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## AFTD BRINGS FTD EDUCATION TO LA

### The 2019 Association for Frontotemporal Degeneration Education Conference

will be held on Friday, May 3 in Los Angeles! Join AFTD and hundreds of members of a nationwide FTD Community for a day of learning, sharing and making connections with others who understand FTD. Learn more: [www.theaftd.org/events](http://www.theaftd.org/events)

## INAUGURAL SYMPHONY FOR SCIENCE EVENT TO BENEFIT MGH FTD UNIT

Don't miss this special May 20th event at Boston Symphony Hall. Learn more: [www.SymphonyforScience.org](http://www.SymphonyforScience.org).

## Dear FTD Unit Community Members,

It is an exciting time in the MGH Frontotemporal Disorders Unit with many special events planned for 2019. Community events are an important pillar of our mission to provide the highest quality of care while working tirelessly towards a cure for these devastating diseases. We are proud to offer events that have the power to promote resilience for our entire FTD Community.



Our FTD Community extends beyond the walls of MGH. We have developed important connections with many excellent outside providers such as speech-language therapists, psychologists, memory care programs, care management services, genetic counselors, support group facilitators, elder law attorneys, and hospice programs. It takes a village to care for families living life with FTD. We rely on your feedback about experiences with your local providers so that we can continue to grow our network for care. This also connects us with providers who would like to receive individualized education about the disorders we care for, allowing us to broaden the list of providers knowledgeable about FTD and atypical AD in New England.

We know that it was not your choice to live life with FTD, Alzheimer's or a related dementia. We are humbled that you have chosen us to be a part of your care team, honored that you choose to participate in research, and grateful for the many donations to our program. By becoming citizen scientists in research, advocates in the community and peer mentors to one another, you inspire us to move forward. Thank you for all that you have done in support of our program. We look forward to another amazing year.

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

## Spotlight on Staff:

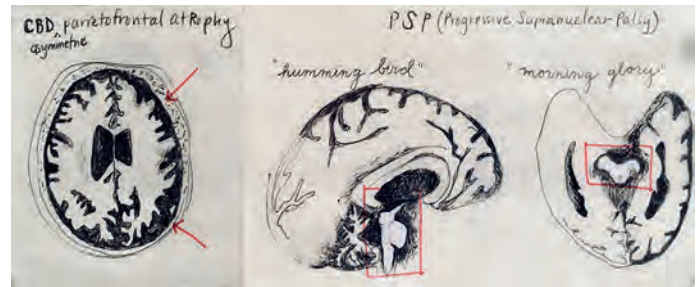
Katelynn Getchell,  
Clinical Research Coordinator

ART AS A PATHWAY TO UNDERSTANDING



**What do you find interesting about working with the Dickerson Lab?**

The Dickerson lab is a dynamic and collaborative unit comprised of brilliant and compassionate people across all disciplines. Members of the lab are constantly in communication working to improve research practices, brainstorm new projects, analyze trends in data, review the best ways to help patients and caregivers, and explore new studies that add to our collective knowledge. I find this level of collaboration, as well as the depth of passion everyone has for neurodegenerative research and patient care, completely captivating. Moreover, I am inspired and fascinated by how strong and tight-knit the FTD community is. That level of connectivity, strength and hope is incredibly unique, and I am blessed that I am able to be a small part of it.



Original sketches, Katelynn Getchell

**Tell me a little about your future professional interests. Do you think this work is impacting how you think about your future career in science or healthcare?**

The MGH FTD Unit is a paragon of patient-centered care. I am constantly inspired by the level of devotion the staff has to all patients and caregivers. As someone aspiring to become a physician, there is no better group to learn from and strive to emulate. In addition, working with patients and their families in the FTD Unit has been an extremely rewarding experience, and one that has certainly solidified my decision to apply to medical school. Finally, the FTD unit has shown me how comprehensive and impactful an integration of research and clinical practice can be. Not only are the patients followed in clinic, but they also often become a part of a larger effort to one day eradicate these diseases. It has made me determined to incorporate research into my future career in healthcare.

**You are also an artist. Do you think there is an overlap in your interests in science and art?**

Absolutely. I believe my interests in science and art are constantly complimenting and informing one another. Art has given me an ability to visually represent my world in a nuanced way, and approach the field of science with new perspectives.



