Winter 2024/2025 Update

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Notes from the ED

We hear it constantly - people are amazed to connect with others in the same position. All our families have heard for generations is how rare being impacted by inherited ALS and FTD is. Now, through our collective efforts that feeling is gone. We are so proud to provide the space and opportunity for this transformational connection.

Ensuring our diseases are set up for the best possible outcome by the most aggressive testing of possible therapeutics at all disease stages is a perspective we must bring to any gathering of ideas for ALS and FTD.

Building community and being in person have costs associated, and we are so thrilled two generous foundations allowed us to conduct a successful matching campaign to close 2024. We must continue to support this work financially if we want it to continue.

Finally, a huge shout of appreciation to the many volunteers of End the Legacy driving so many of our efforts forward. If you see a name you recognize below please reach out and thank them!

In Solidarity

Jean Swidler

EndtheLegacy.org

Education

Guidance Webinar

Following the publication of the first ever historic guidance for the at risk genetic ALS and FTD community in 2024, we were proud and grateful to host the reports lead authors Drs Benatar and Heiman-Patterson for the first informational webinar on this important topic. Watch the video here, with subtitles in French, Spanish, German and Italian.

Genetic Education

In February we debuted a new service: Genetic Counselling Education by a licensed genetic counselor. These free sessions allow impacted community members to learn important information about genetic counselling and testing without creating a medical record. Visit here to learn more and sign up.

Support

Summit

Our community was desperate for a space where being at risk for genetic ALS and FTD was the norm and not an outlier. We created that with our first community summit in 2024 and we are hard at work getting our June 2025 event in Philadelphia ready! Cheers to organizing committee members Kerri, Stephen, Lauren, Betsy, Mindy, Debbie, Jary and Wanda and our support from the

local host ALS Hope Foundation Brittny and Jamey.

Anyone impacted by inherited ALS or FTD is invited to attend, and all impacted attendees will have full conference attendance and hotel for 2 nights for a nominal registration fee. Travel subsidies are available. Learn more and register here!

Meetings

Our community team meetings are the heartbeat of our movement. A time for relationships to build and plans to be discussed and news to be shared. We have formalized a 2x monthly meeting structure with times friendly for participants around the world. The current times at 9am US Pacific time the 2nd and 4th Friday of each mont, 3pm UTC/GMT time the 2nd and 4th Thursday of each month, and 2nd and 4th Wednesday 5:30pm Australian Eastern time. To get involved in our community meetings email info@endthelegacy.org

Peer Support

Our peer support effort is going strong thanks to the dedication of our amazing volunteer peer facilitators Mindy, Carolyn, and Lauren. Cheers! To sign up to attend our monthly peer support hour which is the 3rd Wednesday of the month at 3pm Pacific time visit here.

Advocacy

ALS MND Symposium

We were so proud to attend the largest annual ALS MND research conference in the world this past December in Montreal. Our own Cassandra Haddad appeared on panel about presymptomatic research in a packed auditorium. Our own Mindy Uhrlaub took lead presenting our poster on existing information to guide at risk monitoring to dozens of fellow attendees. You can see the poster here. We also participated in many important conversations over the few days. Most importantly connections were made with genetic advocates from across the world !

Genetic Non Discrimination

The issue of advancing genetic protections is not going away. While we feel a federal solution is the best outcome we support state level improvements. To that end End the Legacy advocates are involved across the country supporting these efforts including in Nebraska and South Carolina by member Bill - his member spotlight interview is below! Efforts are also being made with large coalitions in Illinois, New York, and Maryland.

Federal Efforts

We are proud to ensure our communities voice is heard on matters of importance to us at the Federal level in the US. We attended the annual More Than Our Stories conference in February and called on the offices of a few Senators while in town. We are working to support a broad coalition call for adequate research funding and are planning to support joint letters. Expect more news on this soon!

Mindy Interview

Mindy Uhrlaub just had a in depth interview published on the ALS focused "I'm Dying To Tell You" podcast - listen to it here!

