MASSACHUSETTS
GENERAL HOSPITAL

FRONTOTEMPORAL
DISORDERS UNIT

FROM CARE TO CURE

WINTER 2021 NEWS FROM THE MGH FRONTOTEMPORAL DISORDERS UNIT

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DR. FAUCI discusses the COVID-19 vaccine, safety for our dementia community and how to move forward with Katie Brandt for the January 25th NAPA Council meeting.

See full interview on Pg 6.

We are proud of every frontline hero!

Dear FTD Unit Community Members,

Every week that goes by, as our team meets with patients and families affected by FTD, PPA, atypical AD, PCA, and related conditions, I feel that we become more resolute in our determination to do our best to help people and develop meaningful treatments and support interventions no matter what. Reflecting back on nearly the past year, we have seen more global devastation than most of us ever thought we would see in our entire lifetime from this pandemic and its many repercussions. To imagine that we are still not past it can sometimes feel overwhelming, but as our team becomes vaccinated, I feel inspired that—in record-breaking time—the research and medical community has poured its mind and heart into this fight and given us tools to get through it. This has enabled our program to safely begin to get back to the work we need to do in person, including brain scans and other procedures that some of you are beginning to come in for again.

As I think back on 2020, I feel tremendously proud of the talented, creative energy that our team channeled toward the goals of continuing to stay connected with our community of patients and families to provide treatment, support, and education; collecting new types of research data through remote and digital assessments; and producing a host of new insights by analyzing data we have collected previously. Our team continued to lead remote support groups and educational forums. We saw more than 150 patients and care partners in remote clinic assessments through telehealth technology. We successfully launched a remote study of advanced care planning in the context of COVID. Fully remote research was launched for projects to measure and track cognitive function in people with PPA and related conditions; this work will soon expand to include people with other conditions. We began resuming research projects safely under a hybrid model, with some remote assessments and some in-person MRI or PET scans or other procedures that require people to come to the hospital. And finally, we submitted more than a dozen abstracts summarizing new research findings from our program to the 2021 Alzheimer's Association International Conference in July; the national and international exchange of scientific information continues to occur at a high level and offer many opportunities to analyze mountains of existing data to make valuable new discoveries.

I am especially proud that we were able to hold our 6th annual Night with the Arts for FTD Gala in October 2020. Even though we couldn't all be together in the Royal Sonesta ballroom, we felt so moved to be with each other online and pay tribute to so many special people in our community. By bonding together, we are able to achieve important milestones in the fight against these devasting diseases.

As we start 2021, I continue to feel inspired by you in our community, and by the amazing members of our team. Our collective resilience will help each and every one of us get through these difficult times. I so look forward to the day when we can once again hug each other in greeting or in parting. Take care and I wish you all well.

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

MGH FTD Unit Online Educational Opportunities

Register and receive online links at Because.MassGeneral.org/FTDSupport
All sessions will be recorded and posted on the MGH FTD Unit YouTube Channel

Community Forum Fridays – Fridays at 10:00AM
Join Katie Brandt, Director of Caregiver Support Services and Public Relations, for conversations with experts across diverse fields to bring relevant information to our community of persons living with a diagnosis, care partners and professional caregivers.

Feb 19th – Legal Planning After a Diagnosis of Alzheimer's or a Related Condition:
A Conversation with Attorney Patricia D'Agostino

Feb 26th – Legal Planning After Young-Onset Diagnosis of Alzheimer's or Related Condition:
A Conversation with Attorney Pam Greenfield

March 5th – How Movement and Music Equals Magic:
A Conversation with Ageless Grace Facilitator, Norie Mozzone

March 12th – The Power of Music Therapy for Connection, Cognition and Care:
A Conversation with Neurologic Music Therapist Caitlin Hebb

March 19th – What If It's Not Alzheimer's?:
A Conversation with Author Lisa Radin

March 26th – Empowerment Through the Lived Experience:
A Conversation with Senior Director of Programs Sharon Denny & Advocate Amy Shives

FROM CARE TO CURE EDUCATION MONTH

Fridays in April @ 10:00AM EST

Join MGH FTD Unit clinicians on Friday mornings this April for our *From Care to Cure* educational webinar series. These special sessions, led by our director Dr. Brad Dickerson, will focus on clinical aspects of Frontotemporal Dementia, atypical and young-onset Alzheimer's Disease and related disorders. Presentations will focus on clinical diagnoses, advances in research, care planning and promoting cognitive resilience.

Register at Because.MassGeneral.org/FTDSupport

CAREGIVER SUPPORT GROUP TUESDAYS

Our weekly online support groups 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 connect to our caregiver community, offer resources and extend emotional support for caregivers at each stage of their journey with dementia.

