MASSACHUSETTS
GENERAL HOSPITAL
FRONTOTEMPORAL
DISORDERS UNIT

FROM CARE TO CURE

SPRING 2023 NEWS FROM THE MGH FRONTOTEMPORAL DISORDERS UNIT

INSIDE THIS ISSUE

WEBINAR *EN ESPAÑOL*

¿Qué es la demencia? Información para Pacientes y Cuidadores

Dr. Sylvia E. Josephy Hernandez, Neurologa, San Jose, Costa Rica and graduate of the MGH FTD Unit Harvard Medical School Neurology Fellowship, hosts our first Spanish language webinar to provide an overview of dementia, person-centered care plans and ways to promote brain health at every stage.

Our MGH FTD Unit YouTube Channel was proud to feature Sylvia E. Josephy Hernandez, MD, Liliana Ramirez Gomez, MD and Ana Maria Rivas-Grajales, MD for our first Spanish language webinar, *¿Qué es la demencia? Información para Pacientes y Cuidadores.* We recognize that families of all cultures experience dementia and we hope to expand our library catalog to offer educational resources that may be accessible to our diverse community.

Check out Page 2 to learn more about the MGH FTD Unit's free video library on YouTube.

Dear FTD Unit Community Members,

We welcome the opportunity to connect with you through our newsletter as we turn the corner from winter to spring. This issue comes out on Rare Disease Day, an international day of recognition for individuals living with rare conditions, including the conditions that we care for, and the clinical care and research efforts focused on discovering effective treatments and cures as well as providing high-quality care.

We know how important public awareness and recognition of rare disease is. It opens the door for policy changes and increased research funding that has the potential to directly impact persons living with a diagnosis and their families. You may have heard the news that Bruce Willis, beloved American actor, is living with FTD. The courage that the Willis family displayed by sharing their private journey with FTD has the potential to make a significant impact. We know that this announcement has created a spotlight for Frontotemporal Disorders that has caused an increase in requests for services and supports. Our hearts go out to the Willis family and we hope that they are able to build connections with other families who are walking, or have walked the journey of FTD. As our Director of Caregiver Support Services, Katie Brandt, says, "Although we do not have a cure today for Alzheimer's, FTD or related dementias, we do have a cure for the isolation and loneliness that may come with a diagnosis. That cure is connection."

This issue is all about connection. You will see an invitation to our upcoming gala event, *A Night With the Arts for FTD*, finally back as an in-person event after three and a half years! This promises to be an especially meaningful year as we come together once again to celebrate our community. You'll also read about Ski with David for PSP, the inaugural ski race and celebration hosted by the Crowley family at Wachusett Mountain to raise awareness, funds and hope for a cure for Progressive Supranuclear Palsy (PSP). And a long-term caregiver shares her thoughts about what life after FTD caregiving can look like. The common thread between each spotlight is connection and making new memories of joy.

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

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

Spotlight on Staff:

Gent Celaj, Clinical Research Coordinator

I am one of the new Clinical Research Coordinators at the Dickerson Lab but originally started out as an intern in April 2022 during my senior year of college! Working with such a prestigious lab and being exposed to high-quality resources and knowledge encouraged me to want to continue with this inspiring group of professionals to further my education as I begin my career.

At Boston University, I majored in psychology and followed a pre-medical track, so a major goal of mine is to attend medical school. While I am unsure of the specific field on which I would like to focus, I find myself most interested in neurology and sports medicine.

Something other lab members may not know about me is that I come from a household of 13(!) people. Growing up with that many people was, as you can imagine, hectic but amazing. My two older brothers and my three first cousins are indistinguishable to me, where I look at them all as my siblings, and I feel really blessed to be able to have that relationship with them.

CAREGIVER SUPPORT GROUP TUESDAYS

Are you caring for a loved one living with Frontotemporal Dementia, atypical Alzheimer's Disease, or a related disorder? Our weekly online support groups meet for an hour over Zoom to provide care for the caregiver. Join us every week, or just once. You can attend on a schedule that works for you. We are here to offer support, resources and connections to our caregiver community at every stage of the journey with dementia.
We hope to see you soon.

Registration Is Required. Please email **FTD.Boston@gmail.com** to register for this free resource.

Upcoming Caregiver Groups:

Tuesdays @ 10:00AM	Tuesdays @ 7:00PM
March 7th, 21st	March 14th, 28th
April 4th, 18th	April 11th, 25th
May 2nd, 16th, 23rd	May 9th, 30th
June 6th, 20th	June 13th, 27th
July 18th	July 11th, 25th
August 1st, 15th, 22nd	August 8th, 29th

KNOWLEDGE AT YOUR FINGERTIPS: THE MGH FTD UNIT YOUTUBE CHANNEL

Our clinical research team is committed to empowering our community with information to navigate life lived with a dementia diagnosis. We know how busy your lives are. To make these educational resources easily accessible, we have launched an **MGH FTD Unit YouTube Channel**.

