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FRONTOTEMPORAL
DISORDERS UNIT

FROM CARE TO CURE

WINTER 2020

NEWS FROM THE MGH FRONTOTEMPORAL DISORDERS UNIT

INSIDE THIS ISSUE

JOIN US ON APRIL 3, 2020!

We are proud to host our 9th annual education day, From Care to Cure, this spring. Register at **Because.MassGeneral.org/FromCaretoCure** for a day of science, education and connections

NIH FUNDS FTD RESEARCH

The National Institute of Health has funded FTD research at $63 million over the next five years. Learn more about ALL FTD, the ARTFL-LEFFTDS Longitudinal Frontotemporal Lobar Degeneration: A multisite research consortium at **ALLFTD.org**

Dear FTD Unit Community Members,

We appreciate this opportunity to share our latest news with you. As most of you know, we are dedicated to advancing our knowledge about and ability to care for people and their families living with Frontotemporal Dementia, Primary Progressive Aphasia, Posterior Cortical Atrophy, young-onset and atypical Alzheimer's disease, and related disorders. As we enter the 12th year of our program, I couldn't be happier with the growth of our team and our ability to join together with more people to fight back against these terrible diseases. We wouldn't be able to make this kind of progress without the participation of patients and family members who devote time and energy to work with us to learn more about these conditions and build the foundations on which new treatments will be developed.

This issue spotlights the many impactful activities of our Speech-Language Pathology (SLP) Program directed by Megan Quimby. I'm sure you will enjoy reading about the cutting-edge research, meaningful clinical care, and compassionate support programs being run by our SLP team. Education and training are intertwined in all of these activities. Our team is also very excited to be performing and planning innovative "intervention" studies aiming to improve language function with transcranial magnetic stimulation and to deliver computer-assisted SLP therapy in person and via telemedicine, while also measuring how these interventions work through functional brain imaging.

We are also excited to be participating in two major new collaborative initiatives focused on FTD, AD and related disorders with funding from the National Institute on Aging, the National Institute of Neurological Disorders and Stroke, the Alzheimer's Association, and the Association for FTD.

These kinds of natural history and biomarker databases are being developed for a variety of diseases after similar efforts in the field of typical, late age-of-onset AD demonstrated their value for planning treatment studies. That is, with a large enough database to draw from, investigators can share this information to improve our understanding of what happens to people with these conditions over time, and to develop better ways of measuring whether new treatments work in meaningful ways. We look forward to sharing some of the work we are excited about in these pages; thank you for your participation and interest!

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

Speech and Language Program Overview

The MGH Frontotemporal Disorders Unit Speech and Language Program consists of Master's and PhD students, clinical fellows, postdoctoral research fellows and licensed clinicians in speech language pathology who are pursuing research and clinical care of patients with Primary Progressive Aphasia (PPA), early onset Alzheimer's Disease and FTD diagnoses. Trainees and clinicians in this program actively collaborate with team members in neurology, neuropsychology, psychiatry and social work.

Program Goals:

- To improve our ability to diagnose, monitor and treat symptoms of PPA and related disorders
- To improve our understanding of the changes in the brain and behavior that characterize PPA and related disorders
- To connect patients and families with additional resources for assessment and treatment, planning and education

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Megan Quimby, MS, CCC-SLP is the Director of the Speech & Language Program in the Frontotemporal Disorders (FTD) Unit at Massachusetts General Hospital (MGH). She specializes in working with individuals with progressive language disorders, helping them by providing evaluation and treatment services that focus on facilitating functional communication. She provides education to community-based organizations such as the Alzheimer's Association. In the past, she has worked at an adult day health program, the Alzheimer's Disease Research Center at MGH and Constant Therapy.

Claire Cordella, PhD, CCC-SLP, is a postdoctoral research fellow in the MGH FTD Unit, as well as a licensed speech-language pathologist. She has a PhD in Speech and Hearing Bioscience and Technology from Harvard University. Her research focuses on apraxia of speech and other motor speech disorders as they occur in primary progressive aphasia. Claire is particularly interested in quantitative approaches to assessment of motor speech disorders, as well as evidence-based interventions for maximizing speech intelligibility and communication effectiveness throughout the entire disease course.

