

FALL 2023

NEWS FROM THE MGH FRONTEMPORAL DISORDERS UNIT

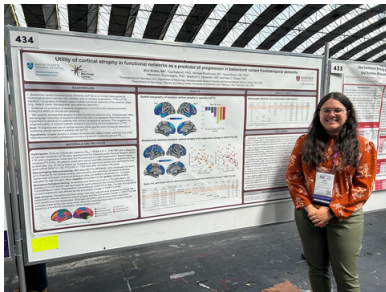
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THE MGH FTD UNIT IN THE COMMUNITY



Katie Brandt and Amy Almeida met
Dr. Bruce Miller at AFTD's
Education Day in May



Erin Krahn, MGH FTD Unit Project
Manager, presents at the
Alzheimer's Association
International Conference in July



Members of the Boston-area FTD
Caregiver Support Group attended
FTD at the Fruitlands in July

Dear FTD Unit Community Members,



We appreciate the opportunity to connect with you through our last newsletter of 2023. As we approach the New Year, we look back on 2023 with wonder and gratitude. The MGH FTD Unit benefited from *Ski with David for PSP*, the inaugural ski race and celebration hosted by the Crowley family at Wachusett Mountain in February to raise awareness, funds and hope for a cure for Progressive Supranuclear Palsy (PSP). In April, our community gathered in person once again at *A Night with the Arts for FTD*, an exuberant night celebrating the strength and resiliency of our FTD community. We also celebrated the arts with the first *FTD at the Fruitlands*, a summer night of community and music in the beautiful setting of the Fruitlands Museum in Harvard, MA.

This issue spotlights Primary Progressive Aphasia (PPA), on the tenth anniversary of a groundbreaking philanthropic commitment to fund PPA research at the MGH FTD Unit. Interviews with Megan Quimby, the Director of the Speech and Language Program, and Nneka Watson, a Clinical Fellow in the Speech and Language Program, illuminate the PPA research the MGH FTD Unit is doing, hopes for the future, and the inspiration both clinicians get from the PPA patients and families they work with.

One thing that both Megan and Nneka shared is the importance of support. We recognize that families dealing with Frontotemporal dementia, Primary Progressive Aphasia, Posterior Cortical Atrophy, young-onset and atypical Alzheimer's Disease and related disorders benefit from a wide net of support that includes medical care, educational opportunities, connections with community resources and access to research. We know that each person approaches the experience of a diagnosis with unique needs and goals of care. You can read about some of the educational and support offerings of the MGH FTD Unit on page 4.

We hope to see you in clinic or online soon! Until then, take care and be well.



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

A Decade of Excellence: PPA Research at the MGH FTD Unit



In 2013, George and Lizbeth Krupp made a generous pledge to fund research at the MGH FTD Unit. On June 29, 2016, MGH leaders, faculty and friends joined together to celebrate the Tom Rickles Endowed Chair in Primary Progressive Aphasia, established by the Krupp Family, and awarded to Brad Dickerson, MD, the Director of the MGH FTD Unit. This gift has enabled a greater focus on our ability to accurately diagnose, better understand the disease process and guide families for the highest quality of care while living with PPA.

(L to R) Lee Rickles, George Krupp, Brad Dickerson, Lizbeth Krupp celebrate the announcement of the Tom Rickles Endowed Chair in Primary Progressive Aphasia Research.

Q&A with Megan Quimby, Director, Speech & Language Program

Megan Quimby is the Director of the Speech & Language Program at the MGH Frontotemporal Disorders (FTD) Unit. She joined the MGH FTD Unit in 2014. Megan is a clinically-certified speech-language pathologist and has a Master of Science degree in speech-language pathology. She specializes in working with individuals with progressive language disorders. We sat down with her to learn more about the MGH FTD Unit's Speech & Language Program and what makes it unique.



Q: Thanks for speaking with us today, Megan. Why do you think that the MGH FTD Unit program is special for people diagnosed with Primary Progressive Aphasia?

A: I'm happy to be here. I think it's important that patients with PPA get specialized care that not only is individualized for the person, but with specialists who have a lot of knowledge about these unique and rare diagnoses. For instance, in their training, speech language pathologists often do not learn about FTD and PPA, maybe one single slide in grad school. It's really important that speech language pathologists and other health professionals are trained in therapy and assessment for these rare disorders.

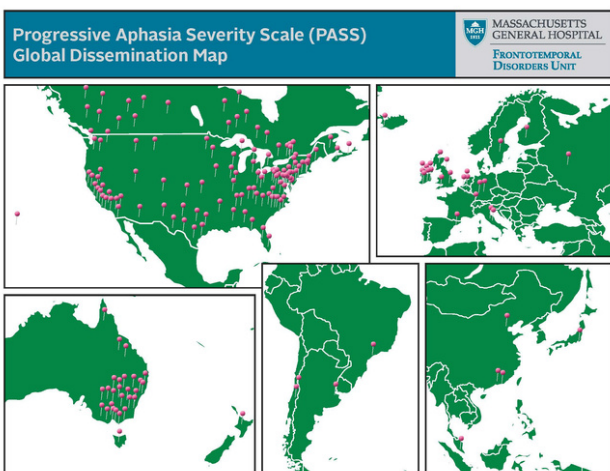
Q: What can patients expect by receiving medical care in a specialty clinic like the MGH FTD Unit?