Original art, Katelynn Getchell

## FACULTY & STAFF

Brad Dickerson, M.D., Director of MGH FTD Unit, Behavioral Neurologist

Daisy (Sapolsky) Hochberg, M.S., CCC-SLP, Founding Speech and Language Pathologist

Diane Lucente, M.S., Senior Genetic Counselor

Scott McGinnis, M.D., Director of Clinical Trials, Behavioral Neurologist

Mark Eldaief, M.D., Behavioral Neurologist

David Perez, M.D., Behavioral Neurologist

Megan Quimby, M.S., CCC-SLP, Speech and Language Pathologist, Director of Speech and Language Pathology Program, FTD Unit

Katie Brandt, M.M., Director of Caregiver Support Services and Public Relations

Bonnie Wong, Ph.D., Neuropsychologist, Director of Neuropsychology Program, FTD Unit

Deepti Putcha, Ph.D., Neuropsychologist

Jessica Collins, Ph.D., Cognitive Neuroscientist, Instructor in Neurology

Alexandra Touroutoglou, Ph.D., Cognitive Neuroscientist, Instructor in Neurology

Raseeka O'Chander, M.A., Program Manager

Samantha Krivensky, B.S., Project Manager

Ryan Eckbo, M.S., Data Analyst

Mike Brickhouse, B.S., Data Analyst

Rania Ezzo, B.S., Research Technician

Alex Zaitsev, M.S., Database Programmer

Katelynn Getchell, B.S., Clinical Research Coordinator

Taylor Delp, B.S., Clinical Research Coordinator

Ryn Flaherty, B.S., Clinical Research Coordinator

Erin Krahn, B.S., Clinical Research Coordinator

Samuel Huang, B.S., Clinical Research Coordinator

### **Trainees**

Cristian Leyton, Ph.D., Cognitive Neuroscience Post-Doctoral Research Fellow

Claire Cordella, Ph.D., Speech Pathology Post-Doctoral Fellow

Shalom (Shaz) Kim, M.S., Speech Pathology Clinical Fellow

Neguine Rezaii, M.D., Behavioral Neurology/Neuropsychiatry Fellow

Amy Newhouse, M.D., Behavioral Neurology/Neuropsychiatry Fellow

Mahdi Razafsha, M.D., Behavioral Neurology/Neuropsychiatry Fellow

Sheena Dev, Ph.D., Neuropsychology Fellow

# MGH FTD Unit Research Studies

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@mgh.harvard.edu](mailto:mghftdunit@mgh.harvard.edu)

## LEFFTDS: LONGITUDINAL EVALUATION OF FAMILIAL FTD

**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

**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.

**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.

## ARTFL: ADVANCING RESEARCH AND TREATMENT FOR FTD

**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. You must have no known gene mutation related to Alzheimer's disease.

**Goal:** To build a clinical research network that can support treatment and prevention studies, and better understand biomarkers of FTD.

**This study involves:** 1-2 visits for cognitive testing, a blood draw, and a possible MRI. Some participants may be asked about an optional spinal fluid sample.

## 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 SUPPORT INTERVENTION

**You may be eligible if:** You are a caregiver of someone who has FTD or ALS with behavioral changes.

**Goal:** This intervention aims to help caregivers by providing them with the support and strategies they need to manage challenging behaviors.

**This study involves:** Caregivers will talk on the phone regularly for 3 months with our Community Resource Specialist, Katie Brandt, as well as complete surveys.



# Fighting History

By: Matt Robinson, Research Participant

I participate in studies to help prepare myself...and others.

Five years ago, my father was taken excruciatingly slowly by FTD.

As I watched him decline, I considered the deep history of mental deterioration that existed in his family. While his mother died three days before I was born, all of her sisters eventually succumbed to some sort of cognitive deterioration.

As I had seen what a loss of brain power could do to a person, I decided that my best weapon was information.

Even before my father was diagnosed, I had been a bit of a closet brain physiologist. I had even gone as far as to get a degree in early childhood education

as I was so fascinated with how the human mind accreted knowledge and how the brain built itself fact by fact. When brain matters became personal, however, my interest escalated significantly.

When my father was officially diagnosed, I called the research team at Mass General Hospital (with whom he had been working) and volunteered for every possible study. I was put through batteries of verbal and written questions and put into an MRI scanner where I looked at pictures of people in various emotional states. While I was eventually able to “game” the tests by predicting what I would need to recall and what I could let go, it was still interesting (and frightening) to be involved.

