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

NOVEMBER 2022 NEWSLETTER

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

Tuesday, November 15,

Volume 15 Issue 11

- **Next Meeting Saturday, November 19, 2022 IPCSG—10:00am PT**.
- **Mitchell Kamrava, MD "Pros & Cons of Brachytherapy vs. SBRT";** a Radiation Oncology Specialist in West Hollywood, CA. He is affiliated with medical facilities Cedars - Sinai Medical Center and Ronald Reagan UCLA Medical Center. He specializes in High Dose Rate Brachytherapy, IMRT (Intensity-Modulated Radiation Therapy), Image Guided Radiation Therapy, Intensity Modulated Radiation Therapy, Internal Radiation Therapy, Interventional Oncology, and various cancers.
  After the meeting we'll have a mix of Christmas/holiday and healthy food including fruit, vegetables and gluten-free. There will also be drinks.
  December 17: No meeting in December. Happy holidays.

- .**For links to further Reading: https://ipcsg.blogspot.com/**
- **If you have Comments, Ideas and Questions,** email to Newsletter@ipcsg.org
- **If you would like some copies of our new brochure by mail for distribution to your friends or physicians, please send email to bill@ipcsg.org or call Bill at (619) 591-8670**

October 2022 Informed Prostate Cancer Support Group Meeting

Summary by Bill Lewis

On October 15th, after 2-1/2 years of Zoom meetings, we were finally able to return to in-person meetings at the Sanford Burnham Prebys auditorium in La Jolla CA. This author was privileged to be the speaker, and his wife Terry organized a luncheon following the meeting in celebration of our return to meeting in person.

"Surviving [Aggressive] Prostate Cancer," by Dr. William Lewis, Ph.D.

Lessons learned from 7 years of living with Gleason 9 cancer that metastasized to a hundred places in the bone. Options for anyone living with prostate cancer, from active surveillance to focal treatments, to radiation or surgery, and on to new treatments. Suggestions for thriving while minimizing cancer growth. Nuggets from summarizing six years of IPCSG meetings for the monthly newsletter. Preview of a book in progress about prostate cancer from a patient's perspective.

Beginning with humorous family stories, his genetic tendency toward prostate cancer and numerous

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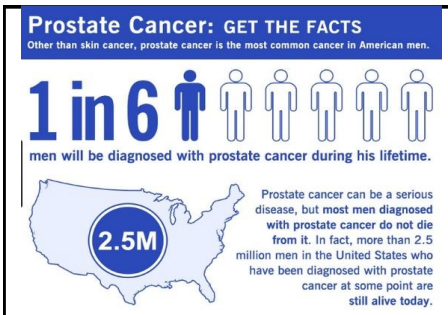

Organization

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

IPCSG

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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.

Meeting Video DVD's

DVD's of our meetings are available for purchase on our website at https://ipcsg.org/purchase-dvds and are generally available by the next meeting date.

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 ; or **Director** Gene Van Vleet @ 619-890-8447.

From the Editor

In this issue:

Bill Lewis produced a summary of his last meeting presentation, Articles of interest include:.

1. There may be a faster, less-painful way to use radiation against cancer.—FLASH may be quicker, with fewer side effects.
2. A Fork in the Road on My 'Cancer Journey' - while fighting PCa, genetic screening finds other cancer risks. Knowledge of family genomics can help in decision making.
3. Ejaculation frequency and prostate cancer - Harvard Health—more activity in youth reduces likelihood of PCa. Compared to men who reported 4–7 ejaculations per month across their lifetimes, men who ejaculated 21 or more times a month enjoyed a 31% lower risk of prostate cancer.
4. Developing therapies for treatment-resistant prostate cancer -- ScienceDaily—Carotuximab prevented the PCa castrate resistant cell's workaround and made the tumor sensitive to androgen-suppressing therapy again. It appears to prevent androgen receptor splice variants in the supporting cells surrounding tumors, further sensitizing the tumor to the androgen suppressor

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health problems and stresses that likely led to his rising PSA in 2015, Dr. Lewis noted the failure of alternative medicine treatment alone – which resulted in innumerable metastases to his bones by mid-2016. Since then, complementary / comprehensive treatments from testosterone suppression, a course of "kinder/gentler" chemotherapy, supplements and repurposed drugs have eliminated nearly all of the metastases, and kept his PSA low in cycles of treatment and "holidays" until now.

