MASSACHUSETTS
GENERAL HOSPITAL

FRONTOTEMPORAL
DISORDERS UNIT

FROM CARE TO CURE

FALL 2020

NEWS FROM THE MGH FRONTOTEMPORAL DISORDERS UNIT

INSIDE THIS ISSUE

We are proud of every frontline hero. Our own Rose Gallagher shares her experience as a frontline worker in the time of COVID-19. Pg 13

COMMUNITY ISN'T CANCELLED AND NEITHER IS THE GALA!

Join us online on October 16th to celebrate our FTD Community at the 6th annual *Night With the Arts for FTD* gala and art show to raise awareness, funds and hope. See page 14 for more info!

Because.MassGeneral.org/FTDGala2020

Dear FTD Unit Community Members,

I feel moved to tears in ways I never have as I reflect back on the last six months. The global devastation that this terrible pandemic has wrought is overwhelming, and the personal losses that some members of our community have experienced are tremendous. The pandemic has made it so vividly clear how important community resources are for care and support of our patients and families and others like them around the world who are living with cognitive impairment and dementia. And some facets of scientific progress toward cures have ground to a halt, especially including clinical therapeutic trials and other studies that require in person examinations, procedures, scans, and other activities deemed to be high risk at present.

At the same time that I feel the pain of these losses, I am also inspired by the many ways that our community and our team have rallied to help each other be resilient. We are fortunate that our team had already been working on tools and technologies to conduct remote activities, mostly because we had heard from many of you that it is difficult to come to Boston and we know there are things that can be done that don't require in person visits—for the purposes of care and support as well as research. Because of that preparation, some of which have been supported by previous generous philanthropic donations, we were able to roll out a number of successful activities very rapidly. The first of these was virtual support groups and educational forums primarily targeting our patient and family community but also including professional education. Since starting in the spring, our sessions have reached more than 1,100 views online and we continue to build momentum as we enter the fall. The second important accomplishment was the transition of our clinic to 95% remote assessments for new and follow up patient visits—although we continue to see a few people in person, we have conducted more than 30 virtual clinics serving more than 100 patients and families. The third major accomplishment was the launching of several research projects that were able to be done fully remotely through video technology. This has also enabled us to more rapidly plan for resuming research projects that can be done 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 made more than a dozen virtual research presentations at the 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 extremely impressed and proud of our amazing team of people who work tirelessly, even if almost entirely from home, to keep all of these activities running even under these stressful and draining circumstances. I feel privileged every day to "go to work" with such a wonderful group of talented, passionate, and resilient people. And I am also gratified to see how responsive you in our community have been to all of these efforts; we could not have made this progress without your participation and constructive feedback.

I am confident that, even if the landscape looks starkly different now than it did at this time last year, that we will be able to maintain the highest standards of care, support, and research as we find new ways to do things and connect with even more of you in the coming months.

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

FTD Unit Caregiver Support Services Adds Team Members

Inola Howe, Clinical Research Coordinator

Inola Howe joined the FTD Unit as a Clinical Research Coordinator in August 2020. In May 2019, she earned her Bachelor of Science in Psychology from Kent State University, and she has a background working in community outreach at a nonprofit victim crisis center. Her role at MGH involves coordinating the caregiver research studies being done in the Dickerson Lab.

"A big part of why I was drawn to the Dickerson Lab was its commitment to equal parts research and empathy. I'm thrilled that I get to be part of a team conducting high-level, multidisciplinary research to find a cure for FTD, while also whole heartedly supporting our patients and their caregivers through such an important time in their lives. I'm excited to be using research to improve lives both now and in the future!"

Amy Marchesano, Caregiver Support Services Specialist

Amy Marchesano, LMHC, is a Licensed Mental Health Clinician, who began as a Caregiver Support Specialist in the MGH FTD Unit in March of 2020. Her experience includes 15 years working with families at every stage of life's trajectory in both medical and community based environments providing clinical services, and family advocacy. Her interest in caregiver research is focused on measuring caregiver burden, and stress, and its effect on families within the FTD community.

"I am excited for a new adventure broadening my knowledge and experience while I support caregivers within the FTD community. I am learning so much from caregivers as I witness their resilience and their resolve, especially during these uncertain times."

CAREGIVER SUPPORT GROUP TUESDAYS

Are you caring for a loved one living with Alzheimer's, Frontotemporal Degeneration or a related dementia? 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 provide a connection to our caregiver community, offer ideas for resources and extend emotional support for caregivers at each stage of their journey with dementia.

