



Informed Prostate Cancer Support Group Inc.

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JUNE 2024 NEWSLETTER
P.O. Box 420142 San Diego, CA 92142
Phone: 619-890-8447 Web: <http://ipcsig.org>



Volume 17 Issue 05

Next IPCSG Meeting **3rd Saturday, July 20, 2024** — Member Roundtable

- **Roundtable**—Three members of the IPCSG group will share stories about their journey with Prostate Cancer. This is your chance to get all your questions answered by people who have "been there, done that".
- **May and June** meetings were **cancelled** due to construction in meeting hall.
- For links to further Reading: <https://ipcsig.blogspot.com/>
- If you have **Comments, Ideas or Questions**, email to Newsletter@ipcsig.org
- **For more information, email bill@ipcsig.org or call Bill at (619) 591-8670**

AnCan Forum Summarized

[6/11/2024 AnCan Forum - Hi-Risk/Recurrent/Advanced PCa Men & Caregiver](#)

Our Mission

[Answer Cancer](#) (AnCan) is about people helping people, peer-to-peer we are people living with various conditions and situations who help others faced with similar issues. We do this collectively and individually by providing answers, advocacy, education, support and navigation to empower people living with serious and chronic conditions to **Be Your Own Best Advocate**.

Vision

AnCan's vision is to provide easily accessible, inclusive virtual peer support for every serious disease and condition allowing widespread participation, especially to those geographically, physically or socially disadvantaged.

AnCan is grateful to the following sponsors for making this recording possible: Bayer, Foundation Medicine, Janssen, Myriad Genetics, Novartis, Telix & Blue Earth Diagnostics.

AnCan respectfully notes that it does not accept sponsored promotion. Any drugs, protocols or devices

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Prostate Cancer: GET THE FACTS

Other than skin cancer, prostate cancer is the most common cancer in American men.

1 in 6 
men will be diagnosed with prostate cancer during his lifetime.



Prostate cancer can be a serious disease, but most men diagnosed with prostate cancer do not die from it. In fact, more than 2.5 million men in the United States who have been diagnosed with prostate cancer at some point are still alive today.

Organization

a 501c3 non-profit organization - all positions are performed gratis



Officers

Bill Lewis President
Stephen Pendergast—Secretary

Additional Directors

Gene Van Vleet
Aaron Lamb
Bill Manning

Honorary Directors

Dr. Dick Gilbert
Judge Robert Coates

Past President –Lyle Larosh

Aaron Lamb, Facilitator
Bill Manning, Videographer
John Tassi, Webmaster
Bill Bailey, Librarian
Mike Corless, Greeter
Aaron Lamb, Meeting Set-up
Stephen Pendergast Editor

NEWSLETTER

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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.

Join the IPCSG TEAM

If you consider the IPCSG to be valuable in your cancer journey, realize that we need people to step up and HELP. Call **President Bill Lewis @ (619) 591-8670 bill@ipcs.org**

From the Editor (SLO)

In this issue:

For original articles see the blog at <https://ipcs.org.blogspot.com/> . First, since there were no IPCSG meetings, we have a claude.AI generated summary of the latest meeting of AnCan’s online forum for advanced Prostate Cancer Patients, since we had no May meeting to report. The AnCan group is based in Arizona, and operates online support forums for cancerpatients, including a drop-in forum for men with advanced PCa.

This month, we include one important items of interest:

A review on Prostate Cancer– shows the worldwide distribution of Prostate Cancer and its treatment.

(Continued from page 1)

recommended in our discussions are based solely on anecdotal peer experience or clinical evidence. AnCan cannot and does not provide medical advice. We encourage you to discuss anything you hear in our sessions with your own medical team.

AnCan reminds all Participants that Adverse Events experienced from prescribed drugs or protocols should be reported to the pharmaceutical manufacturer or the FDA Adverse Event Reporting System (FAERS). To do so call 1-800-332-1066 or download interactive FDA Form 3500 <https://www.fda.gov/media/76299/download>

AnCan's Prostate Cancer Forum is back (<https://ancan.org/forums>).