Following the chapter plan for a book he is writing about cancer, he shared what he has learned so far about dealing with any prostate cancer from IPCSG speakers, online information, doctors and personal experience. These topics included: First Considerations, The big picture, Diet – food and supplements, Exercise, Minimizing stress, Emotional helps, Positive emotions (positive people relationships, service, religion), and Strong reasons for living. Moving into the technical aspects, Dr. Lewis discussed PSA, Imaging, Active Surveillance and Treatments. Then The Decision Process (Gather information, Long life or Quality of life?, Your doctor, and The "personality" of your cancer) and finally Emerging science and treatments – New drugs, New tests, and New procedures (including surgery & radiation improvements). Book chapters yet to be drafted include The Biome and Complementary / comprehensive options (How to choose supplements and Energy healing).

Last year, after reviewing lab tests, his oncologist, Dr. Shahrooz Eshaghian (now with the Los Angeles Cancer Network) said in relation to Dr. Lewis' comprehensive medicine choices, "Whatever you are doing, keep doing it." In the annual in-person visit this year in Los Angeles, he looked at me pensively, tilting his head from side to side, and then demanded, "Take off your hat." After a few more moments, he declared, "In the four years I have been seeing you, you haven't aged a bit!" The photo taken in 2017, shown in the video, shows how I looked a year before I started seeing him, and the video itself shows how I look now. Prostate cancer is a disease of "accelerated aging," so his declaration is a testimony of the effectiveness of the way I have modified his treatments / guidelines to stay healthy. Unfortunately, I couldn't reply that he and his staff hadn't aged either. Without exception, they all looked significantly older - an effect I think of soldiering on through the pandemic years, wearing masks all day long, as they treat and try to help patients. They are sacrificing their health for others.

In honor of the late George Johnson, who always wanted member-speakers to share the spiritual side of their prostate cancer journey, I will mention that much of my spiritual strength comes from my participation in activities at the LDS temple just off the 5 freeway in La Jolla. A tour inside a similar temple is available online by searching "Rome Temple Tour."

As is mentioned below, the IPCSG meeting video is now available online. A copy of the slides from the talk and documents mentioned therein, are all available from Dr. Lewis at lewis.bill@gmail.com, or by request through the IPCSG mailing address. These include all of the cancer book chapter drafts, summaries of the books Radical Remission and How To Starve Cancer, information on digesting enzymes to prevent diarrhea, and info on using a buffing machine to diminish neuropathy symptoms. Become "informed!"

A dvd of the October 2022 meeting & talk will be available for purchase from the IPCSG by the time of next month's meeting. Order online from the IPCSG.org website. It can now be watched online at https://youtu.be/VVD_aupYkRA – you can watch the whole meeting, or skip to the talk or the Q&A using the options in the note below the video on YouTube.

Articles of Interest

Kristin Houser

There may be a faster, less-painful way to use radiation against cancer.

The first-in-human trial of FLASH radiotherapy found the experimental treatment to be safe and effective — suggesting that there may be a faster, less painful way to use radiation against cancer.

The status quo: Radiation therapy is a common cancer treatment that uses high doses of radiation to kill or slow the growth of cancer cells. Usually, this is done by aiming a beam of radiation directly at a tumor for a few minutes. This part of the process is painless, like getting an X-ray.

Patients typically undergo daily treatments five days a week for several weeks, and including setup time, a treatment usually takes about 15 to 30 minutes.

With traditional radiation therapy, dosages may have to be limited to avoid painful side effects.