Though my initial tests found no notable issues, the fact that I made my living as a writer (and that I had boxed in college and taught boxing since) kept me concerned. After all, if I lost my vocabulary, I would lose my livelihood. As such, I continue to check in with the team at MGH and have also connected with a neurologist who is tracking my brain annually.

My father’s disease greatly snuck up on him. I do not want to have people say the same of me. I want to be informed and prepared and to live my life to the best of my abilities according to my mental means.

With the help of The Association for Frontotemporal Degeneration (AFTD) and the team at the MGH FTD Unit, I can keep fighting!



Matt and his dad, Peter Robinson

## BOSTON-AREA FTD SUPPORT GROUPS

Please email [ftd.boston@gmail.com](mailto:ftd.boston@gmail.com) to join our support group email list.

### 2019 Meetings in Newton, MA

Last Tuesday of Every Month\*

#### Upcoming Four Groups:

**April 23rd\*, May 28th, June 25th & July 30th**

*\*Please note special date for April 2019 meeting*

Newton-Wellesley Hospital  
Silverman Boardroom, 2nd Floor  
Newton, MA

7:00–9:00 PM

Facilitator: Katie Brandt

### 2019 Meetings in Cambridge, MA

2nd Tuesday of Every Month

#### Upcoming Four Groups:

**April 9th, May 14th, June 11th & July 9th**

Mount Auburn Hospital  
Clough Conference Room  
Cambridge, MA

7:00–9:00 PM

Facilitator: Amy Almeida

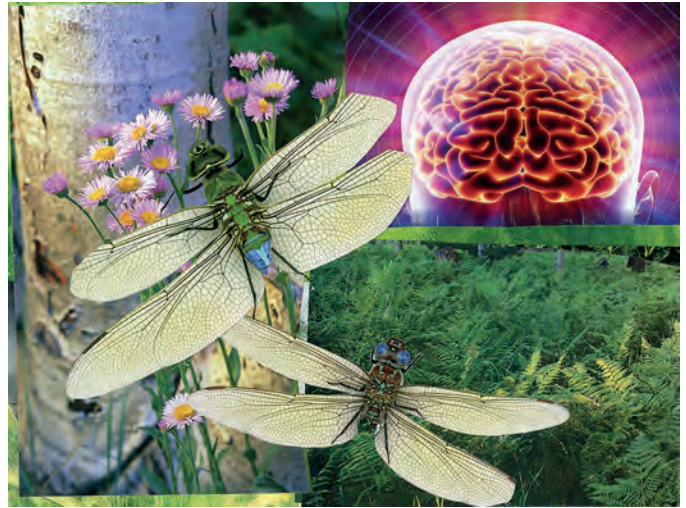
# Patients with Passions

## Spotlight on Carol Procter



Accomplished cellist with the Boston Symphony Orchestra...photographer and creator of mixed media collages and other evocative images...energy healer and Transformational Breath Facilitator. Carol Procter is all of these things and more: Carol is a highly creative woman passionately living life to her fullest with a diagnosis of Alzheimer's, specifically Posterior Cortical Atrophy (PCA).

Following her retirement from 38 years of playing the cello with the BSO, Carol promptly began to seek new outlets for her creativity, including shooting photos to accompany her agenda of travelling, and collecting images to use in her mixed-media collages. When she was diagnosed with Alzheimer's, Carol realized that time was of the essence and found the impetus to complete several unfinished projects, among them her "Alzheimer's Series," a set of collages expressing her inner experiences and insights into living with PCA. *Beauty and the Brain* is a mixed media collage on paper that she created in 2018. For a look at this and more of Carol's evocative images, visit her website: [www.carolprocter.com](http://www.carolprocter.com).



*Beauty and the Brain* mixed media collage on paper 14 x 17 2018

### **Solo Exhibition at Preservation Hall, Wellfleet, MA**

May 3–May 31, 2019

Exhibition opening May 4, 3:00 – 6:00 PM

Talk at 4:00 PM - Carol will speak about her artistic process, both before and after her diagnosis of Alzheimer's

### **Speaking Engagement and Reception at Preservation Hall, Wellfleet, MA**

May 18, 4:00PM

### **Lost Treasures**

Carol's cello recordings *Lost Treasures* is now available for purchase (\$20).

Order the CD by writing to Carol on her Contact Page,

[www.carolprocter.com/contact](http://www.carolprocter.com/contact).