Jeanne Gallée is a 4th year doctoral student in the Harvard-MIT Program in Speech and Hearing Bioscience and Technology Program (SHBT). Her research is clinically focused in the area of Primary Progressive Aphasia (PPA), where she explores the neural networks that are recruited to maintain or relearn language. In order to gain hands-on experience with PPA, she completed all coursework and clinical training for clinical certification in speech-language pathology at MGH's Institute of Health Professions 2017-2019. She was awarded the Dingwall Foundation's $30,000 Dissertation Fellowship in the Cognitive, Clinical, and Neural Foundations of Language in July 2019.

Shalom (Shaz) Henderson, MS, CCC-SLP, is a licensed speech-language pathologist at the MGH FTD Unit. She joined the FTD Unit in January 2018 as a graduate student and completed her clinical fellowship in July 2019. She has a Master of Science degree in speech language pathology from the MGH Institute of Health Professions. Clinically, she evaluates patients in areas related to speech and language and provides education and recommendations for patients and their caregivers. In addition, her research focuses on semantic cognition and its disorders in primary progressive aphasia.

Daisy Hochberg, MS, CCC-SLP, is a speech-language pathologist in the research program of the MGH FTD Unit, where she has worked since 2007. Her experience includes the evaluation of speech and language abilities in patients with progressive language disorders, as well as in providing treatment services that aim to facilitate functional communication. Her research has focused on the development and use of a scale to measure the presence and severity of language symptoms in this patient population.

Emmaleigh Loyer, MS, CF-SLP, joined the FTD Unit as a graduate student in April 2019. After earning a Master's degree in Speech-Language Pathology from the MGH Institute of Health Professions, she became a clinical fellow in September 2019. Emmaleigh has a background in cognitive neuroscience, neuropsychology, and clinical research. Her role involves evaluating patients with PPA and related disorders, providing education and support to patients and caregivers, and contributing to ongoing research studies. She is particularly interested in functional communication in PPA and the utility of telepractice in treatment for neurodegenerative disorders.

Understanding Primary Progressive Aphasia (PPA)

Primary Progressive Aphasia (PPA) is a neurological disorder that involves a progressive loss of language functioning. Unlike a stroke or traumatic brain injury, PPA is a degenerative condition related to shrinkage in the parts of the brain responsible for speech and language. In order to be classified as PPA, language must be the most prominent area of impairment when symptoms first begin. Other areas of cognition, such as memory and reasoning, are usually not affected in the early stages of the disease, but they often become impaired as the disease progresses. Individuals with PPA may experience a variety of language difficulties such as coming up with words, understanding others, and transforming thoughts into speech or writing. PPA researchers have recognized three separate variants that describe clusters of symptoms that often co-occur. Although not all patients clearly fit into a single category, clinicians use the variants as a guideline to make predictions about the underlying cause and future course of the disease. A brief description of the logopenic, semantic and non-fluent variants of PPA can be found below.

LOGOPENIC VARIANT (lvPPA)

- Word finding difficulty

AND

- Impaired repetition of sentences and phrases

Areas of preservation often include:

- Fluent and grammatical speech
- Understanding the meaning of words

SEMANTIC VARIANT (svPPA)

- Word finding difficulty

AND

- Difficulty understanding meanings of words

Areas of preservation often include:

- Fluent and grammatical speech
- Repetition

NON-FLUENT VARIANT (nfvPPA)