The challenge: By shrinking a tumor, radiation therapy can not only fight cancer, but also potentially relieve patients' pain or other symptoms caused by it. But the beam of radiation can damage healthy tissue near the tumor, too, *causing* pain and other side effects.

To minimize these adverse effects, doctors have to limit the radiation dosage, which may reduce how effective the treatment is at fighting the cancer.

> "[FLASH radiotherapy] offers the possibility of delivering larger doses of radiation, which could result in higher cure rates."
>
> *John Breneman*

The FLASH effect: FLASH radiotherapy is a promising alternative to traditional radiation therapy.

It delivers a dose of radiation that's over 300 times higher than traditional radiation therapy in just a fraction of a second. This induces something called the "FLASH effect" — a not-entirely-understood phenomenon in which the radiation still attacks the tumor, but doesn't harm surrounding tissue.

"This offers the possibility of delivering larger doses of radiation — which could result in higher cure rates for patients with resistant tumors — without increasing side effects," said John Breneman, principal investigator of the new trial.

In animal studies, FLASH radiotherapy has been shown to be safe and just as effective as traditional radiation therapy without causing unexpected side effects. Now, a University of Cincinnati-led team has shared the results of FAST-01, the first-in-human trial of the treatment.

One FLASH radiotherapy treatment lasts just 0.3 seconds.

The trial: The primary goal of the trial was to prove that FLASH radiotherapy is safe for people and has a feasible workflow. A secondary goal was to determine its efficacy by measuring how much pain relief it provided patients.

The trial included 10 patients with painful cancerous growths in the bones of their arms or legs. Each received one FLASH radiotherapy treatment — lasting just 0.3 seconds — at the site(s) of their cancer.

Their pain, use of pain meds, and adverse effects were measured the day they received the therapy, 15 days later, and one, two, and three months after treatment.

"We did not see any unexpected additional toxicity with the substantially shorter treatment."

Emily C. Daugherty

The results: Patients' average time on the table was just 15.8 minutes per treated site — demonstrating that the workflow is feasible — and of the 12 total cancer sites treated, pain was fully relieved in six and partially relieved in two others.

"[B]oth pain relief and side effects were in-line with what might have happened with conventional radiation," said lead author Emily C. Daugherty. "We did not see any unexpected additional toxicity with the substantially shorter treatment."

Looking ahead: Ultimately, the researchers believe FLASH radiotherapy would be most useful for treating cancers in the brain, lungs, or gastrointestinal area, as the tissues around those tumors are particularly vulnerable to damage from traditional radiation therapy.

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It could also be useful for treating cancers in children, who are more sensitive to the side effects of radiation therapy.

Since the limb treatments didn't produce any unexpected side effects in people, they've begun enrolling patients in FAST-02, a trial that will target cancerous growths in the bones of the thorax, which surround the heart and lungs.

We'd love to hear from you! If you have a comment about this article or if you have a tip for a future Freethink story, please email us at tips@freethink.com.

medpagetoday.com

A Fork in the Road on My 'Cancer Journey'

Howard Wolinsky

Special Reports > A Patient's Journey

— Recent events reminded me that prostate cancer isn't my only cancer concern

by Contributing Writer, MedPage Today November 7, 2022

For the past 12 years, I have been focused on my diagnosis of low-risk prostate cancer, and in 2016, I began sharing my experience and covering the latest developments in the field in my "A Patient's Journey" blog for *MedPage Today*.

But in recent months, a few events reminded me that prostate cancer isn't my only cancer concern, putting a new twist in my journey. Colorectal cancer, the second most common cause of cancer deaths for men and women, also needs to be on my radar.

My mother, Edith, died a painful death at age 66 in 1988 from liver and spinal metastases.

She had a mix of cancers, including colon cancer, which resulted in two surgeries to remove parts of her colon, a hysterectomy to remove uterine cancer, and a lumpectomy to remove breast cancer. She also had skin cancer along the way.

It may sound like Lynch syndrome, a condition that includes a similar melange of cancers, but she was never tested for that syndrome, let alone any other inherited cancer.

