Fall 2024 Update

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Notes from the ED

This fall has been a busy and impactful time for End the Legacy, and we are incredibly proud of all we've accomplished together. The efforts and milestones detailed below reflect our collective work toward a better future for families facing ALS and FTD. If our mission resonates with you, we invite you to consider supporting this important work. Your donation will have twice the impact with a 2-for-1 matching opportunity—learn more about this special challenge here.

As a small organization, we rely on the support of our community to continue our essential work. Without your generosity, we won't be able to move forward.

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If you believe in the importance of timely ALS and FTD diagnoses, we hope you will find inspiration in our latest Care updates. What a change this care would have made for so many of our loved ones.

If you value the dignity of every family, we believe our advocacy updates will resonate with you - especially our reporting on concerns from ISFTD. Researchers there declared all people with C9orf72 expansions, for life, are "significantly cognitively impaired." This from results that showed c9orf72 carriers scoring within normal ranges, if mildly lower then controls and the knowledge that our families have been stellar members of our communities. A key concept of research is that statistical significance is not the same as actual significance.

If you think community breeds comfort, check our support section. We are coming back together in person in 2025 and hope you can join us!

If you want to make progress and impact on disease care and treatment, see our research updates - there are new sites for longitudinal studies and valuable perspectives from our community.

If you believe we deserve to know what is being published about us, consider our education updates, which include revamped web pages and new webinars.

And finally, if you want to connect with the real human cost of these diseases and the strength of our families read the Member Spotlight interview at the end.

It's a lot, but so is the mission of our team!

In Solidarity,

Jean Swidler
End the Legacy Executive Director

Care
We are proud to have pioneered the concept that the personal health of those at risk of genetic ALS and FTD should consider that risk. See our new web page detailing that priority here.

A signature achievement since our founding was helping to inspire, sponsor, participate, and assist in the drafting of the 2024 Review article published in the Journal of Neurology, Neurosurgery and Psychiatry just a few days ago. The project, led by Drs Michael Benatar and Terry Heiman-Patterson, established for the first time that being monitored while at risk for genetic ALS and FTD is sound and recommended if desired. Other recommendations related to exercise, diet, and more are contained in the report. ETL paid for the open access fee, so all can read this groundbreaking development: https://doi.org/10.1136/jnnp-2024-334339 .

We are also proud to share the first End the Legacy Center of Compassion for those at risk of genetic ALS and FTD is open and seeing patients! Congratulations to the team at ALS Hope Foundation and Temple Neurology for this momentous development. To learn more email cassandra.haddad@temple.edu .

Research

In September, our small organization attended the International Society for Frontotemporal Dementia meeting in Amsterdam. This premiere gathering for FTD science was the perfect place for ETL members Jean, Jary, and Daniel to debut a poster on the issue of using loved ones as behavioral and cognitive informants in research and care for healthy individuals at genetic risk for FTD entitled “Informants (Study Partners) in asymptomatic FTD research: Highlighting uncharacterized & uncommunicated potential risk.” See it here.

We are proud to help ensure members of our community know what research is available for them to participate in, and to promote and encourage research that could benefit our community. In this vein, we were excited to share the news many more sites of the new Prevent ALL ALS national USA study for those at risk of genetic ALS went live. Our Executive Director is proud to serve as a patient advisor to the effort. See where you could be seen for this longitudinal study and others here.

We have been disappointed by the setbacks and repeated failures in ALS drug development over the years. As individuals whose personal health is deeply implicated in the endeavor to cure or slow this terrible disease, we proffered some simple requests to increase the odds of success in trials testing new therapeutics (beyond trying them earlier in the disease). Read it here.

Advocacy
Ensuring the perspectives and needs of our community is heard loud and clear is a key area of our mission. This fall we delivered on this resoundingly: We attended, listened intently and spoke up when needed at the bi-annual International Society for Frontal Temporal Dementia meeting. You can see more about what we accomplished at the meeting here.

Our own Cassandra Haddad spoke in the main plenary for the Northeast ALS Consortium Conference this October. See her inspiring remarks here.

The amazing Wanda Smith organized a genetic community outreach table at a large Alzheimer’s walk in San Diego she was joined by representatives from For Their Thoughts, AFTD, Cure VCP , and End the Legacy board member Nadia Sethi. Go Team!

A dedicated team member, Bill, was interviewed for this in-depth article on genetic non-discrimination in the Atlantic Monthly. His efforts with others and End the Legacy continue to pass legislation barring genetic discrimination in insurance products in South Carolina. Go Bill!

Education

Ensuring our community is up to date on important news and information related to our risk is a pillar of our organization we are so proud of. That continued this fall.

We ensured the great expense related to allowing us to attend the ISFTD meeting in Europe was well justified by reporting out to all those interested highlights for those impacted by genetic ALS and FTD. Read about it here.

Since our founding we have been bringing updates straight from the source with informative webinars with esteemed clinicians and researchers freely accessible. This fall we debuted a new web format for seeing our archive easily here.

We hosted two fascinating and important webinars this fall - one a genetic research education series installment focused on TARDPB, and one with the author of a recent publication establishing a method to calculate family-specific penetrance rates for C9orf72 kindreds. Both are available on our webinar page.

Our genetic information guide for C9orf72 was updated as well. See it here.

Support
Our weekly meetings and monthly peer support hours have been continuing - we cheer all who participate!

Following on the heels of our first in-person event in 2024, our 2025 End the Legacy Genetic ALS & FTD Community Summit has been announced for June 6-8th in Philadelphia with local hosts the ALS Hope Foundation and Temple Neurology! To learn more, email info@endthelegacy.org . Subsidies for travel will be available for impacted community members.