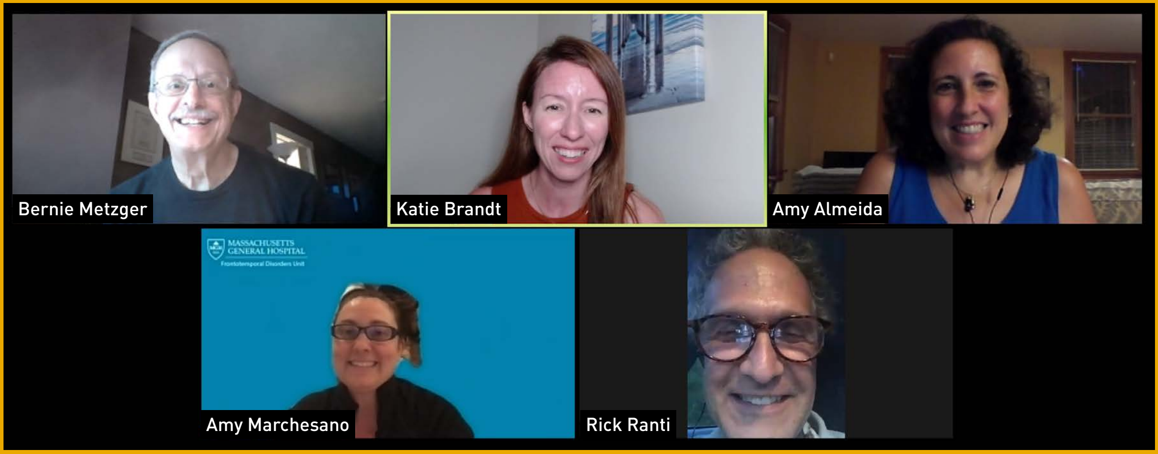
Registration for support group is required.

Fall caregiver groups begin on September 8th and will run as follows:

Tuesdays @ 7:00PM
September 8th & 29th, October 13th & 27th, November 10th & 24th, December 8th & 22nd

Tuesdays @ 10:00AM
September 15th & 22nd, October 6th & 20th, November 3rd & 17th, December 1st & 15th

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



AFTD Affiliated Support Group - Our online caregiver support group is run by support group leaders who have been trained by the Association for Frontotemporal Degeneration. Learn more about the resources available through AFTD at www.theAFTD.org.

MGH FTD Unit Fall 2020 Online Programming Fridays @ 10:00AM EST

Registration is free and available today: Because.MassGeneral.org/FTDSupport
**Zoom links will be sent out the morning of the online event*

Community Forum Fridays

Join Katie Brandt, Director of Caregiver Support Services and Public Relations, for live discussions with community experts, colleagues and friends to address topics that are relevant to caregivers and families living life with dementia.

Sept 11th – Overview of Fall 2020 Webinar Series & 6th Annual Gala Kick Off
Featured Speaker: Rich DiMare, Performer, 6th Annual Night With the Arts for FTD

Sept 18th – Connecting As Caregivers: The Power of Support Groups
Featured Speakers: Amy Almeida, AFTD Support Group Facilitator & Bridget Moran-McCabe, AFTD Support Services Manager

Sept 25th – Caregiver Roundtable: Shared Wisdom from Experienced Caregivers

Oct 2nd – Setting Up for Success: Managing Challenging Behaviors at Home
Featured Speaker: Amy Marchesano, MGH FTD Unit Caregiver Support Specialist

Oct 9th – Connections for Care: Accessing Resources for Dementia Care & Caregiver Support

Oct 16th – **SPECIAL EVENT: 7:30PM EST**
A Night With the Arts for FTD:
6th Annual Gala & Art Show to Benefit the MGH FTD Unit

Oct 23rd – From Care to Cure: 2020 Gala Presentations
Featured Speaker: Brad Dickerson, MD, Director, MGH FTD Unit

Oct 30th – Staying Healthy Together: Updated Guidelines for Staying Safe from COVID-19

Nov 6th – Navigating the Holidays Together & Apart: Caring for Your Loved One at Home and In Memory Care During the Holidays

Stay Tuned for the Launch of Our MGH FTD Unit ***From Care to Cure*** Educational Webinar Series this fall with Brad Dickerson, MD, and members of our clinical research team for live discussions on essential topics for navigating life with a dementia diagnosis.

Photo credit: Joshua Touster

Caregiver Perspectives: Being Present

An interview with Patty O'Keefe, caregiver to her husband, Tom

Tom and Patty O'Keefe

When the presence of COVID-19 required the shutdown of adult day health programs and senior centers, we knew that life would become challenging for many caregivers. The juggling act of work and caregiving is often a delicate balance when you have help in place, so this "new normal" would take true acrobatic skills. Patty O'Keefe is a caregiver who has shown resilience, creativity and determination adapting to life during the pandemic with her husband, Tom. At support group, she shares her tips and her positivity with others. In an interview with Amy Almeida, AFTD Caregiver Support Group Facilitator, Patty shares some of her tips for getting through each day, the importance of coffee and new ways to find respite.

