MASSACHUSETTS
GENERAL HOSPITAL

FRONTOTEMPORAL
DISORDERS UNIT

# FROM CARE TO CURE

SUMMER 2021

NEWS FROM THE MGH FRONTOTEMPORAL DISORDERS UNIT

## INSIDE THIS ISSUE

## AFTD FIND HELP, SHARE HOPE

On May 13th and 14th, AFTD convened its 2021 Education Conference online. With over 1,200 registrants and presentations from leading experts, advocates and caregivers, it brought practical information, research updates and hope to families living with FTD all across the world. See recordings of this extraordinary online event on the **AFTD YouTube Channel** today.

*We are proud of every frontline hero!*

## Dear FTD Unit Community Members,

Amidst the ongoing pandemic, we continue to provide clinical care, pursue new research, offer a variety of caregiver support activities and identify advocacy opportunities. We couldn't be happier that the lifting of restrictions is increasing access to adult day health programs and in-home services, visits with loved ones in memory care and the resumption of in-person research visits for brain scans and other procedures. I hope you enjoy the topics we highlight in this issue of our newsletter, and that you will be able to take the opportunity to visit our MGH FTD Unit YouTube Channel and access the growing library of content. We are recording as many interviews and presentations as possible so that you can access content at your convenience.

It is so impressive to recognize the amazing accomplishments of the global scientific community in bringing COVID vaccines to millions at record speed. As we go to press, we just received another remarkable announcement: the FDA authorized conditional approval for aducanumab, the first medication that is able to consistently lower brain amyloid, which hopefully will help slow the progression of the illness. Many scientific questions remain, which is why conditional approval requires another study, but at some point in the coming months it will become more widely available and people with Alzheimer's disease will be able to discuss the pros and cons of trying it with their medical providers.

We know that many of you will have questions about whether or not the approval of aducanumab will impact your or your loved one's treatment plan. Our hospital teams and health care system leadership are working together in a coordinated way to evaluate how best to make this medication available to the people who may benefit from it, and we will update you as new information about this process is available over the coming months.

In 2011, President Obama called for an aggressive and coordinated national plan to accelerate research on Alzheimer's disease and related dementias, and to provide better clinical care and services for people living with dementia and their families. This call to action led to a federal commitment to increase efforts to find effective treatments. Now, 10 years later, we are entering a new era in the field. The approval of aducanumab will be part of the history of Alzheimer's disease and how our community of scientists, clinicians and families worked together tirelessly to bring better treatments to patients and families. People like you, who have told your story in one way or another, raise everyone's awareness about how important it is to keep traveling the journey from caring to curing. People like you, who have participated in new studies whether or not they will directly benefit you, help us build momentum on this journey. We still have a long way to go, and we will travel together until we reach the destination that helps everyone. Take care and be well.

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

# Spotlight on Staff:

## Ryn Flaherty, Senior Clinical Research Coordinator

## LOOKING WITHIN FOR FUTURE DISCOVERIES

### Tell us about your experience working in the Dickerson Lab. Have you always enjoyed science?

I have always wanted to be a scientist, even since the young age of 8 years old. I joined the lab in 2018 as a Clinical Research Coordinator after earning a BS in Neuroscience from Brandeis University. One of the most exciting experiences I have had while working with Dr. Dickerson and our team is that I was the first Clinical Research Coordinator working on LEADS (Longitudinal Early-Onset Alzheimer's Disease Study). This is the first study to focus on individuals living with a diagnosis of Alzheimer's Disease before the age of 65. Prior to this study, younger people with Alzheimer's Disease didn't have access to research. I am proud to have been a part of working with our team to make that access possible. In 2020, I had amazing experience of presenting a poster about LEADS at the Alzheimer's Association International Conference (AAIC), which was great, despite being held online. It has been incredibly rewarding to be the first Clinical Research Coordinator for LEADS and help with the beginnings of this critically important study.

### What are your future career endeavors? Do you have goals for a future in neuroscience?

I am honored that I have been accepted into New York University's PhD program in Biomedical Sciences. I plan to choose a concentration for my degree in Biomedical Imaging. My career interests include neuroimaging with a focus on neurodegeneration. I have seen the impact of neuroimaging for the research participants that we work with in the Dickerson Lab and I know my experience here will influence my future studies. My goal is to stay in academia and one day have my own lab, using neuroimaging to further identify and support future discoveries. I am excited to look at brain images in novel ways in order to discover new things about these disorders that affect people's lives in such devastating ways.