## **NINDS HOSTS 2019 ALZHEIMER'S DISEASE RELATED DEMENTIAS SUMMIT**

**Bethesda, MD – The National Institute of Neurological Disorders and Stroke (NINDS)** hosted the 2019 Summit for Alzheimer's Disease Related Dementias March 14 – 15, 2019. Summits are held to respond to the National Alzheimer's Project Act (NAPA) and solicit input from internationally recognized experts and to develop prioritized recommendations to guide scientific research during the next five to ten years.

This work informs new recommendations to the NAPA Council based on expert input. This year's Summit focused on diagnostic challenges, dementia nomenclature, health disparities and emerging scientific topics in the field for FTD, vascular dementia, Lewy Body and other related dementias. We are thankful for this important focus on the atypical dementias. To learn more:

[aspe.hhs.gov/national-alzheimers-project-act](http://aspe.hhs.gov/national-alzheimers-project-act)



# Why is Clinic at MGH So Busy?

By: Daisy Hochberg, MS, CCC-SLP,

Founding Speech and Language Pathologist, MGH Frontotemporal Disorders Unit

## Making Every Visit Count for Patients, Caregivers, and Clinicians



For many of you—a patient or family and friends dedicated to the care of a loved one—the experience of coming to our clinic for an appointment can be time consuming. While we try our best to be punctual, appointments sometimes begin late, and appointment activities often take a long time. Here we provide a brief explanation of some of the structure and procedures that take place in clinic.

Dr. Dickerson and his team spend one day each week in clinic, usually Mondays, with the rest of the week spent on research activities. As the only FTD and atypical AD specialty clinic in New England, we have received an increasing number of patient referrals over the years. With this growing demand for new patient appointment slots, there is a growing need for follow-up slots as well. In addition, our team strives to reduce the time it takes to schedule an appointment, whether that is for a new patient or for an urgent follow-up. To accommodate the needs, Dr. Dickerson has grown our team of neurologists, fellows, caregiver support staff, and other professionals. This growing multidisciplinary team allows us to offer more services and see more patients on any given day, but it also requires more time to meet

with patients and families and for the team to discuss their collective perspectives.

In addition to the full clinic schedule, there are many activities that take place during a visit to obtain a complete picture of the patient, including review of any prior evaluations and imaging or other diagnostic test results, neurological examination, cognitive assessment, and an interview with the care partner. To make the day run as efficiently as possible, Dr. Dickerson and his team prepare for clinic by mapping out a plan and coordinating activities with staff members in advance, including reviewing available records. Despite this preparation, there are times when, for example, a care partner needs extra time to discuss a concern, or a newly diagnosed patient benefits from extended time to complete a speech and language evaluation. We try to accommodate the need for extra time as often as possible.

We always appreciate your patience and understanding, and we continue to work to improve the structure and flow of the clinic day, and the quality of our communication with all of you. Feel free to let us know anytime if you have feedback.

### KAREN ZANDER

**Karen Zander is a powerful patient making a difference at her adult day health program,**

Julia Ruth House, located in Westwood. Karen is an amateur classical musician and was a member of the New Philharmonia Orchestra for 40 years. Now she plays the piano for attendees at Julia Ruth House two days a week. For the past four decades, Karen has worked in healthcare, first as a psychiatric nurse, and then as a hospital consultant in case management. She is a Fellow of the American Academy of Nursing. Karen and her husband, Bernie, have been married for 42 years and have raised two daughters, Elise and Vicki. At Julia Ruth House, Karen is a Dickerson Community Ambassador. When we asked Karen “What are you showing us through this experience?” Her response was immediate: “Hope matters.”

[Newphil.org](http://Newphil.org)  
[TheJuliaRuthHouse.com](http://TheJuliaRuthHouse.com)



*Community events are at the heart of our program. We believe that building connections builds resilience. We hope to see you at an event soon!*



**MGH Frontotemporal Disorders Unit  
2019 Community Events**

**March 24th** – Strike Out FTD Family Bowling Event  
Buy Tickets Today: [Because.MassGeneral.org/StrikeFTD](http://Because.MassGeneral.org/StrikeFTD)

**April 5th** – From Care to Cure Educational Event  
Register Today: [Because.MassGeneral.org/FromCaretoCure](http://Because.MassGeneral.org/FromCaretoCure)

**Save the Dates!**

**May 20th** – *Symphony for Science*  
Join us and the Kendall Square Orchestra for a night of music and science at Boston Symphony Hall featuring members of the Boston Symphony, including Keith Lockhart on piano. Ticket and event information available at [www.SymphonyforScience.org](http://www.SymphonyforScience.org).

