason that the cost-benefit ratio for prostate cancer screening will improve if PSA screening is followed by a limited targeted biopsy based on contrast-enhanced ultrasound," said Dr. Trabulsi. "This also means contrast-enhanced ultrasound can act as another monitoring tool for active surveillance in low-grade cancer patients, potentially preventing unwarranted treatments."

Announcements

**Medicare open enrollment begins October 15th and ends December 7th.
Research your options and what is changing in 2013.**

NETWORKING

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

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

Member and Director, John Tassi continues to develop our new website that we believe is simple and easy to navigate. **Check out the Personal Experiences page and send us your story.** Go to: <http://www.ipcsg.org>

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

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

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

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

We Need Help

All services for our group are performed by volunteers. As is usual in our type of organization we have a few doing a lot for many. We need people to step up and help in the following areas:

1. Fund Raising. We need help from anyone with any knowledge or willingness to become involved in acquiring grants to support our organization. We need someone to organize fund raising activities.
2. Information Technology. Any techies out there that can help take advantage of the facilities available where we meet--such as live remote conferencing.

Anyone interested please contact:

Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org

Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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 (OCIO) worked to define and collect detailed benefits and premium rating information from insurers across the country, and starting October 1, 2010, consumers will also be able to find information about health insurance options such as: Monthly premium estimates; Cost-sharing information, including annual deductibles and out-of-pocket limits; Major categories of services covered; Consumer's share of cost for these services; Percent of people in the plan who pay more than the base premium estimate due to their health status; Percent of people denied coverage from a health plan.

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

NOTE

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

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

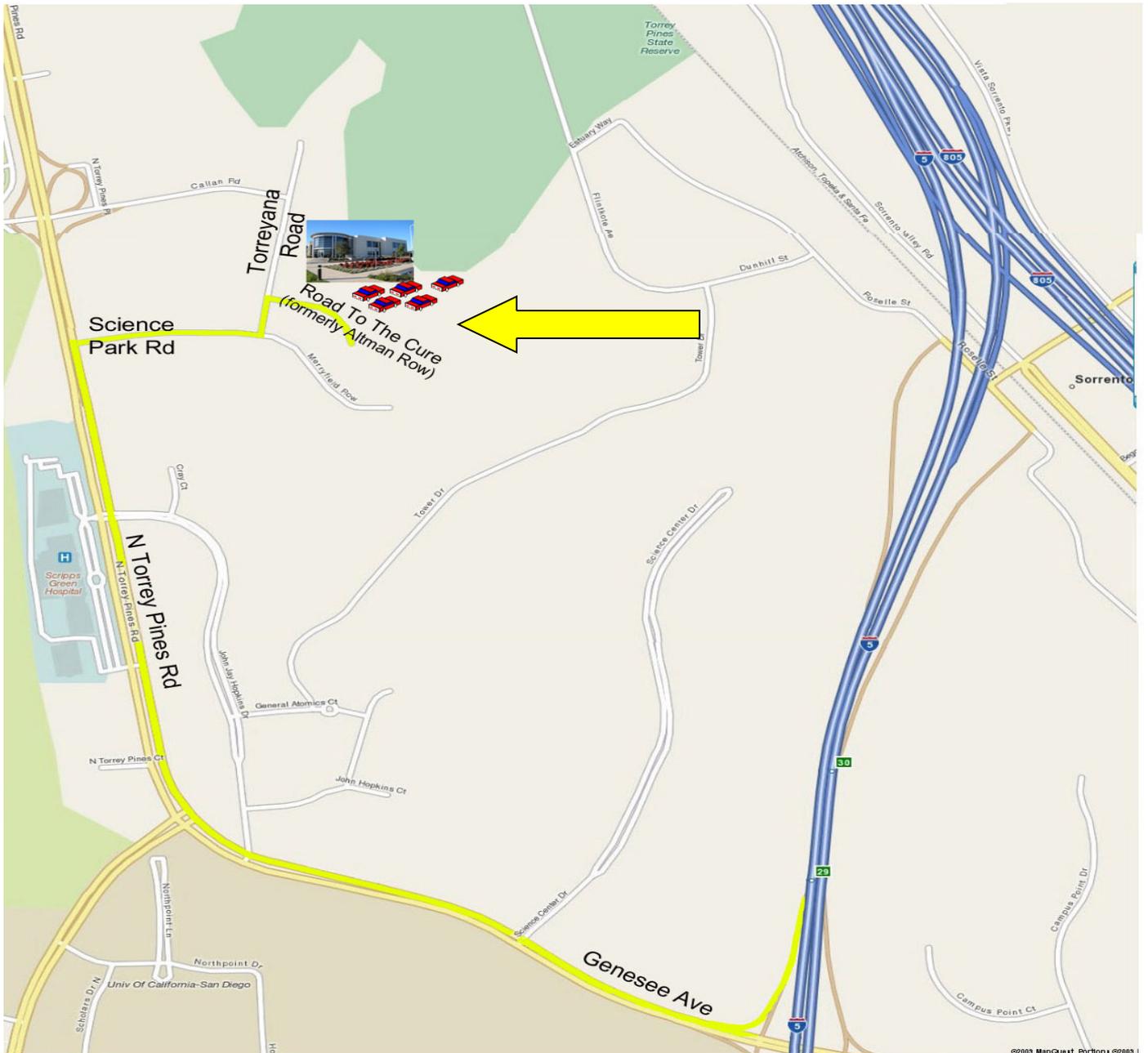
If you have particular knowledge that would be helpful to our goal of creating a base of information, please volunteer your efforts to the committee. Contact Gene Van Vleet, e-mail gene@ipcsg.org or cell phone 619-890-8447 who may redirect your inquiry to an appropriate person for response.

FINANCES

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

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

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



**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).