

SUMMER 2024

NEWS FROM THE MGH FRONTEMPORAL DISORDERS UNIT

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## LEADS FAMILY MEETING

**LEADS**   
Longitudinal Early-Onset  
Alzheimer's Disease Study

**LEADS** and the **Alzheimer's Association** are hosting the **LEADS Family Meeting** on Saturday September 7th. This **hybrid** event is designed for anyone impacted by young-onset dementia (symptom onset before age 65) including but not limited to LEADS participants, their families, caregivers, researchers, clinicians. Attendees will have the opportunity to share insights and experiences with each other and with researchers in the field.

The **in-person** event will begin at 11:00 am at MGH Charlestown Navy Yard, 149 13th St., Boston, MA. Parking and lunch will be provided. The **online** event will begin at noon. Register for the **free** in-person event by emailing Katie Brandt at [katherine.brandt@mgh.harvard.edu](mailto:katherine.brandt@mgh.harvard.edu). Register for the online event **here**.

## Dear FTD Unit Community Members,

As August winds down, I've been reflecting on what the summer has brought and what I'm looking forward to this fall. Shortly after the summer solstice, I was privileged to perform as part of the Wall of Grass fundraiser honoring Stu Kimball, Bob Dylan's longtime tour guitarist and MGH FTD Unit research participant. Despite living with young-onset Alzheimer's disease, Stu makes the most of every day and continues to create beautiful music. You can read more about Wall of Grass on page 2 of this newsletter.



In late July, I headed to the Alzheimer's Association International Conference in Philadelphia with many members of the Unit. Our team presented research findings in scientific and poster sessions. We also took the opportunity to learn about the latest advances in research into frontotemporal degeneration, Alzheimer's disease and related dementias. We share some of our experience at AAIC on page 3.

Looking ahead, as we have highlighted in prior newsletters and notes, the MGH FTD Unit is part of many multi-center research studies. One of these studies, the Longitudinal Early-Onset Alzheimer's Disease Study (LEADS), is hosting a nationwide Family Meeting on **Saturday September 7th**. I'm proud to announce that the MGH FTD Unit will be hosting an **in-person** gathering for this meeting and I will be presenting to the meeting from our in-person conference location at MGH. See the article to the left to learn more.

*A Night with the Arts for FTD* will be returning to its traditional October timeframe this year. We will be gathering at the Royal Sonesta in Cambridge once again for the **ninth** annual fundraising gala and art show on October 25th. (See more on pages 4 and 5.) I hope you will join us for this special evening.

We appreciate your continued engagement with our clinic and research programs. We hope to see you at an event, in clinic or online soon! Until then, take care and be well.



Bradford C. Dickerson, MD  
Director, MGH Frontotemporal Disorders Unit

# Wall of Grass Honors Stu Kimball



Stu Kimball, a fixture of Boston’s music scene and a 15-year veteran of Bob Dylan’s touring and recording band, was the featured guest artist with local folk-rock collective Wall of Grass at a fundraiser for the MGH FTD Unit on Thursday, June 27th, at the Boston Harbor Distillery. During the concert, Stu collaborated with Dr. Brad Dickerson, the director of the MGH FTD Unit and world-renowned neuroscientist in the field of Alzheimer’s and related dementias, in a moving rendition of the Dylan classic “Forever Young.” The concert was sold out and, due to overwhelming demand, a livestream option was added to allow engagement from around the world. A recording of the event is now available to watch on the MGH FTD Unit’s YouTube channel.

Stu’s commitment to the MGH FTD Unit is not just musical. After his diagnosis with young-onset Alzheimer’s Disease in 2020, he became part of the Unit’s ongoing research program. Stu hopes the research he is part of can provide insight for the treatment of others, explains Michelle Kimball, his wife. “Early detection is extremely important. It can mean months or years of a higher quality of life for people who are sick and for their loved ones.”