Q1: What is your normal routine (before COVID-19)?

A1: Each morning, I'd get up before Tom and have my coffee. I'd put a banana on the kitchen counter for Tom then get him showered and dressed. I'd throw the laundry in and get showered and dressed myself. We'd then head off to the Julia Ruth House, the adult day health program Tom attended. From there I'd go to work. Tom would spend the day at the Julia Ruth House, having breakfast and lunch there. I'd leave work around 4:15 to pick him up. We'd head home after that.

Q2: How has that routine changed?

A2: I still try to have my coffee before Tom wakes up. My coffee is really a priority, it sets the mood for the day. I still get him up, showered and dressed before I start work. I've found that if he resists my instructions, if I address him with a British accent, he'll go along. I find that I'm using the British accent a lot more nowadays. It's better than yelling or getting frazzled because that will upset Tom. If I'm trying to cook and Tom is "helping" me, say he dumps an ingredient into the bowl at the wrong time, yelling doesn't work. Yelling won't fix the problem of a recipe done out of order. What's done is done. Using the British accent helps both of us calm down. I found that it would take us both a while to calm down before and this helps avoid that.

September 2019 - Amy Almeida and Katie Brandt celebrate with Patty at the Julia Ruth House Fall Yard Sale to raise awareness and funds to benefit the MGH FTD Unit

Food and mealtimes are very important to Tom. At 11:45 each day, I step away from work to make lunch. In the morning and afternoon, I leave out bowls of healthy snacks for Tom so he has something to munch on while I'm working. I find that having snacks available helps with his compulsive eating.

Q3: How are you dealing with working from home while simultaneously caregiving?

A3: I have a phenomenal team at work. They know I'm dedicated to our team and the company. They have been kind and accommodating. No one minds if Tom photobombs a video call.

Q4: How are you coping with less help?

A4: The Julia Ruth House is checking in. I send them pictures so they can see what Tom has been up to. With respect to the loss of paid companions, we're trying to make the best of it. We're isolating at our house on the Cape because it's easier for Tom to get out at a social distance than it would be at our home in Boston.

Q5: How do you continue to do the things you did for self-care?

A5: I find that gardening has given me a sense of accomplishment. I can see the progress I've made cleaning up the yard or planting new flowers. My gardening is also an opportunity for Tom to get outside and exercise as he walks around the yard. We do try to walk everyday at lunchtime or after work.

Here on the Cape, we can walk to the beach so we often do that and just sit on a bench, watching the ocean.

We have some dear friends who are visiting outdoors, at a safe distance. Family and friends are doing our grocery shopping for us. We're also videoconferencing with family and friends. I'm part of a Friday night happy hour videoconference. I miss having Tom's family and friends come over for a visit so I can get out for a walk or go to support group.

Q6: Anything else that's helping you survive?

A6: Wine! Caregiving is isolating at the best of times. Actually, FTD caregiver support group prepared me for quarantine. In group, I learned from more experienced caregivers that the FTD journey is a series of phases. I've learned that if I'm frustrated by the phase we're in, it will eventually change. Tom had a habit of tapping on tables, the arms of chairs, anything he could reach and it drove me crazy. He's out of that phase now. Since it's harder to get groceries, Tom's compulsive eating isn't as much of a problem.

Patty integrates work and caregiving by welcoming Tom in her home office.

I try not to dwell on things. I want to be with my boyfriend Tom as long as possible. I try to look at the blessings we have. I'm blessed to be able to take care of Tom by myself right now.

Note: This interview has been edited and condensed for clarity.

The Julia Ruth House is a home-based, senior adult day care center located in Westwood, MA. Programming is designed to meet the educational, physical, social and personal needs of each participant. Learn more at TheJuliaRuthHouse.com

Tom enjoys a beach visit with staff and friends from the Julia Ruth House.

Caregiver Perspectives: Respite and Reflection

By: Gary Kent, Caregiver to his wife, Lia

Gary and Lia enjoy traveling.

Being a caregiver for someone with FTD is not for the faint of heart. As a caregiver, I learned that the only constant is change – I'm always finding new ways to adapt to my wife Amalia's ever degrading mental and physical abilities as she needs more and more help clothing, feeding, bathing, and moving. I felt the world getting smaller with each change in her behavior or newfound physical limitation. At times, I felt like I was the patient, not the caregiver. It was like I received a new diagnosis along with my wife. There were times when being a caregiver is like being a patient. You may have symptoms of caregiver burnout, you need a plan and support to keep going and you need to connect with experts (others who have walked the path before you) in order to keep going.

