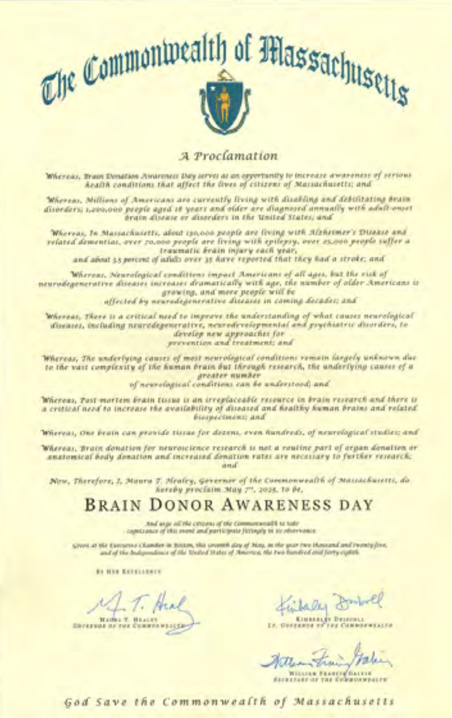
MASSACHUSETTS GENERAL HOSPITAL
FRONTOTEMPORAL DISORDERS UNIT

FROM CARE TO CURE

SPRING 2025 NEWS FROM THE MGH FRONTEMPORAL DISORDERS UNIT

INSIDE THIS ISSUE



The Commonwealth of Massachusetts

A Proclamation

Whereas, Brain Donation Awareness Day serves as an opportunity to increase awareness of serious health conditions that affect the lives of citizens of Massachusetts; and

Whereas, Millions of Americans are currently living with disabling and debilitating brain disorders; 1,200,000 people aged 18 years and older are diagnosed annually with adult-onset brain disease or disorders in the United States; and

Whereas, In Massachusetts, about 130,000 people are living with Alzheimer's Disease and related dementias, over 70,000 people are living with epilepsy, over 25,000 people suffer a traumatic brain injury each year, and about 3.5 percent of adults over 35 have reported that they had a stroke; and

Whereas, Neurological conditions impact Americans of all ages, but the risk of neurodegenerative diseases increases dramatically with age, the number of older Americans is growing, and more people will be affected by neurodegenerative diseases in coming decades; and

Whereas, There is a critical need to improve the understanding of what causes neurological diseases, including neurodegenerative, neurodevelopmental and psychiatric disorders, to develop new approaches for prevention and treatment; and

Whereas, The underlying causes of most neurological conditions remain largely unknown due to the vast complexity of the human brain but through research, the underlying causes of a greater number of neurological conditions can be understood; and

Whereas, Post-mortem brain tissue is an irreplaceable resource in brain research and there is a critical need to increase the availability of diseased and healthy human brains and related biospecimens; and

Whereas, One brain can provide tissue for dozens, even hundreds, of neurological studies; and

Whereas, Brain donation for neuroscience research is not a routine part of organ donation or anatomical body donation and increased donation rates are necessary to further research; and

Now, Therefore, I, Maura T. Healey, Governor of the Commonwealth of Massachusetts, do hereby proclaim May 7th, 2025, to be,

BRAIN DONOR AWARENESS DAY

And urge all the citizens of the Commonwealth to take cognizance of this event and participate fittingly in its observance.

Given at the Executive Chamber in Boston, this seventh day of May, in the year two thousand and twenty-five, and of the Independence of the United States of America, the two hundred and forty-eighth.

BY HER EXCELLENCY

MAURA T. HEALEY
GOVERNOR OF THE COMMONWEALTH

KIMBERLEY DRISCOLL
LT. GOVERNOR OF THE COMMONWEALTH

WILLIAM FRANCIS GALVIN
SECRETARY OF THE COMMONWEALTH

God Save the Commonwealth of Massachusetts

Governor Maura Healey proclaimed May 7th as Brain Donor Awareness Day in Massachusetts.

Click on the image to go to the **MGH FTD Unit website** in order to read the text of the proclamation.

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.

Although most people know the old adage about "April showers bringing May flowers," probably not too many people know that May also brings Brain Donor Awareness Day. This year, Governor Maura Healey proclaimed May 7th to be Brain Donor Awareness Day in Massachusetts. (You can read more about it below.) In this issue, we are highlighting our brain donation program, sharing some messages from families who have participated in brain donation and the role brain donation plays in educating the next generation of neuropathologists. If you have not considered brain donation, I hope these articles can begin a conversation within your family and with our clinic.

