December 2019 NEWSLETTER
P.O. Box 420142 San Diego, CA 92142
Phone: 619-890-8447 Web: http://ipcsg.org
We Meet the Third Saturday of Each Month
(except December)

Next Meeting: October 19, 2019 - Dr. Phranq Tamburri, NMD - Prostate & Naturopathic Specialist
10:00am—12:00 @ Sanford Burnham Prebys Medical Discovery Institute Auditorium

Dr. Tamburri specializes in the assessment of prostate cancer and its numerous treatment options. With over a decade of clinical experience and training both as a naturopathic physician and at an early residency that included training with Mayo certified urologists, he is uniquely qualified to interpret and consult what both ‘sides’ of medicine are telling the patient. He also is the only integrative physician utilizing the state of the art color Doppler ultrasound (TRUSP) to accurately image the prostate along with providing the PCA3 molecular prostate cancer urine test for a heightened assessment.

• For further Reading: https://spendergast.blogspot.com/2019/03/prostate-cancer-news-of-interest-for.html
• For Comments, Ideas and Questions, email to Newsletter@ipcsg.org

September 2019 Informed Prostate Cancer Support Group Meeting:
Member “Experts” Tell Their Stories
Summary by Bill Lewis

1. Bill Trepanier (66 years old; background is real estate in San Diego)
   Current Status: Feeling fine and doing OK. PSA is <0.1, Gleason score is 6, and Stage is T2b (The tumor involves more than one-half of one side of the prostate, but is not in both sides.)
   History: About 20 years ago, a physician’s assistant offered to do a PSA test during a routine physical exam. The test, and a repeat test, returned higher-than-normal results. Bill was scared and uncertain. Not fully understanding what PSA meant, he decided to go outside Kaiser for second opinions. Not wanting cancer in his body, he chose surgery, which gave him about 12 years without recurrence, so he is happy about the choice. However, in retrospect, he feels he should have searched for a urologist more experienced in prostate removal and sparing of nerves – erectile dysfunction (ED) has not been fun.
   When his PSA rose again, he had 39 radiation treatments for the prostate bed. No particular side effects. A C-11 acetate PET scan showed cancer in a lymph node on his left side near his prostate. So he had 25 more radiation treatments to eradicate the cancer.
   He hopes that the radiation treatments were successful. In February 2020, he will stop his hormone (Continued on page 3)
In the Newsletter this Month

Contributions from our members highlight this issue, with more case management stories from Bill Trepanier, Bill Pitts, and Tom Selgas as summarized by Bill Lewis.

In Articles of Interest, an abstract of an article by Cai on managing intermittent ADT for Multistatic Cancer shows improved results for a new protocol. An article from Denmark shows how sports can help men with PCa have fun and improve their results. Maybe some men in our group would like to try something here. Another article abstract discusses how certain ADT drugs change PSMA PET/CT results. Lastly, a Medscape article shows how BRCA2 genetic mutations can be used in selecting men for enhanced screening.

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 Lyle LaRosh @ 619-892-3888; VP Gene Van Vleet @ 619-890-8447; or Meeting facilitator George Johnson @ 858-456-2492.
therapy and see whether his PSA stays at <0.1. Until then, he is on Lupron and Zytiga (with prednisone), which may eliminate microscopic groups of cancer cells throughout his body. He also had some Casodex. No side effects from the Casodex or Lupron. The Zytiga (1200 mg daily – with or without food doesn’t seem to matter for him – gives him hot flashes, which are mostly eliminated by Gabapentin). If his PSA rises, he will undergo a different PET scan to look for new tumors, and perhaps get more radiation and go back on Lupron and Zytiga.

He had a heart attack in 2000, has an implanted defibrillator, and takes various medicines for that condition. He’s currently working with a nutritionist on his diet. He’s gone back to the gym for cardio and muscle strength – with his wife, which has been fun. From a spiritual standpoint, he does meditation and prayer.