Subscription is free! We look forward to connecting with you online, building community and knowledge, together.

Subscribe to the MGH FTD Unit YouTube Channel today! **YouTube.com/c/MGHFTDUnit**

From Care to Cure *features presentations from MGH FTD Unit clinicians about the medical and scientific aspects of FTD, Alzheimer's and related dementias.*

Community Forum Friday *features conversations with community experts about topics relevant to living life well with dementia.*

Spotlight Events *feature MGH FTD Unit community events and special guest speakers.*

Caregiver Perspective: Out of the Fog

By: Chris Boyer

When I was a caregiver in the midst of my husband Frank's 11-year battle with FTD/PPA, I didn't spend much time imagining what was on the other side for me—what my life would be like when I was just Chris, with a whole singular existence to put together. I was determined, however, not to let the trials of FTD take my life along with Frank's, that I would come out on the other end of the disease as a whole person…but I had no idea what that should look like.

Frank passed away on January 24, 2020. One month later, the world started its unbelievable venture into a Covid reality marked by lockdowns, isolations, and so much more. For me, it was the start of a life without my partner of 50 years and a real, somewhat forced opportunity to breathe on my own and think about being me, just Chris.

And so, at 70 years old, I took my first-ever ballet class; I was no Margot Fonteyn, but I did enjoy smiling and laughing at myself. I tried my hand at acrylic painting; again, no gallery awards coming my way, but my still-life fruit did begin to look more like apples than eggs. I ventured from writing the kind of technical and marketing copy that helped me earn my living, to writing creatively short stories, some poetry, and even a stab at a novel. It was enlightening and absorbing and, unlike ballet, I'm still doing quite a bit of creative writing today.

But while all of this was helping me to get a foothold into filling the hours that were set free from the responsibilities of caregiving, none of it was making a dent at filling what I call the "helping-void;" that satisfying feeling of knowing I was doing something worthwhile to help; an endeavor that would make a difference.

One day, during a very soggy week in October I was feeling particularly "down," pretty much without purpose. Determined not to give in to gloom, I put on my L.L. Beaniest raingear, leashed up my always-eager retriever Ben, and headed out in the weather. We live on Cape Cod, so our destination was the wide expanse of Mayflower Beach. It was completely fogged in, not another soul in sight, or so I thought until I heard, "Excuse me. Do you live here? I could use some help." Just like that, out of the fog walked an answer to filling my "helping-void."

The woman enthusiastically explained that she was looking for people to become trained sea turtle volunteers, to help move cold-stunned sea turtles that were stranding on Cape Cod's north-side of beaches to safety and then rehabilitation.* I knew nothing about it, only that I wanted to help—the main prerequisite was walking on the beach! That same evening, I attended an informational meeting at the local library where I heard all about the plight of these very sweet turtles—mostly green turtles, Kemp's ridleys, and loggerheads—and about how the shape of Cape Cod, the cold water temperatures, and certain wind and tide conditions can trap these migrating animals while they are trying to make their ways from Maine back to the warmer waters of the southern U.S. The cold water stuns them, like a kind of hypothermia; the high tide carries them up onto the beach; and then when the water recedes, they are left there helpless…until the rescue process begins.

First the volunteers walk the beaches, with informed direction about where the turtles are most likely to strand. When one is found, the goal is to get them above the high tide line using children's sleds, and warm them somewhat by covering them with either a towel or dry seaweed. The volunteers then call staff at Mass Audubon who are prepared to pick up the turtles as quickly as possible, load them safely in banana boxes in a vehicle, and take them to rehab centers in Wellfleet and Quincy, or to the New England Aquarium. There the healing process begins, with the goal of eventually releasing each turtle healthy enough to survive again on its own. And it works!

It works for the turtles, and it worked for me too. I was once again helping with a purpose, and this time I was out in nature, getting fresh air, meeting new people, learning new things every day, and seeing wonderful, positive results—swimming, happy turtles. For me, rescuing cold-stunned sea turtles gave me the opportunity to take one step forward into Lennon and McCartney's conviction that: *Ob-La-Di, Ob-La-Da, Life Goes On, Brah.*

** The sea turtle work is conducted under a permit issued by the US Fish and Wildlife Service which is jointly administered by the National Oceanic and Atmospheric Administration.*

*** Photo credits: Sandra Restrepo.*

Stranded and waiting for rescue.

Rescued and beginning the journey to recovery.