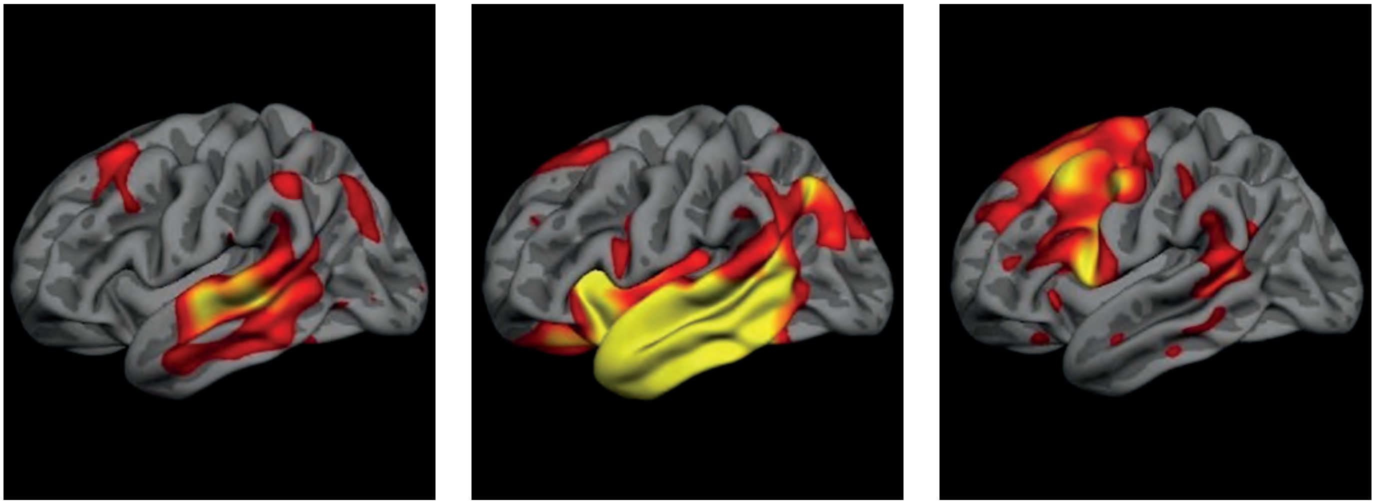
- Agrammatism in language production

OR

- Effortful/halting speech

Areas of preservation often include:

- Understanding the meaning of words



Above are prototypical patterns of brain atrophy observed through MRI in logopenic, semantic and non-fluent variants of PPA, respectively.
Images from MGH FTD Unit.

Treatment for Primary Progressive Aphasia

A member of our team may suggest a referral for speech-language therapy after meeting with a new or existing patient. As there are different approaches to speech-language therapy, it is helpful to work with a speech-language pathologist (SLP) who has knowledge of progressive speech and language disorders. We can help to identify an experienced SLP at MGH or at a facility closer to home. In the MGH FTD Unit Speech and Language Program, we recommend an approach to treatment that focuses on strategies to compensate for the communication difficulties the patient and his/her communication partner may be experiencing. This is different from the approach that a SLP may take with someone who has an aphasia due to a stroke, where the goal may be to regain lost language abilities. Because individuals diagnosed with primary progressive aphasia (PPA) experience a gradual decline in language abilities over time, it is helpful to focus on improving communication using compensatory and other augmentative strategies, with the idea that strategies can be modified over time.

We typically recommend speech-language therapy for 8-10 sessions and highly encourage communication partners to attend with the patient. "Check-in" sessions can be reinstated with the SLP on an as needed basis. So, what are some examples of communication strategies? The SLP may suggest changes to the family's conversation style, such as slowing down when talking, repeating something until the patient understands, phrasing questions and comments in simpler ways, and asking the person to describe a word when coming up with the name is difficult. Other strategies may include utilizing assistive technology such as an iPad or a communication notebook, and using other modes of communication like drawing, writing, or gesturing. The SLP's goal will be to work with the patient and family to uncover the most helpful strategies for that family at that point in time, keeping in mind that each person with PPA is unique.

LEARN MORE ABOUT PPA ON THE MGH FTD UNIT YOUTUBE CHANNEL:
Bit.ly/FTDYouTube

RESOURCES FOR PRIMARY PROGRESSIVE APHASIA

The Association for Frontotemporal Degeneration
Patients and caregivers can access support and education through AFTD directly and also through a nationwide network of clinicians and volunteers. Although they are the Association for FTD, they hold a wealth of information and connections for patients and care partners navigating life with PPA.
www.theAFTD.org

Boston-area FTD Caregiver Support Groups
Please email **ftd.boston@gmail.com** to join our support group email list.