### You often volunteer in the community. Do you think that there is a connection between your volunteerism and your future career interests?

I am a strong advocate and volunteer for LBGTQIA+ community attending various events for transgender rights. When I think about how my volunteer work relates back to my experiences in the Dickerson Lab, I am inspired by the many research participants and care partners that we work with who must advocate for themselves. It reinforces the importance of dignity, respect and personhood at every stage of the journey with a neurodegenerative condition. It has been a privilege to walk with our participants every step of the way, gaining a unique perspective about their lived experience, learning information that we hope will contribute to future treatments and, one day, a cure.

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## 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 Groups:***

**Tuesdays @ 10:00AM**

May 4th & 18th
June 1st, 15th & 22nd
July 6th & 20th
August 3rd, 17th & 24th

**Tuesdays @ 7:00PM**

May 11th & 25th
June 8th & 29th
July 13th & 27th
August 10th & 31st

# RESEARCH OPPORTUNITIES

### ALLFTD: ARTFL LEFFTDS LONGITUDINAL FTD STUDY

**You may be eligible if:** You have a diagnosis of bvFTD, PPA, PSP, CBD/CBS, or bvFTD-ALS. You may also be eligible if you are from a family with a mutation in a gene known to cause FTD (such as C9orf72, MAPT, and GRN) or have a significant family history of FTD suggesting a familial genetic mutation. Participants from familial FTD families may or may not be identified with the mutation themselves, and may or may not be experiencing FTD symptoms.

**Goal:** To examine changes in brain functioning that may result from FTD and find factors that predict disease course in people who already have, or may later be diagnosed with FTD. To build a clinical research network that can support treatment and prevention studies, and better understand biomarkers of FTD.

**This study involves:** Annual study visits that include an MRI, cognitive testing, blood draw, optional lumbar puncture, and an optional skin biopsy.

### PRIMARY PROGRESSIVE APHASIA RESEARCH

**You may be eligible if:** You have a diagnosis of PPA or are cognitively normal.

**Goal:** To better understand the progression and symptoms of PPA and differentiate subtypes of PPA.

**This study involves:** Annual visits that include MRI, language and cognitive testing, and a blood draw.

### IMAGING TAU, AMYLOID, AND NEURODEGENERATION

**You may be eligible if:** You are age 40-90 and diagnosed with AD, PCA or PPA.

**Goal:** To better understand how the proteins tau and amyloid affect brain regions and relate to symptoms.

**This study involves:** Annual visits for MRI, amyloid and tau PET scans, and cognitive testing.

### FTD FAMILY STUDY

**You may be eligible if:** You are from a family with a mutation in a gene known to cause FTD (such as C9orf72, MAPT, and GRN) or have a significant family history of FTD suggesting a familial genetic mutation.

**Goal:** To see if there is a preclinical FTD stage where people at risk for FTD have brain changes but no symptoms.

**This study involves:** Annual MRI and cognitive testing. People who cannot undergo MRI for medical reasons may still be able to participate in testing.

### LEADS: LONGITUDINAL EARLY-ONSET ALZHEIMER'S DISEASE STUDY

**You may be eligible if:** You have a diagnosis of young-onset Alzheimer's Disease

**Goal:** To better understand the progression and symptoms of young-onset Alzheimer's Disease.

**This study involves:** Regular visits that may include brain imaging, language, cognitive testing and potential blood or spinal fluid draws.

### CAREGIVER WELLBEING

**You may be eligible if:** You are caring for someone with Alzheimer's Disease, FTD, PCA, PPA, or dementia.

**Goal:** To gain better understanding from caregivers of how certain factors (caregiver personality, patient symptoms, relationship quality) effect mental health and the caregiver experience.

**This study involves:** Caregivers will fill out online surveys regarding their experience as caregivers every 6 months. Time commitment includes up to 1 hour per survey session.

