

SPRING 2024

NEWS FROM THE MGH FRONTEMPORAL DISORDERS UNIT

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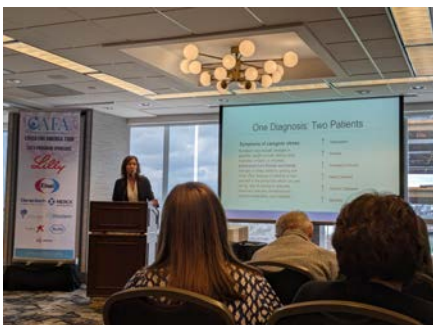
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THE MGH FTD UNIT IN THE COMMUNITY

On Wednesday, June 12th, Katie Brandt, MM was a panelist at the Alzheimer's Foundation of America's Educating America Tour when the tour stopped in Boston. Before the event, Ms. Brandt penned an [opinion piece](#), published in the Boston Herald on June 5th, that called for greater support for family caregivers. See page 3 to learn more about AFA's Educating America Tour.



Katie Brandt appeared on the WCVB 5:00 news to promote the Alzheimer's Foundation of America's Educating America Tour.



Ms. Brandt spoke about the caregiver trifecta and empowering families to plan at every stage of dementia.

Dear FTD Unit Community Members,

We are excited about the opportunity to connect with you to share news and updates from our clinical research program.



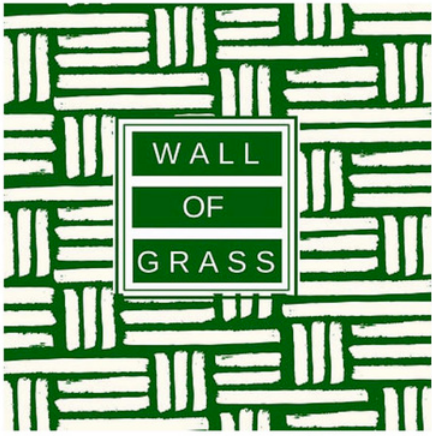
The month of June brings with it the summer solstice, a day with more hours of sunshine than any other day of the year. The Alzheimer's Association recognizes this moment of extended light as a catalyst for their campaign, [The Longest Day](#), recognizing our community's ability to fight the darkness that a diagnosis of Alzheimer's, FTD or a related dementia may bring. This year, I have more hope than ever that the dawn of a new era of treatment is just over the horizon. As a part of my role as an educator for clinicians in the wider neurology community, I have the privilege of co-directing the Harvard Medical School Dementia Course. This four-day course brings together leading experts across the United States and around the world to provide targeted education to clinicians in multiple fields of practice about the diagnosis, care and management of dementia. The syllabus for the Course follows a rigorous curriculum, beginning with the biology of dementia, diagnosis and treatment, ultimately leading to issues related to social work and hospice. What was so inspiring at this year's course was the addition of presentations about the newest therapeutics to provide treatment for Alzheimer's disease. These new treatments are not a cure but the first of their kind to receive FDA approval to address the underlying biology of Alzheimer's, changing the course of the disease in a meaningful way for people in the early stages. Many attendees expressed optimism about the future of care for Alzheimer's disease and related dementias. It reminded me of the incalculable gifts that patients, caregivers and families have contributed by participating in the research and clinical trials that led to the approval of these drugs.

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

Upcoming Community Events



Thursday June 27, 2024 Boston Harbor Distillery

Stu Kimball, a fixture of Boston’s music scene and a 15-year veteran of Bob Dylan’s touring and recording band, will be the featured guest with local folk-rock collective Wall of Grass at a fundraiser for the MGH FTD Unit, dedicated to early-onset Alzheimer’s disease research, on Thursday, June 27, at the Boston Harbor Distillery at 8 p.m. The in-person show is sold out but due to overwhelming demand, a **livestream option** has been added. In appreciation for contributing \$20 or more to the MGH FTD Unit, donors will receive a link to the concert livestream.

This is the latest fundraiser by Wall of Grass, which is dedicated to giving back to the community through music and routinely includes an A-list of Boston-

based musicians, including Joe Donnelly, Sal Baglio, Susan Cattaneo, Jamie Walker, Kelly Knapp, Jimmy Ryan, Laurie Sargent, and many others.

Stu’s commitment to the MGH FTD Unit is not just musical. After his diagnosis with early-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.”

Stu is probably most well-known as Bob Dylan’s tour guitarist after playing a record 1,323 shows with the legend and contributing his playing to the Grammy-winning Modern Times and other Dylan albums. Stu’s years as an important member of the Boston and international music scene—as a guitarist, singer-songwriter, and producer — span five decades. He has played on sessions for Al Green, Stevie Nicks, Diana Ross, Carly Simon, Nona Hendryx, Darlene Love, Clarence Clemons, and Arthur Baker, and toured and produced albums with Peter Wolf and Carly Simon.

Stu continues to perform as much as possible, and still finds the same joy in making and sharing music that he has for all his life. “I always try to play from the heart, to play with soul and conviction,” he says. On June 27th, Stu will be playing with joy and purpose that the cure of tomorrow is not so far from the care of today.



Wednesday July 17, 2024

Fruitlands Museum Harvard, MA



Join your friends from the Boston-area FTD community for an outdoors, in-person concert by the Concord Band at the Fruitlands Museum featuring music composed by John Williams and John Philip Sousa. The concert will start at 7:15 pm but you are welcome to join us for a BYO picnic beforehand. Gates open at 5:00 pm. Admission to the concert is \$15/carload for members of the Trustees and \$20 for non-members. In the event of rain forcing cancellation, all ticket holders will be contacted by the Trustees via email in advance of showtime.