Conclusions: If he could start over, he would be more selective in the doctors he works with, start with Dr. Lam in Marina del Rey, and get involved with the IPCSG much earlier. He has found an amazing amount of information here.

Lessons learned: Don’t be afraid to speak up to any of the health care providers that you don’t agree with. Be your own case manager. Do the best research that you can on your personal situation. Ask for help if you need it and talk to as many people as you can that have more knowledge. Gene Van Vleet was a greatly-appreciated mentor, and George Johnson and Chuck Grim were also very helpful.

2. **Bill Pitts** (77 years old; retired educator living in La Mesa, CA)

Current Status: Feeling great and very grateful. PSA is about 1.0 and holding steady in annual testing. His treatment consists of exercise and diet (fish, chicken, fruit and vegetables, with no red meat or dairy products) for his cancer and for a heart condition.

History: PSA test in 2001 was slightly high. The biopsy was very painful. Gleason: 6, in the right side. He was given one month to decide on surgery or radiation. He had “controlled fear” about the cancer. So he looked for information. The Livingston Clinic was very helpful, giving him men’s names and phone numbers. One of them, Bill Ditka (now deceased), strongly advised him to attend the IPCSG.

Here he learned “he had time to decide,” was told of a UCSF Medical Center study offering a free MRI, and was told of Dr. Duke Bahn’s Color Doppler imaging process. He visited Dr. Bahn yearly for four years. By 2009, his PSA had risen to 9.3 and Dr. Bahn advised him to be treated. Dr. Bahn and Dr. Ukimora (USC; now moved to Japan) gave an IPCSG presentation on Focal Cryo Ablation. He was considered a good candidate, since the tumor was only on one side of the prostate. Minimal side effects were likely. He could expect regular continence, and Viagra would probably give satisfactory erections.

The ablation was done as an outpatient at the USC Medical Center in Los Angeles. The catheter was removed a few days later, and side effects were just as predicted.

He went on a vegan diet and drinks a mix of green tea and turmeric with a little honey for taste. Used visual imagery and affirmative prayer. During this time, the PSA stopped progressing and went down to one point.

Conclusions: Fortunate to be directed to IPCSG. Active surveillance was terrific advice. Finding the right medical folks was due to the IPCSG, and he was able to put off treatment until he found the right one for him.

George Johnson pointed out that whereas cryo-therapy has a reputation for causing ED (erectile dysfunction), this is not a problem with the focal (targeted) procedure Dr. Bahn uses.

3. **Tom Selgas** (79 years old; retired Kodak chemical engineer since 1981)

Current Status: PSA is 0.66, no sign of cancer in a Gallium 68 PSMA PET/CT scan done in May at UCLA. Works out 3-5 days a week. Feels great … but may need a nap, and has minor memory issues.

History: Started quarterly PSA testing at age 40 in Rochester NY. PSA gradually rose from below 4 to about 8. He had 3 biopsies (1997, 1998, and 1999) and two TURP procedures (transurethral re-
section of the prostate; “roto rooter”) in 2000 and 2003, all of which gave negative results for cancer. Continued quarterly PSA results were in the range of 7-9 through 2009. He then moved to San Diego. In early 2011, a biopsy showed Gleason 4+3, with all 12 cores positive (over 50% each). PSA was 16.6. Stage = T1c (not detectable by DRE [digital rectal exam] but found by needle biopsy). His doctors saw potential problems with surgery due to his TURPs affecting his bladder, and recommended meeting with Dr. Mundt at UCSD to discuss radiation. He met Gene Van Vleet at the Jan. 2011 IPCSSG meeting (“the most fortunate meeting ever”), and began visits with Dr. Scholz of the Marina del Rey group, Prostate Oncology Specialists. He was given 6 months of Lupron, and 45 sessions of IMRT radiation at UCSD. Dr. Scholz also had him start exercise to maintain muscle and bone, with Fosamax to help prevent bone loss. He joined 24 Hour Fitness and still works out as noted above.