Defining Respite

When my wife was diagnosed with FTD Primary Progressive Aphasia (PPA), I had to rapidly figure out how to care for her while continuing to work a full-time job, in addition to picking up roles that my wife previous performed like paying bills. To be honest, I just couldn't keep up. I heard people around me say, Gary, you need to take care of yourself. I thought to myself 'yeah, when I get some free time,' which NEVER happened. Some folks talked about getting respite but I had no idea what the word meant so I looked it up:

Respite is a short period of rest or relief from something difficult or unpleasant.

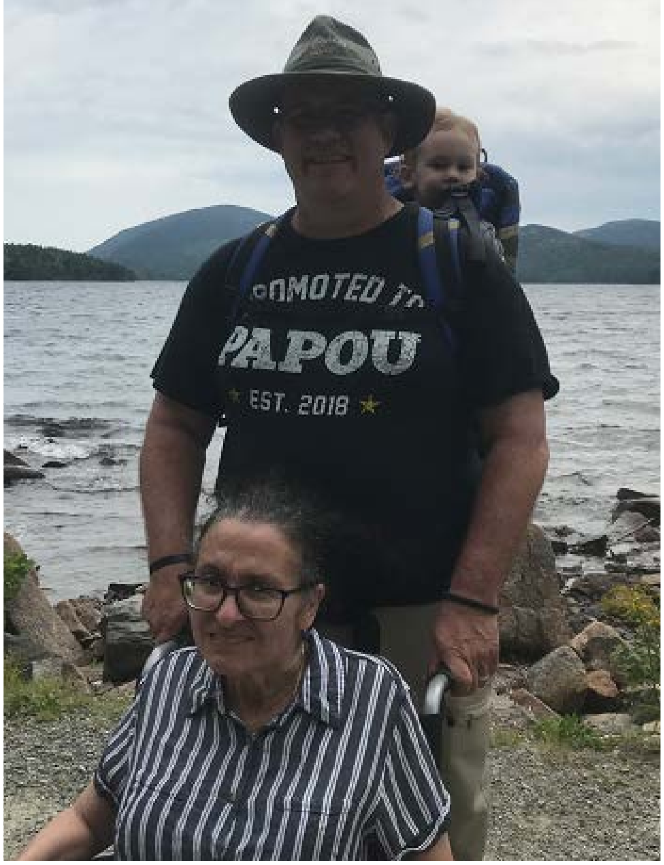
My research indicated that that respite would make me a better caregiver because I would be more energized and refreshed. My experience is that, even though we can no longer carry on a verbal conversation, respite helps me have a better relationship with my wife. I found that respite can be achieved in small private peaceful moments, sometimes when I have extra set of hands to help or even while I am on my own as the sole caregiver. Here are a few different types of respite that are important to me.

- ***Regular doctor's visits and annual physicals*** because if I'm sick or injured, I won't be able to care for Lia. I need to take care of myself so that I can take care of her.
- ***Including counseling in self care*** helps me maintain my mental resilience and positive attitude.
- ***Regular exercise*** so that I am strong enough to care for my wife through all phases of FTD (OK, I need help with this one).
- ***Social visits with family and friends*** to receive their love and support and overcome the painful silence of FTD PPA.
- ***Taking time to have fun*** with my 1st grandson by participating in swimming lessons or viewing the "polar express" on a local train.

I Can't Get Respite Without Help - It Takes A Village

There is simply too much to do as an FTD caregiver, I couldn't do this all by myself. I had to overcome a number of preconceived ideas. When my FTD Support Group leader suggested that I get a companion for my wife to spend a few hours with her each week and give me a break, I said to myself "my wife doesn't need a companion, I'm her companion." After delaying for a few months, I finally took the leap, called MinuteWomen Homecare and they sent me Cathy. This was a truly lifechanging decision. Finally, I had a few hours to

Lia finds joy relaxing outside at home.



Gary & Lia embraced becoming Papou & Mimi with the arrival of their grandson, Liam.

take a nap, get my haircut even go to the gym, while someone else took care of Amalia. But that was only the beginning. I still needed more help so that I could continue to work full time. After additional prompting, I eventually relented and called a local elder day care facility where my wife could visit 3 days a week – then I could actually plan meetings at work face to face. And more recently, when it became more and more difficult to bathe, I finally got some awesome women to come to the house to bathe my wife twice a week. I learned that I had to be willing to put my loved one in the hands of another, and once I submitted, Lia's life changed for the better, and so did mine.

New Memories of Joy Through Respite

I never thought about how to find respite as a means for getting away from caregiving. For me, it was more about continuing to "live life on the move" with my wife and not succumb to the suffocating, narrowing of vision and activities. It would've been so easy to withdraw from the world into an increasingly smaller footprint constrained by doors and alarms, locks and gates with the best intentions of protecting my loved one and making it easier to be a caregiver. Following that epiphany, we have been on the move since she was diagnosed. And while I can never really tell what these experiences mean to my wife in her current condition today - does she know where she is, or who she is with, or what is going on around her? All I know is that she liked these activities before she got sick - so let's continue them today.