Recent Educational Events about FTD and Dementia

LEADS

Longitudinal Early-Onset Alzheimer's Disease Study

LEADS held its Early-Onset Dementia Family Meeting in January 2024 in conjunction with the Alzheimer's Association. This conference was intended for patients, families and caregivers impacted by early-onset dementia and offered attendees information and opportunities to share insights and experiences with each other as well as with researchers in the field.

Conference sessions on topics such as scientific progress and community resources are now available on the [LEADS website](#).



In April 2024, the MGH FTD Unit, with MADRC and Union Capital Boston, presented *Noche de Cine y Charla sobre la Demencia de Inicia Temprano* (Movie Night and Discussion about Early-Onset Dementia). The event consisted of a screening of the short film *Pedacito de Carne*, a drama that follows a young Hispanic woman caring for her mother, as both adjust

to their new roles, followed by a live Q&A session with the filmmakers and an MGH Neurology Department clinician to raise awareness about young-onset dementia, its impact on caregivers and brain health for all. **This event was conducted in Spanish.** The Q&A is now available to watch on the MGH FTD Unit's [YouTube channel](#). If you don't understand Spanish, you can use YouTube's auto-translate feature to read subtitles in your preferred language.



AFTD held its 2024 Education Conference in Houston in May. This conference offered a unique opportunity to connect with people who understand the journey, learn about available resources and supports, and engage with experts to gain insight on the latest in FTD research and approaches to care. All of the keynote remarks and many of the breakout sessions were recorded and are now available to watch on [AFTD's YouTube channel](#).

Something new this year was a [fireside chat](#) between Emma Heming Willis, the caregiver for her husband, Bruce Willis, and AFTD CEO Susan L-J Dickinson. During this fireside chat, Ms. Heming Willis discussed the journey to diagnosis, the outpouring of support from Bruce's fans throughout the world, and her resolve to work on behalf of AFTD's community and all families affected by this disease.



The [Alzheimer's Foundation of America](#) brought its [Educating America Tour](#) to Boston in June. The Tour connects communities across the country with information about Alzheimer's disease, brain health, caregiving and more. Dr. Andrew Budson spoke about the importance of research and early diagnosis. Katie Brandt, MM explained what the Caregiver Trifecta is and how to empower families to plan for personhood, dignity and connection at every stage of care. Molly Perdue, Ph.D. described how to keep caregivers healthy and shared modifiable risk factors for cognitive loss. A [video recording](#) of the conference is now available.

Learn more about the caregiving resources available from the Alzheimer's Foundation of America [here](#).

A Night with the Arts for FTD



Join Us

MASSACHUSETTS GENERAL HOSPITAL
FRONTOTEMPORAL DISORDERS UNIT

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
Questions? Email Katherine.Brandt@mgh.harvard.edu

All proceeds to benefit the MGH Frontotemporal Disorders Unit



Artists Wanted for Sermos Memorial Art Show



The story of Kemon Sermos and Sybil Falk Sermos is a legacy of love, creativity and generosity. Life-long artists, Kemon and Sybil exhibited their art at shows across New England. When Kemon was diagnosed with Frontotemporal Dementia (FTD) in 2014, Sybil characteristically responded by turning to art to process the changes the disease would potentially have on their lives. *A Night With the Arts for FTD* was sparked by Kemon and Sybil's vision to use art as a way to honor the human experience and recognize the capacity of all individuals to create, regardless of cognitive capacity.

Sybil and Kemon passed away in 2020 and 2021 respectively. In 2021, the MGH FTD Unit was honored to recognize their many contributions to our search for a cure by dedicating the Sermos Memorial Art Show in their memory. This patient- and caregiver-centered art show continues Kemon and Sybil's legacy of love, creativity and generosity.

If you or a loved one is an artist and would like to show your work in the Sermos Memorial Art Show at *A Night With the Arts for FTD* on Friday October 25th, contact Katie Brandt at Katherine.Brandt@mgh.harvard.edu for more information.



Jerry Horgan Walks for FTD

When Jerry Horgan was younger, he cycled across the United States to raise money for hemophilia research. When his wife Kelly was diagnosed with frontotemporal dementia (FTD), Jerry used the endurance and perseverance he developed during that bike ride to care for her.

After Kelly's death in January 2023, Jerry wanted to celebrate her life and raise awareness about FTD. After thinking about it and training, he decided to walk from Portland, ME to the main campus of MGH in Boston, MA. Over nine days, Jerry walked 116 miles, finishing on a beautiful June day. Across these miles, he met many people and shared the story of Kelly's journey with FTD. After hearing his account, numerous people made donations to the MGH FTD Unit in Kelly's memory. Jerry's endeavor raised over \$10,000 for the clinical care and research efforts of the MGH FTD Unit. While relaxing after the completion of the walk and reflecting on the generosity of the strangers he met, Jerry noted that "when people see goodness in the world, it brings out the goodness in them."

Jerry, thank you for your goodness!



Jerry Horgan in New Hampshire during his 116 mile Walk for FTD



Jerry and Emily Horgan at MGH after Jerry's walk to raise awareness, funds and hope that the cure of tomorrow is not so far from the care of today.

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 to register for this free resource.



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

July 2, 16, 23

August 6, 20

September 3, 17

October 1, 15, 22

November 5, 19

December 3, 17

June 25

July 9, 30

August 13, 27

September 10, 24

October 8, 29

November 12, 26

December 10

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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