Memories of my mother's ordeal hit me hard when I received a genetics report in August from the PROMISE registry (Prostate Cancer Registry of Outcomes and Germline Mutations For Improved Survival and Treatment Effectiveness) on prostate cancer. The report revealed I carried no prostate cancer variants but that I was at risk for inherited colorectal cancer. This was followed by an ER scare for a bowel obstruction in September.

My Discovery of a Genetic Risk for Colon Cancer

As an advocate for prostate cancer patients, I have recommended that they "spit for science" and take a free DNA test by joining the PROMISE registry, a collaboration between investigators at the University of Washington in Seattle and Johns Hopkins in Baltimore. PROMISE researchers are studying about 30 mutations linked to hereditary colorectal, male breast, melanoma, pancreatic, prostate, and stomach cancers.

The discovery of mutations such as *BRCA2* in a patient with low-risk Gleason 6 lesions can dramatically change the treatment plan, with surgery being preferred over active surveillance.

I drank the PROMISE Kool-Aid. They found no genes linked with prostate cancer, such as *BRCA* variants or variants for Lynch syndrome.

Medical News from Around the Web

But I didn't walk away scot-free. I had a gene variant associated with an increased risk for colon cancer and colon polyps, known as *APC*. My report said there is a 3.3% chance for anyone just walking down the street to develop this sort of colon cancer by age 80.

Susan*, a senior genetic counselor at Color Genetics, which runs the DNA testing for PROMISE, told me I had a "founder variant," found more commonly in the Ashkenazi Jewish population (my people). She said my mother's

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colon cancer likely was associated with this DNA variant.

"With this variant, we don't worry so much about colon polyps, but we do think that the risk for colon cancer is a little bit elevated," she said.

She said more frequent colonoscopies -- every 5 rather than 10 years -- are recommended for people with this variant. My two brothers, my sister, and I have been following this accelerated testing schedule because of our mother's history. Susan suggested sharing my results with my siblings and our children.

I broke the news to my sons, one 39 and the other 44, who are already convinced of their poor genetics. The idea of colonoscopies was not well-received. I tried to stress that if they were to test negative for this variant, they could follow the every 10-year plan rather than the every 5-year plan. But if they have this variant, they may need more frequent colonoscopies to give them the chance to treat colon cancer as early as possible.

After I shared my news, one of my brothers opted to get tested. He too was found to have the *APC* marker. Another brother is mulling over what to do.

My sister wasn't interested. Why? It turns out she had already undergone DNA testing about 5 years earlier because of her breast cancer diagnosis, and was also found to be a carrier of the colon cancer gene. At the time, she had told me that Lynch had been ruled out. But inexplicably, she didn't share the colon gene findings.

With the new information from my report, I continued about my normal life, just slightly more aware of my heightened risk for colon cancer.

My Unexpected Trip to the Hospital

Not long after, around the time of my 75th birthday in late September, I began feeling persistent, sharp lower left abdominal pain. After a week or so, I finally decided to see my family physician at the University of Chicago, but I discovered he was booked through Christmas.

So, I called his office and was advised to see one of his colleagues via a telehealth visit.

During the appointment, I spoke to the doctor and described my pain. He agreed with my self-diagnosis of diverticulosis. In the course of a week, I had cramping, diarrhea, nausea, and vomiting.

As a precaution, the family medicine specialist ordered a CT.

Following the outpatient CT, I went home and received a call from the doctor soon after: "You need to be in the emergency room. Tell them you have a 'hot colon.' You have a bowel obstruction. That should get their attention."

Not so much. Five hours later, I finally reached the ER.

A young emergency doctor, who looked like a surfer with a bleached hairdo, began talking to me about the possibility of surgery or passing a nasogastric tube to remove an obstruction to save precious bowel tissue. He said cancer had to be ruled out. This sounded frightening and reminded me of my mother's travails.

Next, a silver-haired hospitalist became my doctor of record and offered a more sober scenario. She said the odds were that I would not need an intervention as the blockage would likely resolve on its own in a matter of hours or as long as a week. But she said I needed to be admitted for observation.