After dropping to 0.5, his PSA gradually rose to 1.9 in May 2017. An Axumin F18 PET/CT scan found his cancer had spread to a lymph node, which had not been radiated. SBRT (stereotactic body radiation therapy) was given, and his PSA dropped to <0.1. Dr. Lam (of Prostate Oncology Specialists) treated him with Casodex (150 mg / 50 mg) for 12 months, along with Femara (which helps prevent breast growth due to the Casodex). After that, by May of this year, his PSA rose to 0.36. A Gallium 68 PET/CT scan was negative – no cancer detected. If his PSA rises to 2, then the plan will be to restart Casodex. He still takes Finasteride.

He had had fatigue and memory problems caused by taking “too many medications.” Stopped Omeprazole, Atorvastatin, Metformin. Mental confusion cleared up. His doctor says this was likely due to discontinuing the statin. Takes Zetia (reduces absorption of cholesterol from the diet), Berberine (reduces high cholesterol), Niacin (lowers LDL Cholesterol and boosts HDL Cholesterol) and Crestor (2x5mg/wk, instead of prior normal statin dose) and has very good cholesterol levels.

Other health issues: a hole in the macula of his eye, a vagectomy, and a small growth on his wrist. Two pathologists came to opposite conclusions, but a UCSD 400-gene sequencing analysis indicated in is not melanoma.

Conclusions: Though he hopes it won’t be necessary, he will go back on Casodex if needed. He will continue to ask Gene, George, Chuck, Larry and others in the IPCSSG for advice. In retrospect, his choice would still be radiation. He is thankful.

Group Comments: George Johnson has found no one who has had successful “nerve sparing” surgery. The nerves are a web, not a single or few strands that can be avoided. One member said a friend got good results with a particular, hand-chosen doctor at UCLA.

A new member volunteered to create a database of members willing to talk to others about the specific therapies they have gone through. To some extent, this need is currently being served by “breakout sessions” at the end of member-story meetings like this one, where members can ask for each other’s phone numbers. He also recommended goodrx.com for comparing prices of drugs at different pharmacies. He got a particular medication ten times cheaper by mail than from a large-chain local pharmacy by using this website.

More details are given in the video of this presentation, including the PowerPoint slides, which will be available for purchase via the website shortly before the next meeting, or at the October meeting on the 19th.

Member Suggested Items:
From Joel Pointon:
GoodRX.com—My Primary Care Doctor at Sharp told me about it when I found a 30 day supply of a medication to be $400 with insurance at CVS....but less than $60 for the same drug and a 90 day supply via a mail-order pharmacy. I have also found Pricing at 25% at a Walgreen’s across the street from my CVS.

Prostate Cancer Foundation - Wellness Guide
"You've got two options, but, Mercy Hospital is 20 minutes closer, but the nurses at Saratoga Hospital are really hot."

"I'm a close relative, and I did some research on the Internet about his condition, so I feel I'm more qualified to take care of him than some nurse."

"Relax, that's just our new display!

"Stop apologizing – you're just doing your job."
Abstract--New Protocol of Intermittent Androgen Deprivation Therapy for Patients With Metastatic Prostate Cancer: A Retrospective Study - Clinical Genitourinary Cancer:

Jianliang Cai

Figure 1 is a Kaplan-Meier Curve Showing Progression-Free Survival (Total IADT Duration) of Different IADT Protocols. Log-rank Test, $\chi^2 = 7.505, P = .006$ is how survival is improved by the new protocol. Abbreviation: IADT = intermittent androgen deprivation therapy.

Background--The optimal points for halting and resuming treatment in intermittent androgen deprivation therapy (IADT) for metastatic prostate cancer patients are controversial.

Patients and Methods--In the 65 metastatic prostate cancer patients in group 1, androgen deprivation therapy was stopped when prostate-specific antigen (PSA) levels reached a nadir and was resumed when PSA levels doubled and $\geq 1.0 \text{ ng/mL}$ (new protocol). In the 62 patients in group 2, androgen deprivation therapy was stopped 3 months after PSA $= 0.2 \text{ ng/mL}$ and resumed at PSA $\geq 4.0 \text{ ng/mL}$ (Chinese Urological Association guideline). The total IADT duration, overall on-treatment and off-treatment time, tumor clinical progression ratio, performance status improvement, and treatment-related adverse effects were retrospectively analyzed.