Newton Wellesley Hospital
Last Tuesday of Every Month – 7:00 - 9:00 PM
Co-Facilitators: Katie Brandt & Bernie Metzger

Mount Auburn Hospital
2nd Tuesday of Every Month – 7:00 - 9:00PM
Facilitator: Amy Almeida

The Alzheimer's Association
On a nationwide scale, they offer support groups, education and counseling services to patients, caregivers and families with Alzheimer's and all related dementias, including PPA.
www.ALZ.org

What Happens During a Clinic Appointment?

When patients and their caregivers come to our clinic, they will interact with many members of our interprofessional team, which includes neurologists, caregiver support specialists, social workers, nurses and speech-language pathologists. In order for us to provide personalized and high-quality care, we work closely with both patients and their caregivers. During a visit, patients complete cognitive and language testing and caregivers participate in an interview where they are asked to share their perspectives and insights with a clinician. After this is complete, patients and their caregivers will meet with our team to review recent testing results such as MRI scans and neuropsychological evaluation, and discuss a patient's diagnosis, prognosis and treatment options. Additionally, our team will provide helpful resources and make appropriate referrals to specialists who are trained to provide treatments that aim to increase a patient's quality of life. These treatments include speech-language therapy, counseling, support groups, occupational therapy, and physical therapy. Caregivers are provided ample opportunity to ask questions throughout the visit to ensure they feel supported and educated at the conclusion of their appointment. Finally, we develop a follow-up plan to schedule the next appointment at our clinic. It is important to keep in mind that initial clinic visits typically take a few hours as our multidisciplinary team is devoted to providing a comprehensive evaluation for the purposes of diagnosis, treatment and ongoing care.

Becoming a Patient in Our Program

If you or a loved one would like to be seen in our clinic, please e-mail us at **MGHFTDUnit@partners.org**.

Upon receiving your e-mail, a member of our team will reach out to discuss your case and to recommend next steps, which may include obtaining a referral from your primary care provider and requesting medical records.

Here are the steps involved in getting a referral to our clinic:

- Your primary care physician (PCP) or neurologist will need to enter a referral into the EPIC system, or fax the referral to the MGH Neurology Access Center at (617) 724-0412. Your PCP or neurologist will need to indicate in the referral that you are requesting an appointment with Dr. Dickerson at the Memory Disorders Unit. For questions regarding new patient referrals, please call (617) 724-6387, option 2.
- If you are not a patient within Partners Healthcare, it is highly likely that we will not have access to your medical records. Please send available records including imaging and neurology/neuropsychology notes with the referral. This will help expedite the process of facilitating the referral and reviewing your case.

Upon receiving the referral, Dr. Dickerson and our team will review the case and determine if you or your loved one should be seen in this clinic or be referred to a different specialty clinic at MGH. Depending on this decision, our patient coordinator may be in contact with you or your family to schedule an appointment. If referred to a different specialist, you will be contacted by that clinic's patient coordinator. Please keep in mind that the patient coordinator will not be able to schedule an appointment if you are not registered as a MGH patient. You may register as a new patient by calling (866) 211-6588.

Research in the Speech and Language Program

In addition to caring for patients clinically, our team is committed to participating in and leading research related to the diagnosis, management and treatment of speech and language disorders that commonly occur in PPA and other neurodegenerative disorders. Our PPA research program is largely funded through the National Institute on Deafness and Other Communication Disorders (NIDCD), an arm of the National Institutes of Health (NIH). Through NIH NIDCD grants, we are able to pursue several different types of studies relating to PPA, including longitudinal cohort studies, experimental interventional studies, as well as multi-site collaborative projects with other PPA programs across the nation.

As a team, we believe in the importance of translating novel research findings to clinical practice while also acknowledging the critical role of the patient experience in guiding research questions and directions. We could not do any of the research we do without the commitment and enthusiasm of you, our patients and families. In the spirit of this ongoing partnership, we are happy to share some recent research highlights from our team as well as to let you know about ongoing opportunities to participate in research with us.

TABLET-BASED TREATMENT

In PPA, one of the first issues many people face is the loss of words in everyday communication. Therefore, the first goal of this treatment study is to see if training personalized words can help maintain and improve your ability to use them. For this, we will use a treatment delivered via technology, where patients can benefit from weekly practice from the comfort of their homes. Weekly sessions will be led by a clinician from our team over a video conference call. We are also interested in how the brain helps us maintain and improve language. That's why we will look at the brain before and after treatment to see if we can identify any changes in how it functions. With this study, we hope to help future treatments for PPA and to better understand what is causing the progressive language problems that we see.