**October 18th** – *A Night With the Arts for FTD*  
Fifth Annual Gala and Art Show to Benefit the MGH Frontotemporal Disorders Unit  
Ticket Sale and Sponsorship Information Available Soon

## AMY ALMEIDA: GALA VOLUNTEER

When Katie Brandt and Dr. Dickerson approached me in 2014 to participate in the first A Night With the Arts for FTD fundraising gala, I was somewhat hesitant to say yes. I had never attended a fundraising gala, never mind helped to plan one. I was caring for my mom and facilitating a support group for FTD care partners. However, given the warm care and support my mom and our family received from the MGH FTD Unit and Katie's support group, I couldn't say no. Now, almost four years later, I am co-chair of the fifth annual A Night With the Arts for FTD and our first four galas raised thousands of dollars for research and support services at the MGH FTD Unit! Being part of the gala planning committee has enabled me to contribute to the MGH FTD Unit in excess of any financial donations I could make. I've also been pleased to bring an approach to event planning that seriously considers the needs of people with FTD and their care partners. Since getting involved with A Night With the Arts for FTD, I've been delighted to participate in other community events sponsored by or benefiting the MGH FTD Unit including Strike Out FTD and From Care to Cure.



In an effort to build on the spirit and generosity that has made A Night With the Arts for FTD and its other community events so successful, the MGH FTD Unit is launching a Community Events Committee (CEC). This committee will plan events to promote and grow the local FTD community. Recognizing how busy most people dealing with FTD are, in-person meetings will not be required. We're interested in committee members with creative ideas; event planning skills; or networks that can be called upon to donate raffle/auction prizes, attend/publicize events, volunteer at events, etc. If interested, please contact me ([amy.m.almeida@gmail.com](mailto:amy.m.almeida@gmail.com)) or Katie Brandt ([Katherine.Brandt@mgh.harvard.edu](mailto:Katherine.Brandt@mgh.harvard.edu)) for more information.

# Raising Awareness, Running for Resilience

By: Jessica Krauss and Katie Brandt

Jessica Krauss is a Millis High School (MHS) senior on a mission to raise awareness and donations for a cure for FTD. In the fall of 2017, Jessica's father was diagnosed with FTD and ALS. Inspired by her love for her Dad, Jessica decided to dedicate her Senior Project to FTD. Jessica coordinated an informational session with MGH staffer, Katie Brandt, to present to over 100 members of the MHS community. The presentation informed staff and students about FTD, focusing on taking action as members of a community. Jessica has coordinated a 5k Run for FTD to raise funds for the clinical research program in the MGH FTD Unit. So far, she has raised over \$6,000. Through the support of her parents, four siblings and the Millis community, Jessica's run will raise more than just funds for FTD research, she will raise hope that families can be resilient in the face of FTD.

## 5K RUN FOR FTD

Sunday, April 7, 2019

Start Time: 11:00 AM

Location: Oak Grove Farm, Millis, MA

Registration: \$20 per person

[www.Because.MassGeneral.org/RunFTD](http://www.Because.MassGeneral.org/RunFTD)



Jessica welcomed Katie Brandt, Director of Caregiver Support Services and Public Relations, to Millis High School for a school-wide presentation about FTD.

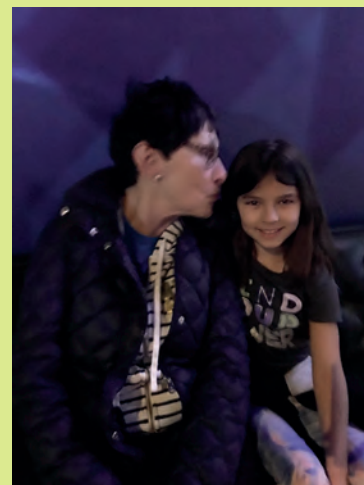


Jessica welcomed the support of her mother and siblings during her Senior Project Presentation.

## PHILANTHROPY IS FUN AT ANY AGE



Eight-year-old **Grace Lavigne** was inspired to start a fundraising campaign for a cure for FTD because of her love for her Nana, Mary Ciccariello. In an interview at the recent Strike Out FTD Family Bowling Event, the second grader said that she felt "pretty good" about raising \$20.26 in her first fundraising efforts. Grace collected donations by applying her handmade glitter tattoos while spreading the word about FTD.