If you'd like to comment on anything you see in our Recordings or read in our Reminders, just sign up and go right ahead. You can also click on the Forum icon at the top right of the webpage. All AnCan's groups are free and drop-in ... join us in person sometime! You can find out more about our 12 monthly prostate cancer meetings at <https://ancan.org/prostate-cancer/>

Sign up to receive a weekly Reminder/Newsletter for this Group or others at <https://ancan.org/contact-us/>

Join our other free and drop in groups: Men (Only) Speaking Freely...1st & 3rd Thursdays @ 8.00 pm Eastern <https://ancan.org/men-speaking-freely/>

Veterans Healthcare Navigation... 4th Thursday @ 8.00 pm Eastern <https://ancan.org/veterans/>

Editor's pick: Two men with metastasis sites that raise thorny questions (bn).

Topics Discussed:

His de novo metastasis was discovered less than a week ago -- family rallies to his side as he weighs who to see and how to treat;

midway through Provenge -- leukapheresis yesterday, infusion in two days -- what to expect?;

radiating a spot near his clavicle means a tricky tradeoff;

insurance cutover puts Orgovyx so near yet so far;

will node radiation reignite bad radiation prostatitis?;

at a treatment crossroads, but his spirits are too low to act;

testosterone rising after ADT -- why gynecomastia now?;

Pluvicto's been great and he wishes it could last.

Topics Discussed Summary

High-Risk Recurring Prostate Cancer Support Meeting The AnCan virtual support meeting for high-risk recurring and advanced prostate cancer is a peer-to-peer support group where individuals can share their experiences and learn from each other's journeys. The meeting is facilitated by moderators Ben Nathanson, Len Sierra, John Antonucci, and Rick Davis, who are passionate about supporting patients and caregivers. The meeting aims to provide emotional support, share knowledge, and facilitate connections among participants who are going through similar challenges. In this meeting, Jeffrey, a newly diagnosed patient with stage four node-positive prostate cancer, shares his story and experiences. He expresses feelings of confusion, hopelessness, and frustration with the diagnosis. The moderators and other participants offer emotional support and provide guidance on finding the right medical team, including medical oncologists and surgeons. The group discusses the importance of genetic testing, clinical trials, and treatment options. They also share information on reputable medical centers and doctors, such as MD Anderson and Houston Methodist. The meeting concludes with an invitation for Jeffrey to share more about his wife's compiled list of medical professionals and his experience with clinical trials.

Biopsy and Treatment Options for Prostate Cancer A patient with prostate cancer has undergone a biopsy and is seeking guidance on treatment options. The discussion highlights the im-

(Continued on page 4)

portance of considering a liquid biopsy, as it may provide a more comprehensive understanding of the cancer's progression. Somatic testing and germline testing are also recommended to determine the origin of the mutations. The patient is advised to consult with a good oncologist and consider ADT treatment to stop the growth of the cancer. The conversation also touches on the importance of discussing treatment options with a GU medical oncologist, considering that hormone therapy and chemotherapy may be part of the treatment plan.

Provenge Treatment for Prostate Cancer Patients Provenge, a type of immunotherapy, is discussed as a treatment option for prostate cancer patients. The conversation highlights the potential benefits of the treatment, including a significant improvement in longevity, even if PSA levels remain low. The speakers share their personal experiences with the treatment, including its side effects, such as flu-like symptoms and the importance of staying hydrated. They also discuss the importance of consulting with a doctor and considering alternative treatment options, such as radiation therapy. The conversation underlines the importance of weighing the potential benefits and risks of the treatment and discussing individual situations with healthcare providers.

Radiation Therapy Concerns for Lymph Node Treatment A patient is discussing their concerns with radiation therapy to treat a lymph node near their heart. The doctor mentioned that the radiation may cause bleeding, which could be a serious complication. The patient is weighing the risks and benefits of the treatment, including the possibility of radiation-induced bleeding.

