Fall Newsletter & Winter Appeal and 2025 Review

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Director's Letter

Dear End the Legacy Community Members and Supporters:

This fall has been an eventful one for the movement for those at genetic risk of ALS and FTD. From our first in person meeting in Australia attended by 20 impacted individuals and expertly facilitated by volunteers Paige, Assunta and Sharon to a successful weekend of community at the 2025 Alliance Meeting in Toronto our movement continues to grow and make an impact. For the first time those at risk in France had the chance to meet with others in an organized fashion facilitated by our amazing bilingual volunteer Emma and a steering committee is forming there. I was privileged to give presentations at NEALS in October and at the Alliance meeting yesterday. Cassandra shared a poster at NEALS and will be doing a new one at the Symposium in San Diego later this week. It is with amazement I can share 5 Centers of At Risk Care have debuted in the United States in just the last few months with more coming. And we have so much planned for 2026. Scroll down to see more about this amazing work. And congratulate our friend Mindy on her continued successful book launch, spreading the carrier experience far and wide. She also conducted a member spotlight interview with Alyssa below our updates. Finally we want to thank the amazing Linde for her time serving on our leadership board. She is staying involved and we cheer her efforts with us and elsewhere with CureMAPT.

As we empower genetic advocates around the world and ensure care is available we need your support to keep this movement thriving. This giving Tuesday your donations will be matched 2 for 1, making a triple impact for every dollar donated. Support End the Legacy here.

Member Spotlight Alyssa, interviewed by Mindy Uhrlaub

1. What is your connection to ALS/FTD?

My connection to this journey is deep. It began with my grandfather, Tom Nash Sr., who passed away from ALS in 2014. He struggled for many years, but his official diagnosis came when the disease was already advanced. The full name for what we were experiencing came in 2015, with my father, Tom Nash Jr.'s, official diagnosis of FTD. We were navigating the changes in my dad while simultaneously watching my grandfather's battle. For those in this community, you know

that the struggle begins years before the dates on a diagnosis or death certificate. Because of this, I genuinely don't have a stretch of time in my life without ALS/FTD. In 2016, a year after my high-school graduation and my father’s diagnosis, at the age of 20, I found out I carry the same C9orf72 gene.

2. When it comes to ALS/FTD, what are you most hopeful about, and what frustrates you the most?

I am most hopeful about the accelerating pace of research and the advancements that are happening. Being a part of the ALLFTD research study since 2016 has become a lifeline for me—I am grateful to still be asymptomatic. What frustrates me the most is the damage this disease has inflicted on my family and myself, particularly the agonizing, slow process of it taking my father. This frustration is often coupled with the fear that still lingers for my own future. While the list of frustrations can feel endless, I firmly believe hope is the stronger force.

3. Can you please tell us something about you that we don't already know?

I have the ability to use both the creative and analytical sides of my brain. I originally entered college planning to double major in Art and Chemistry, but the two worlds didn't mesh well—my lab and studio times conflicted. I had to shift Chemistry to a minor. Though life interfered with my studies, I absolutely intend to finish in the future. In the meantime, I am a practicing artist who perhaps analyzes her pieces a little too much! Most recently, I completed a pretty massive project: I was the artist for the Pets of FTD Calendar 2026 in collaboration with Go-Mo Creatives. Keep an eye out, it's coming very soon!

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Community Support

Online Connection

Two Regular Offerings:
Community Team Meetings
Monthly Peer Support

Hundreds of individuals served

2025 French Meeting
2025 Innovation

In-Person Summits

Our 2nd Annual North American Summit in June 2025 in Philadelphia, PA with **ALS Hope** saw an 80% growth in impacted attendees from 40-72.

2025 Innovation The Pacific Region Meeting in Melbourne, Australia with 20 impacted attendees was hosted with the help of **Racing For MNDi**, a local genetic MND research funder.

Before End the Legacy there was:

- No way for community members to meet in organized spaces
- No dedicated in person gatherings for our community



"As a genetic ALS/FTD carrier I often felt alone. The people I meet through the peer support hour really understand me. As a volunteer peer facilitator, I take pains to make sure that everyone is heard."