Care

The first dedicated at risk genetic ALS and FTD clinic recognized by End the Legacy as a center for our community is continuing at Temple Neurology. We are in talks to bring this method of care at sites across the country. If you are interested in this effort email us at info@endthelegacy.org

Research

Advising CDC

We cheer the addition of the at risk community as a nexus of the CDC ALS Registry. We have provided vital input in early stages and are currently gathering community feedback at our next community meetings the 2nd week of March.

Adding Studies

Our recruiting studies section has a few new studies: Everything ALS has a remote study, and ALL ALS has more prevent sites activated in the US.

Survey Planning

We have a dedicated team working hard to develop a survey to gauge community input on the new monitoring guidance. Cheers to Daniel, Jary, Wanda, Cassandra, Mindy and Nadia for your hard work! Look for more on this in the coming months.

Member Spotlight - Bill , interviewed by Mindy Uhrlaub

1. What is your connection to Familial ALS/FTD?

My story begins when I was twenty years old. I was the seventh of eight kids. Around age 65, after his limp would not improve, my dad told us that he had been diagnosed with ALS. This news made us anxious because his dad had died of what we thought was ALS as well. There was no other history of ALS in the family. He died on September 30, 1987, when he was 67. We discussed this obvious connection with his neurologist who told us that Dad had sporadic ALS and that his connection to his dad was a freak of nature; really bad luck.

Believing that Dad’s case was sporadic, all the kids continued to live our lives as we planned. Personally, I questioned the assessment that the coincidence was sporadic, so I saw a neurologist about every five years. My birth order gave me peace of mind. My older siblings were likely to develop ALS before I would, and I could rest easy if none of them developed ALS.

In early 2016, my sister began exhibiting forgetfulness and showing a significant cognitive decline. She was diagnosed by her family doctor with Alzheimer’s. Her condition continued to deteriorate, and without knowing that there might be a family history, the Hospice caretaker said that her late symptoms resembled ALS. This was unusual, I thought, because she did not have ALS. Whew! She died on December 14, 2019, at age 71.

All changed in July 2020, after my older brother gave me a call in the evening. We talked business for a little and at the conclusion of the call, he said he had something else to mention. He then told me that he had ALS and that the gene mutation identified was C9orf72. My mind was blown and overwhelmed! What is C9orf72? I went straight to Google for the answers and dreaded the result I found.

I contacted my General Practitioner for a referral to an ALS specialist. She referred me to an ALS Neurologist in Charlotte, NC, who ordered a genetic test. Four weeks later, I received a phone call from the doctor. I was positive for the same thing as my brother, and presumably, as my father and grandfather! The weight of the world rested on my shoulders. How do I tell my kids? What do I tell my grandkids? How do I plan?

I first told my oldest son that his uncle had ALS. Within 24 hours, he put the connection together that ALS ran in the family and he asked about me. I told him I was positive for C9. I stressed that with the explosion of research, a cure was likely to be found before he’d be at risk. I then told my daughter. She works in the medical field and immediately put the connection together. ALS ran in

the family, and I had the defect. She knew she had a 50/50 chance, and if she tested positive, her kids each had a 50% chance. I told my other two sons who soon understood that they were at risk.

I then received an email from my brother-in-law in Namibia, telling me that my sister had been acting very strangely and needed full-time care. She was diagnosed with Alzheimer's and soon was institutionalized in a great facility in Swakopmund. I made plans to visit before she passed. I posed the C9 connection to her caretakers, but the concern never materialized, and she never received any genetic testing. However, I'm certain that it was bvFTD that took her life on August 1, 2023, at age 75.

Of the eight children who are at risk, four tested negative for the C9 repeat, two are certain positive for the C9 repeat, and two were never tested and presumed positive for C9.

2. How does knowing your genetic status affect you?

I'm 60 years old and know that the average age of disease onset is 58 in the United States. Penetrance is the question with which I wrestle. What is my likelihood of developing ALS or FTD? My neurologist says it's 100%. I've taken this knowledge to plan for my significant care by purchasing property that adjoins my daughter's property to assist my wife with care if and when needed.

