



Friday, January 17, 2025

**JANUARY 2025 NEWSLETTER**  
**PO Box #12322 La Jolla, CA 9203**

**Web: <http://ipcsg.org>**



Volume 18 Issue 01

- **Next Meeting Saturday January 18 2025, 10:00am with Dr. Arno J. Mundt, MD and his colleagues from UCSD Moores Cancer Center Radiology who will give their annual update on Radiation Therapy.**



- **For links to further Reading: <https://ipcsg.blogspot.com/>**
- **If you have Comments, Ideas or Questions, email to [Newsletter@ipcsg.org](mailto:Newsletter@ipcsg.org)**



**In Memoriam —**

William "Bill" Lewis, who turned his own battle with prostate cancer into a mission to help others as president of San Diego's Informed Prostate Cancer Support Group (IPCSG), has died. He was 71.

We remember Bill for his warm smile, cheerful demeanor, and tireless dedication to helping others facing prostate cancer. As a volunteer president of the group, he stepped up to fill the need and took a leading role in securing educational speakers and developing marketing initiatives to raise awareness about the disease. His sharp mind, trained with a PhD in Chemistry, contributed much to the group monthly newsletter summarizing the monthly meetings for those who couldn't attend, deciphering technical jargon, as well as catching any errors in final edit. His untiring efforts supported by

*(Continued on page 3)*

**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**

- TBD President
- John Gottlieb—Treasurer
- Stephen Pendergast—Secretary

**Additional Directors**

- Gene Van Vleet
- Aaron Lamb
- Bill Manning

**Honorary Directors**

- Dr. Dick Gilbert
- Judge Robert Coates
- Past Presidents –Bill Lewis, Lyle Larosh
- Aaron Lamb, ..... Facilitator
- Bill Manning, ..... Videographer
- John Tassi, ..... Webmaster
- Bill Bailey, ..... Librarian
- Mike Corless, ..... Greeter
- John Cotter, ..... 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. Email [Info@ipcs.org](mailto:Info@ipcs.org) and let us know how you can help!

**From the Editor (SLO)**

**In this issue:**

For original articles see the blog at <https://ipcs.blogspot.com/>. First, we have a brief summary notice of the passing of our president, Bill Lewis. Bill's contributions to the IPCSG and this newsletter will be greatly missed.

This month, we include a couple items of interest:

1. PSMA-PET Scans Reveal Hidden Cancer in Nearly Half of "Non-Metastatic" Prostate Cancer Patients—*prior scans and biopsies missed a lot.*
2. New Study Shows ERLEADA® Outperforms Competitors in Metastatic Prostate Cancer Treatment.—*questions to ask your oncologist if you are on enzalutamide or similar meds for mCRPC*

The **Prostate Cancer Patient Summit** will be held at UC San Diego Park & Market on February 1, 2025. The event is organized by UC San Diego Moores Cancer Center in partnership with the Prostate Cancer Foundation.

Contact information for the event is provided through the UC San Diego Office of CPD, located at 9500 Gilman Drive in La Jolla, CA. Interested parties can reach out via phone at (858) 534-3940 or email at [cpdoffice@health.ucsd.edu](mailto:cpdoffice@health.ucsd.edu). Here is a link for the [event website](https://na.eventscloud.com/ereg/index.php?eventid=816013&) and [registration](https://na.eventscloud.com/ereg/index.php?eventid=816013&).

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his spouse helped the organization to recover from a long hiatus during the COVID19 pandemic and attract new members and encourage informal group information exchanges at the meetings.

After being diagnosed with prostate cancer in 2014, Lewis approached his condition with remarkable determination and intellectual rigor, becoming what he called his "own case manager." Despite initially facing financial barriers to treatment after losing his health insurance, he developed a comprehensive approach combining traditional medicine, lifestyle changes, and alternative therapies.

His dramatic improvement surprised even his medical team - particularly after a bone scan had initially given him just six to nine months to live. Lewis went on to document his journey and treatment protocols in detail, freely sharing his experiences through support group meetings and a book he was writing to help others.

A passionate advocate for patient education, Lewis made himself available to counsel others by phone, offering both practical guidance and emotional support. He gave a memorable presentation about his cancer journey at an IPCSG meeting in October 2022, which was recorded and shared online via YouTube.