Mindy's book detailing her story is available now and taking the world by storm! Visit mindyuhrlaub.com to learn more.

Importance of Funding

Every $200 will pay for a month of online connection.
Every $700 will provide for the costs of an in-person summit attendee.

Melbourne Summit Leaders



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Education

Webinars by the Numbers

1 French webinar

4 webinars for a genetic ALS and FTD audience to date with a **5th** planned for November.

2025 Innovation

AI translation captions in **5** languages all available for free on YouTube.

367 attendees averaging **91** people for each webinar.

1500 views of our 2025 videos on YouTube.



Webinar with Richard Bedlack, MD, PhD

Website

Endthelegacy.org

Our website is a dedicated source of important information for the inherited ALS and FTD community. In 2025 over 4,000 unique visitors accessed our web-based resources.

Before *End the Legacy,* no information dedicated exclusively to those impacted by Genetic ALS & FTD was openly accessible. When webinars on ALS or FTD were held, genetic community members would have to derail conversations into the myriad ways science topics only touch those impacted by genetics.

Importance of Funding

Every $500 donated will provide transcription and subtitle translation into multiple languages for educational webinars.

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Research

By the Numbers

1 fellowship funded

2 Papers published in top journals with ETL ED Jean Swidler as co-author

2 posters accepted with original findings

714 Visitors to our Recruiting Studies webpage in 2025

The Fellowship *2025 Innovation*



A fellowship was awarded to Dr Soto-Albrecht, an MD-Phd Candidate at Penn with a connection to C9orf72.

Other Highlights

Before *End the Legacy*, there was:

- no way for those at risk to easily find what research was available for them to participate in.
- no organized voice for the at risk community in research settings.

Importance of Funding

$500 pays for an average cost of conference registration for a genetic Advocate.



Cassandra Haddad, CRNP Presenting our poster on the risks of informant dyads at the NEALS annual meeting.

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Advocacy

Coalition ALS org letter urging approval of ALLFTD by NIH

ALLFTD was approved one month after the letter was delivered, following several months of delay.



Subject: ALLFTD Renewal 17 July 2025

To:Richard Hodes, MD, Director of the National Institute on Aging
Walter Koroshetz, MD, Director of the National Institute of Neurological Disorders and Stroke
National Institutes of Health, 9000 Rockville Pike, Bethesda, MD 20892

We are advocates for those impacted by the terminal and devastating condition Amyotrophic Lateral Sclerosis (ALS, also known in the United States as Lou Gehrig's disease). This disease is in desperate need of research breakthroughs, and there is broad agreement that a promising hope for those breakthroughs will come from studying people impacted by the genetic or inherited forms of the disease.

You regularly hear from us on the vital importance of research studies dedicated specifically to ALS. In this letter, we are letting you know about the importance to our community of a study focused instead on the related disorder of Frontotemporal Degeneration or FTD.

The most common genetic cause of ALS is also the most common genetic cause of FTD. ALLFTD, an ambitious multicenter NIH-funded study of those impacted by this genetic driver of ALS and FTD, has been ongoing for over 5 years and is currently under consideration for renewal by your centers. This study has hundreds of carriers of the gene mutation in question who may develop ALS or FTD, and the continued categorization of their biology over time is essential to continue to make breakthroughs in these linked diseases.

Genetic ALS & FTD: End the Legacy Executive Director Jean Swidler shares this message: "My family has had multiple people die from C9orf72 associated ALS in each of the generations before mine. As a public carrier of the C9orf72 expansion I know I face a great likelihood of developing either ALS or FTD or both. The continued development of the ALLFTD genetic cohort through continued funding by the NIH is an important tool for all impacted by these diseases but especially the many of us at risk for C9orf72 disease."

We call on you to fund this study and further propel ALS and FTD research for the many suffering now and the countless destined to suffer in the future if promising scientific research is not funded.