TRANSCRANIAL MAGNETIC STIMULATION

Another method of treatment used in the lab is brain stimulation, also called **repetitive Transcranial Magnetic Stimulation (rTMS)**. rTMS has been shown to be helpful in people with other brain disorders by reducing the effects of depression or stroke. Our goal is to see the effects of non-invasive brain stimulation on language ability in individuals with PPA. We measure change by testing language ability and taking pictures of the brain using **Magnetic Resonance Imaging (MRI)**. We are also comparing the outcomes of real rTMS to placebo rTMS, where the latter looks and sounds just like real rTMS without stimulating the brain. This will help us identify the specific benefits that rTMS may have in helping people with PPA recover language.

OTHER RESEARCH OPPORTUNITIES

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

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

MGHFTDUNIT@partners.org

ALL FTD: the ARTFL LEFFTDS LONGITUDINAL FTD STUDY

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. 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.

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. 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 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.

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.

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.

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 FOCUS GROUPS

You may be eligible if: You are a caregiver of someone who was diagnosed with FTD, Alzheimer's Disease or a related dementia before the age of 65.

Goal: This intervention aims to collect information from young-onset dementia caregivers about how video decision aids can help improve healthcare decisions.

This study involves: Caregivers will take online surveys and participate in a one-time focus group or interview for 3 to 4 hours.

A NATIONAL AND GLOBAL MOVEMENT FOR RESEARCH

The newly-funded ALLFTD study is capitalizing on five years of work of two very successful North American studies (LEFFTDS and ARTFL) to further integrate these studies into the largest study of FTD worldwide. **The second project—LEADS—is a 15-center U.S. study of young-onset AD, which we have been running for about a year.** Another ongoing project, the 4-Repeat Tau Neuroimaging Initiative, focuses on Progressive Supranuclear Palsy and Corticobasal Degeneration. All of these studies, as well as a number of similar studies globally, are focused on evaluating patients regularly (usually annually) with standardized clinical measures and brain imaging with MRI and PET as well as spinal fluid and blood measures in order to develop so-called "natural history" and biomarker data regarding these conditions.

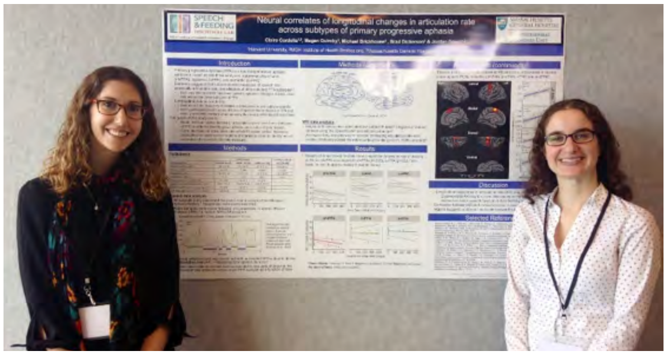
Research Highlights

Our research team presents PPA-related projects at national and international conferences

Dr. Cordella has recently published the results of her dissertation project in the journal Neurology. The study investigated the utility of using a quantitative speech measure—specifically a measure of a person's rate of speech in casual conversation—to diagnose patients who have a motor speech impairment. The study also investigated whether this speech rate measure could be useful in detecting changes over time in a person's speech, because this would be relevant for clinician providers looking to document these changes and give information to patients and families about what to expect over the course of the disease. Lastly, the study used neuroimaging methods to determine which regions of the brain might be responsible for the changes in speech that many of our patients experience. This understanding is important as intervention studies emerge (including in our own laboratory!) that aim to stimulate certain brain regions to affect speech or language outcomes.