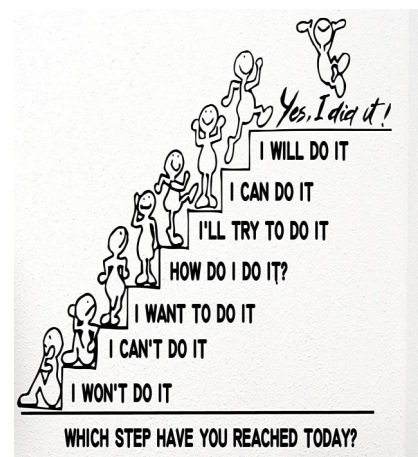
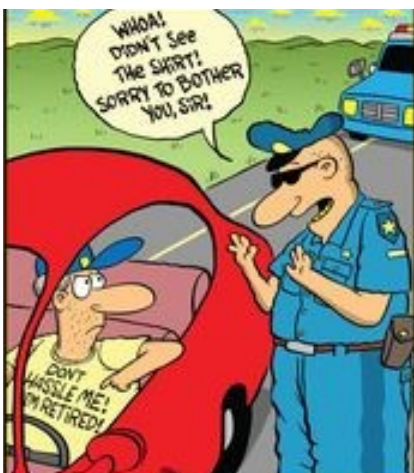
Prior to his illness, Lewis had faced several life challenges, including a heart attack and business difficulties. However, he transformed these hardships into motivation to help others, exemplifying resilience and compassion throughout his journey.

Gene Van Vleet, Director of the Informed Prostate Cancer Support Group, noted that Lewis had a "peaceful transition" and praised his leadership, compassion, and unwavering commitment to the organization's mission.

Lewis, who believed strongly in the power of positivity and spirituality in healing, lived by the principle that one could "live long and well, even with aggressive prostate cancer." He is remembered for his generous spirit and dedication to empowering others with knowledge in their fight against prostate cancer.

You can read Bill's own story on the web site at <https://ipcs.org/bill-lewis> or a video of his cancer journey in his own words on youtube at [https://www.youtube.com/watch?v=VVD\\_aupYkRA&t=1361s](https://www.youtube.com/watch?v=VVD_aupYkRA&t=1361s)

## On the Lighter Side



## Items of Interest

### PSMA-PET Scans Reveal Hidden Cancer in Nearly Half of "Non-Metastatic" Prostate Cancer Patients

A UCLA-led study has found that advanced imaging technology detects previously unseen cancer spread in nearly half of prostate cancer patients thought to be metastasis-free. The research, published January 3 in JAMA Network Open, raises important questions about current staging methods and treatment strategies.

Researchers at UCLA Health, led by Dr. Jeremie Calais and Dr. Adrien Holzgreve, examined 182 patients who showed no metastatic disease using conventional imaging. When these same patients underwent PSMA-PET/CT scans (prostate-specific membrane antigen positron emission tomography), the results revealed distant metastases in 46% of cases, with 24% showing polymetastatic disease.

"PSMA-PET/CT continues to evolve as the most accurate imaging method for staging prostate cancer," said Dr. Holzgreve. "While the study design and previous evidence do not allow us to consider the findings as practice-changing, they strongly support that PSMA-PET is more sensitive for localizing anatomical sites of biochemical recurrence compared to conventional imaging alone."

The findings are particularly relevant in light of the recent EMBARK trial, which demonstrated survival benefits for enzalutamide treatment in patients classified as non-metastatic using conventional imaging. The new research suggests many of these patients may actually have had undetected metastatic disease.

This builds on previous work, including a 2019 study in The Lancet Oncology that first highlighted PSMA-PET/CT's superior detection capabilities. Dr. Calais, who was also involved in that earlier research, notes that the current findings align with a growing body of evidence supporting PSMA-PET's clinical value.

"Probably, a high percentage of patients with strong suspicion for a recurrence would benefit from PSMA-PET/CT when conventional imaging shows no evidence of metastatic spread," said Dr. Calais. He suggests focusing first on patients with high-risk features, as they have the greatest clinical need for accurate imaging-based treatment decisions.

The research team, which included collaborators from Germany's LMU University Hospital, emphasizes the need for additional studies to demonstrate how this more accurate staging information should influence treatment choices. An international consortium investigating PSMA-PET's prognostic impact has already enrolled more than 6,000 patients, with preliminary analyses suggesting the technology outperforms traditional clinical prognostic tools.

The work was supported by multiple organizations including the Deutsche Forschungsgemeinschaft, the UCLA-Caltech Medical Scientist Training Program, the Prostate Cancer Foundation, the National Institutes of Health, and the Society of Nuclear Medicine and Molecular Imaging.