As we roll into nicer weather, we want to encourage everyone to get out and enjoy it. We recognize that it can be difficult for people walking the journey of FTD and related conditions to exercise in the way they used to, so we identify several adaptive sports organizations this month.

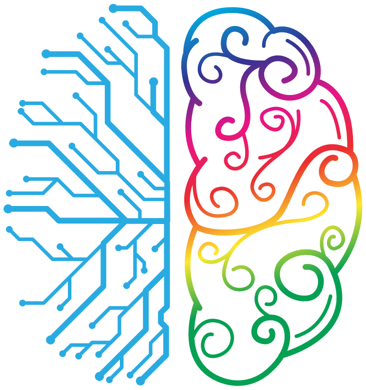
We also spotlight Lorenzo's House, a dynamic non-profit based in Chicago that provides support to families living with younger-onset dementia (YOD) across the US and the world. Lorenzo's House offers online support groups for children (4 – 35+ years old) of a parent or guardian living with YOD as well as the carepartners of these individuals. This is an incredible organization providing vital services to an underserved group touched by dementia.

Finally, I want to encourage everyone to watch the keynote address Katie Brandt presented at AFTD's 2025 Education Day. Katie shared how dementia has shaped her life. Katie ended her speech with the hopeful message that "Love will end FTD!" It's available now on AFTD's **YouTube channel**.

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

The Gift of Brain Donation



The MGH Frontotemporal Disorders Unit is a specialized clinical research program, focused on atypical and young-onset dementias, including Frontotemporal Dementia, Progressive Aphasia, Alzheimer's Disease, and related illnesses. Currently, these diseases do not have treatments to cure, reverse or stop their progression. Our multidisciplinary team of clinicians and researchers is committed to providing care to improve the quality of our patients' lives. The precious gift of brain donation can provide information for research studies conducted by the MGH FTD Unit, as well as for research throughout the United States and internationally.

There are many benefits to brain donation, including:

- Families get closure in terms of understanding what has caused the damage in the brain of their loved one. Many times, an accurate diagnosis can only be confirmed with a brain autopsy.
- Clinicians improve their skills because they learn every time that a clinical diagnosis is contradicted by a brain autopsy. Identifying the differences between pre- and post-mortem diagnoses and reviewing the medical record can help clinicians improve their diagnostic expertise.
- Information from brain autopsy increases the value of the brain scans, neuropsychological testing and other data that has been collected on patients during the course of their disease. For example, for many years, blood has been collected from people during research visits. If a person has donated their brain, researchers are able to go back to those blood samples and identify things that they may not have known to look for at the time.
- Brain donation plays a significant role in the process on training the next generation of neuropathologists. Read the interview with MGH neuropathology fellow Dr. Elizabeth Conner on page 4 to learn more.
- Families struggling with Frontotemporal Degeneration/Dementia and other neurodegenerative disorders often report a feeling of helplessness against the progression of the disease. Participating in research can instill hope and empowerment because it gives families the opportunity to help future generations.

The MGH FTD Unit and our partners at the Massachusetts Alzheimer's Disease Research Center (MADRC) also conduct research on brain aging in healthy adults. MADRC's brain donation program welcomes donations from healthy adults. These healthy brains provide an important comparison against which to differentiate brains from donors diagnosed with neurodegenerative diseases.

If you or your loved one is a patient of the MGH FTD Unit and want to learn more about brain donation, please contact MGHFTDUnit@MGH.Harvard.edu. If you are not affiliated with the MGH FTD Unit and are interested in brain donation, please call MADRC at (617) 726-5571 or email Judy Johanson at jjohanson1@mgh.harvard.edu.

Understanding Brain Donation: An Irreplaceable Gift for Dementia Research

If you are interested in learning more about brain donation, you can watch a conversation between Katie Brandt and Dr. Matthew Frosch, Director of Neuropathology at Mass General Hospital and the Neuropathology Core of the NIA-supported Massachusetts Alzheimer's Disease Research Center on the **MGH FTD Unit YouTube Channel**.

