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FTD TODAY

New PPA Support Group Created for Early Stage Patients and Caregivers in Charlestown

Beginning in April, the MGH FTD Unit will host a monthly PPA Support Group in our Charlestown office. This group will support early stage PPA patients and caregivers. We recognize the power of support groups to help families navigate the journey of living with PPA and hope this will make more resources available to connect patients and caregivers with experienced professionals and each other.



Our pilot PPA support group provided inspiration for our new group.

To inquire about joining our PPA Support Group, contact Megan Quimby at MQuimby@mgh.harvard.edu.

Welcome to this issue of our newsletter, and thank you for your interest. I am delighted to showcase the work of our tremendously talented team and others who are making great progress in understanding Frontotemporal Dementia, Primary Progressive Aphasia, and other early onset and atypical forms of cognitive impairment. As always, it is a pleasure to share updates from a variety of perspectives with you.



In thinking back on 2016-2017, I am very encouraged by the tremendous science discussed at the 10th International Conference on FTD in Munich in September, where our team made several exciting presentations. I am always inspired to see the many scientists, doctors, and other clinicians who are dedicating tremendous effort toward understanding FTD, PPA, and related conditions and advancing our ability to care for and hopefully some day cure these diseases. People from around the world at all stages of their career and from many disciplines are fighting back against FTD. It is particularly encouraging to see the growth in the number of students, other trainees, and junior faculty who are bringing their energy and passion to FTD research. We have continued to bring back news from the cutting edge of research to our local community in our annual From Care to Cure educational events.

Every day I feel proud and humbled to work with a team of incredibly talented and hard working women and men who care deeply about our work and about our partnerships with patients and families. Because of them, we are able to deliver what I believe is unparalleled clinical care for patients and families living with these conditions. The variety of educational activities for lay and professional audiences are made much stronger by our team's efforts. And the many research projects advancing our knowledge of FTD, PPA, PCA, and other conditions as well as normal aging would not be possible without the tireless energy and intelligence of our team members. I want to take this opportunity to give my deepest thanks to our outstanding team. I know you will enjoy reading more about the fantastic array of ideas and activities summarized in these pages.

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

Spotlight on Staff:

MADELINE GRIMM, MGH INSTITUTE FOR HEALTH PROFESSIONS GRADUATE STUDENT



Madeline Grimm joined the FTD Unit in January 2016; she is the FTD Unit's Graduate Assistant in Speech Language Pathology through from the [MGH Institute of Health Professions](#). As a student, her role includes administering language evaluations for Primary Progressive Aphasia patients, statistical analyses of language data and helping to facilitate the PPA support group. Madeline's key accomplishments while working in the lab include analyzing data for a presentation at the International FTD Conference in Munich this past summer, and compiling data for a roundtable discussion for the 2016 Clinical Aphasiology Conference. Madeline is pursuing her Master's degree in Speech, Language Pathology and notes that her favorite part of working in the FTD Unit is interacting with patients and their families, while simultaneously learning new knowledge in the field of FTD.

FACULTY & STAFF

NEUROLOGISTS

Brad Dickerson, MD, Director
Mark Eldaeif, MD
Scott McGinnis, MD
David Perez, MD

NEUROPSYCHOLOGIST

Bonnie Wong, PhD/ABPP-CN

SPEECH-LANGUAGE PATHOLOGISTS

Daisy Hochberg, MS, CCC-SLP
Megan Quimby, MS, CCC-SLP

SENIOR GENETIC COUNSELOR

Diane Lucente, MS, LCGC

SPEECH PATHOLOGY

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Lee Richardson, MS, CF-SLP

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Cristian Leyton, PhD,
Neuroscience
Deepti Putcha, PhD,
Neuropsychology

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Rose Gallagher, BS, Nurse
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Samantha Krivensky, BS,
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Kay Sweeney, MS,
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Center for Human
Genetic Research
Janet Sherman, Ph.D.,
MGH Psychology
Assessment Center

BOSTON-AREA FTD SUPPORT GROUPS:

Free, community-based support for
members of our FTD Community

FTD Caregiver Support Group

2nd Tuesday of Every Month
7:00 – 9:00PM
Mount Auburn Hospital,
Cambridge

To Join,

Contact ftd.boston@gmail.com

FTD Caregiver Support Group

Last Tuesday of Every Month
7:00 – 9:00PM
Newton Wellesley Hospital,
Newton

To Join,

Contact ftd.boston@gmail.com

PPA Patient & Caregiver Support Group

Third Thursday of Every Month
10:00 – 11:30AM
MGH FTD Unit Offices,
Charlestown

To Join,

Contact MQuimby@mgh.harvard.edu

MGH FTD Unit Research Studies

The Massachusetts General Hospital Frontotemporal Disorders Unit needs your help in our fight against these diseases, and our efforts to improve brain health.

LEFFTDS: LONGITUDINAL EVALUATION OF FAMILIAL FTD

You may be eligible if: You or someone in your family carries a gene related to FTD, namely, MAPT, PGRN, and C9ORF72. Participants may or may not carry the gene, and may or may not be experiencing FTD symptoms

Goal: To examine brain changes in gene carriers who do not have symptoms, and find factors that predict disease course in people who already have, or may later be diagnosed with FTD.

This study involves: Annual study visits for 3 years that include MRI, cognitive testing, blood draw, and an optional skin biopsy.

FTD FAMILY STUDY

You may be eligible if: You are in a family with probable hereditary FTD.

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 can still participate in testing.

IDEAS: IMAGING DEMENTIA - EVIDENCE FOR AMYLOID SCANNING

You may be eligible if: You are age 65 or older, on Medicare, have MCI or dementia, and have no prior knowledge of your amyloid status.

Goal: This is a study of clinical care where participants will learn about their amyloid status. The goal is to better understand how knowledge of amyloid status affects diagnosis and treatment.

This study involves: One amyloid PET scan that is part of clinical care and billed to insurance.

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.

ARTFL: ADVANCING RESEARCH AND TREATMENT FOR FTD

You may be eligible if: You have a diagnosis of FTD, PPA, PSP, CBD/CBS, or FTD-ALS, or you are a healthy family member of a patient with FTD. You must have no known gene mutation related to Alzheimer's disease.

Goal: To build a clinical research network that can support treatment and prevention studies, and better understand biomarkers of FTD.

This study involves: 1-2 visits for cognitive testing, a blood draw, and a possible MRI. Some participants may be asked about an optional spinal fluid sample.

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.

To inquire about research, please contact us our Research Coordinators:

Kay Sweeney
kksweeney@partners.org;
Samantha Krivensky
skrivensky@mgh.harvard.edu

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.

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.

CAREGIVER SUPPORT INTERVENTION

You may be eligible if: You are a caregiver of someone who has ALS with behavioral changes.

Goal: This intervention aims to help caregivers by providing them with the support and strategies they need to manage challenging behaviors.

This study involves: Caregivers will talk on the phone regularly for 3 months with our Community Resource Specialist, Katie Brandt, as well as complete surveys.

CAREGIVER WELLBEING SURVEY

You may be eligible if: You are a caregiver of someone diagnosed with a neurodegenerative disease.

Goal: To better understand how the experience of caregiving affects mental health and wellbeing.

This study involves: Completing surveys every 6 months about your experiences.

What matters for Brain Health?

By: Bonnie Wong, PhD/ABPP-CN, MGH Frontotemporal Disorders Unit

As clinicians who work with individuals concerned with developing dementia, we are often asked: what should I do to improve my memory? How do I prevent or slow cognitive decline? How do I keep my brain healthy?

The topic of brain health has garnered a great deal of attention over the past two decades, with a proliferation of studies looking at health habits and activities that may slow or even reverse age-related or pathologic cognitive decline. A large-scale study completed in Finland in 2013¹ suggested that modifying multiple lifestyle factors can prevent or slow decline in individuals at-risk for developing significant cognitive impairment. Findings from this and more recent studies point to at least seven habits with the potential for maintaining optimal brain functioning.