The study, published in JAMA Network Open, examined 182 patients who were considered to have non-metastatic hormone-sensitive prostate cancer based on standard imaging techniques. When these same patients underwent more sensitive PSMA-PET/CT scans, the results showed:

- 84% had detectable cancer activity
- 46% had distant metastases that were missed by conventional imaging
- 24% had polymetastatic disease (5 or more lesions)

"Our results suggest that patients' high-risk non-metastatic hormone-sensitive prostate cancers are understaged by conventional imaging," said Dr. Jeremie Calais of UCLA Health, a co-author of the study.

The findings have important implications for treatment decisions and clinical trials. They specifically add context to the recent EMBARK trial, which evaluated enzalutamide treatment in patients deemed to have non-metastatic disease through conventional imaging.

# Understanding New Prostate Cancer Imaging Research: A Patient's Guide

## *What The Research Found*

A new study shows that an advanced imaging technique called PSMA-PET/CT can find cancer spread (metastases) that traditional scans miss. In the study:

- Nearly half of patients thought to be free of metastatic disease actually had cancer spread
- The technology was particularly helpful for high-risk patients
- The findings could affect treatment decisions for many patients

## Questions to Ask Your Doctor

# 1. "Would PSMA-PET/CT scanning be appropriate for my situation?"

Possible answer: Your doctor may recommend PSMA-PET/CT if:

- Your PSA levels are rising after initial treatment
- Other scans haven't found the source of rising PSA
- You're considered high-risk based on your PSA doubling time or other factors
- Treatment decisions depend on knowing if/where cancer has spread

# 2. "Is PSMA-PET/CT scanning available in my area?"

Possible answer: While this technology is becoming more widely available, it's not yet at all treatment centers. Your doctor can tell you about:

- Local availability
- Need for referral to another center
- Insurance coverage and costs
- Alternative options if it's not available

# 3. "How might finding previously undetected cancer spread change my treatment?"

Possible answer: Finding spread could lead to:

- Changes in treatment approach
- Different medication choices
- More targeted radiation therapy
- Adjustments to hormone therapy plans

# 4. "What are the limitations of PSMA-PET/CT scanning?"

Possible answer: Important considerations include:

- False positives can occur (around 16% of cases)
- Not all insurance plans cover it yet
- May not detect very small cancer deposits
- Interpretation requires special expertise

# 5. "Should I wait for a PSMA-PET/CT scan before starting or changing treatment?"

Possible answer: This depends on:

- How urgent your treatment needs are
- Your risk level
- Current symptoms
- Available treatment options

## *Key Takeaways for Patients*

1. PSMA-PET/CT is a more sensitive tool for detecting prostate cancer spread
2. It may be especially valuable for high-risk patients

3. The results could affect treatment choices
4. Not everyone needs this type of scan
5. Discuss with your doctor whether it's appropriate for your specific situation

### **Working with Your Healthcare Team**

- Keep track of your PSA levels and how quickly they change
- Share any new symptoms with your doctor
- Ask about the role of imaging in your care plan
- Discuss how new findings might affect your treatment
- Don't hesitate to ask for explanations of scan results

Remember: This research helps doctors better understand who might benefit from PSMA-PET/CT scanning, but every patient's situation is unique. Your doctor can help determine if and when this imaging would be helpful in your specific case.

## **PSMA-PET/CT Detects Metastatic Prostate Cancer Missed by Other Imaging | MedPage Today**

[medpagetoday.com](https://www.medpagetoday.com)

Senior Editor, MedPage Today

[Oncology/Hematology](#) > [Prostate Cancer](#)

### **— Distant metastases identified in 46% of "negative" cases, including polymetastatic disease in 24%**

by [Charles Bankhead](#), January 6, 2025

Prostate-specific membrane antigen (PSMA)-PET/CT imaging identified metastatic prostate cancer in almost half of high-risk cases missed by conventional imaging, a retrospective analysis showed.

Overall, PSMA-PET/CT detected distant metastasis in 84 of 182 cases (46%) that were negative by other types of imaging, including polymetastatic disease ( $\geq 5$  lesions) in a quarter of patients. PSMA-PET/CT identified metastatic disease in more than half of patients treated with definitive radiotherapy (RT) or by radical prostatectomy and salvage RT.

The findings suggest that patients with high-risk, nonmetastatic, hormone-sensitive prostate cancer (nmHSPC) are frequently understaged by conventional imaging and challenge interpretation of trial results that have relied on conventional imaging, reported Jeremie Calais, MD, PhD, of UCLA Health in Los Angeles, and co-authors in [JAMA Network Openopens in a new tab or window](#).