## Miles for Mike

Mike Gordon was a kind, genuine and compassionate gentleman who was always there to offer help to anyone, especially his children, siblings and friends. A hard working man during the week, Mike turned to leisure on his days off and weekends. He enjoyed snowmobiling, boating, walking, fishing, traveling, dining out and taking quiet Sunday drives to nowhere in particular with his beloved wife, Shirley. He passed away in June 2020, having lived with FTD for fourteen years. Like many caregivers, Shirley wanted to give back to the community that had assisted her and Mike’s journey with FTD and launched Miles for Mike in 2021. This virtual walk raises awareness of FTD and funds for the MGH FTD Unit and occurs in late July each year to celebrate Mike’s birthday.

The fourth annual Miles for Mike was celebrated on July 28th this year. Since its founding, Miles for Mike has raised over \$26,000 for the clinical research and care efforts of the MGH FTD Unit. Dr. Brad Dickerson, director of the unit, shares that “efforts to raise funds through Miles for Mike are invaluable. As a rare disease, the field of Frontotemporal Dementia needs people like Shirley who are committed to raising awareness and philanthropy. Thanks for the incredible work!”



Shirley Gordon prepares a reception for participants in the fourth annual Miles for Mike fundraiser on July 28, 2024.

# The MGH FTD Unit at the Alzheimer's Association International Conference

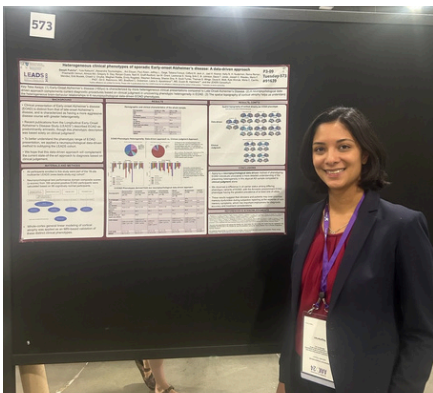


The Alzheimer's Association International Conference (AAIC) is the largest international meeting dedicated to advancing dementia science and clinical practice. Each year, researchers, clinicians and dementia professionals from all career stages meet at AAIC to share breaking research discoveries and clinical practice education that will lead to improvements in diagnosis, risk reduction and treatments for Alzheimer's disease and other

dementias. From basic science to dementia care, every aspect of the field's growing knowledge of dementia is incorporated into this world-class conference.



Member of the MGH FTD Unit gathered with researchers from across the U.S. at the LEADS Investigator Meeting where they made plans for the next phase of the LEADS Study, including the addition of international site locations



Dr. Deepti Putcha, Director of the MGH PCA program, presents her poster on "Heterogeneous clinical phenotypes of sporadic Early-onset Alzheimer's disease: A data-driven approach"

Katie Brandt and Dr. Nequine Rezaii enjoy mingling with thousands of scientists working towards a cure for FTD, Alzheimer's disease and related dementias.



If you'd like to learn more about the scientific advances that were announced at AAIC this year, the MA/NH Chapter of the Alzheimer's Association has a podcast for you! The Speaking of

Alzheimer's podcast presented "AAIC: Latest Breakthroughs in Dementia Research" with Dr. Rebecca Edelmayer, Vice President of Scientific Engagement for the Alzheimer's Association. Dr. Edelmayer shared developments in blood tests to diagnose Alzheimer's disease, how GLP-1 drugs (a class of drugs treating diabetes and weight loss) may also protect the brain, advances in tau research, and more.



# A Night with the Arts for FTD



**Join Us**

You are invited to  
**MGH Frontotemporal Disorders Unit**  
**NINTH ANNUAL GALA EVENT**  
**A NIGHT WITH THE ARTS FOR FTD**  
Featuring  
**SERMOS MEMORIAL ART SHOW**  
Dinner, Live Music, Live Auction & More!  
**FRIDAY, October 25, 2024 • 6:00PM**  
THE ROYAL SONESTA HOTEL – 40 EDWIN LAND BOULEVARD, CAMBRIDGE, MA  
*Black Tie Optional*  
Tickets and Sponsorships: [Because.MassGeneral.org/FTDGala2024](https://Because.MassGeneral.org/FTDGala2024)  
Questions? Email [Katherine.Brandt@mgh.harvard.edu](mailto:Katherine.Brandt@mgh.harvard.edu)  
All proceeds to benefit the MGH Frontotemporal Disorders Unit