Exercise: Cardiovascular health has been found particularly important in preventing neurologic changes that lead to cognitive decline. Studies suggest that moderate-intensity aerobic activities can promote the creation of new brain cells (a process called *neurogenesis*), increase brain volume (considered a sign of brain health), and reduce the size of age-related “holes” in the brain’s white and gray matter. In animal studies, exercise was found to double production of new neurons in the *hippocampus* (the area of the brain necessary for learning and memory) compared to the brains of sedentary animals. Other studies suggest that sedentary individuals who later become active can not only show an increase in gray-matter volume but may reduce the risk of developing significant memory decline in certain dementias by up to 50 percent over a five-year period. While most studies to date have examined exercise as a preventative to developing dementia, research trials are increasingly studying physical activity as a *treatment* for cognitive problems in dementia, with promising results.

The question often is: How much exercise is “the right amount” and what type of exercise is the best? Run, dance, garden, vacuum, or walk the dog? Currently, the Department of Health and Human Services recommends 150 minutes per week (about 30 minutes a day over five days) of moderate intensity physical activity for adults, and a target heart rate somewhere between 110 to 140 beats per minute. ***But it is best to work closely with your primary care doctor to identify the best way to start an***

exercise program that is right for your physical abilities and health profile.

Sleep: Sleep is necessary for making new memories, forming new connections, and pruning old ones. After just one night of bad sleep, we experience problems with attention, focus, memory, and speed of thinking the very next day. Persistent, chronic sleep disruptions are also associated with developing high blood pressure, narrowed blood vessels, and diabetes. Problems such as sleep apnea (a condition that involves disruptions in breathing during sleep) increase the risk for stroke and hypoxic injuries (damage due to oxygen deprivation) and can cause damaging short- and long-term changes in the brain. Recent studies also suggest that sleep may play a crucial role in our brain’s “housekeeping”: As you sleep, your brain may be acting as a “mental janitor,” clearing out toxins and proteins that have accumulated over the course of the day, which can lead to Alzheimer’s-like changes in the brain.

If you experience excessive day-time fatigue despite getting a full night’s sleep, or chronic sleep problems, you should speak to your primary care physician about pursuing a sleep evaluation and learn ways to improve sleep quality.

Diet: Many theories have been put forth about what diets can best reduce the likelihood of significant cognitive decline. While dietary factors may help reduce inflammatory responses in the body, it is unclear if they similarly impact the brain. Results from animal studies suggest that intermittent fasting may reduce the risk of stroke and neurodegenerative disorders, as it may produce proteins that protect brain cells and enhance ability to repair damaged DNA. Studies are needed, however, to understand the physiological mechanisms and benefits for humans.

To date, research suggests that a heart-healthy Mediterranean diet is a brain-healthy, and possibly “neuroprotective” diet. Before making dietary changes, however, consult your primary care doctor, who can tailor nutritional recommendations to your health history.

Mental stimulation: Scientists once believed that myelination (the process of insulating connections and facilitating rapid communication between brain cells) in the brain occurs almost exclusively during infancy and childhood and then slows or halts altogether in adulthood. Studies have shown, however, that learning new skills (rather than practicing well-learned ones) and remaining mentally active even in adulthood can increase the volume of the brain, in part through increased myelination: learning new skill strengthens existing connections, creates *new* connections, and builds brain and cognitive “reserves”.

What are the best skills to learn to strengthen and maintain a healthy brain? Ideally, the skill should be novel and interesting. It should be challenging, but not impossibly hard to learn. The skill should also have some level of inherent “intensity,” either because it is fundamentally challenging to master or because it is timed. Most importantly, whatever the new skill is, it should pose a constant, adaptive challenge as the learner improves; it shouldn’t become a mindless activity. So, learn how to sing, read music, play an instrument, dance, speak a new language, or learn about literature in an interactive book club to help maintain optimal brain functioning.