DANCING & LIVE MUSIC

ART SHOW

LIVE AUCTION

RAISING AWARENESS, FUNDS & HOPE

MASSACHUSETTS GENERAL HOSPITAL
FRONTOTEMPORAL DISORDERS UNIT

Join Us

YOU ARE INVITED TO
THE MGH FRONTOTEMPORAL DISORDERS UNIT

EIGHTH ANNUAL GALA EVENT

A NIGHT WITH THE ARTS FOR FTD

FEATURING

SERMOS MEMORIAL ART SHOW

Dinner, Live Music, Live Auction & More!

FRIDAY, APRIL 28, 2023 ▪ 6:00PM

THE ROYAL SONESTA HOTEL – 40 EDWIN LAND BOULEVARD, CAMBRIDGE, MA

BLACK TIE OPTIONAL

Buy Tickets and Sponsorships Online: Because.MassGeneral.org/FTDGala2023

Questions? Email Katherine.Brandt@mgh.harvard.edu

All proceeds to benefit the MGH Frontotemporal Disorders Unit

PRESENTATION BY DR. BRAD DICKERSON

COCKTAIL HOUR & DINNER

Racing Towards a Cure for PSP

On the slopes of Wachusett Mountain, David Crowley was known as the Ski Guy. As the co-owner and operator of Wachusett Mountain, David's career and life mission has been to share the joy of skiing with the world. However, several years ago, that joy seemed to be on the verge of being taken away from David when he was diagnosed with Progressive Supranuclear Palsy (PSP) by the clinicians at the MGH FTD Unit. PSP is a frontotemporal disorder (FTD), involving changes in the frontal and temporal lobes of the brain that impact speech, vision, balance and cognitive ability. PSP is a rare disease, often affecting people ages 45-65. Unfortunately, this disease is physically debilitating and affects all aspects of daily function. There is no known cure.

Like so many families, David, his wife, Julie, their four children and three grandchildren were determined not to let PSP take the joy from their lives. Since Wachusett Mountain and skiing have played such a large role in all of their lives, the Crowley family decided to hold a community event, Ski with David for PSP, to raise awareness, funds and hope that tomorrow's cure for PSP is not so far from today's care. Julie said "This disease can take so much. We want to help educate people about what PSP is and give back to the folks at the MGH FTD Unit."

David Crowley with his adaptive skiing buddies, Bruce Gasko and Andy Hicks.

On Sunday February 12, 2023, the Crowley family and friends, Wachusett Mountain community and families and clinicians from the MGH FTD Unit gathered to ski with David. The day-long event featured the inaugural Ski with David to Cure PSP ski race, a raffle and a chance for skiers to learn more about PSP and the role the MGH FTD Unit plays in supporting the Crowley family's efforts to maintain David's quality of life.

*The **Wachusett Adaptive Program** works to help people of all ages and abilities enjoy winter snow sports. For more information, please email adaptive@wachusett.com or call **978-464-2300 ext 3308.***

Interested in hosting a community event? Contact Alexandra Van Strien at avanstrien@partners.org or 617.724.9411 to find out how the MGH Development Office can support your efforts.

Friends and family of David Crowley gather to cheer him on in the first run of the inaugural Race for a Cure for PSP.

Despite a diagnosis of PSP, David has not stopped skiing. He was the first racer of the day, speeding downhill on the sit-ski he uses as part of the Wachusett Adaptive Program which allows people of all ages and abilities to enjoy winter snow sports. Over 150 skiers participated in the Ski with David to Cure PSP ski race. Many of the more than 4,000 skiers and snowboarders at Wachusett that day stopped by the information tables staffed by Katie Brandt, Director of Caregiver Support Services and Public Relations for the MGH FTD Unit, and Alexandra Van Strien, Director of Development for MGH Neurology, to learn about PSP while buying raffle tickets. Dr. Brad Dickerson, Director of the MGH FTD Unit, skied with his family and presented short remarks. Dr. Dickerson said "I was blown away by the family and their community's commitment and generosity. It was an amazing event!" This amazing event raised over $100,000 for the clinical care and research efforts into PSP at the MGH FTD Unit. The Ski Guy once again brought the joy of skiing to Wachusett Mountain.

The Crowley family, Dr. Brad Dickerson and friends celebrate Ski with David for PSP.

Julie, David, Jr., David, Lisbet, Lilly, Trudy and Nate Crowley enjoy the day.
** Photo credits: The Crowley Family.*

Nate Crowley readies Wachusett Mountain for the inaugural Race to Cure PSP.

Katie Brandt and Mary Cadwallader staff an information table about PSP.

Make a Clinic Appointment
MGHFTDUnit@mgh.harvard.edu

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