MASSACHUSETTS
GENERAL HOSPITAL
FRONTOTEMPORAL
DISORDERS UNIT

FROM CARE TO CURE

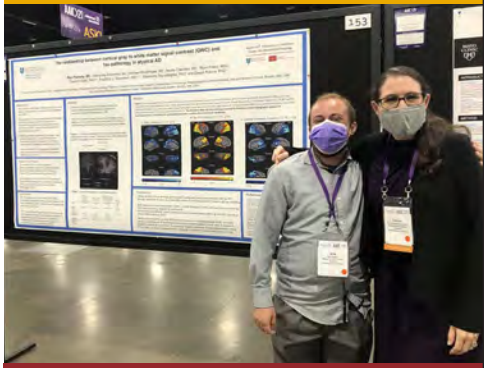
FALL 2021 NEWS FROM THE MGH FRONTOTEMPORAL DISORDERS UNIT

INSIDE THIS ISSUE

STAFF TRAVEL TO AAIC!

The Alzheimer's Association International Conference is the largest and most influential international meeting dedicated to advancing dementia science. In 2021, our staff contributed scientific posters and participated online and in-person in Denver, CO. We are proud to be a part of these international efforts to push dementia science forward.

Learn more! **ALZ.org/aaic**



Sylvia Josephy, MD and Ryn Flaherty attending AAIC in-person to present scientific posters, highlighting ongoing research from the Dickerson Lab.

Dear FTD Unit Community Members,

As we say goodbye to summer and welcome the change that fall brings, it is a time to reflect on the continued endurance of our community. Many of our patients and their care partners have shared with us that the ongoing pandemic continues to impact the way they live their lives. Attending online support groups, wearing a mask for in-person medical appointments, and assessing safety before attending group events have become the new normal. We have heard your concerns about continued safety as we approach the colder months where indoor events are more prevalent, and we want to assure you that Mass General Brigham is providing continual monitoring and adjustments to hospital protocols that keep safety front and center. You can reach out to our team at any time to discuss your questions and concerns. We are committed to navigating this time together, making sure that you feel comfortable for all clinic and research appointments.

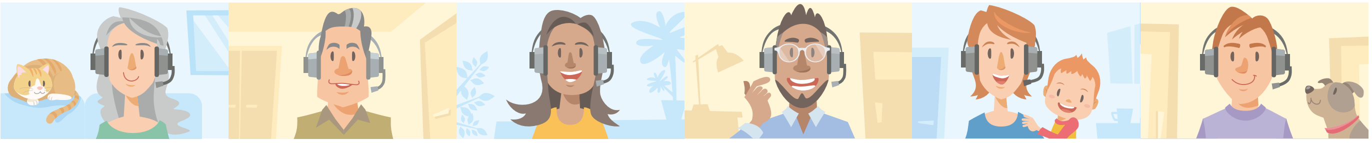
This issue spotlights many impactful activities and achievements from our dynamic staff. Diane Lucente's appointment by the Senate President to the newly formed Massachusetts Rare Disease Advisory Council will bring the lens of a Genetic Counselor to the Council and shine a light on the importance of patient-centered care planning. We share a piece from the Greek newspaper, *Ekathimerini*, where an interview with Alexandra Touroutoglou highlights the benefits of a worldview to support innovation in Alzheimer's disease and related dementia research. We extend congratulations to Katie Brandt for the conclusion of her four-year appointment on the National Alzheimer's Project Act (NAPA) Advisory Council, of which she was co-chair for two years. Our connections with state and national policy initiatives and the global research community contribute to our success as a clinical research program. We are proud of our team's ability to build connections outside of our lab that strengthen our program.

We are happy to announce that we will be celebrating our 7th annual gala, *A Night With the Arts for FTD*, as an online event on Friday, October 15th. Last year's gala was one of our most meaningful with over 400 attendees from across the nation and around the world, united in the hope that the cure of tomorrow is not so far from the care of today. Community isn't cancelled and our online event is a way to build community connections that extend beyond the walls of a ballroom.

Our clinical research program continues to thrive because of your engagement. You inspire our commitment to provide the highest quality of care while working tirelessly towards a cure for Alzheimer's disease, Frontotemporal disorders and related dementias. Thank you for all that you have done to remain connected with our community. We hope to see you online on October 15th! Until then, take care and be well.