## Rare Disease Day

MassBio is a not-for-profit organization that represents and provides services and support for the world's leading life sciences supercluster. MassBio is committed to advancing Massachusetts' leadership in life sciences and represents over 1,100 biotech companies, academic institutions, disease foundations and other organizations involved in life sciences and healthcare. Every year, MassBio celebrates International Rare Disease Day in Boston by gathering together hundreds of patient organizations, government agencies, medical researchers, life science companies and patients to share stories and recognize the great work being done in Massachusetts and beyond to provide new treatments and cures for rare diseases that affect nearly

30 million Americans. For the past four years, Katie Brandt, MGH FTD Unit Director of Care-giver Support Services and Public Relations, has represented our rare patient population as the emcee for the event. The 2019 panels were "Supporting Patient Well-Being Beyond Outcomes" and "Fulfilling our Social Contract for the Whole Patient."



*Katie Brandt emceed the 2019 event with Bob Coughlin, President & CEO, MassBio*



*Katie Brandt is pictured with members of the 2019 Rare Disease Day Patient and Industry Panel Members and event attendees.*

### NATIONAL ORGANIZATION FOR RARE DISORDERS

The **National Organization for Rare Disorders (NORD)** is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 280 patient organization members, is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient services. Each year, NORD leads the charge for International Rare Disease Day in the United States, setting the theme for the year and spearheading federal policy initiatives that support rare disease patients and families.

Learn more: [RareDiseases.org](https://www.RareDiseases.org)

# Caregiver Perspectives

By: Chris Boyer, Long-time Caregiver to Her Husband Frank

To quote the late basketball legend John Wooden, “Things turn out best for those who make the best of the way things turn out.” That’s good advice for anyone, but especially pertinent for caregivers of people with FTD. Our day-to-day lives are so unpredictable—we just don’t know what will happen next, how long it will take to happen, and how long that phase will last. When we accept this new role, whether it’s willingly or unwittingly, we are charged with the formidable burden of deciding another’s life choices, and that’s heavy.

How do we do this? How do we go on and on and on for as many years as our loved one’s journey takes? How do we maintain our patience, our sense of humor, and most importantly, our physical, mental, and emotional health? For me, the answer has been in identifying and using different tools of self-care that give me a break and remind me that there is a “me” beyond “me the caregiver,” and this has taken discipline.

Following are a few of the “rules” I have adopted for myself during the 10 years I have spent as my husband’s primary caregiver.

- Stay in the moment—when you’re with your loved one and when you’re alone. Focusing on “right now” is never quite as scary as obsessing about the unknown future or fretting about the past.
- Surround yourself with information, support, and true friends. You never know where or from whom help will come.
- Let go of expectations about the people who disappoint, frustrate or even infuriate you, whoever they might be. Try to accept that some people just can’t step up to the challenges of helping out in ways you might have thought they would.



Frank and I now celebrate our holidays at Harbor Point at Centerville, a dementia care assisted living facility staffed with people who know how to treat FTD and other memory-impaired residents with care, compassion, and respect.

- Remember you still have a “me,” and that it’s important to do things you like to do when you can. And remember too that it’s perfectly fine to enjoy those things.
- Get the tough stuff out of the way in the beginning—the wills, POAs, health care proxies, etc.—so there’s a plan in place and you don’t have to stress about those necessary tasks while you’re stressing about the day-to-day issues of caregiving.
- Remember, respect, and cherish the aspects of your loved one that may not seem to be a part of them any longer. Try to think back to what they would have done or decided before FTD, and then do your best to show consideration for that part of them.
- Allow yourself to grieve; this whole situation is very, very sad and immerses us a life of continual loss. At the same time, try to find a way for you

## CAREGIVER RESOURCES

**NIH National Institute on Aging**—Find resources for caregiving through the US Department of Health and Human Services

[www.nia.nih.gov/health/caregiving](http://www.nia.nih.gov/health/caregiving)

**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.

[www.theAFTD.org](http://www.theAFTD.org)

**The Alzheimer’s Association**—On a nationwide scale, they offer support groups, education and counseling services to caregivers of all dementia patients.

[www.ALZ.org](http://www.ALZ.org)

**CurePSP**—CurePSP is the leading source of information and support for prime of life neurodegenerative diseases.

[www.PSP.org](http://www.PSP.org)

**Posterior Cortical Atrophy**—A site dedicated to supporting people with PCA and their caregivers.

[PCA-vision.org](http://PCA-vision.org)

and your loved one to enjoy a little part of each day, realizing that today could very well be the best day your loved one has left.