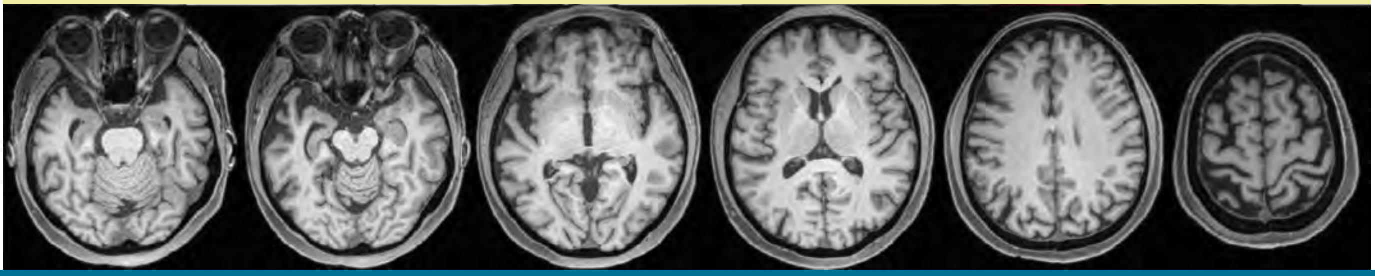
### 4RTNI-2: FOUR REPEAT TAUOPATHY NEUROIMAGING INITIATIVE

**You may be eligible if:** You are between 40-80 years old and are cognitively normal, or have probable PSP or CBS.

**Goal:** To better understand how the proteins tau and amyloid in the brain relate to PSP and CBS symptoms.

**This study involves:** 3-4 visits over 24 months including a combination of MRI, cognitive testing, blood draw, and tau and amyloid PET scans. Spinal fluid sample is optional.

**To inquire about research, please contact our Research Coordinators at:**
MGHFTDUNIT@mgh.harvard.edu



# Empowerment Through the Lived Experience: An Interview with Amy Shives

*By Katie Brandt, MM*
*Director of Caregiver Support Services and Public Relations, MGH Frontotemporal Disorders Unit*

*Amy Shives, FTD Advocate and AFTD Volunteer raises her voice for others living with a diagnosis*

On March 26, 2021, the MGH FTD Unit Community Forum Friday webinar series presented *Empowerment Through the Lived Experience: A Conversation with Senior Director of Programs Sharon Denny and FTD Advocate Amy Shives.* The session, facilitated by Katie Brandt, aimed to shine a light on the essential role that persons living with a diagnosis can play in our greater dementia community. Shives brought the authentic voice of lived experience. Denny brought the perspective of a patient advocacy organization that has been strengthened by incorporating the perspectives of individuals living life with a diagnosis of Frontotemporal Dementia. What followed was a conversation about resilience, respect and rethinking dementia.

## *Programming for the Person*

Sharon Denny has been working with AFTD since 2008, directing strategic development of support, education and advocacy for people living with FTD and their care partners. Under her leadership, FTD has expanded its Helpline, built a national network of support groups and led an effort to include people living with FTD in fulfilling AFTD's mission. Denny acknowledged that FTD is a diverse group of disorders with many different clinical presentations, making the need for AFTD to be the organization that brings all those voices together even more critical "We've really found a lot of value in making sure that we're including people with a diagnosis in the work that we do so that we can be maximally effective in every part of our mission" said Denny. AFTD is an organization with deep roots of volunteerism, engagement and inclusion. Founded in 2002 by Helen-Ann Comstock, a woman who had lost her husband to FTD, AFTD knows the value of a determined advocate.

## *Diagnosis: You*

Amy Shives is a known advocate in the national dementia community, serving as a current board member of the Frontotemporal Dementia Advocacy Resource Network and an active alumnus for the Alzheimer's Association early stage advocacy group. She is a volunteer with the Association for Frontotemporal Degeneration (AFTD) and shares her perspective to inform programming, information and services. Shives talks about how her work as a volunteer speaks to who she has always been "I had been a volunteer my whole life with my kids as the ballet mom, the volleyball mom, the cheerleader mom and most of us did that with our kids. I was out there and working full time as a counselor in a college [in addition to parenting] so it was always part of me." Shives' hopes that her message of purpose and personhood reaches others who are living with a diagnosis, emphasizing that "you don't need to change who you are as a person just because you have received a diagnosis."

> *There will be a lot more opportunities for people down the line either to speak for themselves or to speak on behalf of others that they love and that they are journeying along with… I really appreciate the folks that we're working with and [who] have been raising their hands with us. Well, I know that we all have more to do. I just think it's a really hopeful time.*
>
> *Amy Shives, FTD Advocate*

## *Planning for Purpose*

The experience of receiving a diagnosis of FTD, Alzheimer's disease or a related condition can challenge an individual's sense of autonomy and independence. A new future is ahead, and often plans must be rewritten. Shives talks about the importance of making an impact "I feel a very strong sense of purpose [and] I'm honored to be in the situation that I am in. Volunteering brings together the different facets of living with this disease. We know that finding purpose can be challenging when goals that you took for granted before are literally taken away.