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

MGH FTD Unit Fall 2021
Community Forum Friday Webinar Series
Join Us Fridays @ 10:00AM EST



Use this link to participate in the live broadcast: mgh-ftd-events.girostudio.com

Sept 10th – A Night With the Arts for FTD: Raising Awareness, Funds and Hope
Special Performance: Original Composition by 2021 Featured Artist Bernie Metzger

Sept 17th – What I Learned From Caregiver Support Group:
A Conversation with AFTD Support Group Leader Amy Almeida, PhD and
Alzheimer's Association Memory Specialist, Jill Hovanasian, MSW, LCSW

Sept 24th – Understanding Brain Donation: An Irreplaceable Gift for Dementia Research
A Conversation with Matthew Frosch, MD, Director of Neuropathology, MGH

Oct 1st – Understanding the Research Experience
A Conversation with MGH FTD Unit Research Staff and Clinicians

Oct 8th – Discussing Intimacy and Sexuality After a Diagnosis of Dementia
A Conversation with Jennifer Pilcher, Ph.D., CMC, Owner, Clear Guidance, LLC

Oct 15th – **SPECIAL EVENT – 7:00PM EST**
A Night With the Arts for FTD:
7th Annual Gala & Art Show to Benefit the MGH FTD Unit

There will be no morning program on October 15th!

Oct 22nd – Celebrating A Night With the Arts for FTD
A Night With the Arts for FTD Recap, Gala Co-Chairs Katie Brandt & Amy Almeida

Oct 29th – Resources for Young-Onset Dementia
A Conversation with Nicole McGurin, MS, CDP, Programs & Services Director,
Alzheimer's Association and Rhiana Kohl, Caregiver & Alzheimer's Disease Advocate

Nov 5th – Grief Supports for Children and Families
A Conversation with Camille Adler-Roth, LICSW, CCLS
Children's Program Manager, Care Dimensions

Nov 12th – Understanding Hospice Care and Processing Grief
A Conversation with Bernice Burkarth, MD, HMDC, FAAHPM
Chief Medical Officer of Home Health Foundation

Nov 19th – Navigating the Holidays with a Loved One with Dementia
A Conversation with Barbara Moscowitz, LICSW, Founder, Associate Director of
Education and Support, MGH Dementia Caregiver Support Program

Can't make the livestream? No problem! All MGH FTD Unit Community Forum Friday episodes will be recorded and posted on our MGH FTD Unit YouTube Channel.

Spotlight on Staff:

Diane Lucente, MS, CGC, Genetic Counseling Manager, MGH FTD Unit

RARE DISEASE ADVISORY COUNCIL APPOINTEE

The Massachusetts Legislature passed health care legislation in 2020 that included the creation of a Rare Disease Advisory Council (RDAC). The Senate President's office was called upon to appoint experts to fulfill the mission of the Council by bringing together stakeholders from across the rare disease continuum to provide feedback and recommendations, enhancing our state government's ability to improve the lives of those in the rare disease community. We are thrilled to announce that Diane Lucente has been appointed to the Council by Senate President Karen Spilka. Ms. Lucente will provide expertise as a Genetic Counselor to inform Council activities, priorities and goals.

Creating an RDAC in Massachusetts will give rare disease patients a unified voice in Massachusetts state government. Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, and best practices for the care of those with rare diseases. It will also be tasked with creating a rare disease plan for the state and developing methods to publicize the profile of the social and economic burden of rare diseases to ensure health care providers are informed.

In creating this Council, Massachusetts joins fourteen other states that have already enacted similar legislation in support of their rare disease community and proven that the RDAC can be an invaluable resource. Those states include: Alabama, Connecticut, Illinois, Kentucky, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Pennsylvania, Tennessee, Utah, and West Virginia. We are proud of Ms. Lucente's appointment and look forward to the Council's impact.

> ***"I look forward to addressing the important issues that individuals face living with rare disease."***

Alex Touroutoglou, PhD, Director of Imaging Operations, MGH FTD Unit

ACHIEVING INTERNATIONAL RECOGNITION IN ALZHEIMER'S RESEARCH

Portrait by Artist Titina Halmazati

"I am not just a scientist. I am a Greek scientist."

Alexandra Touroutoglou, PhD, Cognitive Neuroscientist, Director of Imaging Operations, MGH FTD Unit, and Assistant Professor of Neurology at Harvard Medical School, was recently featured in the Greek newspaper, *Ekathimerini*. As president of the **Hellenic Bioscientific Association of the United States**, Dr. Touroutoglou reflected on her childhood in Greece, and the perseverance that brought her to the United States, to conduct this important work. "I grew up in Ptolmemaida, Greece and my parents were non-scientists, but they highly valued education. I knew I wanted to be a scientist and I wanted to study medicine. In Greece, when I finished my PhD, there was no neuroscience lab in the whole of Greece. I was drawn to Boston by the labs that were using this innovative technique of functional MRI where they were looking inside someone's brain and I was fascinated. So, when I got an offer from Harvard Medical School for my postdoctoral studies, I accepted in a second." This exceptional news piece highlights Dr. Touroutoglou's significant scientific contributions to the field of Alzheimer's disease research and recognizes her team's important studies on Superagers, a unique group of older adults who maintain youthful brains and are being followed through Harvard Medical School research. Dr. Touroutoglou outlines how this important work helps to decode how the human brain ages and how this could one day impact treatment of neurodegenerative brain diseases.