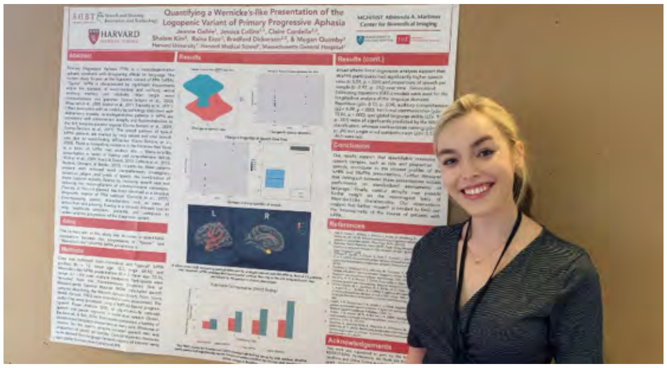
This study is part of Dr. Cordella's larger research focus on quantifying speech impairments in PPA in order to understand how to better diagnose, and ultimately treat, these debilitating speech-related symptoms in PPA. We are incredibly grateful to the patients and families that have participated and continue to participate in this research at the MGH FTD Unit!

Jeanne Gallée's project aims to define the trajectory of logopenic variant PPA by measuring speech, language, and brain atrophy. Measures of speech can include how quickly someone speaks and how much someone speaks in a given conversation. Language measures refer to abilities such as the understanding and production of both spoken and written output. Measures of atrophy allow us to see how intact or healthy specific regions of the brain area. Jeanne examined these measures in almost 50 individuals in order to establish how each of the individual components of speech and language relate to brain atrophy, and how these might differ by the individual. The findings of this research has the potential to effectively identify differences in disease trajectory and thereby help patients, caregivers, and clinicians prepare and implement appropriate intervention.



Claire Cordella presented her poster, "Neural Correlates of Longitudinal Changes in Articulation Rate Across Subtypes of Primary Progressive Aphasia," at the 2018 Conference on Motor Speech in Savannah, Georgia.

Shaz Henderson's project investigates semantic memory, which refers to our mental representations of meaning of words, objects, people, and facts. The prevalence of semantic memory impairments in PPA varies across its variants, with semantic impairment being most prominent in svPPA. By examining the brain-behavior relationships of semantic memory in PPA, Shaz's aim is to better understand the patterns of semantic memory impairment in PPA in order to formulate a stronger diagnostic classification between PPA variants. This could potentially inform early management of symptoms, predict later emerging symptoms in PPA, and help clinicians plan for more effective interventions.



Jeanne Gallée presented her poster, "Quantifying a Wernicke's-like Presentation of the Logopenic Variant of Primary Progressive Aphasia," at the 2019 Clinical Aphasiology Conference in Whitefish, Montana.

Shaz Henderson presents at the 2018 American Speech-Language-Hearing Convention in Boston, Massachusetts.

Training the Next Generation

The Speech-Language Training Program at the MGH FTD Unit allows a unique opportunity to graduate students and clinical fellows to work with patients and families affected by PPA and related disorders, develop and refine clinical skills, and immerse in various laboratory-wide research projects

"I feel incredibly fortunate to be a member of the Speech-Language Training Program at the FTD Unit. Due to strict state regulations, it is very difficult to find a clinical fellowship in a medical setting in Massachusetts and the FTD Unit is one of the few sites that has the desire and ability to hire fellows. Our team is not only committed to conducting groundbreaking research and providing quality patient care but is also devoted to training the next generation of clinicians. As a clinical fellow, I work closely with an interdisciplinary team that includes neuropsychologists, caregiver specialists, social workers, and neurologists. The opportunity to learn from specialists whose expertise falls out of the scope of practice of speech-language pathology has been invaluable. Collaborating with others at the FTD Unit has allowed me to hone my clinical and research skills and made me a stronger, more compassionate clinician. I am thankful for the guidance from my many mentors and look forward to continuing my work as a fellow over the next year." –Emmaleigh Loyer, MS, CF-SLP

"I completed my clinical fellowship in speech-language pathology within the training program at the FTD Unit, and found the experience to be rewarding and informative. I completed my clinical fellowship part-time while also earning my PhD, and I found that working directly with patients opened my eyes to the difficulties in diagnosing and treating speech and language symptoms in PPA and related disorders. This experience has informed both my approach to clinical care as well as my research in many important ways. One of the highlights of completing a clinical fellowship at the MGH FTD Unit was the opportunity to work not only with a wonderfully talented group of speech-language pathologists, but also neurologists, neuropsychologists, and social workers."