They took an X-ray at about 5 p.m., and soon thereafter the radiologist issued report -- there was no longer a blockage. Yet, no one shared the good news with me until the next morning.

During the course of the night in the hospital, I had a 101-degree fever.

At 10:30 a.m. the next day, the surgeon finally informed me there was no blockage and said: "We won't be sharpening the knives." I was relieved. He added: "It's easy to decide to do surgery. It's hard to decide not to."

After another day of observation, I finally walked out of the hospital.

Looking Ahead

About a week later, I finally caught up with my family doctor, who basically declared me fit. The pain in my gut stopped after 3 weeks. I now think my pain may have been stress-related.

As I approach age 80 as a carrier of the *APC* variant, I do have questions, such as whether I should continue getting screened with colonoscopies and whether the DNA finding has any impact on that.

I have an appointment scheduled with a gastroenterologist to see if there are any other twists and turns in the journey ahead.

**Person's name has been changed*

Howard Wolinsky is a Chicago-based medical writer. He has written the blog, "A Patient's Journey," for MedPage Today *since 2016. He is the editor of the Substack newsletter, TheActiveSurveillor.com. Wolinsky has no professional or paid*

affiliation with the PROMISE Registry.

Ejaculation frequency and prostate cancer - Harvard Health

health.harvard.edu

Despite the importance of prostate cancer, its causes remain unknown. Scientists do know that genetics plays a strong role, and they have sound evidence that diet and other lifestyle factors are also important.

Since the prostate is a reproductive organ that produces fluid for the ejaculate, researchers have long wondered if sexual factors influence a man's risk of prostate cancer, but a Harvard study provides good news for sexually active men.

The Harvard ejaculation study

The Health Professionals Follow-Up Study has been collecting information about a large group of volunteers since 1986. All the men are health care providers, including dentists, pharmacists, veterinarians, optometrists, ophthalmologists, and podiatrists. Most are white. In 1992, 29,342 men between the ages of 46 and 81 provided information about their average number of ejaculations per month in young adulthood (age 20–29), middle age (40–49), and in the most recent year. Ejaculations included sexual intercourse, nocturnal emissions, and masturbation. The volunteers provided comprehensive health and lifestyle data every two years until the study concluded in 2000.

The scientists found no evidence that frequent ejaculations mark an increased risk of prostate cancer. In fact, the reverse was true: *High ejaculation frequency was linked to a decreased risk*. Compared to men who reported 4–7 ejaculations per month across their lifetimes, men who ejaculated 21 or more times a month enjoyed a 31% lower risk of prostate cancer. And the results held up to rigorous statistical evaluation even after other lifestyle factors and the frequency of PSA testing were taken into account.

Ejaculation data from Down Under

An Australian study of 2,338 men examined the impact of sexual factors on the occurrence of prostate cancer before the age of 70. Like the Harvard research, the Australian investigation evaluated total ejaculations rather than sexual intercourse itself. Like the American men, the Australians who ejaculated most frequently enjoyed a reduced risk of prostate cancer. The effect was strongest for the frequency of ejaculations in young adulthood, even though prostate cancer was not diagnosed until many decades later. Even so, the apparent protection extended to all age groups. In all, men who averaged 4.6–7 ejaculations a week were 36% less likely to be diagnosed with prostate cancer before the age of 70 than men who ejaculated less than 2.3 times a week on average.

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A piece of the puzzle

The studies from the United States and Australia do little to answer these critical questions — but they do open a new avenue for research. Since both report that a high frequency of ejaculation early in adulthood has the greatest impact on the risk of prostate cancer decades later, they call attention to the role of events early in life, when the prostate is developing and maturing. There is certainly precedent for

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a long lag between cause and effect. For example, childhood sunburn is a major risk factor for malignant melanomas in adulthood, and prenatal factors that influence birth weight appear to influence the lifetime risk for hypertension and heart disease.