If I could make one recommendation to my brother and sister caregivers, it is this – please be open to accepting change. It doesn't mean that it is easy, or that you like it, but try to open your heart and mind to the reality that things can not stay as they have always been. It is so important to build a care support team so that you can get the respite that you need. Sometimes it can be difficult to take that initial step. *I guarantee that you will be happy when you do.*

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5 IDEAS FROM GARY AND LIA FOR CAREGIVER RESPITE

- ***Enjoy the world*** – Take a trip. We visited London, my wife's favorite destination. Travel with friends to give you an extra hand.
- ***Get outside*** – Get in your car and drive to the beach to take a long walk (or wheelchair ride) on the boardwalk.
- ***Take some risk*** – Reap the reward by spending a peaceful week at a remote camp in the Maine woods.
- ***Get creative*** – Just because you can't leave your spouse alone, doesn't mean you can't workout. Search AmazonPrime for an exercise video and sweat to old school aerobics in the living room while your spouse watches.
- ***Make it a family outing*** – Head to Acadia National Park with your family. We had lots of extra hands to help out while we biked, hiked, and saw the sunrise on Cadillac Mountain.

Caregiver Perspectives: Building a Village

By: Bernhard Metzger

Bernhard Metzger, BA Computer Science, MBA organizational development, has been a caregiver for over twenty years. He first helped care for his mother-in-law. Thirteen years ago he graduated to helping his wife who became paralyzed from the chest down and learned the ins-and-outs of wheelchair repair, catheter replacement, airplane travel with an spinal cord injury patient and adaptive architecture. Two years ago he embarked on his "advanced degree" choosing to focus on the rare intersection of Behavioral variant FTD and Spinal Cord Injury. He recently started, in a fit of anger, a selective line of clothing known as FTDSucks™.

"It takes a village" people will tell you upon hearing your latest challenge. You think "Where the heck is this village everybody is talking about?"

My wife of 43 years became paralyzed from the chest down 12 years ago. Our lives were turned upside down as she had to relearn just how to get through a day. Together we faced hurdles and overcame them together. We had survived job changes, teenagers and the running of my wife's case management consulting business. My wife continued to travel, teach, and consult, frequently with me along as her caregiver. I learned how to fix wheelchairs and change a catheter. I found it difficult but I love a challenge believe I can figure out almost anything.

Then she was diagnosed with FTD. Watching her progression was like watching paint chip. We could no longer face the hurdles together. I was alone. I needed help.

This is a heartless, difficult disease. No matter how much help one gets, it's bad. Those of you who know me, also know my mantra "FTD Sucks" (see the shirt). However, it only truly sucks if you are alone. With help it can just suck.

Bernie and Karen celebrate the wedding of their daughter, Victoria, at Golden Pond.

Bernie and Karen enjoy activities at Golden Pond

One of my favorite scenes from "The West Wing" involves Leo and Josh (who was suffering from PTSD). In the scene a man falls into a hole. After several passers-by fail to help:

> *"Then a friend walks by, 'Hey, Joe, it's me can you help me out?' And the friend jumps in the hole. Our guy says, 'Are you stupid? Now we're both down here.' The friend says, 'Yeah, but I've been down here before and I know the way out.'*

The point is others have been where you are. They can help. They are your village. Some of those in the village will be people you haven't met yet. Some may help you with just one thing or may be by your side throughout the journey.

To build the village first think "Where do I need help". Make a list of these which may include things such as, getting monetary assistance, help with laundry, meeting someone for coffee, medical help, understanding assisted living. This list will ebb and flow and is critical in helping you recognize how a particular individual may be able to help you.

Once you have the beginning of the list, think about how to handle it:

1. Define your challenges/problems/issues – if you don't know the problem, you can't solve it.
2. Find resources/people who can solve the problems. Support groups, care managers, friends, state programs, people who have "been down here before", and others can help with this.
3. Learn how to let go of control; that is, once you have identified others who can help you, let them. Don't micromanage.
4. Learn how to step back and view the evolving situations from above. This will enable you to react to issues as they arise.

For long term issues I have a friend with whom I speak regularly about issues. Others with whom I speak about "normal" stuff. I have a care manager who has help me navigate. Sometimes problems come up which require a one-time solution or consult. I play viola in a community orchestra. I was having problems concentrating on the playing. I needed help. That is when I remembered about a member of the of the Boston Symphony, whose wife died of this disease. Whom better to ask? I called him up and asked "How did you deal with this issue?". His response was enlightening. He said, "I frequently gave myself credit just for showing up. As a player, one normally has good days and bad days. So don't be so hard on yourself."