*Katie Brandt interviewed Amy Shives, AFTD Volunteer, and Sharon Denny, AFTD Senior Director of Programs, for the 2021 MGH FTD Unit Community Forum Friday Webinar Series to shine a spotlight on the lived experience of an FTD diagnosis.*

Denny emphasizes that when advocates are ready to raise their voices, organizations need to be ready to hear them. "I think the main takeaway is that every voice counts and every voice matters, especially in FTD." To strengthen the commitment to inclusion, Denny encourages organizations "…to include the voices of people who are living with the disease, even when it means that the rest of us have to do our work a little differently." This can be tremendously rewarding and increase an organization's impact by developing programming and services informed by those who will be most likely to utilize them. Denny noted "…the way in which we're creating a community together and we're tackling these issues together, that's where the strength comes from. That's where we will make a difference."

### *Starting with a Single Step*

Both Denny and Shives encourage individuals living with a diagnosis to consider getting involved whether at the local, state or national level, there is a great need for the authentic voice. Shives knows that each person will experience their diagnosis differently and that they come to this new life stage with unique experiences, skill sets and values. "The first step is going to be different for many people. Find your path. Your path is your own" said Shives. Reminding us that "…people can bring their voice to bear and especially in terms of reducing stigma it's all hugely important."

### *Uniquely Common*

While no two experiences will be the same, Shives hopes that one common denominator will be the joy of making new connections and building new relationships along the way, giving even greater meaning to the advocacy role. "I have friends all over the world, I learn from others. Hearing people speak for themselves and for others makes me hopeful." Shives spoke about the upcoming dates on her calendar, the places she has visited and the media opportunities she engaged in. She described resilience in action. Reducing the stigma by challenging the stereotype. And, along the way, keeping her heart open to joy.

## SUPPORT FOR FTD CARE PARTNERS THROUGH AFTD

Life with FTD can be extremely isolating. That's why it's so important to develop a network of social, emotional and practical supports. AFTD can help you forge connections with people who understand FTD.

AFTD maintains a list of local FTD support groups in your state. New groups are added regularly. Have questions from the start? Call AFTD's toll-free HelpLine at 866-507-7222, or contact us by email at info@theAFTD.org.

## SUPPORT FOR PERSONS LIVING WITH AN FTD DIAGNOSIS THROUGH AFTD

AFTD holds a monthly online support group for people who have FTD using the internet video platform Zoom. Contact the HelpLine at 866-507-7222 for more information.

Visit *Support for People With FTD* on the AFTD webpage for words of encouragement from people who have FTD and additional support options.

www.theAFTD.org/living-with-ftd/support-for-people-with-ftd/

# Speaking for the Silenced: An Interview with Dorian Banister

*By Amy Marchesano, LMHC*
*Caregiver Support Specialist, MGH Frontotemporal Disorders Unit*

On March 5, 2021, individuals and families affected by FTD had the opportunity to speak directly to representatives from the U.S. Food and Drug Administration (FDA) to provide input based on their personal experience with FTD. This event was called an Externally Led Patient-Focused Drug Development (PFDD) Meeting. The Association for Frontotemporal Degeneration (AFTD) coordinated this meeting, spotlighting authentic voices to prepare the FDA for future evaluation of potential therapies and treatments for FTD.

A powerful speaker at this PFDD was Dorian Bannister, AFTD volunteer, support group facilitator, advocate and former FTD caregiver to her beloved son Matthew. When Matthew was diagnosed with FTD at the devastating age of 28 years old, Dorian became his advocate and caregiver. Through this experience, Dorian realized the critical needs that families face when navigating life with a young-onset dementia.

*Dorian honors her son by volunteering and running support groups for AFTD.*

Since Matthew's passing in 2016, Dorian has become an inspirational guide for other families on the journey of caregiving. She is a relentless advocate at the local, state and national level, communicating with healthcare providers and elected officials, to make sure that the needs of families living with FTD are recognized. In a conversation with Dorian, we learned about what drives her passion for education, advocacy and care for those with FTD.

### *An Unexpected Plan*

When Matthew started showing early symptoms of FTD, there was no clear path to an accurate diagnosis. Dorian shared with us her quest to label the condition that was stealing the personality of her intelligent, outgoing son. After many failed attempts and misdiagnoses, FTD was finally considered as an explanation.