Registration Is Required.

To register for this free caregiver resource please email FTD.Boston@gmail.com

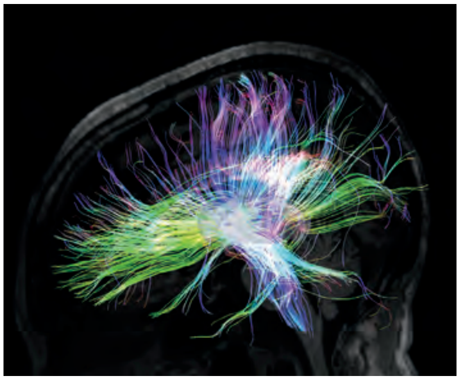
2021 caregiver groups will run as follows:

Tuesdays @ 7:00PM
February 9th & 23rd, March 9th & 30th
April 13th & 27th, May 11th & 25th
June 8th & 29th

Tuesdays @ 10:00AM
February 2nd & 16th, March 2nd, 16th & 23rd
April 6th & 20th, May 4th & 18th
June 1st, 15th & 22nd

RESEARCH OPPORTUNITIES

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



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.

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.

CAREGIVER COVID-19 SUBSTUDY

You may be eligible if: You are a caregiver of someone with dementia.

Goal: To better understand how caregivers engage in care planning in the context of COVID -19, and how video decision aids may help caregivers make healthcare decisions.

This study involves: Caregivers will complete surveys and watch three short health care videos online. Then they will complete a series of 3 follow up calls one day, one week, and one month after. The total time commitment is up to three hours.

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.

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.

LEADS: LONGITUDINAL EARLY-ONSET ALZHEIMER'S DISEASE STUDY

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

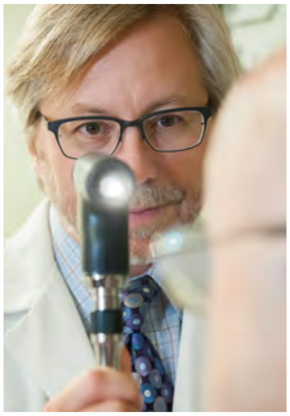
Goal: To better understand the progression and symptoms of young-onset Alzheimer's Disease.

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

> "Participating in research helps us to feel less isolated as we make our way through this journey."
>
> *- Caregiver Research Participant*

Understanding New Technology for Diagnosis and Care: An Interview with Brad Dickerson, MD

Katie Brandt, Director of Caregiver Support Services and Public Relations, had the chance to talk with Dr. Dickerson about emerging technology for blood tests to diagnose Alzheimer's Disease.



Katie Brandt (KB): Dr. Dickerson, it is incredible to think about having a blood test available to help confirm a diagnosis of Alzheimer's Disease (AD). Can you provide some insight into this new technology, what it means to families affected by AD and the impact it has for you as a physician?

Brad Dickerson, MD (BD): For more than 20 years, people have been trying to figure out if you could measure things in the blood that would reflect what's going on in the brain, and in particular, in the brains of people who might have AD. The two main proteins aimed to measure are Amyloid and Tau. We all have tiny concentrations of Amyloid and Tau floating around in our blood, and this is presumably coming from our brain. However, there have been a number of challenges and much that hasn't really been understood about why that happens. We know a lot about the blood brain barrier and how drugs and other things either get into the brain or are blocked from getting into the brain. However, we don't know nearly as much about how proteins produced in the brain are cleared from the brain and leave the body. We know that these proteins can be measured through spinal fluid using a spinal tap or lumbar puncture. We've been using those measures as biomarkers of Amyloid plaques and Tau tangles for a long time. It has been a really valuable standard clinical test, both in practice and in research trials. The problem is, you need to see a neurologist, or specialist who then will do the lumbar puncture. It is not as simple as ordering a blood test from a lab.

KB: I would imagine that when a patient or research participant is thinking about having a lumbar puncture, it also feels more complicated and they may have additional worries or concerns. Most people have had blood drawn in their life, but not everyone knows what the experience of having a spinal tap is like.