Bernie wore his FTDSucks™ uniform to an event at the Royal Sonesta hotel with Brad Dickerson, MD and other FTD Unit community members.

You do not have to travel this road alone. Seek help. Everything you can get help with frees you up to be your loved-one's companion and friend, not just a caregiver.

Bernie and his daughter before the ceremony at Golden Pond. Victoria wears a white silk wedding gown worn by three Zander women before her: her grandmother; her mother, Karen; and her sister, Elise.

HONORING LOVE AT GOLDEN POND

On Saturday, August 22nd, Bernie Metzger and Karen Zander celebrated a family milestone with the wedding of their daughter, Victoria Metzger to Doug Johnston. The nuptials took place at Golden Pond, allowing Karen to be a part of the ceremony. Lisa Jacobs, Chief Operating Officer for Golden Pond, stated "We are honored that the Zander family considers this their home and have invited us to share in this private and beautiful moment in their lives."

After a honeymoon in Boston, the happy couple will retire to their home in San Francisco where Doug's company develops industrial robots and Victoria will continue in her role as an ICU Nurse, a career inspired by Karen's professional career in the nursing industry.

To learn more about Golden Pond:
www.GoldenPondAL.com

CAREGIVER RESEARCH OPPORTUNITIES

The caregiver support team not only provides support, education and guidance for families in the FTD community, but also conducts valuable caregiver research studies in the Dickerson Lab.

The caregiver support team not only provides support, education and guidance for families in the FTD community, but also conducts valuable caregiver research studies in the Dickerson Lab.

The goal of these studies is to gather data to further understand and measure elements of the caregiver experience. The more we understand about caregiver challenges and decision making, the more our team can develop initiatives and new studies to provide much needed support that caregivers need.

One current study, **The Caregiver Video Intervention**, examines the effect that viewing health care videos may have on decision making for advanced care planning. Caregivers participate by providing feedback in the form of a 2-hour focus group over zoom. In addition to the completion of online surveys. Anyone caring for a loved one with early onset dementia is eligible and participants are compensated for their time. Further analysis of the responses will assist us in developing interventions to help caregivers in the future.

As many have experienced, making decisions in the context of a pandemic can be challenging. Therefore, in conjunction to The Caregiver Video Intervention Study, **The Caregiver Video COVID-19 Sub-Study** was developed to focus on decision making and planning in the context of the COVID-19 pandemic. Caregivers similarly watch short health care videos at home, online, at their leisure, and respond to surveys. The study then includes three follow up calls with a team member. Like The Caregive Video Intervention Study, participants are also compensated for their time.

Another study, **Caregiver Wellbeing** involves simply filling out an online survey every 6 months, regarding your experience as a caregiver. It is not compensated, however provides a valuable connection to the FTD lab. It provides us with important data to support our research efforts. Because this study follows caregivers over multiple years, it allows us to see how caregivers' challenges and experiences change over time.

Whether you would like to participate in one, all, or just want more information; If you are interested in research we would love to hear from you!

Become a caregiver research participant!
Contact Inola Howe, Clinical Research Coordinator, at IAHOWE@mgh.harvard.edu or call (617)-726-1459.

RESEARCH VOICES: CAREGIVER RESEARCH PARTICIPANT, CHARLIE LYNCH

While so many researchers are working on a cure for FTD, the staff in the MGH FTD Unit are on the front lines with the caregivers. Participating in caregiver research is my way of fighting back at FTD. The questions are thought provoking. They allow me to answer questions I may not have asked myself. It provides me with the means of feeling good about my strengths while also showing me areas I have to improve in.

Being asked also gives me a sense of pride in the fact that by being asked to participate in research by such an amazing group of professionals means that my opinions are valued and I'm doing a pretty good job.

Thank you again for everything you all do for us.
-Charlie Lynch, Caregiver to his wife, Mary

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.

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.

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.

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.

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

MGHFTDUNIT@partners.org

CAREGIVER VIDEO INTERVENTION:

You may be eligible if: You are a caregiver of someone who has been diagnosed with dementia.

Goal: This intervention aims to provide caregivers with information about healthcare decisions they may need to make as they care for their loved one with dementia.

This study involves: Caregivers will complete surveys and attend a one-time online focus group with MGH FTD Unit team members.

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.