I didn't come to these "rules" quickly or all at once, and I certainly don't follow them perfectly. When Frank, my husband and partner of almost 50 years, was diagnosed with FTD/PPA Semantic at MGH almost 10 years ago, he was just 61 years old. We weren't yet considering retirement, our plans for our future were still just starting to take shape, and we both felt healthy, optimistic, and young, with a lot of good times ahead of us. But within two years, Frank was no longer reading or writing and within three his comprehension was markedly compromised. We sold his CPA practice, forcing him into an early retirement, sold our family home of 35 years to move to something more manageable, and started to live with his diagnosis.

Getting involved in the research at MGH and becoming a part of the FTD community—including the invaluable caregiver support groups—were important steps that provided us with incredible support from compassionate people who were also at the cutting edge of the disease. They began to educate us about the disease, brought us together with others battling similar challenges, and provided us with resources that helped us feel we were not alone in the darkness attributable to ignorance of the disease.

I learned fairly quickly that the progression of FTD doesn't stand still and that new challenges would continue to arise, whether dealing with the difficult issue of taking the car keys away, or deciding to give Frank mostly sandwiches to eat because he was struggling with using utensils. I began to realize that if I wasn't patient, flexible, and creative, I wasn't going to continue to be a loving and effective caregiver for very long.

I believe in the important role gratitude can play in keeping a positive attitude, and I use it to help myself put one foot in front of the other when it

seems almost impossible. I keep a journal dedicated to our FTD journey and although it's not likely that I'll want to go back and read about the frustrating days, the sad days, or even the good days, the journal does serve to remind me that even during the tough times, I made it through, and I did my best. My own written words remind me that I should go easy on myself, because this is not an easy life, and the trials are there in black and white if I need to be reminded of them. Meditation, yoga, and walking our wonderful dog also play huge parts in helping me maintain a positive attitude.

Perhaps most importantly, now, almost 10 years since we started down this road, I try to remind myself to meet Frank where he is today, to take my cues from him, and then to go on in the day from there. I've had to drop the denial and admit to myself that Frank will never again be the brilliant professional accountant, the able, reciprocating partner, or the reliable, steadfast friend that he was before FTD. Instead, he will continue to evolve as the Frank he is each day, which right now can best be described as loving, kind, childlike, and still able to fill my heart with joy. When people who have not seen him in a while ask, "How's Frank?" I often respond, "I have known him for over 45 years, but I never knew him when he was 4 or 5. Now I do ... and he's adorable."



*This is me being "me" on a recent trip to Bethel, Maine for cross-country skiing with friends and my now-constant companion, Ben.*



## CAREGIVER TIPS

- Meet your loved one where they are in their own world today.
- Stay in the moment—when you're with your loved one and when you're with just you.
- Surround yourself with information, support, and true friends.
- Join a support group to share with others and learn from their experiences.
- Let go of expectations about the people who disappoint, frustrate or even infuriate you.
- Remember you still have a "me," and that it's important to do things you like to do when you can.
- Get the tough stuff out of the way in the beginning—the wills, POAs, health care proxies, etc.—so there's a plan in place.
- Remember, respect, and cherish the aspects of your loved one that may not seem to be a part of them any longer.
- Give yourself permission to grieve.

**The MGH Frontotemporal Disorders Unit** is made up of an interdisciplinary team of compassionate and sophisticated staff and clinicians dedicated to the highest quality of care for patients and families living with neurodegenerative conditions including Frontotemporal Degeneration, Primary Progressive Aphasia, atypical Alzheimer's and other forms of cognitive impairment. We are committed to raising awareness and hope for FTD through our exemplary clinical care and research work.



Join us in the fight to #ENDFTD today!

## LOCATIONS

### MGH FTD Unit Clinical Care

Our patient care clinic is located at the MGH Main Campus in the Wang Ambulatory Care Center.

Massachusetts General Hospital  
15 Parkman Street, WACC 835  
Boston, MA 02114  
617-726-1728

### MGH FTD Unit Research Center

The majority of our research is performed at our facility in the Charlestown Navy Yard in partnership with the Martinos Center for Biomedical Imaging.


149 13<sup>th</sup> Street, Suite 2691  
Charlestown, MA 02129  
617-726-5571

## CONTACT US:

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