They discuss the logistical, scientific and emotional aspects of brain donation, a topic that is sensitive for many families. We hope this information will empower our community with information that may help them make a choice for an irreplaceable gift.

Families Who Have Participated in Brain Donation Say ...

> My husband was involved in studies from the time he was diagnosed at age 52. As a physician, he wanted to continue to contribute to the medical profession in any way he could. His last contribution was his brain when he died at age 62.

> Appreciate all the incredible work you do!

> In honor of my Mother, who was in the Alzheimer's study for several years, I am currently participating in the study, after her passing.

> We miss her terribly and know she would be honored to have supported brain research.

> When my husband was diagnosed we decided we would do whatever we could to possibly spare another family our fate. His participation in NIH studies and, at his passing, brain donation were simple acts of love and empathy for all those who shared this devastating diagnosis.

> My Mother's wish was to donate her brain, after her passing, which she did, so we can research why a cure hasn't come about yet.

Frequently Asked Questions about Brain Donation

Who can donate to the MGH research program?
Research participants and clinical care patients at MGH are able to donate. This is a donation that contributes meaningfully to our research and the body of knowledge about brain pathology because we have collected extensive information about them during life. Individuals who have been diagnosed with FTD, but have not participated in our program may also be able to donate with coordination from the treating physician.

Is there any cost to the family for donation?
The procedure is done without cost to the family if the individual has been a patient or a research participant at MGH. In some cases, transportation costs can be covered.

Are there special considerations I need to make about my religious beliefs?
All the major religions support organ and tissue donation. Since brain donation is a unique gift, if you have any specific questions or concerns about your religion's position on this issue, you may want to talk with a religious leader of your faith. Special accommodations can be made to respect the time constraints associated with certain faiths. Families are still able to have an open casket ceremony for their loved one who has donated.

Must the brain autopsy be performed at Massachusetts General Hospital?
We encourage research participants to have autopsies performed at MGH, if at all possible. In some cases, we will pay for the cost of transporting the donor to the hospital and, after the autopsy, to the funeral home. If a subject lives at a considerable distance, we will help make different arrangements.

Q&A with Neuropathology Fellow Elizabeth Conner, MD, MPH

Dr. Elizabeth Conner earned bachelor of arts, master in public health and medical degrees from the University of Tennessee. After completing her residency in anatomic pathology at Massachusetts General Hospital (MGH), she joined the MGH Department of Pathology as a neuropathology fellow in July 2024. We sat down with Dr. Conner to understand the importance of brain donation to her training in pathology.

Q: Dr. Conner, thank you for taking the time to speak with us today. What makes MGH a special place for you to train in neuropathology?
A: Happy to be here! As a fellow, the diversity and the different types of diseases and pathologies that we get to see here is amazing. We have opportunities to see a wide variety of neurogenerative diseases and we have a really collaborative group here. We're able to see the neurologic history of the patient and then correlate that with what we see when we examine the brain under the microscope. This gives us a comprehensive approach to how we diagnose neurodegenerative diseases as pathologists.

We also have the opportunity to be a part of a really wonderful education program. The Massachusetts Alzheimer's Disease Research Center's (MADRC) research and education core is comprised of both clinicians and researchers. We not only have a chance to have focused learning about neurodegenerative diseases, but we also have support for research and leadership development. So it's a well-rounded, comprehensive training program.

Q: It sounds like you are learning how to be a clinician and researcher. How do you think participation in MADRC's brain tissue bank will help your career in the future?
A: I have a front row seat in seeing how we operate an Alzheimer's Disease Research Center (ADRC) brain tissue bank and am learning how that works. This brain tissue bank is a vital resource for research and innovation when it comes to neurodegenerative diseases. Being part of that, as a trainee, and actively participating and helping to coordinate brain donations with the ADRC is giving me a deep understanding about how the ADRC runs. As I move forward in my career, it will be critical to be able to take those experiences and that knowledge forward and be able to participate in brain tissue banking. Hopefully, I will have gained the insights to potentially run a program myself in the future.

Q: What is impactful about being a neuropathology fellow?
A: One of the most impactful parts of being involved in MADRC is the ability to work with families and help them to fulfill their loved one's wishes with regard to brain donation. As pathologists, we don't often get the opportunity to speak with patients and families. I'm really grateful to be able to reach out to families and hear their stories as part of the brain donation process.