A: I think it's a lot more likely that they would be diagnosed correctly and be given important resources relevant to their diagnosis if they were in a specialized program such as the MGH FTD unit. We have seen many patients who have been misdiagnosed in the past. Fortunately, local providers have referred them to our program. After this referral, we can provide more in-depth knowledge about available treatments, potential medications that may be beneficial as well as support systems for both patients and families.

Q: I know the MGH FTD Unit developed the Progressive Aphasia Severity Scale (PASS). How is the PASS impacting care for patients with PPA? (See below for more information about the PASS.)

A: We receive inquiries daily from clinicians around the world for the PASS because they want to use it with their PPA patients. With the PASS, the clinician does not just assess the patient's abilities with paper and pencil tests, but also interviews the patient and their family or care partner. This in-depth information about the patient's language allows the clinician to provide a PASS rating based on several different assessments.

(Q&A continued on page 3)



Progressive Aphasia Severity Scale (PASS)

Clinicians and researchers in the MGH FTD Unit developed the PASS as a scale to rate the presence and severity of difficulties in a variety of aspects of speech, language, and functional communication skills. The goal is to provide health care providers and investigators with a tool that can be used in identifying strengths and weaknesses in a patient's communication skills which can assist in diagnosis and treatment planning, as well as monitoring symptom progression over time. A number of other teams around the world have been taught how to use it. The MGH FTD Unit hopes the PASS will be incorporated into studies that may lead to new treatments for PPA.

Q&A with Megan Quimby (cont.)

When other health professionals are asking for the PASS instrument that means that they are learning about the importance of finding out from family members how the patient is doing at home, on a daily basis, and not just looking at a *Boston Naming Test* score of 10 out of 30. These clinicians are making an assessment of who this patient is and their abilities based on the PASS. The MGH FTD Unit is not only helping train speech language pathologists in our lab, but also collaborating with other centers is helping patients and families around the world.

Q: What kind of research on PPA is the MGH FTD Unit currently focusing on?

A: We're doing a lot of what are called natural history studies, longitudinal observational studies which allows us to not only diagnose at baseline what we think is going on with patient's communication, but also in their brain. We monitor them every three to six months with different assessments and gather different types of images like MRIs and PET scans. By following them so frequently, it allows us to see how they're doing over many years. We hope this research will be useful as new disease-altering treatments are developed. You can't really know how a treatment is helping if you don't know how the regular course of the disease progresses. Our studies will help clinicians and research understand this progression.

Q: Will this research help patients and their families in the shorter term, before disease-altering treatments are available?

A: Yes, it does. By monitoring patients so closely, we are better prepared to answer patient's and family members' questions about what to expect as this disease normally progresses. It helps patients and families understand what to expect and how to prepare for the future.

Q: What do you think is coming for the future for people living with PPA?

A: There are more people who can benefit from our clinic and our research program as clinicians and families learn about the MGH FTD Unit. More people involved in research will allow us to find a cure in the future. In the near term, we are creating a stronger support system for these patients and families who unfortunately encounter these rare diseases. In addition, the training of the health professionals about PPA is just becoming better and widespread which means that there will be more health professionals to help with finding a cure.



In 2018, an MGH FTD Unit music therapy group supported people impacted by PPA.

Q&A with Nneka Watson, Clinical Fellow, Speech & Language Program



Nneka Watson, MS CF-SLP is a speech-language pathology clinical fellow at the MGH FTD Unit. She holds a Master of Science degree in speech-language pathology from the MGH Institute of Health Professions. Nneka conducts speech and language evaluations to monitor symptoms and progression in patients with progressive language disorders.

Q: Thanks for talking with us about your experience in the MGH FTD Unit. How did you come to join the Unit?

A: I did a concentration in grad school in adult neurogenic disorders so I always had an interest in the sort of disorders that the MGH FTD Unit treats. In my classwork, we did not really go very in depth into PPA. I think we had maybe one slide on it during our aphasia class. So when I saw this position pop up on the placement website, I was so excited to apply and so excited once I got it. I started in September 2022 doing a six month clinical placement at the unit which is a little bit unusual, typically, our placements are only three months. So I got double the time to really learn and absorb.

It really deepened my passion for helping and developing more knowledge about how to best support people who are facing such challenges, because the challenges of PPA are unique. There's a real need for speech pathologists who really have a depth of understanding about how to support patients with PPA as communication shifts and changes over time. It's been a very meaningful dream come true to sort of work as a clinical fellow now in a more official capacity with this team. Getting the chance to learn and be mentored by such brilliant, supportive, kind experts in PPA at the unit has been just so meaningful.

Q: When you think about working with the patients with PPA at the MGH FTD Unit, what is what gives you hope?

A: That's such a good question. Because I think about that every day. Every single time that we leave an assessment, I always wish that there was more that we could offer to patients and their families. What gives me hope is one, the patients and families. The amount of love and support that they pass back and forth between each other all the time is one of my favorite things about working here. I think that amount of love has to mean something when it comes to figuring out ways to fight back against these disorders. Working on such an amazing team also gives me hope. I think every single person at the MGH FTD Unit is so passionate, so knowledgeable, so determined. There's just so much innovation and creativity and passion within this team.

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
January 2, 16, 23	January 9, 30
February 6, 20	February 13, 27
March 5, 19	March 12, 26
April 2, 16, 23	April 9, 30
May 7, 21	May 14, 28
June 4, 18	June 11, 25
July 2, 16, 23	July 9, 30
August 6, 20	August 13, 27
September 3, 17	September 10, 24
October 1, 15, 22	October 8, 29
November 5, 19	November 12, 26
December 3, 17	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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