Results--In groups 1 and 2, the median total IADT durations were 51 and 46.5 months (significant difference, $P = .006$), median overall on-treatment times were 28 and 27.5 months (no significant difference, $P > .05$), and median overall off-treatment times were 23 and 19 months (significant difference, $P < .001$), respectively. Multivariate Cox regression analysis indicated that patients in group 1 had significantly higher progression-free-survival (hazard ratio, 0.634; $P = .014$). Two cases of clinical progression occurred group 1 and 5 in group 2; there was no significant difference ($P > .05$). There were no significant differences between the groups in terms of performance status improvement and treatment-related adverse effects.

Conclusion--The new protocol was found to be beneficial, showing less biochemical/clinical progression, satisfactory performance status, and acceptable treatment-related adverse effects.

Men Have Fun in Prostate Cancer Trial: In a randomized trial, football, or soccer as it is known in the United States, benefitted men with prostate cancer in multiple ways.

Nick Mulcahy "I would rather die on the football field than in a hospice, no doubt about that." — Lasse, 80 years old "When we're out there...you might hear it...we become kind of like boys again, you know? And you think you can conquer the world!" — Patrick, 73 years old

Men with prostate cancer just want to have fun — and play football/soccer instead of doing cancer-specific exercises, preferably while wearing a spiffy team uniform.

This and other unorthodox clinical pearls come from a first-of-its-kind clinical trial among 214 men with prostate cancer in Denmark. The men, with an average age of 68, were randomized to play football twice a week for 6 months or to usual care.

At 1-year of follow-up, the football group had significant improvements in mental health and body mass index and fewer hospital admissions compared with controls, report the investigators, led by Eik Dybboe Bjerre, PhD, postdoctoral scientist, University Hospital of Copenhagen, Denmark.

Also, there was no increased risk of fracture among

(Continued on page 7)
the footballers, which was important because 19% of participants had skeletal metastases at baseline. Once the study, which took place at football clubs (FC) in five towns and is known as the FC Prostate Community trial, showed acceptable safety, the Danish Football Association started the initiative at 15 additional clubs in other locations. Both in the trial, which ran from 2015 to 2018, and afterward, recruitment was through posters and fliers in local urology departments. At the twice-a-week hourly sessions, the men divided up and played five vs five against each other. Games were monitored by two volunteer coaches, who received minimal education about prostate cancer. The players at some locations paid for their own uniforms to formalize their gear.

The new 1-year data were published online October 1 in *PLOS Medicine*. The trial defies conventional wisdom about cancer patients and exercise, suggested Bjerre. "The men’s primary motivation is not being healthy," Bjerre told *Medscape Medical News*. Instead, they were motivated by "having fun with peers" and being in a structured environment, he said. "They don’t talk about prostate cancer or health when they come," he observed. Being a footballer, commented Bjerre, is the antithesis of being a cancer patient: "The men said that playing football means they are not in a passive patient role."

Importantly, among patients allocated to the football group in the clinical trial, 59% chose to continue playing after the 6-month intervention. That was significant, said Bjerre. "We all know exercise is healthy for you, but don’t really know how to promote this behavior, especially among men," he commented. The trial indicates that team sports may be a good health promotion for cancer patients — and encourage long-term adherence. Arjun Gupta, MD, oncology fellow, Johns Hopkins University, Baltimore, Maryland, who highlighted the study on Twitter, agreed.

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**Evaluation of PSMA expression changes on PET/CT before and after initiation of novel antiandrogen drugs (enzalutamide or abiraterone) in metastatic castration-resistant prostate cancer patients** | SpringerLink: [link.springer.com](https://link.springer.com)
First Online: 05 October 2019

**Abstract** -- Evaluation of PSMA expression changes on PET/CT before and after initiation of novel antiandrogen drugs (enzalutamide or abiraterone) in metastatic castration-resistant prostate cancer patients.