–Claire Cordella, PhD, CCC-SLP

"As a part of my doctoral studies in neuroscience, I have completed over 400 hours of clinical training to become certified in speech-language pathology. I acquired a large majority of these hours in the FTD Unit, both through clinic and in the lab. The unique opportunity to have direct contact with patients and caregivers has not only strengthened my clinical toolkit, but has also shaped the questions I aim to pursue in my career. The training program has directly influenced my desire to answer questions specific to treatment and the neural mechanisms that support treatment responsiveness in neurodegenerative disease. Working with the highly interdisciplinary team at the FTD Unit has greatly enhanced my understanding of clinical assessment and care for populations with PPA and related disorders."

–Jeanne Gallée

"My roles within the FTD Unit have evolved over the past few years from a graduate student, a clinical fellow, and now a clinically-certified speech-language pathologist. And learning has not stopped! Working with individuals and their families living with PPA and related disorders has not only instilled in my heart the need for more therapeutic and targeted interventions to improve patients' quality of life, but also ignited my passion to pursue research to join efforts with like-minded scientists and clinicians who are devoted to finding a cure for PPA and related disorders. My tenure at the FTD Unit has impacted my decision to apply to a PhD in Medical Science, which I will be starting next year!"

–Shaz Henderson, MS, CCC-SLP

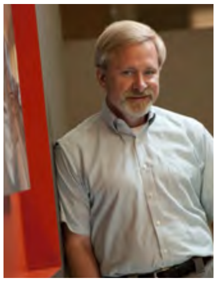
Evaluating PPA Around the World

The Progressive Aphasia Severity Scale (PASS) was developed in 2010 by Daisy Hochberg, MS, CCC-SLP, Brad Dickerson, MD and colleagues in the MGH FTD Unit to more accurately diagnose and monitor the symptoms associated with Primary Progressive Aphasia (PPA). This tool provides information to help patients, families and clinicians better understand PPA.

Each 📍 represents a request for the PASS. The PASS has been shared with more than 240 students, clinicians and researchers around the world.

Patients with Passions

Spotlight on David Tubridy



An architect who surfs. A Featured Gala Artist who is proud to be a grandfather. A Citizen Scientist, fundraiser and volunteer. Today, Dave Tubridy is a central figure in our MGH FTD Unit community, and it began with a decision to give back when he was in need. “When I came into the diagnosis of PPA, I thought to myself, MGH is a great place. Let me help.”

Dave is a consistent volunteer in ongoing research projects in the MGH FTD Unit. “I think it is such a difficult time in the beginning and to have this whole group of scientists meeting with you helps. It is being a part of something bigger than yourself. You feel like there is a bigger good and that something my help you, but it will also help someone else.” Dave and his wife, Aileen, talked about the importance of being connected with an expert team focused on scientific advances for treatment for PPA. “It is so rare and so few people know what PPA is. Coming in for appointments is comforting because you know you are the center of attention with people who understand what you are going through.”

The Tubridy Family sponsored the 2016 gala event, A Night With the Arts for FTD, supporting our clinical research program and lighting up the dance floor late into the night.

Aileen said that it is not just the medical and research support that have made a difference in their journey with PPA. “It is very special what you guys do. I have never been connected with a program that is so comprehensively caring for the emotional and scientific aspects of living with a condition. The care is amazing.” Dave and Aileen have participated together in support groups, attended several gala events, bowled with family at Strike Out FTD and enjoyed the inaugural Symphony for Science event. When asked what his message would be to those who are still looking for support, Dave said “I would say come again. It can take a few times. The warmness makes a difference, but there is a much bigger sense of community and it helps to be a part of that rather than being lonely.” Dave plans to continue his work as a research participant, confident that this will help make important discoveries for patients today and in the future.

Dave Tubridy participated as an active member of the 2017 “Harmonizing Together” PPA Music Therapy Support Group.

Dave Tubridy and his wife, Aileen, celebrate at the 2018 gala event, A Night With the Arts for FTD.

Attendance at the annual From Care to Cure Education Day provides the opportunity to hear about the latest updates in clinical practice and research for PPA.