Help and Hope in the Time of COVID-19

COVID-19 Resources

State and Federal COVID-19 Resources

US Center for Disease Control – cdc.gov/coronavirus/2019-ncov/index.html

Massachusetts Department of Public Health – mass.gov/resource/information-on-the-outbreak-of-coronavirus-disease-2019-covid-19

MA COVID-19 (Coronavirus) Pandemic Hotline – Call 211 or www.211.org

Massachusetts General Hospital – massgeneral.org/news/coronavirus

Alzheimer's Association Resources

alz.org/help-support/caregiving/coronavirus-(covid-19)-tips-for-dementia-care

Association for Frontotemporal Disorders Resources

theaftd.org/living-with-ftd/covid-19-and-ftd/

Hotline Resources for Persons with Dementia and their caregivers

Alzheimer's Association 24/7 Hotline – 800.272.3900

Association for Frontotemporal Degeneration Hotline – 1.866.507.7222 or info@theaftd.org

TIPS TO REDUCE THE SPREAD OF CORONAVIRUS:

- Establish a routine for your family to wash hands frequently for 20 seconds.
- Wear a mask when around others.
- When possible, maintain a distance of 6 feet from other people.
- When coughing or sneezing, use tissues, and wash hands afterwards.
- Wipe down frequently contacted surfaces with alcohol-based cleanser.
- Avoid large gatherings.

Singing Happy Birthday twice while washing your hands can keep you on track for 20 seconds of scrubbing.

Taking Action During COVID-19

Spotlight on Rose Gallagher, RN, MGH Memory Disorders Unit Nurse & Frontline Hero

Rose dons PPE for a day on the frontlines of COVID-19 care

My time spent redeployed as part of MGH's COVID-19 response was certainly something I will not soon forget. I was moved by the way our hospital came together to care for others and each other as the world seemed to change overnight. Although we all wished the pandemic wasn't happening, the commitment to care and well-being was an honor to witness and be a part of in some small way.

I was redeployed to a COVID-19 isolation hotel once an overwhelming need for community care was recognized. We cared for COVID-19 positive patients ranging in age from 9 months old to 97 years old. We celebrated patient birthdays and graduations, gently walked through clinically and emotionally difficult moments, applauded every discharge, and tried our very best to be a stand in loved one as patients faced this illness alone.

It brought us back to the heart of medicine in so many different ways and to the utmost importance of patient-centered care. I am always proud and humbled to be a part of the MGH community, and now am even more so.

I am happy to be "home" in the Frontotemporal Disorders Unit and Memory Disorders Unit, witnessing the incredible care and compassion I see daily among staff, caregivers, and of course, our patients. You all continue to inspire me and I am so grateful to be a part of this team and community.

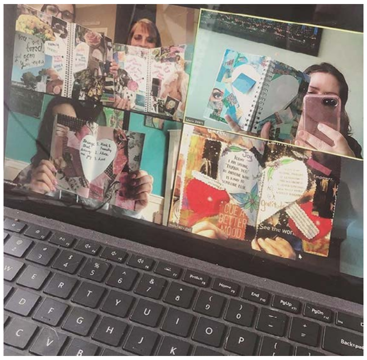
Spotlight on Caregiver, Maria Kent Beers – Where Creativity Blooms

Maria draws inspiration from her mother, Lia

My name is Maria Kent Beers and I am the owner of Art Junk Studios, which is "where creativity blooms" and our mission is to inspire people to find creativity in their daily lives. We offer workshops specifically for people who do not think of themselves as artistic.

As soon as the world started to shut down due to COVID-19, I quickly shifted to hosting online art journaling workshops geared toward helping people relax and find an outlet in quarantine. With simple materials found in people's homes, we were able to have successful "junk journaling" workshops focused on relaxation. I was so happy to see how these classes provided people the space to take a break from the chaos of the pandemic and learn something new.

The success of my business has brought me so much joy as it is all inspired by my mother, Lia, who was diagnosed with Primary Progressive Aphasia and ALS in 2016. When she quickly lost her ability to communicate, I started to re-read her old art blog Art Junk. As I re-read her beautiful words, I felt inspired to create something to carry on her legacy. The Art Junk blog focuses a lot on the importance of creativity in daily life and how you do not need to be an artist to make art. I decided to share this beautiful message with others by starting my business. We offer art journaling workshops taught by me and also partner with other creatives to offer classes that include drawing, baking and fashion styling. My mother and I always said we wanted to start a business together so it gives me a lot of healing to do this with her creative spirit as the focus.



Online classes keep Art Junk Studios active during COVID-19.

I am so touched to see the continued love and support for my mother and her artwork. She is a Featured Artist once again at this year's gala and knowing that her art will continue to bring inspiration to the FTD community gives our family a lot of joy.

A portion of all of my profits is donated to FTD research. To learn more, go to ArtJunkStudios.com. To read Lia's original Art Junk blog, go to ArtJunk.TypePad.com.

ART junk STUDIOS

Community Isn't Cancelled and Neither is the Gala!

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 16, 2020 • 7:30PM

Sponsorships & Tickets Available: Because.MassGeneral.org/FTDGala2020
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

Buy your ticket before October 2nd and you will be entered into a contest to win a gala party box from Cardullo's Gourmet Shoppe!