Dorian advocated for an expert opinion, leading Matthew to the care of FTD expert, Bruce Miller, MD, at the University of California San Francisco Memory and Aging Center, who could provide an explanation for Matthew's symptoms and confirm a diagnosis of FTD. Needing care closer to home, Matthew was referred to Brad Dickerson, MD at the Massachusetts General Hospital Frontotemporal Disorders Unit, who could take the lead for Matthew's care.

### *A Care Plan with Love*

Eventually, as Matt's FTD progressed significantly, he required around the clock, specialized care, that could not be provided at home. Matt, at over 6 feet tall, fit and strong, would often require at least one adult to safely assist him with everyday tasks such as personal care or eating. After facing the challenges of FTD's behaviors, and enduring heightened caregiver stress, Dorian faced the emotional decision to partner with a skilled nursing environment to provide him with the

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**LEARN MORE ABOUT THE FDA PATIENT FOCUSED DRUG DEVELOPMENT MEETING**
www.theAFTD.org/get-involved/patient-focused-drug-development/

*Before FTD, Matt was an active, adventurous and outgoing young man.*

24/7 care that he needed. Utilizing her knowledge as an occupational therapist, was able to secure a tailored, specialized placement for her son through the state of Maine. However, due to the lack of local resources, the placement was located three hours away from their home.

> *"FTD robs people of their voice. I share Matt's experience because I won't let his voice be silenced."*

Ultimately, this challenge did not discourage Dorian. She remained open-minded and intrepidly proceeded ahead with the placement despite the distance. She was immediately impressed with the dedication, support, and loving care the staff and professionals provided to Matthew. Not only were the medical staff experts in his treatment plan, but tremendously caring, open minded, creative and willing to learn. They gave Matt appropriate care and loved him like family. Dorian emphasized, "They were always willing to listen, and go the extra mile for Matt. I tell other caregivers, don't be afraid to reach out and partner with a skilled nursing facility or memory care assisted living facility for your loved one. It may be the best thing you can do."

## *Planning for Self-Care*

Due to her experience as a caregiver, Dorian knows firsthand the importance of self-care to protect a caregiver's health and well-being. As a support group facilitator, she Is a strong advocate for caregivers taking time to focus on themselves. This may include attending support group, organizing respite for their loved one or activities that support their own mental health. Respite that allows caregivers to recharge their batteries and nourish themselves is truly important. She recommends, "Make yourself part of your loved one's care plan." Dorian is also known to give her support group participants "homework" to carry out an act of self-care, no matter how big or small, before the next meeting. This could be as simple as reading an article, taking a walk, or enjoying a bubble bath depending on whatever works best for each individual.

## *Planning for a Cure*

Dorian continues to lead the charge in fighting back against FTD. As a volunteer for both AFTD and the Alzheimer's Association, she advocates for increased funding for research and services to support care and a cure for all forms of dementia. Dorian's advocacy activities include providing testimony at the Maine State house, raising awareness that dementia is not just for the elderly, and that policies must reflect the needs of all families affected. Dorian's empowering messages of strength and love remind us that we are not powerless against FTD. Matthew's tenacious spirit continues on in her work, reminding all of us that love is limitless. Voices in need will not be silenced. We will move forward with hope.

*Matt, visiting with his sisters and nephew at his long term care facility.*

# Legal Planning After a Diagnosis of Frontotemporal Dementia, Alzheimer's Disease or a Related Condition

Understanding the Legal Landscape of Planning and FTD

Patricia C. D'Agostino
Margolis & Blood, LLP

Pam Greenfield
Greenfield Planning Group

Katie Brandt interviews attorneys Pam Greenfield (top) and Patricia D'Agostino (bottom) for Community Forum Friday webinars

One of the first things that many families face after receiving a dementia diagnosis is the need for care planning. Assembling a team of medical providers, home care assistants and helpful family members and friends is critical to building the foundation for future care. During this time of action and planning for the future, questions may arise around issues of legal and financial planning. This is an opportunity to invite an elder law attorney to become a member of your care team. We know that each family has unique circumstances that require customized planning with an experienced professional. That is why our 2021 Community Forum Friday webinar series features two interviews with a focus on legal planning after a diagnosis. Katie Brandt, Director of Caregiver Support Services and Public Relations, spent time with attorneys Pam Greenfield of Greenfield Planning and Patricia D'Agostino of Margolis and Bloom to discuss first steps, common questions and typical concerns for families on the road to legal planning.