"PSMA-PET/CT continues to evolve as the most accurate imaging method for staging prostate cancer. Our results underline this is valid also for the hormone-sensitive disease stage," co-author Adrien Holzgreve, MD, also of UCLA Health, told *MedPage Today*. "While the study design and previous evidence do not allow us to consider the findings as practice-changing, they strongly support that PSMA-PET is more sensitive for localizing anatomical sites of biochemical recurrence compared to conventional imaging alone."

"Overall, we need more outcome-validated data to prove a clinical benefit of using PSMA-PET, for example, using survival data," he added. "Yet, our findings illustrate there is a strong rationale for the use of PSMA-PET/CT imaging at biochemical recurrence in patients with high-risk hormone-sensitive prostate cancer."

Proving a clinical benefit with use of PSMA-PET/CT is difficult at this point in the absence of high-quality data.

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"Probably, a high percentage of patients with strong suspicion for a recurrence would benefit from PSMA-PET/CT when conventional imaging shows no evidence of metastatic spread," said Calais. The study encompassed cancers with increased risk of metastatic disease and with an increased risk for shorter survival, and "it may make sense to first focus on these patients with high-risk features, as defined by serum tumor marker levels and histopathological features, for example, as they have a higher clinical need for imaging-based treatment decisions."

In the prostate cancer setting of biochemical recurrence after definitive primary therapy, androgen receptor pathway inhibitors (ARPIs) have demonstrated clinical benefit in both metastatic disease and in patients with no prior exposure to chemotherapy, the authors noted in their introduction to the study. The phase III [EMBARK opens in a new tab or window](#) trial showed that patients treated with single-agent enzalutamide (Xtandi) or the ARPI plus androgen deprivation therapy (ADT) had significant improvement in metastasis-free survival as compared with ADT plus placebo.

Enrollment in EMBARK was based on negative results with conventional imaging, which [underdetects metastatic disease opens in a new tab or window](#) as compared with PSMA-PET/CT.

For their analysis, Calais and colleagues retrospectively analyzed PSMA-PET/CT findings in patients from four prospective studies who met inclusion criteria for the EMBARK trial: increasing PSA level >1.0 ng/mL after radical prostatectomy and salvage radiotherapy or 2.0 ng/mL above the nadir value after definitive radiotherapy, PSA doubling time  $\leq 9$  months, and serum testosterone  $\geq 150$  ng/mL.

Additionally, EMBARK excluded patients with distant metastatic disease (M1) detected by any conventional imaging, prior hormonal therapy (neoadjuvant or adjuvant) for >36 months at the time of definitive RT, more than 6 months of short-course ADT with less than 9 months of washout before randomization, or advanced systemic therapy for prostate cancer.

Data analysis included 182 patients who had a median pre-scan PSA level of 2.6 ng/mL. Overall, 84% of the patients had positive PSMA-PET/CT results, including 80% (73 of 91) after radical prostatectomy, 92% (36 of 39) after definitive RT, and 85% (44 of 52) after radical prostatectomy and salvage RT. PSMA-PET/CT detected distant metastatic disease in 46% (84 of 182) of the patients, including 34% after radical prostatectomy, 56% after definitive RT, and 85% after radical prostatectomy and salvage RT.

PSMA-PET/CT detected polymetastatic disease in 24% (43 of 182) of patients, including 19% after radical prostatectomy, 36% after definitive RT, and 23% after prostatectomy and salvage RT.

PSMA-PET/CT has been evaluated more extensively in castration-resistant prostate cancer (CRPC). Although results from the current analysis cannot be directly extrapolated to the nonmetastatic CRPC setting, published data support use of PSMA-PET/CT in selected patients with nmCRPC.

"Our conclusions are sound for both disease stages and underline the high value and potential broad applicability of PSMA-PET/CT," said Calais.

Holzgreve said more studies are needed to refine patient selection criteria for PSMA-PET/CT and to demonstrate a clinical benefit.

"This will also help to assess the cost-effectiveness of PSMA-PET/CT and to further facilitate its implementation in clinical guidelines and routine practice," he said. "We currently assess the long-term follow-up data for the patient cohort that we analyzed in this study. Several efforts are made in our and other institutions to corroborate the prognostic value of PSMA-PET."

"We are part of a large international consortium investigating the prognostic impact of PSMA-PET in comparison to established clinical prognosticators," Holzgreve continued. "So far, more than 6,000 patients have been included. The analysis suggests that PSMA-PET outperforms established clinical prognosticators."

[Charles Bankhead](#) is senior editor for oncology and also covers urology, dermatology, and ophthalmology. He joined MedPage Today in 2007. [Follow](#)

(Continued on page 8)

## New Study Shows ERLEADA® Outperforms Competitors in Metastatic Prostate Cancer Treatment

A comprehensive real-world study has revealed that ERLEADA® (apalutamide), manufactured by Janssen Pharmaceutical Companies of Johnson & Johnson, significantly outperforms other treatments for metastatic prostate cancer, including a direct survival advantage over enzalutamide.