**Objective** -- To investigate the association between Prostate-Specific Membrane Antigen (PSMA) expression changes on positron emission tomography–computed tomography (PET/CT) and the response to treatment following the start of enzalutamide or abiraterone in metastatic castration-resistant prostate cancer (mCRPC) patients.

**Methods** -- All consecutive ⁶⁸Ga-PSMA-11 PET/CT scans routinely performed at our institution during more than 4 years were retrospectively screened for inclusion. We included mCRPC patients with a baseline PSMA PET/CT performed less than 2 months before the start of either enzalutamide or abiraterone, and a follow-up PSMA PET/CT performed no more than a year after, while still under
those novel antiandrogen drugs (NAD). The associated clinical records were reviewed. Patients were considered treatment responders if they presented decreasing PSA levels > 50% or a radiological response based on RECIST 1.1 criteria. PSMA expression changes on the follow-up PET/CT were assessed using per-patient dominant response criteria to classify patients as PSMA-responders (complete disappearance of pathologic PSMA uptake, or a decreased uptake of the majority of lesions) or PSMA-non-responders (new PSMA-expressing lesions, increased uptake of the majority of lesions, or stable PSMA expression of the disease). Descriptive statistics and measures of associations (two-sided Fisher’s exact test and Phi coefficient) were calculated.

Results -- A total of 11 and 15 patients were included in the enzalutamide and abiraterone groups. Median follow-up was 110 (IQR 76–124) and 87 (IQR 71–242) days, respectively. All treatment responders (3 enzalutamide and 4 abiraterone) were considered PSMA-responders, and all treatment non-responders (8 enzalutamide, 11 abiraterone) were considered PSMA-non-responders. PSMA PET response was thus perfectly associated with conventional response criteria (p = 0.006, Phi = 1 for enzalutamide; p = 0.001, Phi = 1 for abiraterone). In our cohort, no PSMA expression flare phenomenon was detected on follow-up PET/CT scans at a median follow-up of 3 months. However, an early and short-lived flare cannot be excluded.

Conclusions -- This retrospective study suggests that, after a median follow-up of 3 months under enzalutamide or abiraterone, PSMA expression changes on PET/CT are strongly associated with response to treatment. Prospective studies are needed to better understand PSMA expression dynamics following the start of enzalutamide and abiraterone, along with the role of PSMA PET/CT in response assessment.

Men With BRCA2 Mutations Should Be Offered PSA Screening, Researchers Say:
By Will Boggs MD
October 07, 2019
NEW YORK (Reuters Health) - Men with mutations in BRCA2 have an increased risk of prostate cancer and should be offered prostate-specific antigen (PSA) screening, according to the team behind the IMPACT study.

Recent findings (https://bit.ly/2kL3BX1) from the ongoing EMBRACE study demonstrated an increased risk of prostate cancer in men with BRCA mutations, with a higher risk and more aggressive disease in those with BRCA2 mutations, as reported by Reuters Health.

In a paper online September 16 in European Urology, Dr. Rosalind A. Eeles of the Institute of Cancer Research, in London, and colleagues report interim findings from IMPACT on the utility of PSA screening and other data after three years of screening, stratified by BRCA status.

The study included 919 BRCA1 carriers, 709 BRCA1 noncarriers, 902 BRCA2 carriers, and 497 BRCA2 noncarriers (median enrollment age, 54 years).

At baseline, 7.7% of nearly 3,000 participants tested had a PSA >3.0 ng/mL and 2.4% were diagnosed with cancer.

After four PSA screens, cancer was diagnosed in 5.2% of BRCA2 carriers and 3.0% of BRCA2 noncarriers and in 3.4% of BRCA1 carriers and 2.7% of BRCA1 noncarriers.