Sincerely,

Genetic ALS & FTD: End the Legacy
ALS Hope Foundation
ALS Strategy Consulting
ALS United
ALS Association
ALS United Greater New York
Les Turner ALS Foundation
I AM ALS
ALS Network

Other Highlights

- Hill visits
- ACT for ALS push
- Genetic discrimination pushes: Bill Musick has taken the fight for simple protections for genetic information to legislators in both Nebraska and South Carolina testifying in both state legislative bodies.
- Before *End the Legacy*, the needs of our communities were invisible in policy discussions.



John William Musick, *Patient Advocate*



Policy meeting with Senator Schiff

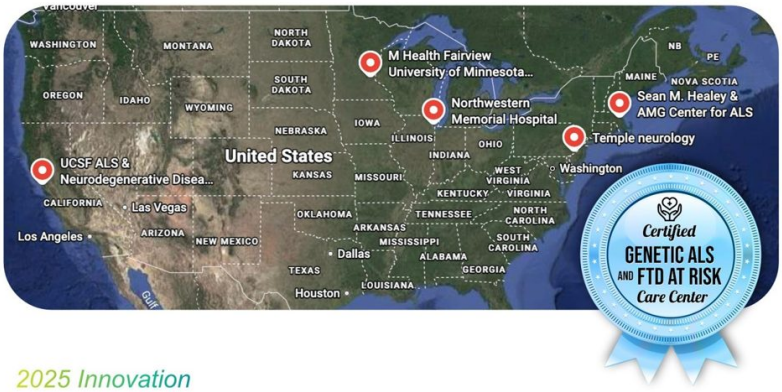
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Care

5 total recognized care centers across the US

1 care survey prepped to understand community desires



Temple Neurology, Philadelphia, PA

UCSF - Northern California

Northwestern Medicine, Chicago, IL

Massachusetts General, Boston MA

University of Minnesota

Your support can make this map light up with care available across the world wherever carriers are.

2025 Innovation

Genetic Counseling Education - non medical, free time with a genetic counselor learning about genetic counseling and why people engage in it.



Cassandra Haddad, CRNP

End the Legacy Vice Chair, Temple Neurology At Risk Care Clinic

"Presymptomatic care means walking beside people long before symptoms begin—monitoring biomarkers and physical changes over time by establishing a baseline for each individual, offering guidance and resources, and connecting families with research and community support. It's proactive, compassionate medicine designed to replace fear with knowledge and isolation with belonging.

Providing this kind of care is the most meaningful work of my life. Building the first clinic dedicated to individuals and families at genetic risk for ALS and FTD brought together everything I've learned as a clinician and everything I've lived as a family member. It's a privilege to have carried my advocacy into clinical care—turning purpose into practice. We're proud to be pioneering this movement as more clinics join us in providing this care, and to stand beside people who face unimaginable challenges with courage and grace, ensuring they never have to do it alone."

An important part of at risk care is knowing the practicalities of having risk in your medical record. A genetic counselor is best to educate on those risks. We offer genetic counseling education for free time with a genetic counselor to learn about the importance of genetic counseling.

Importance of Funding

Every $500 unlocks 1/10th of a care grant to recognize at risk care centers.

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2026 Planning

Stay tuned for these exciting initiatives planned for 2026:

- Further international specific meetings
- End the Legacy's 3rd Annual Genetic ALS & FTD Community Summit - our largest summit to date - will be held in Sacramento, CA, from September 24–26, 2026, with local host ***ALS Network***.
- More webinars, including some hosted by our new Science Liaison, Dr. Soto-Albrecht.
- Revamped research opportunities web portal with ability to look for gene specific research
- Harness coalitions of adult onset inherited neurodegenerative conditions to push for earlier access in clinical trials through consortia
- Launch of a survey of our community to gauge interest in at-risk care
- International consortia planned to address respectful research in presymptomatic c9orf72
- Further development of care guidance, including the spread of at-risk care, creation of teaching materials, and funding of a trainer position.

2nd Annual Community Summit



Newsletter images