Socialization: Humans are social creatures. We’ve long known that maintaining strong and positive social connections and interactions is important for instilling feelings of safety and supporting mood. Social interaction additionally offers another avenue for mental stimulation, as it involves behaviors that require the exercise of memory, attention, and mental control. Thus, socialization helps “oil” the brain’s cognitive processes, and readies them for cognitive tasks in other areas of life. So, cultivate those personal connections and keep socializing! Find classes in topics you’re interested in, meet like-minded people, and exercise those cognitive skills in real-time. To maximize the benefit of these activities, find classes or groups that also involve physical activity and/or cognitive challenge (e.g., Tai Chi classes, a bridge or book club, or group dance class).

Mood and stress management: Unmanaged, **prolonged** exposure to high levels of stress can damage the brain. Stress can lead to metabolic changes and blood pressure problems that may whittle away at muscle tissue, impair the immune system, and disrupt

sleep, not to mention reduce immunity and increase inflammatory responses in the body. Stress also limits mental flexibility and problem-solving, rendering us less adaptable in new situations or able to find ways to make the changes necessary to reduce stress. Prolonged stress can also release hormones like cortisol, which can damage the brain and block the formation of new neurons in the hippocampus.

Some of the best ways to manage stress include physical exercise, socialization/cultivating social networks, therapy, involvement in meaningful and enjoyable activities that you look forward to, and participating regularly in mind-body activities (yoga, Tai Chi, meditation).

Live a purposeful life: Studies have shown that having “purpose” in one’s life can lead to better cognitive functioning. “Life purpose” can be defined as the “tendency to derive meaning from life’s experiences and possessing a sense of *intentionality* and goal directedness that guides behavior”. The reasons that a strong sense of purpose benefits the mind and body are not entirely understood. Some studies suggest that people who believe their lives have meaning may take better care of their health. Other studies suggest that life purpose protects the brain against the negative effects of stress (by lowering levels of stress hormones circulating in the body). Engaging in purposeful activities may contribute to the mental stimulation and challenge that leads to new connections in the brain, and increased brain and cognitive reserve. Having a sense of purpose also helps us stay motivated and engaged in those activities that keep our brains going.

How do you find what gives your life purpose? Examine the activities in your life that you look forward to and gets you out of bed every day: This can be a hobby you are passionate about, volunteering for a cause you believe in, or spending time with family in activities that everyone enjoys.

Summary: What’s the bottom line? The general rule seems to be what is good for the body is good for the brain while a healthy brain allows you to maintain a healthy body. Keep moving, keep learning, and find ways to excite those neurons and their connections. So, keep that annual physical, get quality sleep, exercise, and find what activities give spice to your life!

1 Ngandu T, Lehtisalo J, Solomon A, et al. (2015). A 2 year multi-domain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): randomised controlled trial. *The Lancet*, vol. 385, No. 9984.

Letting the Light In: How I Learned About FTD

By: Carol Reichert

We've all had the experience of learning something new, and suddenly seeing it everywhere, as if it followed us around, tapping on our shoulders to ensure we didn't forget. For me, it was FTD.

I am a flamenco dancer. Last year, my teacher, Yosi Karahashi, launched an organization called [Flamenco Therapy](http://FlamencoTherapy.org). Her father had suffered a series of strokes, and she wanted to use flamenco rhythms, movement, and music to improve the function of people with neural disease. When Yosi asked me to dance with the group, I thought "what a beautiful way to entertain people with dementia." It never occurred to me that we might improve the health of their brains.

Enter Bonnie Wong, my flamenco classmate and a neuropsychologist. At Flamenco Therapy's first board meeting, Bonnie told me about patients she worked with who had different forms of dementia, some I'd never heard of it. She talked about researchers studying how music and movement therapies can improve their social function, communication, and thinking abilities. Really? My picture of a dementia patient slumped over in a wheel chair conjured up one word: unreceptive.

"From the moment I checked in, I had a profound feeling; this is a family."

Bonnie invited me to the FTD gala to learn more. I'd been to many fundraisers but this one was different. From the moment I checked in, I had a profound feeling: this is a family. The guests and volunteers were all in this together, and they warmly welcomed me in.