Attorneys Greenfield and D'Agostino are elder law attorneys, meaning that their practice focuses on the unique needs of aging adults and individuals coping with conditions that typically affect older adults, like dementia. Working with an elder law attorney can guide you to answer common questions related to funding for specialized care, protecting assets for future generations and how to appoint a substitute decision. You can find an elder law attorney near you by going to the National Academy of Elder Law Attorneys (NAELA.org) website. While early planning is encouraged, it is never too late to talk with your family about your goals and wishes for the future. An elder law attorney can help guide the way for important discussions, decisions and action steps to a secure tomorrow.

Just starting out with legal planning? Here are a few tips to make the first steps a little easier:

### INTERVIEW QUESTIONS FOR PROSPECTIVE ATTORNEYS

- How many years have you been practicing estate planning and elder law?
- What proportion of your practice is devoted to these fields?
- Have you worked with families experiencing life with dementia?
- Are you a member of the National Academy of Elder Law Attorneys?
- Do you charge for your initial consultation?
- How do you determine your fees?

### DOCUMENTS TO GET STARTED

- Durable Power of Attorney
- Health Care Directive
- Health Care Proxy
- HIPAA Release
- Trust
- Will

Ready to learn more? Check out the full interviews with attorneys Greenfield and D'Agostino on the **MGH FTD Unit YouTube Channel:** YouTube.com/c/MGHFTDUnit

# Ageless Grace with Norie Mozzone

*By Katie Brandt, MM*

*Director of Caregiver Support Services and Public Relations, MGH Frontotemporal Disorders Unit*

*Norie builds connections and community through the Ageless Grace program*

The MGH FTD Unit Community Forum Friday webinar series aims to bring expert voices to our community of persons living with a diagnosis, care partners and healthcare providers to provide information that can improve care and quality of life while living with dementia. In How Movement and Music Equals Magic, Norie Mozzone, Program Coordinator for the MGH Dementia Care Collaborative (DCC) talks with Katie Brandt about the importance of movement for self-care, real connections over virtual platforms and the power of Ageless Grace for resilience.

Through her role in the MGH DCC, Mozzone leads Ageless Grace, a brain fitness program based on neuroplasticity that activates all five functions of the brain – analytical, strategic, kinesthetic learning, memory and imagination. “It is based in the concept of play for neuroplasticity and almost anyone can participate regardless of ability” notes Mozzone. Twice each week, she runs a class “in the Zoom-room” for individuals living with dementia and their care partners. This seated-movement program guides participants through exercises paired with music to promote health and well-being. During a time where there is so much worry about what tomorrow may bring, it is an opportunity to focus on the present. “We know that for our loved ones with cognitive impairment it can be really difficult to pull things from the past or anticipate what might happen in the future. Sometimes the present is the only place to be and it is a privilege to spend an hour with our participants in this way” said Mozzone.

> *It’s okay if your partner can’t do it the way you’re doing it or the way somebody else in another Zoom square is doing it. We are offering the invitation to choose what feels good in your body and in your spirit and that offers the opportunity to connect with each other and the group.*

In addition to the feelings of connection elicited by the weekly classes, participants also report that it cultivates a sensation of freedom. Mozzone says “I invite participants to choose to engage in every exercise and to do what feels good to them. The idea of choice can be so empowering for individuals, a positive place to build on the rest of their day.” Mozzone hopes that the example of making healthy choices in class will extend to other aspects of their daily routine for both individuals living with a diagnosis and their care partners. To learn more about Ageless Grace and the other programs offered by the MGH DCC, see the information below and reach out to the team in the MGH DCC.

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## MGH DEMENTIA CARE COLLABORATIVE

The MGH Dementia Care Collaborative is committed to improving the experience of patients and families living with Alzheimer’s Disease and related dementias by changing the way our healthcare system understands and treats these individuals. They are a resource for patients, families and clinicians. The Dementia Care Collaborative provides comprehensive education, clinical co-management services, and emotional and social support to all who are navigating the complex journey of dementia. Led by director Christine Ritchie, MD, their expert team is transforming memory care through education, collaboration and support. Find out more about programs, services and supports at **DementiaCareCollaborative.org**.