Discussion on Hormone Therapy Options for Prostate Cancer Patients The conversation revolves around the discussion of hormone therapy options for prostate cancer patients, specifically the use of Lupron and Orx, as well as the consideration of spot radiation for certain lesions. The participants share their personal experiences and insights, highlighting the importance of individualized treatment plans and the need for ongoing discussions with healthcare providers.

Alternative Paths for Prostate Cancer Diagnosis and Treatment This conversation highlights the importance of considering alternative approaches for prostate cancer diagnosis and treatment, particularly for patients with rising PSA levels. The discussion centers around the use of PSMA PET scans, which can be costly and may not be covered by insurance. The speakers share their personal experiences and provide insights into the challenges of navigating the complex healthcare system.

Struggling with PSA Test Results and Advocating for oneself This conversation revolves around a gentleman's struggles with PSA test results and advocating for himself in the presence of his doctor, Dr. Fleming. The individual is grappling with depression, lack of exercise, and uncertainty about his PSA test results, which led to frustration and feelings of being dismissed by his doctor. The conversation highlights the importance of self-advocacy and seeking support from healthcare professionals and others who understand the challenges faced by those living with prostate cancer.

Contributor Summary

Here is a summary of the transcript with the major points made by each main contributor:

Ben (moderator):

- Welcomes everyone to the meeting, introduces moderators and topic of discussion
- Emphasizes meeting provides peer support, not medical advice
- Asks newcomer Jeff about his background and diagnosis
- Advises Jeff to see a specialized medical oncologist rather than just a urologist
- Suggests getting 2-3 expert opinions from specific doctors the group recommends
- Discusses options for genetic testing and screening for mutations
- Puts links in chat to resources on treatments like Provenge
- Answers various member questions and asks other moderators/doctors to weigh in

Jeff (newcomer):

- Recently diagnosed with advanced prostate cancer, meeting with oncology team soon
- Planning to get multiple expert opinions to make treatment decisions
- Feeling confused and out of control but has strong family support
- Interested in learning as much as possible about his cancer and treatment options

Rick (founder):

- Welcomes Ben back as a regular moderator
- Chimes in occasionally to provide thoughts and advice to participants

Len:

- Shares his experience with radiation proctitis after prostate radiation
- Considering spot radiation for metastases seen on PSMA PET scan
- Debating whether to radiate largest/hottest nodes given risks to GI tract
- Discusses retreating with PLUVICTA and insurance coverage questions

Chuck:

- Receiving Pluvicto therapy and has seen good response so far
- Asking about taking breaks between Pluvicto treatments to extend duration of response
- Feeling much better with more energy since starting Pluvicto
- Wants to know if interrupting treatment could cause cancer to grow rapidly

Ken:

- Had prostate surgery 14 years ago, slow PSA rise in recent years
- Recent PSMA PET didn't show clear findings, possibly due to bladder uptake
- Struggling with depression that has impacted advocating for himself
- Advised to follow up with doctor on additional scans and to resume exercise

Dr. John, Dr. Jack, Dr. Jeff (doctor participants):

- Provide medical information and opinions in response to various patient questions
- Discuss pros and cons of different scans like CT, MRI, Axumin
- Share knowledge on expected side effects of drugs like Provenge
- Weigh in on treatment approaches and when to use different therapies

Eric:

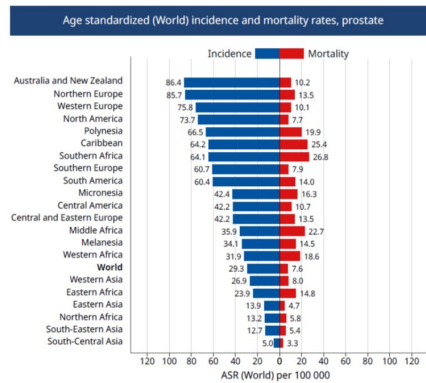
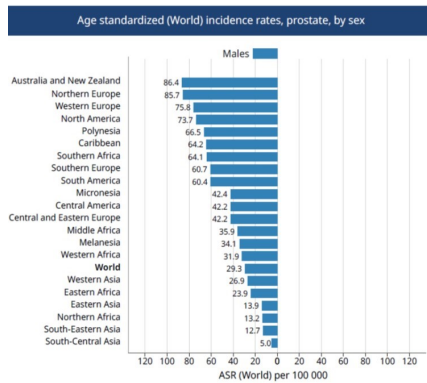
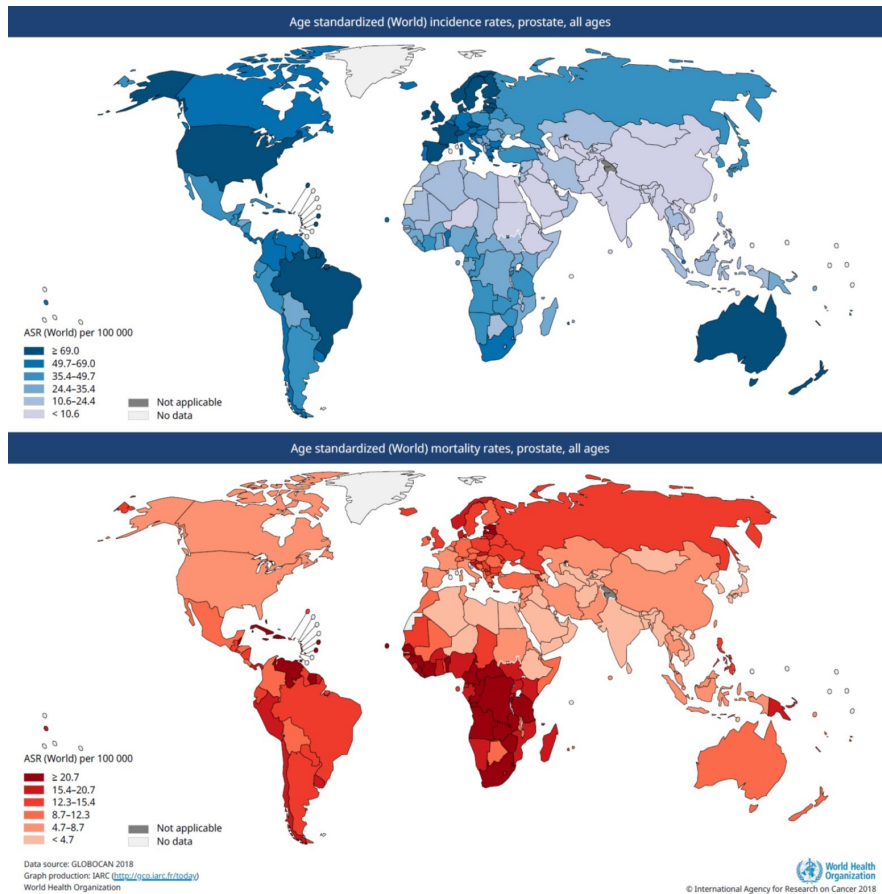
- Starting Lupron soon but insurance changes may allow coverage of Orgovyx
- Asking if he should delay Lupron to get Orgovyx in a couple weeks
- Advised he could likely start Xtandi now while waiting on Orgovyx

In summary, the meeting covered a wide range of topics related to prostate cancer diagnosis, imaging, treatment options, side effect management, and dealing with insurance issues. Participants sought advice from the moderators and doctors on their specific situations. The main themes were weighing risks and benefits of different treatment approaches, and empowering patients to advocate for themselves to get the best care possible. The community provides knowledge, support and guidance to help men navigate their prostate cancer journey.

On the Lighter Side



Items of Interest



[Prostate Cancer Epidemiology Worldwide incidence and mortality rates](#) (source : WHO)

A review on Prostate Cancer

The incidence

The incidence is the number of new cases every year in a particular population. Based on Globocan 2018, prostate cancer is the second most frequent malignancy (after lung cancer) in men worldwide, counting 1,276,106 new cases [6]. Prostate cancer incidence rates are highly variable worldwide as it reflects ethnic variation as well as differences in the use of diagnostic testing (picture 13).