In 1807 William Wordsworth wrote, "The child is father of the man." With respect to prostate cancer, though, sexual activity in adolescence may be a predictor of risk in adulthood.

Developing therapies for treatment-resistant prostate cancer -- ScienceDaily

sciencedaily.com

Investigators from Cedars-Sinai Cancer have identified an investigational therapeutic approach that could be effective against treatment-resistant prostate cancer. Results of their Phase II clinical trial, published in the peer-reviewed journal *Molecular Therapy,* have led to a larger, multicenter trial that will soon be underway.

Cancer of the prostate, a small gland just below the bladder, is the second-leading cause of cancer-related death in men. Many prostate tumors are not aggressive and may require no or minimal treatment. Aggressive tumors are initially treated with surgery or radiation therapy.

In about one-third of patients, the cancer comes back after initial treatment, said Neil Bhowmick, PhD, research scientist at Cedars-Sinai Cancer, professor of Medicine and Biomedical Sciences and senior author of the study. Those patients are usually treated with medications that suppress the actions of testosterone and other androgens -- male hormones that help prostate tumors grow.

"Patients do really well until the tumor figures a way around the androgen-suppressing therapy," Bhowmick said. "One way that it can do this is to cause cells to make only part of the protein that the drug binds to, rendering the drug useless. The partial proteins are called splice variants."

Through research with human cells and laboratory mice, study first author Bethany Smith, PhD, a project scientist in the Bhowmick Lab, figured out that the cancer cells were signaling to the surrounding supportive cells through a protein called CD105 to make these slice variant proteins. Investigators then conducted a trial in human patients to test a drug that they hoped would keep those partial proteins from forming by inhibiting CD105.

In the trial, nine patients whose tumors were resistant to androgen-blocking therapy continued that therapy but were also given a CD105 inhibitor called carotuximab. Forty percent of those patients experienced progression-free survival, based on radiographic imaging.

"Every single one of the patients in our trial was totally resistant to at least one androgen suppressor, and the normal course of action would be to simply try a different one or chemotherapy, which research has shown generally doesn't stop tumor growth for more than about three months," Bhowmick said. "Carotuximab prevented the cancer's workaround and made the tumor sensitive to androgen-suppressing therapy."

Importantly, Bhowmick said, carotuximab also appears to prevent androgen receptor splice variants in the supporting cells surrounding tumors, further sensitizing the tumor to the androgen suppressor.

"We found that this therapy may be able to, especially in early cancers, resensitize select patients to androgen suppression. This could allow patients to avoid or delay more toxic interventions such as cytotoxic chemotherapy," said Edwin Posadas, MD, co-director of the Experimental Therapeutics Program, medical director of the Urologic Oncology Program/Center for Uro-Oncology Research Excellence (CURE), associate professor of Medicine at Cedars-Sinai and a co-author of the study. "We also hope to find ways of predicting which patients are most likely to benefit from this approach by testing blood and tissue samples using next-generation technologies housed at Cedars-Sinai Cancer."

Study co-author Sungyong You, PhD, director of the Urologic Oncology Bioinformatics Group, pinpointed three biomarkers that could help indicate which patients will respond to this investigational therapy, and the team will validate those markers in a new clinical trial. This will allow future studies to target patients most likely to be helped by this intervention, Bhowmick said.

Funding: The study was supported by Department of Defense grant number W81XWH-17-1-0154 and Veterans Administration grant number I01BX001040.

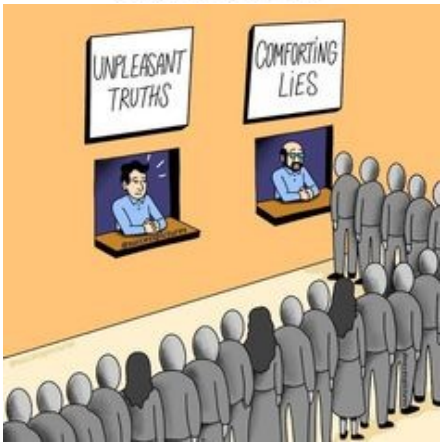
Story Source:

Materials provided by **Cedars-Sinai Medical Center**.