Gala Grit and Glamour in 2020

By: Katie Brandt and Amy Almeida, ***A Night With the Arts*** for FTD Gala Co-Chairs

When the pandemic hit, we adjusted to life with remote work. We developed new routines that centered around online support groups and weekly Community Forum Fridays over Zoom. We watched our community grow, maintaining old connections and building new ones. Where we initially felt ripped apart, we began to stitch ourselves back together. And then we thought about the gala, wondering if our 6th annual gala event would move forward as planned. We thought about all the families that come together each year, dancing, laughing, hugging and making new memories of joy. *A Night With the Arts for FTD* has always been more than a fundraiser. It is hope that the cure of tomorrow is not so far from the care of today.

Community isn't cancelled and neither is the gala! This phrase has become our mantra as we plan for this year's gala event. Join us on October 16th to see why *A Night With the Arts for FTD* is so important to our community. It's time to break out our party clothes and champagne glasses. This year may take a little bit more grit, but that won't stop the glamour.

John Kearney, five-time Gala attendee, won't let the pandemic stop him from celebrating from home in 2020.

2020 Featured Artist, *A Night With the Arts for FTD*

Spotlight on Sybil Sermos, Artist, Caregiver, Advocate and Philanthropist

Sybil and Kemon, the inspiration behind A Night With the Arts for FTD, have attended every Gala event.

> *"Art is everywhere if one just looks around. There is artistic talent in the way people decorate their homes, decorate a cake, arrange flowers, or wrap a gift." – Sybil Sermos*

When asked how she began her career in the arts, Sybil recalls staying home sick from school, coloring in her coloring books and using fabric to make clothes for dolls. When her mother gifted her movie star & ballerina paper cutouts, she took a hat box and created her first diorama stage using fabric, glue, scotch tape and those cutouts. An artist was born.

At the recommendation of her high school art teacher, she applied and received a scholarship with the Museum of Fine Arts. While attending this program, her artwork was exhibited and she won several honorable mentions.

Sybil attended the Massachusetts College of Art majoring in Commercial Art. During college she continued to create abstract watercolor paintings based on nature. In her senior year she entered an art show sponsored by Jordan Marsh and was overwhelmed when she received the popular vote for an abstract painting. Sybil worked in the Commercial Art field until she accepted a teaching position at the Art Institute of Boston where she taught lettering and design.

Through mutual friends, Sybil met Kemon who owned a small art gallery in Cambridge where he displayed her artwork. They became friends and were married in April 1968, raising a son and daughter. Sybil and Kemon created and founded "Holly Dolls by Sybil" and "Evan's Friends Puppets" named after their children. They were sold in Filenes, Jordan Marsh, and Sax Fifth Avenue. Sybil was a board member of the Winthrop Art Association and served as President for a term. Sybil's and Kemon's art pieces were exhibited at the Arnold Gallery in Marblehead throughout the years.

Sybil credits her friends as well as the staff at her assisted living, Stone Hill in Andover, for their encouragement in finding ways to ease the boredom and isolation caused by the current pandemic. She remembered the dioramas she created as a young girl and again used scotch tape, glue, and whatever other materials she could recycle to create her an exhibit for the community at Stone Hill to enjoy.

Sybil creates dioramas and other pieces of art for others to enjoy at Stone Hill in Andover.

Art exhibit piece: Social Club Wedding, *inspired by childhood creations.*

Make a Clinic Appointment
MGHFTDUnit@partners.org

Learn About Research
MGHFTDUnit@partners.org

MGH Frontotemporal Disorders Unit Staff & Clinicians

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- Diane Chang, MD
- Mark Eldaief, MD
- Neguine Rezaii, MD

Speech-Language Pathology
- Megan Quimby, MS, CCC-SLP
- Daisy Hochberg, MS, CCC-SLP
- Emmaleigh Taylor, MS, CCC-SLP

Nursing
- Rose Gallagher, RN BSN

Caregiver Support
- Katie Brandt, MM
- Amy Marchesano, LMHC

Clinical Fellows
- Sylvia Josephy, MD
- David Kim, MD

Affiliated Clinicians
- Steve Haggarty, PhD
- Diane Lucente, MS, LCGC
- Scott McGinnis, MD
- David Perez, MD
- Janet Sherman, PhD

Clinical Scheduling Team
- Sam Huang
- Courtney Sullivan
- Angela Villareyna

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- Raseeka O'Chander, MA
- Angela Villareyna

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

Caregiving
- Katie Brandt, MM
- Amy Marchesano, LMHC

Imaging
- Mike Brickhouse
- Nicole Carvalho
- Ryan Eckbo
- Alexandra Touroutoglou, PhD
- Alexander Zaitsev

Neuropsychology
- Bonnie Wong, PhD
- Sheena Dev, PhD
- Deepti Putcha, PhD

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