



WINTER 2024

NEWS FROM THE MGH FRONTEMPORAL DISORDERS UNIT

INSIDE THIS ISSUE

Upcoming Events | 2
All About ALLFTD | 3
Community Support | 4

THE MGH FTD UNIT IN THE COMMUNITY

On Friday, March 15th, Dr. Brad Dickerson and Katie Brandt, MM will be presenting “Dementia in Middle Age: Updates on Frontotemporal Dementia & Early Onset Alzheimer’s Disease” as part of the Massachusetts Alzheimer’s Disease Research Center’s (MADRC) webinar series *Talk with the Doc(tor)*.

In this webinar, Dr. Dickerson and Ms. Brandt will address:

- Types of Frontotemporal Dementia (FTD) and Early Onset Alzheimer’s Disease
- (EOAD)
- Causes of FTD & EOAD
- Approved and experimental treatments for FTD and EOAD
- The unique care and support needs of people and families living with young onset dementia

Learn more and register now at bit.ly/TWTDMarch2024 or use the QR code below.



Dear FTD Unit Community Members,



We appreciate the opportunity to connect with you through our first newsletter of 2024. This issue comes out before International Rare Disease Day,

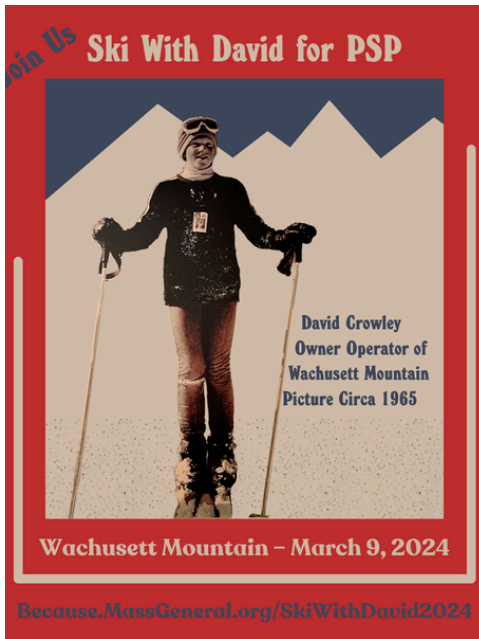
which will be celebrated globally on February 29th, the rarest day of the year. This is a special day in our community because many of the patients we care for are living with a rare condition. We know that living with a rare diagnosis can increase feelings of isolation and loneliness and that is why we are committed to developing community events that build connections and support for persons living with a diagnosis, caregivers and family members. All care doesn’t happen in the clinic and joining an online or in-person community event can provide essential support to cope with the challenges that life lived with FTD or a related condition presents. It is a reminder that alone we are rare, but together we are strong.

On page 2 you will read about our upcoming events, beginning on March 9th when the Crowley Family will host *Ski with David for PSP* at Wachusett Mountain to raise awareness, funds and hope for a cure for Progressive Supranuclear Palsy (PSP). On April 25th, our community will gather in-person and online for *Noche de Cine*, a community event presented in Spanish and centered around the screening of *Pedacito de Carne*, a short film that shines the spotlight on a Hispanic family’s FTD experience. This is an example of one of our efforts to reach families in our local community and around the world who would benefit from expert information delivered in multiple languages. FTD affects individuals living in diverse cultures and we hope to create opportunities that expand access to high quality care, research engagement and caregiver support. We look forward to hearing from our community members with ideas for additional ways that we can expand these efforts.

We hope to see you at a community 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



Saturday March 9, 2024

Wachusett Mountain

Join David Crowley and his family at Wachusett Mountain for an afternoon in support of MGH. *Ski with David for PSP* will feature a ski race and raffle.

As the co-owner and operator of Wachusett Mountain, David's career and life mission has been to share the joy of skiing with the world. However, several years ago, that joy seemed to be on the verge of being taken away from David when he was diagnosed with Progressive Supranuclear Palsy (PSP) by the clinicians at the MGH FTD Unit. PSP is a frontotemporal disorder (FTD), involving changes in the brain that impact speech, vision, balance and cognitive ability. The Crowley family hopes that everyone who participates in *Ski with David for PSP* will share David's joy of skiing on March 9th.