It really is an honor for me as a neuropathology fellow, to be part of MGH and MADRC, to be able to train here and do that work with families. I know that it will certainly have a lasting impact on me and my career. I'd like to thank all the families who have been part of this really wonderful gift for education and research.

MGH FTD Unit in the Community

Thiago Da Silva Paranhos Pereira, MGH FTD Unit research fellow, presented research about the use of transcranial magnetic stimulation in the treatment of primary progressive aphasia in April at the American Academy of Neurology Annual Meeting in San Diego

Katie Brandt, MC, introduced Dr. Alexandra Touroutoglou at the Harvard College Alzheimer's Buddies Symposium on April 12

Amy Almeida and Katie Brandt at the Harvard College Alzheimer's Buddies Symposium on April 12

Dr. Bonnie Wong, Dr. Alexandra Touroutoglou and Katie Brandt presented at the Harvard College Alzheimer's Buddies Symposium on April 12

FTD Fun at the Fruitlands – June 18, 2025

Join your friends from the Boston-area FTD community for an outdoors, in-person concert by the **Concord Band** at the **Fruitlands Museum** in Harvard, MA on Wednesday, June 18. 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 $24/carload for members of the Trustees and $30 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. The rain date will be July 2.

MGH FTD Unit in the Community

Katie Brandt presented the keynote address at the Alzheimer's Association of Rhode Island's annual Caregiver's Journey Conference on April 17

MGH FTD Unit staff and members of the PCA Program enjoyed a guided tour of de Cordova Sculpture Park on May 8

Katie Brandt, Amy Almeida, Shawn Caron and Chris Milliken at AFTD's annual Education Conference on May 2. Videos of conference sessions are available **HERE**.

Katie Brandt presented the keynote address at AFTD's annual Education Conference on May 2. Watch the video on AFTD's **YouTube Channel**.

Get Ready for Summer with Adaptive Sports Programs

Spaulding Adaptive Sports Centers

Spaulding Rehabilitation offers numerous sports and recreational activities online and in-person across eastern Massachusetts.

Explore a variety of land and water-based sports including cycling, tennis/pickleball, kayaking/canoeing, swimming, running, golf, yoga, and archery in-person.

Dance, fitness, yoga and boxing classes as well as personal training are available online.

View Spaulding's summer adaptive sports program schedule **HERE**.

Eastern Adaptive Sports

Eastern Adaptive Sports (EAS) believes that people with physical and cognitive challenges can live vibrant, active, healthy lives surrounded by family, friends and community who believe a disability is not a limitation, it is an opportunity. Based at Squam Lake in New Hampshire, EAS offers water skiing, cycling and fishing.

MDI Wheelers

MDI Wheelers provides safe and comfortable rides on special electric-assist trikes for people who would like to cycle on the carriage roads of Acadia National Park but need assistance. All rides are free and begin at Eagle Lake.

Waypoint Adventure

Waypoint Adventures prides itself on being a place where "I can't" becomes "Yes, I can!" Waypoint Adventures offers guided, experiential programs tailored to meet people right where they are, providing personal growth and team triumph – as participants discover their purpose, value, strengths, and abilities.

Waypoint Adventures hosts individual and group opportunities in a variety of activities including cycling, hiking, kayaking and canoeing. Waypoint Adventures also rents adaptive sporting equipment like off-road wheelchairs.

Northeast Passage

Northeast Passage empowers people living with disabling conditions to define, pursue and achieve whole life health, community engagement and fulfillment through the purposeful use of sports and recreation. As part of the University of New Hampshire, Northeast Passage also develops and promotes best practices in the fields of therapeutic recreation and adaptive sports.

Northeast Passage offers a variety of individual and team sports and recreation, including archery, cycling, golf, court sports, water skiing, rugby, basketball, lacrosse and soccer. Northeast passage also rents a variety of adaptive equipment.

The Value of Adaptive Sports

My husband Tom and I were very active until he was diagnosed with dementia in 2019. We continued to hike and kayak but as Tom's disease progressed, it became increasing difficult to get him out to do the kind of experiences we had both enjoyed so much. I have always based Tom's care on maximum involvement in fun activities, to the extent he could participate. Tom has participated in adaptive ski and cycling programs that provided him with an opportunity to get out in the fresh air and revisit locations that we had many fond memories of. I hope that these experiences have helped Tom have a better quality of life and mental outlook as we bravely face the inevitable decline that his disease process brings.