The research, published in *Prostate Cancer and Prostatic Diseases*, analyzed nearly 5,000 patients and found that 66% of those treated with ERLEADA® plus androgen-deprivation therapy (ADT) were alive at the two-year mark, compared to 55% for patients on enzalutamide and 59% for those receiving abiraterone acetate plus prednisone with ADT.

A separate head-to-head retrospective analysis of 3,719 patients, presented at the European Conference of Oncology Pharmacy, showed that ERLEADA® reduced the risk of death by 23% compared to enzalutamide at 24 months. "This real-world evidence showed a statistically significant and clinically meaningful improvement in survival with apalutamide over enzalutamide," noted Dr. Neal Shore, medical director at the Carolina Urologic Research Center.

Patients taking ERLEADA® achieved superior treatment responses, with 70% showing significant PSA reduction at three months, compared to 60% for enzalutamide. Additionally, 49% achieved a 90% reduction in PSA levels, demonstrating deeper response to the therapy.

The findings coincide with Janssen's introduction of a new 240mg single-tablet option for ERLEADA®, making it the first-and-only once-daily, single-tablet androgen receptor inhibitor approved for these patients. "Each person and their cancer are unique and, as such, there is no one-size-fits-all approach to treatment," said Dr. Luca Dezzani, Vice President of Medical Affairs at Janssen Scientific Affairs, LLC.

Since its FDA approval in 2019, more than 100,000 patients worldwide have been treated with ERLEADA®. However, the research revealed that many patients still receive ADT alone, despite current medical guidelines recommending combination therapy. The study's findings strongly suggest that ERLEADA® plus ADT should be considered as a preferred first-line treatment option for suitable patients with metastatic prostate cancer.

### Survival outcomes of apalutamide as a starting treatment: impact in real-world patients with metastatic hormone sensitive prostate cancer (OASIS) | Prostate Cancer and Prostatic Diseases

[nature.com](https://www.nature.com)

Karsh, Lawrence I.

*Understanding Your Treatment Options for Metastatic Prostate Cancer: Latest Research Findings Key Findings About ERLEADA® (apalutamide) + ADT:*

- Better survival rates: 66% of patients were alive at 2 years
- Faster response: 70% of patients showed significant PSA reduction within 3 months
- Reduced death risk: 23% lower risk of death compared to enzalutamide
- Available as a convenient once-daily single tablet (240mg) or four 60mg tablets

*Questions to Ask Your Oncologist*

1. "Am I currently receiving combination therapy or ADT alone?"
  - A: You might be on ADT alone, but research shows better outcomes with combination therapy
2. "Would ERLEADA® be appropriate for my specific situation?"
  - Your doctor will consider:
    - Your current stage of cancer



- Overall health and medical history
  - Other medications you're taking
  - Previous treatments you've received
3. "What are my PSA levels, and how often should we monitor them?"
- Regular PSA monitoring helps track treatment effectiveness
  - Research shows ERLEADA® can help achieve deeper PSA responses
4. "What side effects should I watch for?"
- Common side effects include:
    - Fatigue
    - Joint pain
    - Rash
    - Decreased appetite
    - Falls
    - High blood pressure
5. "How will we know if the treatment is working?"
- Your doctor may look for:
    - PSA level changes
    - Imaging results
    - Physical symptoms
    - Regular check-ups
6. "If I have trouble swallowing pills, what are my options?"
- ERLEADA® can be taken:
    - As a single 240mg tablet
    - With applesauce
    - With orange juice
    - Through a feeding tube if necessary
7. "How does the cost compare to other treatments, and is it covered by my insurance?"
- Ask about:
    - Insurance coverage
    - Financial assistance programs
    - Out-of-pocket costs

Remember to:

- Keep track of any side effects you experience
- Maintain a record of your PSA levels
- Discuss any concerns about your treatment plan with your healthcare team
- Bring a family member or friend to appointments to help take notes and ask questions

This summary is based on recent research, but individual results may vary. Always consult with your healthcare team for personalized medical advice.

## NETWORKING

Please help us in our outreach efforts. Our speakers bureau is available to speak to organizations of which you might be a member. Contact me at [Newsletter@ipcsg.org](mailto:Newsletter@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>

Our brochure provides the group philosophy and explains our goals. Copies may be obtained by mail or email on request. Please pass them along to friends and contacts.

## 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