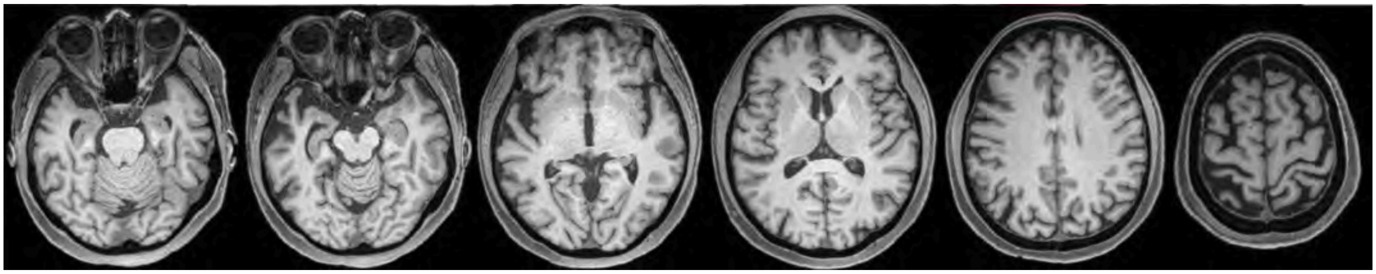
BD: Right, so a lumbar puncture is actually a very safe procedure, meaning that it doesn't cause problems, and it's not even particularly uncomfortable in the vast majority of people. But if you start to think about the importance of obtaining an earlier diagnosis, then a blood test can help you reach a larger segment of the population.

KB: You just touched upon something significant regarding blood tests. If there is earlier opportunity for diagnosis, can you imagine what a blood test would do for the field? Why would that be important to you as a physician when you are thinking about your ability to diagnose people?

BD: The field had been pretty pessimistic about the possibility that we would have blood tests any time before the year 2025 or so. However, in the last couple of years, there's been exponential progress on developing a blood test for abnormal forms of Amyloid and Tau. There's a lot of interest in other kinds of things too, but a blood test that can identify those specific proteins can be transformative. We know that biomarkers of Amyloid and of Tau have really accelerated the field of Alzheimer's research. We hope that that'll happen for Frontotemporal Lobar Degeneration and Lewy Body Disease as well. But we're not there yet.

Therefore, this has only relevance for AD itself as a biological disease in the brain. Yet, in the last couple of years, laboratory technology has advanced by leaps and bounds, enabling us to detect much lower concentrations of abnormal proteins in the whole sea of proteins that are swimming around in our blood. This is truly cutting-edge technology that is being applied here.

In fact, the blood test for pathological forms of Amyloid is already approved by the Food and Drug Administration (FDA). We know that another blood test is in the advanced stages of evaluation. It will probably be approved sometime in 2021. That means that we will have the ability to run those tests. The question then is, how should they be used?



KB: This makes me think about some of the work that you've done to contribute to clinical practice guidelines for the diagnosis of AD and related dementias. I'm wondering how a blood test would impact the guidance for primary care physicians or other providers who are not specialists in progressive neurological conditions like AD.

BD: I've been privileged for the last three years to co-chair the Clinical Practice Guidelines Workgroup under the auspices of the Alzheimer's Association with my good friend and colleague, Dr. Ali Atri. We just concluded our report with the goal to establish contemporary guidelines for how doctors and health care systems think about an evaluation of a person suspected of having symptoms due to AD or a related disorder. We are targeting both primary care clinicians as well as specialists. And that is a pretty tall order, but so important.

> *"I think everyone's goal is to see this as a next step in developing effective treatments that help people in a meaningful way."*

KB: It is incredibly important. Through of my advocacy work with the Alzheimer's Association I learned that up to 50 percent of individuals in the United States living with dementia due to AD don't actually receive a diagnosis of AD. One of the reasons this happens is because there are many areas of the United States where there is a lack of specialists who are able to give those diagnoses. We know that many people are being treated by primary care physicians or going to clinics. We know that individuals who live in lower socioeconomic status or individuals of color are less likely to see a specialist. This makes me ask more questions. Why is it important to receive a diagnosis of Alzheimer's Disease, if that's what you're living with? Why does that matter to an individual?

BD: It is a really important topic. I think the most important reason is for the individual's dignity. While they have early symptoms, they are often still able to participate in saying what they want as their symptoms progress, and who they want making decisions for them and where they want future care delivered.

KB: What I'm hearing from our conversation today is that the presence of an approved blood test for AD could open the door for richer conversations between families and health care providers about meaningful goals of care for families.

BD: Yes, and I think a panel of approved blood tests will catalyze the much-needed educational efforts for primary care clinicians about these illnesses so that they feel empowered to understand what you learn when you do one of these blood tests. This will open the door for the PCP to make a referral to a neurologist, or another specialist in the domain of AD.

I'd like to think, too, about normalizing these conversations. The more we can do that, hopefully the earlier these conversations could happen. It creates opportunity for individuals to fully participate in their care planning, which is a critical piece. At the end of the day, the blood tests are going to be starting points. We all want to move forward as we advance technology and the health care culture around these difficult conversations regarding these challenging symptoms.