The cancer incidence rate per 1,000 person-years was significantly higher among BRCA2 carriers than among noncarriers (19 vs. 12, P=0.031), but did not differ significantly between BRCA1 carriers and noncarriers (14 vs. 11, respectively, P=0.3).

The positive predictive value (PPV) of prostate biopsy did not differ significantly between BRCA2 carriers and noncarriers or between BRCA1 carriers and noncarriers.
The PPV of PSA >3.0 ng/mL was significantly greater in BRCA2 carriers than noncarriers (31% vs. 18%, P=0.025), but not between BRCA1 carriers and noncarriers (23% vs. 15%, P=0.13).

The median age at prostate-cancer diagnosis was significantly younger in BRCA2 carriers (61 years) than in BRCA2 noncarriers (64 years) but did not differ between BRCA1 carriers and noncarriers.

Most BRCA2 carriers (37/48, 77%) diagnosed with prostate cancer had intermediate- or high-risk disease, significantly more than among BRCA2 noncarriers diagnosed with prostate cancer (6/15, 40%). The rate of clinically significant disease rates, however, did not differ between BRCA1 carriers and noncarriers.

Based on these findings, the authors conclude that "systematic PSA screening is indicated for men with BRCA2 mutation. Further follow-up is required to assess the role of screening in BRCA1 mutation carriers."

Dr. Tommy Nyberg of the University of Cambridge, in the U.K., lead author of the recent EMBRACE report, told Reuters Health by email, "The BRCA2 results of the IMPACT and EMBRACE studies seem complementary, and consistently suggest that men with BRCA2 mutations are at high lifetime risks of prostate cancer and that targeting this group of men for regular PSA tests would result in the detection of a high proportion of aggressive cancers."

"I hope that these results will be useful both to the clinician who meets a male BRCA2 carrier, and to inform the debate on targeted prostate cancer screening of high-risk groups," said Dr. Nyberg, who was not involved in the IMPACT study.

Dr. David Margel of Rabin Medical Center, in Petah Tikva, Israel, who recently reviewed the screening and treatment of prostate cancer among carriers of BRCA mutations, told Reuters Health by email, "The main point which is implicit from this manuscript is that men with BRCA2 are at high risk for prostate cancer and should be screened."

It remains to be seen "whether a real difference exists between BRCA1 and BRCA2 mutations," he said. "In Israel there is a predominance among male BRCA carriers of the 3 Jewish founder mutations. And in my experience men with a 185delAG, which is a BRCA1 mutation, have the same risk of prostate cancer as BRCA2."

"The most important endpoints for any cancer screening protocol are cancer-specific and overall mortality," Dr. Margel added. "It would be interesting to see in the future if the screening affects not only cancer diagnosis, but also overall and cancer-specific mortality."

Dr. Heather Cheng of Fred Hutchinson Cancer Research Center and the University of Washington, in Seattle, who also studies prostate-cancer screening, told Reuters Health by email, "It is important for men and their doctors to know that if they carry a BRCA2 mutations, there is an increased risk of prostate cancer and that screening for prostate cancer is warranted. Men with inherited BRCA2 mutations should be counseled and managed differently with respect to prostate cancer screening than average-risk men."

"When considering the risk of prostate cancer, it is important to consider the family history of other cancers, including breast, ovary, pancreas, melanoma, (and) leukemias," she said. "If there are multiple relatives with cancer, especially diagnosed at younger ages (e.g., younger than 50s), genetic counseling referral should be considered. Moreover, knowing about a familial cancer risk may help in tailoring cancer screening strategies for that person, but may also provide valuable information for their relatives."

Dr. Eeles did not respond to a request for comments.

Reuters Health Information © 2019
Cite this: Men With BRCA2 Mutations Should Be Offered PSA Screening, Researchers Say - Medscape - Oct 04, 2019.
**NETWORKING**

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: [https://ipcsg.org/personal-experience](https://ipcsg.org/personal-experience)

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.

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**FINANCES**

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

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

If you have the internet you can contribute easily by going to our website, [http://ipcsg.org](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

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**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.