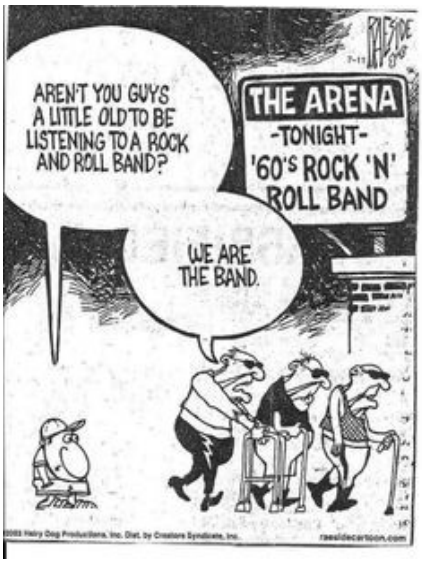
On the Lighter Side

"Give me a few seconds to prepare myself."

"I'LL BETCHA THEY CAN FIRE ROCKETS WITH THOSE THINGS!"



"OK, Mrs. Dunn. We'll slide you in there, scan your brain, and see if we can find out why you've been having these spells of claustrophobia."



NETWORKING

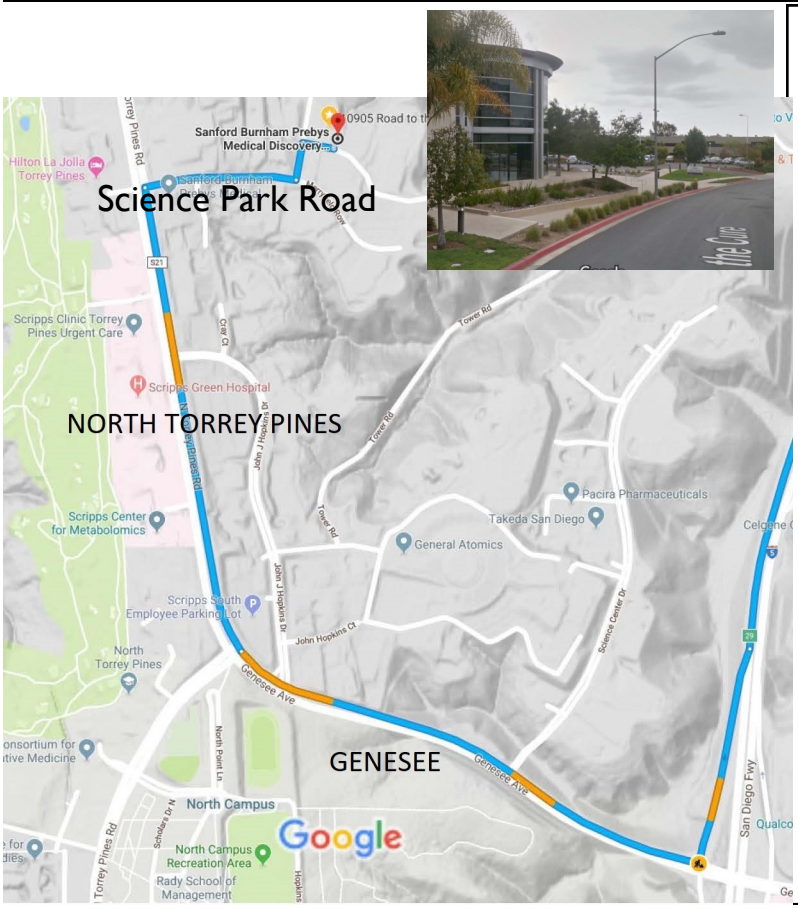
Please help us in our outreach efforts. Our speakers bureau consisting of Gene Van Vleet and Bill Lewis is available to speak to organizations of which you might be a member. Contact Gene 619-890-8447 or gene@ipcsg.org or Bill 619-591-8670 (bill@ipcsg.org) to coordinate.

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.