FlamencoTherapy.org



Yosi Karahashi provided an emotional performance at the 2016 FTD Unit Gala

I had worked for 18 years providing education programs for the pharmaceutical industry, and I was familiar with drug therapy. But the work I did was funded by blockbuster medications. The night of the gala, I learned to appreciate the challenges faced funding treatment in a small market for a rare disease. I learned there's even a day set aside called International Rare Disease Day.

When Yosi and Bonnie danced, the dining room sparked. We all felt alive watching them move. Brad Dickerson talked about how FTD patients feel the same way: engaged emotionally, socially, and cognitively when they participated in music and movement. When Katie Brandt spoke, I wanted to cry. Might these therapies have changed her husband from immobile, uncommunicative, and shutdown to alive inside, even for a short time? It was humbling to learn about a devastating disease that, until recently, I had never heard of.

What I remember most about the night was the artwork created by FTD patients: the detailed rendering of a 19th-century building, the vibrant colors in an abstract. How could patients with shrinking brains have created these stunningly beautiful works?

I still have so much to learn about FTD. After the gala, I asked some friends if they'd ever heard of it. None of them had. I told them what I knew and felt lucky that I could pass on a little knowledge to let the light of FTD into their lives.



SAVE THE DATE
A Night With the Arts for FTD
3rd Annual Gala & Art Show
October 20, 2017
Royal Sonesta Hotel
Cambridge, MA
[Facebook.com/FTDUnitBoston](https://www.facebook.com/FTDUnitBoston)



[A Night With the Arts for FTD](#) is a collaborative effort planned by families, volunteers and staff from our FTD Community. Consider joining our Gala Planning Committee today! Contact Katie Brandt at Katherine.Brandt@mgh.harvard.edu for more information about how you can help make our 2017 Gala a night of awareness, fundraising and hope for FTD.

The FTD Unit is grateful for the gifts made by our generous 2016 donors to support our clinical care, research efforts, supportive programming and educational initiatives. Every gift raises hope for FTD.

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Join the fight to #ENDFTD today!
Make a gift to the MGH FTD Unit online
at giving.massgeneral.org/FTDUnit

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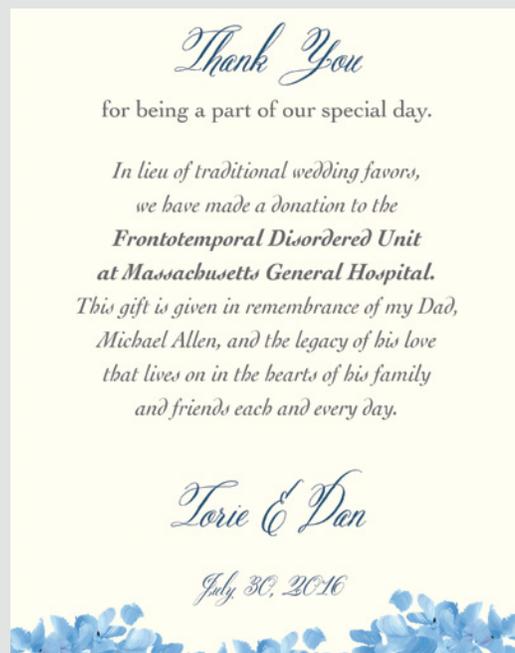
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A donation to the MGH FTD Unit provides powerful support for all areas of our clinical, research and community-based work. It can also provide families with a way to honor loved ones. When Victoria (Allen) Scott was planning her wedding to Dan Scott, she knew that she wanted her father's memory to be a part of the day. In lieu of wedding favors, Victoria and Dan made a donation to the MGH FTD Unit in memory of Victoria's father, Michael Allen. This gift honored the legacy of love that Michael's life left behind in the hearts of his family and friends, while supporting research aimed at a cure for FTD.



Dan and Victoria (Allen) Scott celebrated their July 30, 2016 wedding in Kennebunkport, ME surrounded by family and friends.