Dementia Care Collaborative

# Join Us for Upcoming Events to Benefit the MGH FTD Unit

## MILES for MIKE

### 5K WALK/RUN

**Virtual 5k Walk/Run**
**Sunday, July 25, 2021**

Register @ Because.MassGeneral.org/MilesForMike

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## *Join Us Online*

THE MASS GENERAL HOSPITAL FRONTOTEMPORAL DISORDERS UNIT
INVITES YOU TO OUR ONLINE GALA EVENT

## A NIGHT WITH THE ARTS FOR FTD

**FRIDAY, OCTOBER 15, 2021 • 7:30PM**

Sponsorships & Tickets Available: Because.MassGeneral.org/FTDGala2021
Questions? Email Katherine.Brandt@mgh.harvard.edu

Presentation by Brad Dickerson, MD
Live Musical Entertainment
Patient & Caregiver-Centered Art Exhibit

All proceeds to benefit the MGH Frontotemporal Disorders Unit

# Massachusetts General Hospital Frontotemporal Disorders Unit
# From Care to Cure Educational Webinars

## Overview of MGH FTD Unit From Care to Cure Educational Webinars

The Massachusetts General Hospital Frontotemporal Disorders Unit is a clinical research program dedicated to providing the highest quality of care while working tirelessly towards a cure for Frontotemporal Dementia, atypical and young-onset Alzheimer's Disease and related disorders. Our From Care to Cure webinar series aims to bring the most up to date clinical and research information to the patients and families we care for. Each presentation will be given by a member of our MGH FTD Unit team. All sessions will be posted on our MGH FTD Unit YouTube Channel after they air.

View all recorded presentations on our MGH FTD Unit YouTube Channel:
**YouTube.com/c/MGHFTDUnit**

***Title:*** **An Overview of Frontotemporal Dementia, Alzheimer's Disease and Related Disorders**
***Presenter:*** Brad Dickerson, MD, Director, MGH FTD Unit

***Title:*** **Understanding Primary Progressive Aphasia**
***Presenters:*** Megan Quimby, MS, CCC-SLP, Director of Speech and Language Program, MGH FTD Unit & Daisy Hochberg, MS, CCC-SLP, Founding Member, MGH FTD Unit

***Title:*** **Cognitive Resilience: A Brain Health Care Plan for Care Partners and Their Loved Ones**
***Presenter:*** Bonnie Wong, PhD/ABPP-CN, Director of Neuropsychology, MGH FTD Unit

***Title:*** **Research to Develop Treatments for FTD, Alzheimer's Disease and Related Dementias**
***Presenter:*** Scott McGinnis, MD, Behavioral Neurologist, MGH FTD Unit

***Title:*** **Creating a Person-Centered Care Plan**
***Presenter:*** Katie Brandt, MM, Director of Caregiver Support Services and Public Relations, MGH FTD Unit

**Questions:** Katie Brandt, **Katherine.Brandt@mgh.harvard.edu**

*Make a Clinic Appointment*
*MGHFTDUnit@mgh.harvard.edu*

*Learn About Research*
*MGHFTDUnit@mgh.harvard.edu*

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- Neguine Rezaii, MD

**Speech-Language Pathology**
- Megan Quimby, MS, CCC-SLP
- Daisy Hochberg, MS, CCC-SLP

**Nursing**
- Rose Gallagher, RN BSN

**Caregiver Support**
- Katie Brandt, MM
- Amy Marchesano, LMHC

**Clinical Fellows**
- Sylvia Josephy, MD
- David Kim, MD

**Affiliated Clinicians**
- Steve Haggarty, PhD
- Diane Lucente, MS, LCGC
- Scott McGinnis, MD
- David Perez, MD
- Janet Sherman, PhD

**Clinical Scheduling Team**
- Inola Howe
- Courtney Sullivan
- Angela Villareyna

### FTD UNIT RESEARCH

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- Samantha Krivensky
- Raseeka O'Chander, MA
- Angela Villareyna

**Speech-Language Pathology**
- Megan Quimby, MS, CCC-SLP
- Daisy Hochberg, MS, CCC-SLP

**Caregiving**
- Katie Brandt, MM
- Amy Marchesano, LMHC

**Imaging**
- Mike Brickhouse
- Nicole Carvalho
- Ryan Eckbo
- Alexandra Touroutoglou, PhD
- Alexander Zaitsev

**Neuropsychology**
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- Sheena Dev, PhD
- Deepti Putcha, PhD

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