Dave Tubridy was honored as a Featured Artist for the third time at the 2019 gala event, A Night With the Arts for FTD, for his work as an architect.

WATCH OUR FIRST LEARNING LIVECAST

You can see it anytime on the
MGH FTD Unit YouTube Channel

Bit.ly/FTDYouTube

MGH FTD Unit
Learning Livecast Episode 1:
More Than Words:
Understanding Primary Progressive Aphasia

The Massachusetts General Hospital Frontotemporal Disorders Unit Speech and Language Program presents *More Than Words: Understanding Primary Progressive Aphasia,* an online presentation to better understand Primary Progressive Aphasia, how it is diagnosed and how patients living with this condition are cared for.

JOIN US FOR OUR 9TH ANNUAL EDUCATION DAY: FROM CARE TO CURE

© 2019 Joshua Touster

Friday, April 3, 2020

The Westin Hotel
70 3rd Ave, Waltham, MA
9:00AM – 3:00PM
Breakfast & Lunch Included
Free Parking

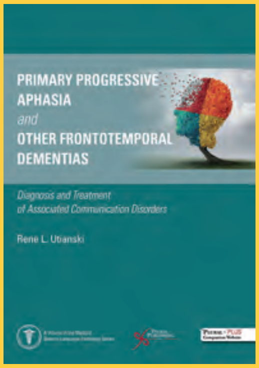
Join MGH FTD Unit clinicians, staff and colleagues for a day of resources, connections and information about Frontotemporal Disorders, atypical Alzheimer's Disease, Primary Progressive Aphasia and related disorders. We hope that learning, sharing and supporting one another helps all members of our MGH FTD Unit Community navigate the journey of care.

Register at: Because.MassGeneral.org/FromCaretoCure

NEW TEXTBOOK HIGHLIGHTS PPA

Megan Quimby, Katie Brandt and Bradford Dickerson, MD coauthored the chapter "Behavioral Variant Frontotemporal Dementia" in the textbook "Primary Progressive Aphasia and Other Frontotemporal Dementias: Diagnosis and Treatment of Associated Communication Disorders." Megan Quimby and Katie Brandt recently presented on the chapter at the American Speech-Language-Hearing-Association Convention in November 2019.

Purchase your copy today at: Bit.ly/PPATextbook



PRIMARY PROGRESSIVE
APHASIA
and
OTHER FRONTOTEMPORAL
DEMENTIAS

Diagnosis and Treatment
of Associated Communication Disorders

Rene L. Utianski

MGH FRONTOTEMPORAL DISORDERS UNIT FACULTY & STAFF

Faculty

Brad Dickerson, MD
Mark Eldaief, MD
Scott McGinnis, MD
David Perez, MD
Bonnie Wong, PhD/ABPP-CN
Jessica Collins, PhD
Alexandra Touroutoglou, PhD
Deepti Putcha, PhD

Affiliated Faculty

Stephen Haggarty, PhD
Janet Sherman, PhD

Staff Members

Katie Brandt, MM
Rose Gallagher, RN BSN
Shalom (Shaz) Henderson, MS, CCC-SLP
Daisy Hochberg, MS, CCC-SLP
Samantha Krivensky, MA
Emmaleigh Loyer, MS, CF-SLP
Diane Lucente, MS, CGC
Barbara Moscowitz, LICSW
Raseeka O'Chander, MA
Megan Quimby, MS, CCC-SLP

Executive Administrative Assistant

Angela Villareyna

Application Developer

Alexander Zaitsev

Data Analysts

Ryan Eckbo
Michael Brickhouse

Clinical Research Coordinators

Ana Eustace
Rania Ezzo
Ryn Flaherty
Sam Huang
Erin Krahn
Courtney Sullivan

Neuroscience PhD Candidate

Jeanne Gallee

Fellows

Sheena Dev, PhD
Michael Kritzer-Cheren, MD, PhD
Neguine Rezaii, MD

Postdoctoral Fellow

Claire Cordella, PhD, CCC-SLP

CONTACT US:

MGHFTDUNIT@partners.org
Find Us Online: www.FTD-Boston.org
Facebook.com/FTDUnitBoston
@FTDUnitBoston

MASSACHUSETTS
GENERAL HOSPITAL

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