Philanthropic gifts can be tailored to honor the unique wishes of our donor families. Please contact Katie Brandt at Katherine.Brandt@mgh.harvard.edu to learn more about how you can make a personalized gift in honor of a loved one today.



In lieu of wedding favors, wedding guests received a custom-designed scroll that honored the memory of Victoria's father, Michael Allen, and noted a gift to the MGH FTD Unit.

We are humbled by the power of philanthropic gifts that can provide bridge funding from one research grant to another, launch innovative support programming, and allow us to reach more patients and families through educational efforts. Each day, these partnerships strengthen our program and our FTD community.

Kathleen Howland
Ruth Hutchins
Lenore Jackson-Pope
Jane & Martin Schwartz
Family Foundation
Anne Marie Johnson
Suzanne Johnson
Brenda Kane-Curry
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 Suzanne Sullivan
 Susan C. Pacino, LLC
 Stanford Family Revocable Trust
 Catherine Syrett
 Janice Hanley Taketa
 Elie Tamer
 Debra Thayer
 Jeffrey Thomas
 Michael Tiner

Suzanne Tiner
 Sarah Tipton
 Sigrid Tishler
 Dorothy Tomasetti Williams
 Eileen Toppa
 Janice Trempus
 Sharon Trojano
 Pamela Tubridy Baucom
 Clare Tubridy Wheadon
 Aileen Tubridy-Kline
 Adrienne Tubridy
 David & Aileen Tubridy
 Joan Tubridy
 Michael Tubridy
 Stephen Tubridy
 Christopher Tullmann
 Robert Tutnauer
 United Way of America
 Jacqueline Veri
 Louise Vozzella
 Catherine Walsh
 Jennifer Warren
 Janet Lee Washington
 Cynthia Westerman
 Mary White
 Maura White
 Janice Wiedemann
 Beverly Williams
 Walter Willier
 Sarah Wilsterman
 Warren Winslow
 WM Gill Landscaping, Inc.
 Julie Wolf
 Suzanne Wolfe
 Sydnee Worth
 YourCause, LLC (Dell Giving)

FTD in the Community

The MGH Frontotemporal Disorders Unit was proud to partner with the Massachusetts Biotech Council to present the 2017 Rare Disease Day Celebration at the Massachusetts State House. FTD Unit Staffer, Katie Brandt, emceed the event as the Massachusetts Ambassador for Rare Disease Day, as designated by the National Organization for Rare Disorders (NORD.) The event brought together almost 400 patients, caregivers, clinicians, researchers, industry experts, elected officials and community members to raise awareness about the impact of rare disease and ways we can all make a difference. We look forward to the 2018 event!



February 28, 2017 MA Rare Disease Day
RareDiseaseDay.org

The MGH Frontotemporal Disorders Unit

is made up of an interdisciplinary team of compassionate and sophisticated staff and clinicians dedicated to the highest quality of care for patients and families living with neurodegenerative conditions including Frontotemporal Degeneration, Primary Progressive Aphasia, atypical Alzheimer's and other forms of cognitive impairment. We are committed to raising awareness and hope for FTD through our exemplary clinical care and research work.



Join us in the fight to #ENDFTD today!

LOCATIONS

MGH FTD Unit Clinical Care

Our patient care clinic is located at the MGH Main Campus in the Wang Ambulatory Care Center. Massachusetts General Hospital

15 Parkman Street
WACC 835
Boston, MA 02114
617-726-1728

MGH FTD Unit Research Center

The majority of our research is performed at our facility in the Charlestown Navy Yard in partnership with the Martinos Center for Biomedical Imaging.

149 13th Street
Suite 2691
Charlestown, MA 02129
617-726-5571

CONTACT US:

MGHFTDUnit@mgh.harvard.edu

Find Us Online: www.FTD-Boston.org

[Facebook.com/FTDUnitBoston](https://www.facebook.com/FTDUnitBoston)

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MASSACHUSETTS
GENERAL HOSPITAL

Frontotemporal Disorders Unit
Massachusetts General Hospital
149 13th Street, Ste 2691
Charlestown, MA 02129