MASSACHUSETTS GENERAL HOSPITAL  
FRONTOTEMPORAL DISORDERS UNIT



# Frequently Asked Questions about A Night with the Arts for FTD



**Q:** Are persons with Frontotemporal Disorders welcome at *A Night with the Arts for FTD*?

**A:** Yes! This is a community event and we welcome persons with FTD, caregivers, family members, friends, colleagues, and industry members. Everyone is welcome to join us as we raise awareness, funds and hope for the cure for FTD!

**Q:** Are children welcome at *A Night with the Arts for FTD*?

**A:** All children are welcome at *A Night with the Arts for FTD* and we have enjoyed having older children attend our

gala event in the past. Please be aware that our event runs late in the evening and includes a speaking program that has been over an hour long.

**Q:** I have dietary restrictions, will I be able to enjoy the provided dinner?

**A:** Reach out to [Katherine.Brandt@mgh.harvard.edu](mailto:Katherine.Brandt@mgh.harvard.edu) for special dietary accommodations by October 20, 2024. On the night of the event, when you sit at your assigned table, speak to your server about any dietary restrictions (allergies, vegetarian, etc) and the Sonesta staff will be able to assist you.

**Q:** Is this donation tax deductible?

**A:** Massachusetts General Hospital is a 501(c)3 tax-exempt organization and your donation is tax-deductible within the guidelines of U.S. law. To claim a donation as a deduction on your U.S. taxes, please keep your email donation receipt as your official record. We'll send it to you upon successful completion of your donation.

**Q:** Is there a block of hotel rooms available to guests of *A Night with the Arts for FTD*?

**A:** There is no block of rooms available but the Royal Sonesta has provided a discount code for guests of *A Night with the Arts for FTD*. If you are interested in reserving a hotel room, please contact Katie Brandt at [Katherine.Brandt@mgh.harvard.edu](mailto:Katherine.Brandt@mgh.harvard.edu) to receive the code.

**Please reach out to Katie Brandt at [Katherine.Brandt@mgh.harvard.edu](mailto:Katherine.Brandt@mgh.harvard.edu) if you have additional questions about *A Night with the Arts for FTD*.**



## CAREGIVER SUPPORT GROUP TUESDAYS

Are you caring for a loved one living with Frontotemporal Dementia, atypical Alzheimer's Disease, or a related disorder? Our weekly online support groups meet for an hour over Zoom to provide care for the caregiver. Join us every week, or just once. You can attend on a schedule that works for you. We are here to offer support, resources and connections to our caregiver community at every stage of the journey with dementia.

We hope to see you soon.

**Registration Is required.** Please email [FTD.Boston@gmail.com](mailto:FTD.Boston@gmail.com) to register for this free resource.



## UPCOMING CAREGIVER SUPPORT GROUPS Tuesdays @ 10: 00 am Tuesdays @ 7: 00 pm

September 3, 17  
October 1, 15, 22  
November 5, 19  
December 3, 17  
January 7, 21  
February 4, 18  
March 4, 18

August 27  
September 10, 24  
October 8, 29  
November 12, 26  
December 10  
January 14, 28  
February 11, 25  
March 11, 25

## KNOWLEDGE AT YOUR FINGERTIPS: THE MGH FTD UNIT YOUTUBE CHANNEL

Our clinical research team is committed to empowering our community with information to navigate life lived with a dementia diagnosis. We know how busy your lives are. To make these educational resources easily accessible, we have launched an MGH FTD Unit YouTube Channel.

Subscription is free! We look forward to connecting with you online, building community and knowledge, together.



Subscribe to the MGH FTD Unit YouTube Channel today! [YouTube.com/@MGHFTDUnit](https://www.youtube.com/@MGHFTDUnit)



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MGH FTD Unit

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## LEARN MORE ABOUT RESEARCH

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