– Sarah Chandler

Lorenzo's House: A Resource for Families Living with Younger-Onset Dementia

In 2017, Diana Shulla Cose's husband was diagnosed with younger-onset Alzheimer's. Almost overnight, the entire family dynamic changed with Diana and her 11 and 14 year old sons taking on a new and difficult identity. Overwhelmed as a primary care partner, single mom and breadwinner, Diana recognized the connection and care gap for her family and understood that her family was not alone. Diana became determined to turn so much sorrow into something bright, imagining a place to sustain and heal her family and others like it. Lorenzo's House was founded in 2021 with a motto, 'We Bring Light' representing its aim to shift the narrative from isolation and suffering to connection and joy. It is through the design and implementation of a holistic model including; Youth Initiatives, Carepartner Connections, Memory Academy and Respite & Healing Spaces that Lorenzo's House has created a place to belong – an alliance of families walking a younger-onset dementia diagnosis united – never alone.

VIRTUAL
5TH ANNUAL
LORENZO'S YOUTH SUMMIT
JUNE 20TH & 21ST 2025

What Is Lorenzo's Youth Summit?
A free, virtual worldwide event that unites the daughters and sons of younger-onset dementia. Together, participants create a space to heal in community and advocate for dementia justice. Children of parents living with a young-onset dementia share lived-experiences and build lifelong connections. Participants amplify their collective wisdom and create a more informed and empathetic world.

Panels for parents that are lead by daughters and sons will be new this year.

REGISTER NOW!

Lorenzo's Light Club is a virtual hangout for young people (ages 4-35+) to connect, have fun, share common stories and build an alliance. Groups meet on the 1st Thursday, and the 2nd and 3rd Wednesday.

REGISTER NOW!

Shine On offers a safe space for children, teens and young adults experiencing grief and loss to find connection and community. Together participants share stories, empathize with those who understand and learn healthy expressions of grief and loss. Sessions are designed and facilitated with grief and loss professionals and trained youth leads.

REGISTER NOW!

Services for Adult Carepartners and Spouses

- **Bright Brunch:** A virtual space for female caregiver partners/spouses of a person walking with younger-onset dementia to feel understood, share common stories, exchange resources and cure isolation.
- **Light Lounge:** A virtual space for male caregiver partners/spouses of a person walking with younger-onset dementia to feel understood, share common stories, exchange resources and cure isolation.
- **Shine On:** A virtual space is for adult carepartners/spouses experiencing grief and loss to find connection and community after their person has passed after walking with younger-onset dementia.
- **Music, Movement & Community:** An in-person & virtual interactive experience where music and expression ignite joy, personal connection, learning and fun!

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.

Upcoming Caregiver Support Groups in 2025:

Tuesdays @ 10: 00 am	**Tuesdays @ 7: 00 pm**
May 20	May 27
June 3, 17	June 10, 24
July 1, 15, 22	July 8, 29
August 5, 19	August 12, 26
September 2, 16, 23	September 9, 30
October 7, 21	October 14, 28
November 4, 18	November 11, 25
December 2, 16	December 9, 23

We hope to see you soon.

Registration Is required. Please email FTD.Boston@gmail.com to register for this free resource.

From Care to Cure Podcast

The MGH FTD Unit has launched *From Care to Cure*, a podcast about frontotemporal disorders. The first season features Dr. Brad Dickerson, renowned neuroscientist and director of the MGH FTD Unit, introducing our clinical research program, explaining what FTD is and examining the process of diagnosis. The podcast will feature the voices of our clinical research team and community experts as they discuss key topics such as care care planning, symptom management and available treatments.

The first three episodes are available now on **Spotify** and **Apple Music**. New episodes will drop monthly. Please follow and share with family and friends.

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.

Subscribe to the MGH FTD Unit YouTube Channel today!
YouTube.com/@MGHFTDUnit

SUBSCRIBE

@FTDUnitBoston
@FTDUnitBoston
@FTDBoston
YouTube.com/@MGHFTDUnit

CONTACT US

MGHFTDUnit@MGH.Harvard.edu

LEARN MORE ABOUT RESEARCH

www.FTDBoston.org