> ***Dr. Touroutoglou reflects on her parents, who were non-scientists but valued education, and recalls her mother's words "Education will be a gold bracelet on your hand."***

Click **HERE** to read the full article in *Ekathimerini*!

Click **HERE** to watch Dr. Touroutoglou talk more about her journey to neuroscience and Alzheimer's Disease research in her interview with the **National Hellenic Society**.

FEATURED ARTIST
ELIZABETH STEVENS

FEATURED ARTIST
RICK RANTI

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 • 7:00PM

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

FEATURED ARTIST
BERNIE METZGER

FEATURED ARTIST
MARYPAT MCGRATH

FEATURED ARTIST
TOM CHANDLER

FEATURED ARTIST
MARK ZAHNISER

FEATURED ARTIST
ANDREA BONSIGNORE

Powerful Podcasts: *Dementia Untangled's* Interview with Katie Brandt

In 2021, The Banner Alzheimer's Institute and Banner Sun Health Research Institute located in Tuscon Arizona, launched a new podcast, *Dementia Untangled*, aimed at unraveling the complex world of caring for a loved one with Alzheimer's Disease or a related dementia. This dynamic podcast provides support and guidance to caregivers through conversations with physicians, experts, and community leaders.

Katie Brandt, Director of Caregiver Support and Public Relations for the MGH FTD Unit, was recently featured as a guest speaker on the podcast's latest episode, "Utilizing The Caregiver Trifecta".

Subscribe to *Dementia Untangled* wherever you get your podcasts, and learn more about untangling the complexities of caring for a loved one living with dementia.

Subscribe online today! **banneralz.org/finding-support/dementia-untangled-podcast**

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

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

From Care to Cure *features presentations from MGH FTD Unit clinicians about the medical and scientific aspects of FTD, Alzheimer's and related dementias.*

Community Forum Friday *features conversations with community experts about topics relevant to living life well with dementia.*

Spotlight Events *feature MGH FTD Unit community events and special guest speakers.*

CAREGIVER SUPPORT GROUP TUESDAYS

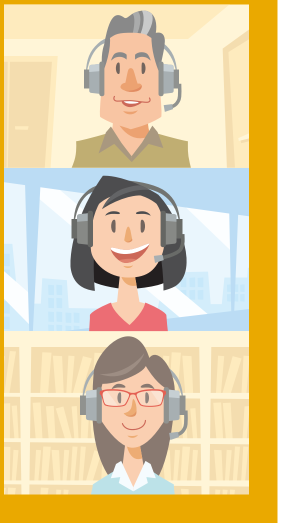
Are you caring for a loved one living with Frontotemporal Dementia, atypical Alzheimer's Disease, or a related disorder? Our weekly online support groups meet for an hour over Zoom to provide care for the caregiver. Join us every week, or just once. You can attend on a schedule that works for you. We 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
September 7th & 21st
October 5th & 19th
November 2nd, 16th & 23rd
December 7th & 21st

Tuesdays @ 7:00PM
September 14th & 28th
October 12th & 26th
November 9th & 30th
December 14th



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.

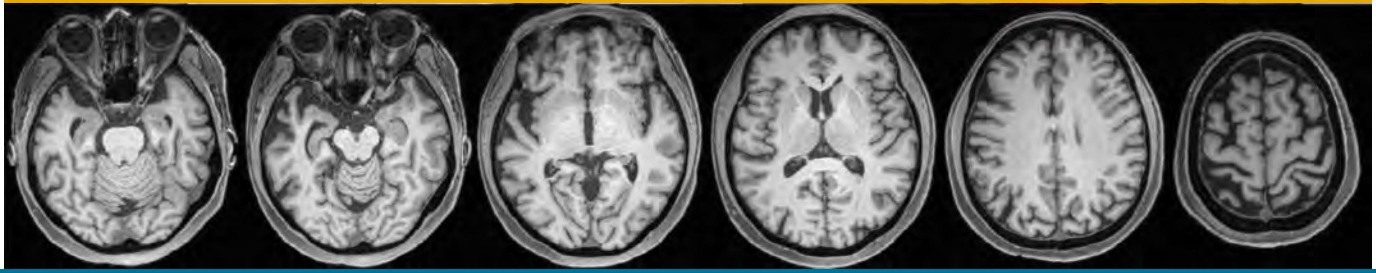
4RTNI-2: FOUR REPEAT TAUOPATHY NEUROIMAGING INITIATIVE

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



Make a Clinic Appointment
MGHFTDUnit@mgh.harvard.edu

Learn About Research
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Sylvia Josephy, MD

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