KB: I'm excited to see how this advancement will impact our policy work in conjunction with education and planning that happens in our clinical research program as well as in the larger Alzheimer's and related dementia community.

BD: Me too. It is really exciting to see this concrete progress being made. I think everyone's goal is to see this as a next step in developing effective treatments that help people in a meaningful way.

Dr. Anthony Fauci Discusses COVID-19 Vaccine; Safety For Individuals Living With Dementia and Moving Forward With Hope

An Interview with Katie Brandt, Director of Caregiver Support Services and Public Relations

Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases spoke at the January 25th meeting of the National Alzheimer's Project Act (NAPA) Advisory Council. Dr. Fauci provided expert perspective on the impact of COVID-19 for individuals living with Alzheimer's Disease and related dementias to inform Council members who are charged with making recommendations to the National Alzheimer's Plan.

Brandt, who is Co-Chair of the Advisory Council, asked Dr. Fauci if there are any additional risks that an individual living with dementia may encounter from the COVID-19 vaccine. Dr. Fauci explained that there are "likely not" any risk factors outside of the expected side effects, such as inflammation. He noted that "There's very little significant inflammatory response after the first shot, considerably more after the boost" he said. Nevertheless, he added, "I wouldn't hesitate to vaccinate an [individual with dementia] because you're concerned that the inflammation associated with the vaccine is going to be harmful to them."

We know that the presence of COVID-19 has affected individuals living in care facilities at a higher rate, making it difficult for people to visit loved ones living there. Brandt asked Dr. Fauci about returning to in-person visits as more people get vaccinated. Dr. Fauci advised that unvaccinated persons should still wear a mask in the presence of those who have been vaccinated "until we are completely certain as to whether the vaccine protects you against infection," noting that "Even if it is 94 to 95 percent efficacious in protecting against clinically recognizable diseases, it may not protect you against asymptomatic infection."

Dr. Fauci also commented on the safety of the vaccine, noting that the speed of vaccine development is "purely a reflection of the extraordinary scientific advances in vaccine platform technology that have occurred that have allowed us to do things in months that normally would have taken years." For all of our families missing visits and hugs with loved ones, we know that a vaccine and a cure for COVID-19 cannot come soon enough.

To see the full interview, go to the MGH FTD Unit YouTube Channel.

Care Tips from Dr. Fauci

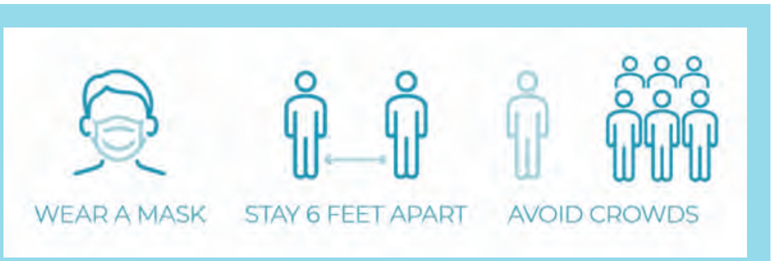
If my loved one has been vaccinated, but I have not, is it safe to resume visits in their skilled nursing facility?

When asked about resuming visits in a skilled nursing facility, Dr. Fauci reminds us that we need to consider the specific conditions in our loved one's facilities as well as our loved one's individual response to the vaccine. And, even if the vaccine is protective against the clinically recognizable disease, it may not protect you against asymptomatic infection. Which means that you may have the virus in your nasal pharynx and you may be spreading it. That is the reason why masks should continue to be worn until we are completely certain as to whether the vaccine protects against infection.

Dr. Dickerson and Dr. Kim follow strict COVID-19 protocols when working in clinic to ensure everyone's safety.

SLOW THE SPREAD OF COVID-19

Take steps to keep you and your loved ones safe by following these important guidelines from the Centers for Disease Control and Prevention



- Wear a mask that covers your nose and mouth to protect yourself and others
- Stay at least 6 feet (about 2 arm lengths) from others who don't live with you
- Avoid crowds. The more people you are in contact with, the more likely you are to be exposed to COVID-19
- Avoid poorly ventilated indoor spaces
- Wash your hands often with soap and water for at least 20 seconds and use hand sanitizer anytime water is not available

TO LEARN MORE ABOUT THE COVID-19 VACCINE:

Center for Disease Control:
CDC.gov/coronavirus

Massachusetts Vaccination Program:
Mass.gov/covidvaccine

Alzheimer's Association:
ALZ.org/alzheimers-dementia/coronavirus-covid-19-vaccine

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