Coping with this is critical. It could easily drive me crazy, but my Christian faith anchors me. As a Christian, I am not my own, but given to Christ. My body is His to do with as He pleases. I accept His plan because He has changed my life and made me a new creation.

3. Short of a cure, what is your hope for people impacted by Genetic FTD/ALS?

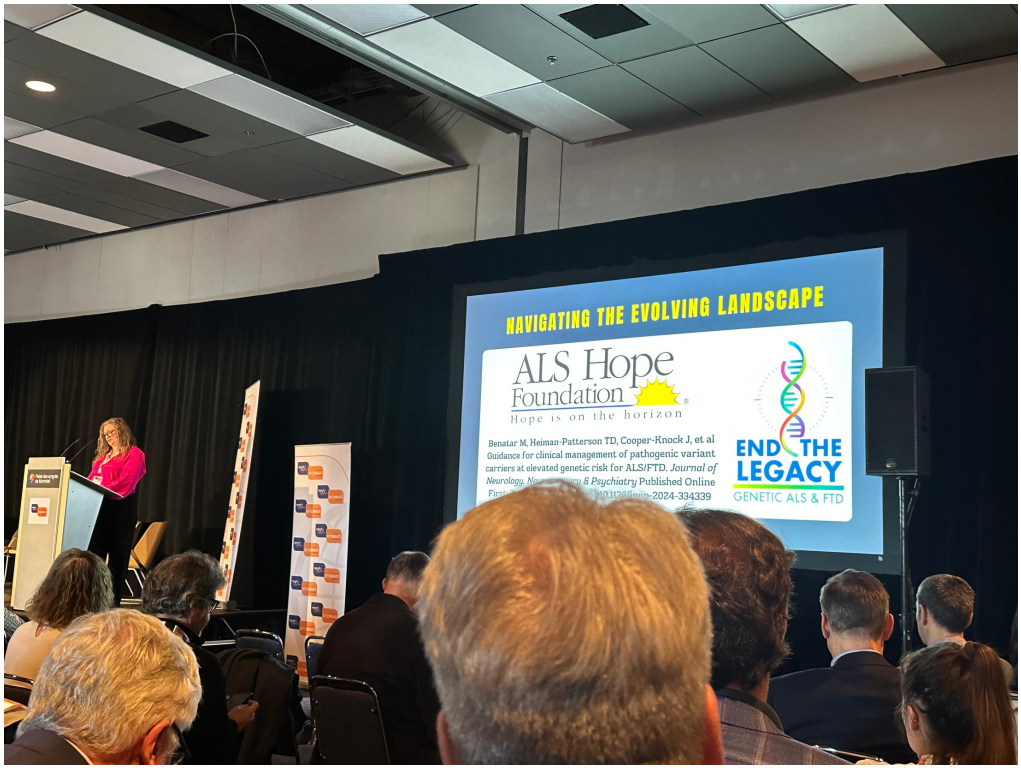
I appreciate the value of End the Legacy, advocating for those at risk for genetic ALS and FTD. Having our voices heard is important to the medical community, pharmaceutical community, research community, regulatory community and legislative community.

Eliminating insurance discrimination in the United States is important to me and I often assist in efforts to outlaw genetic discrimination. We were successful in introducing South Carolina House Bill 4218 last term that would outlaw genetic discrimination in the purchase of life, disability and long-term care insurance policies. Although it did not pass, we hope that we can make more progress in the future.

4. Tell us a fun fact about yourself.

Interestingly, antagonists of C9 patients say that we should not hold responsible professions like airplane pilot or air traffic controller. I'm proud to say that I am a pilot and former plane owner. Some of my greatest joys were in the cockpit of an airplane where I volunteered my time and plane to ferry patients to treatment centers who could not afford the transport for medical care at no cost to them.

Newsletter images





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