Ski with David for PSP will benefit the clinical care and research programs at the MGH FTD Unit, bringing the cure of tomorrow closer to the care of today. Donate now at Because.MassGeneral.org/SkiWithDavid2024.

Thursday April 25, 2024

**East Boston BPL Branch/
Streaming Globally**

Save the date for a screening of the short film *Pedacito de Carne*, a drama that follows a young Hispanic woman caregiving for her mother, as both women have to adjust with the awkwardness and helplessness of their new roles, followed by a live question and answer session with the filmmakers and a MGH Neurology Department clinician to raise awareness about young-onset dementia, its impact on caregivers and brain health for all. This event will be conducted in Spanish; the film will be subtitled in English and Spanish. Registration will open in late March 2024.



Diana Gonzalez-Morrett
Filmmaker & Caregiver



Sandra Gonzalez-Morrett
AFTD Ambassador & Caregiver



Liliana Ramirez Gomez, MD
Clinical Director
MGH Memory Disorders Division



Friday October 25, 2024

**Royal Sonesta Hotel
Cambridge, MA**

Join us for *A Night with the Arts for FTD*, the ninth annual fundraising gala to raise awareness, funds and hope that the cure for FTD is not so far from the care of today.

Tickets and sponsorships for the event will be available in March 2024 at Because.MassGeneral.org/FTDGala2024.

Interested in Participating in Research? All About ALLFTD

What is ALLFTD?

The ARTFL-LEFFTDS Longitudinal Frontotemporal Lobar Degeneration (ALLFTD) Research study aims to learn more about FTD and understand the difference in brain changes due to FTD compared to normal aging.

ALLFTD is funded by the National Institute on Aging and the National Institute for Neurological Diseases and Stroke. Every individual experience with FTD is unique and it is difficult to predict how the disease will play out. ALLFTD wants to better understand brain changes before symptoms occur and in the early and moderate stages of the disease. Once scientists understand these changes, they can build therapies to slow the disease. ALLFTD will not provide medicinal treatment but may work with drug companies that are testing new medicines.



Who can participate in ALLFTD?

ALLFTD is recruiting people who are living with a diagnosis of FTD or have a family history of FTD.

What does the study involve?

Study participation includes yearly visits at a study site, where testing, brain scans and lab tests are conducted. All visits are done with a study partner of your choice and ALLFTD can support your travel expenses. Because this is a longitudinal study, you will be asked to return each year so that researchers can track changes over time.



Where are the ALLFTD study sites?

ALLFTD is at 26 different locations across the United States and Canada, including the MGH FTD Unit. The map to the left shows the sites across North America.

Does ALLFTD benefit study participants?

Yes! ALLFTD is deeply connected to the medical community that is preparing possible treatments for FTD. If a clinical trial for a possible treatment starts, the ALLFTD participants who have an FTD diagnosis may be screened to participate in the trial.

Participating in ALLFTD gives participants the opportunity to receive genetic counseling and support to possibly learn more about their own genetic status. It is important to know that learning about your genetic status is *not* a required part of the study.

How can I join ALLFTD?

If you are connected to the MGH FTD Unit, email Gent Celaj, ALLFTD Study Coordinator, at GCelaj@mgh.harvard.edu. For other study sites, go to www.ALLFTD.org and become connected today!

[Click](#) on the photo to the right to watch a short video and learn more about ALLFTD from study participants Bradford Gremes and Linde Jacobs.



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 in 2024: Tuesdays @ 10: 00 am Tuesdays @ 7: 00 pm

March 5, 19
April 2, 16, 23
May 7, 21
June 4, 18
July 2, 16, 23
August 6, 20
September 3, 17
October 1, 15, 22
November 5, 19
December 3, 17

February 27
March 12, 26
April 9, 30
May 14, 28
June 11, 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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