The mortality rate

The mortality rate is the number of patients who yearly will die from prostate cancer. Prostate cancer is the third leading cause of deaths from cancer in the world with a considerable international variability in the mortality rates. Western countries stand amongst the highest mortality rates because of an increased life expectancy as age is as a recognized risk factor plays a central role with almost 55% of all deaths occurring after 65 years (picture 14) [7].

This review article provides a comprehensive overview of prostate cancer, covering epidemiology, diagnosis, genetics, treatment options, and potential future therapies.

Key points:

- Prostate cancer is one of the most common cancers in men worldwide and a leading cause of cancer deaths, especially in Western countries. Incidence varies by geography and race.
- Diagnosis involves digital rectal exam, PSA testing, prostate biopsy, and imaging like MRI.
- Prostate cancer has a strong genetic component, with family history being a major risk factor. Mutations in genes involved in DNA repair (BRCA1, BRCA2, ATM) and the androgen pathway are implicated.
- Localized prostate cancer is treated with active surveillance, prostatectomy, or radiation. Advanced disease is treated with androgen deprivation therapy and chemotherapy. However, resistance develops frequently.
- New biomarkers like PHI, PCA3 and TMPRSS2-ERG fusion help improve diagnosis. Precision medicine approaches using genomic profiling may enable more targeted therapies in the future.
- Alternative treatments being researched include gene therapy, herbal medicines, and nanotechnology to overcome treatment resistance and reduce side effects of current therapies.

In summary, while diagnostic and treatment advances have been made, prostate cancer remains a major challenge requiring a multipronged research approach spanning prevention, early detection, genetics, and novel therapeutic strategies to improve outcomes.

Variation of Incidence

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Diagnosis and Screening

The review article does not provide specific statistical data on the effectiveness of various prostate cancer diagnostic and screening techniques. However, it does discuss the main methods used:

1. Digital Rectal Exam (DRE):

- A standard diagnostic method where the doctor manually checks for prostate abnormalities.
- Not mentioned as a standalone screening tool.

2. Prostate-Specific Antigen (PSA) testing:

- Cornerstone of prostate cancer screening.
- PSA levels above 4 ng/mL indicate the need for further testing.
- One in four men with PSA between 4-10 ng/mL may have prostate cancer.
- Risk is higher with PSA > 10 ng/mL.
- However, PSA is prostate-specific, not cancer-specific, so elevated levels can also indicate benign conditions.

3. Prostate biopsy:

- Definitive diagnostic method to confirm cancer presence.
- Guided by imaging techniques like transrectal ultrasound (TRUS) or MRI.

4. Magnetic Resonance Imaging (MRI):

- Provides detailed prostate images to target suspicious areas for biopsy.
- Multiparametric MRI may help avoid unnecessary biopsies if DRE, PSA, and prior MRI are negative.

5. New biomarkers (e.g., PHI, 4K, PCA3, TMPRSS2-ERG):

- Emerging tests that improve the specificity and sensitivity of PSA.
- May help reduce overdiagnosis and unnecessary biopsies.

While the article suggests PSA is widely used for screening and MRI is becoming increasingly important for targeted biopsies, it does not provide comparative statistics on the effectiveness of these techniques. More research is needed to quantify the precision and accuracy of these diagnostic tools and biomarkers in different patient populations.

New Biomarkers

The review article discusses several new biomarkers that are being developed and evaluated to improve the accuracy of prostate cancer diagnosis and prognosis. These biomarkers aim to address the limitations of PSA testing, which can lead to overdiagnosis and unnecessary biopsies. The mentioned biomarkers include:

1. Prostate Health Index (PHI):

- A formula combining total PSA, free PSA, and [-2]proPSA.
- Shown to improve the specificity and sensitivity of PSA testing.