Member Spotlight Interview with Maureen Whitmore by Mindy Uhrlaub

1. What is your connection to ALS/FTD?

I am very new to this journey of understanding and advocating for ALS/FTD. Dating back to the 1970's and most likely before that, my family has been deeply impacted by C9orf72 gene. I am the eldest of nine, and my paternal grandmother was one of 12. Our family's ALS journey began with her father's side, although we only recently discovered that. We did not learn we carry the C9 gene until a year ago. I now ask myself how could that be with all the evidence before us? My grandmother was born in 1905 and died of TB shortly after my father's birth in 1929. My Dad was estranged from his mom's family, and we did not know about ALS in my grandmother's family until my 63-year-old brother died of ALS nearly six years ago. Nine of her family members, including siblings, nieces, nephews and cousins had died from ALS. No one on that side of the family has been tested for the gene. My Dad died in 1998 of meningitis at 69 and showed no signs of ALS.

My first exposure to ALS was when my brother was diagnosed during autopsy. We suspected he had ALS toward the end of his life, but it was never confirmed. He did participate in an NIH-funded study at Boston University for Chronic Traumatic Encephalopathy, and they confirmed a stage 3 diagnosis of CTE but never mentioned ALS until he had a comprehensive neuropathological study of his brain. Shortly after that, I lost one of my close friends to ALS. Her father had died of ALS as well. I had to bid farewell to another brother four years ago, and like my first brother, the ALS diagnosis came late and again it wasn’t formally diagnosed until he donated his brain to the Boston University study. He had many unnecessary surgeries on his spine and his arms for ulnar nerve and carpel tunnel syndrome. When his symptoms did not improve, he had an EMG that reflected the possibility of ALS. He too had stage 3 CTE found on autopsy. He’d been having trouble walking and suffered a brain hemorrhage and broken nose during a fall. When he went to have his nose surgically repaired, he died while being induced with anesthesia. Before his death

and in an attempt to get him to a multidisciplinary ALS team, I was put in touch with I AM ALS and Synapticure. He died before we could keep an appointment with Barrow Neurological Institute in Phoenix.
By now, we knew that our family carried a genetic form of ALS. And yet, no one pursued genetic testing until late 2023. My sister-in-law contacted me expressing concerns about my youngest brother (59) and wanted him genetically tested. He agreed, and in early 2024, we discovered he carries the C9orf72 gene. He saw a neurologist who determined he was asymptomatic. In May of 2024, my 67-year-old sister was diagnosed through EMG and genetic testing to have ALS. She is fortunately involved in a multidisciplinary ALS program and is the first in our family to receive an earlier intervention. Two more of my siblings have died of causes unrelated to ALS, but based on some behavioral issues they exhibited, I wonder if they may have had FTD.

2. Did knowing your genetic test results change anything for you? Now that you know your genetic status, what's next?

After my brother tested positive, it took me nearly eight months to submit my saliva. Honestly, I knew about the availability of genetic testing after my brother died three years ago. It was a very scary decision for me. I was anxious and thought for sure I had ALS and would pass this on to my three sons and eight grandchildren. Then I'd rationalize that I did not have it because I'm 73 with no symptoms. Every time I got a muscle cramp or had trouble finding a word I'd be thrown into fear and anxiety. I decided to get tested after engaging in many conversations with people involved in End The Legacy and NextGEN ALS. Being uncertain was taking a toll on my mental health. I also recognized that getting tested was one more step I could take in contributing to the efforts to learn more about this disease and eventually find a cure. When I found out I did not carry the gene, my emotions were all over the map. I expressed a huge sigh of relief for my sons and their families. I'd been "waiting to exhale" before my genetic counselor gave me the results. It was like "tearing off the band aid." I felt sadness and "survivors' guilt" in relation to the rest of my family who may or may not carry the gene and for my sister who is active in her journey. If my parents were alive, they would have 24 grandchildren and 30 great-grandchildren. ALS will impact all of them in some way over time, either as a carrier or a caregiver. My goal all along has been to make sure they understand what this means for them and to connect them with the resources to help them weather the storm brought on by ALS. I plan to be active in advocacy work and research. Denial, which I know I practiced, is no longer an option. I feel very much a part of the ALS community. I hope my story will help others on the fence make the decision to get tested.

3.Tell us something about yourself that we don't already know.

I started my career as a special education teacher and then went on to get my MA in Rehabilitation Counseling. I was licensed as a marriage and family therapist in 1980 and just recently retired my license. I worked for over 20 years at a large HMO (Kaiser Permanente) in Employee Assistance and then as a Healthcare Ombudsman Mediator. In that role, I helped facilitate communication and resolution when healthcare outcomes raised questions and concerns. I retired eleven years ago but still keep my connection as an Ombudsman by covering for my colleagues every so often.

In 2001, some of my colleagues and I were given the opportunity by Service Employees International Union and Kaiser Permanente to provide Critical Incident Stress Debriefing for the healthcare workers who witnessed the horror of 9/11 right after the towers collapsed and who provided care to the wounded. We left with trepidation from California right after the airspace reopened. It was an honor and privilege in such a traumatic time in our country's history.

I keep very busy in retirement. I’m an avid swimmer and love being in the water. I dabble in watercolor and oil painting. Our grandkids, who range in age from five to 15, keep us very busy in all things sports, sleepovers, and babysitting. We also help care for three grand-dogs. My husband of 45 years and I love to travel. Italy and Ireland are by far my favorites. We took a road trip in October have a trip to Japan planned in November. I’m originally from Chicago, and most of my family is there. I often travel back there for family events and reunions. Family togetherness is very important to me.

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