2. 4K Score:

- Measures a panel of four kallikrein proteins in the blood: Total PSA, Free PSA, Intact PSA, and Human Kallikrein 2 (hK2).
- Helps predict the likelihood of high-grade prostate cancer.

3. Prostate Cancer Antigen 3 (PCA3):

- A non-coding RNA that is overexpressed in prostate cancer cells.
- Measured in urine samples after a digital rectal exam.
- Higher specificity than PSA for prostate cancer detection.

4. TMPRSS2-ERG gene fusion:

- A genetic rearrangement present in about 50% of prostate cancers.
- Can be detected in urine samples.
- Associated with more aggressive prostate cancer.

These biomarkers are intended to be used in conjunction with PSA testing and other clinical information to provide a more comprehensive and accurate assessment of prostate cancer risk. By improving the

specificity of prostate cancer diagnosis, these tests may help reduce the number of unnecessary biopsies and the overtreatment of low-risk cancers.

However, the article does not provide detailed information on the sensitivity, specificity, or predictive values of these biomarkers. Further research is needed to validate their clinical utility and determine how they can be best integrated into prostate cancer screening and management strategies.

Treatments

Treatment selection for prostate cancer depends on several factors, including the stage and grade of the cancer, the patient's age and overall health, and personal preferences. The review article discusses the following main treatment options:

1. Active Surveillance:

- Suitable for low-risk, localized prostate cancer.
- Involves regular monitoring with PSA tests, DRE, and biopsies.
- Allows patients to avoid or delay treatment and its potential side effects.

2. Radical Prostatectomy:

- Surgical removal of the prostate gland and surrounding tissues.
- Considered a primary treatment option for localized prostate cancer.
- Often combined with radiation therapy for better outcomes.

3. Radiation Therapy:

- Includes external beam radiation and brachytherapy (internal radiation).
- Used as a primary treatment for localized prostate cancer or in combination with surgery.
- Also used as salvage therapy for recurrent cancer after prostatectomy.

4. Androgen Deprivation Therapy (ADT):

- Hormonal therapy that reduces testosterone levels to slow cancer growth.
- Used for advanced or metastatic prostate cancer.
- Can be achieved through surgical castration (orchiectomy) or medication (e.g., LHRH agonists, anti-androgens).

5. Chemotherapy:

- Uses drugs to kill rapidly dividing cancer cells.
- Typically reserved for metastatic or castration-resistant prostate cancer.
- Commonly used drugs include docetaxel and cabazitaxel.

The article does not provide specific statistics on the effectiveness of these treatments. However, it notes that:

- Prostate cancer remains incurable, and existing treatments are more effective when used in combination.
- ADT can lead to long-lasting remissions in advanced cases but is not curative, as resistance eventually develops.
- New targeted therapies based on genetic markers (e.g., PARP inhibitors for BRCA mutations) are showing promise in clinical trials.

The choice of treatment depends on a careful consideration of the patient's individual circumstances and a balanced discussion of the potential benefits and risks. Ongoing research aims to identify more effective and personalized treatment strategies to improve outcomes and quality of life for men with prostate cancer.

Food for Thought

- Steven Wright, "I intend to live forever so far so good."
- Earl Wilson, "If you think nobody cares if you're alive try missing a couple of car payments."
- Bob Hope, "A bank is a place that will lend you money if you can prove that you don't need it."
- Bill Murray, "The best way to teach your kids about taxes is by eating 30% of their ice cream."
- Anonymous, "I'm not arguing, I'm just explaining why I'm right."
- Willie Nelson, "The early bird might get the worm, but the second mouse gets the cheese."
- Stewart Francis, "My therapist says "I have a preoccupation with vengeance. We'll see about that."

NETWORKING

Please help us in our outreach efforts. Our speakers bureau consisting of Bill Lewis is available to speak to organizations of which you might be a member. Contact Bill 619-591-8670 (bill@ipcsg.org) to coordinate.

Member 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: <https://ipcsg.org/personal-experience>

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!



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.

DIRECTIONS TO MEETINGS