

# YEAR TO DATE REVIEW REPORT

Updated November 2025

# 2025



## END THE LEGACY

GENETIC ALS & FTD

*Prepared by:*

Genetic ALS & FTD:  
End the Legacy





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Philadelphia/North American Summit Planning Committee







## Director's Letter

Dear End the Legacy Community Members and Supporters:

When I look through all our team of dedicated volunteers has accomplished in our short time together I am overcome with admiration and pride. To see where our community stood prior to our founding, and what has been made manifest now and is planned for the future is to see a world turned upside down. It is not often any one organization can spark a movement and change the nature of not one but two diseases as we all have done together. Of course underscoring all we do is the ever present feeling of loss for the family members that have been cruelly taken from us by ALS or FTD, and we hold them in our hearts while we push for better outcomes for us all.

Whether it is in provisioning resources to our families through support/ education and care, advancing our communities interests through advocacy, or supporting and guiding research touching our communities, End the Legacy is executing and innovating. Your continued financial support is needed to keep this momentum going and I hope you will join me in providing tax-deductible donations to End the Legacy. For a limited time we have the chance to double gifts through a matching campaign. Let's not let this chance pass us by!

In Solidarity,

Jean Swidler

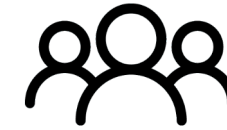
*Executive Director, Genetic ALS & FTD: End the Legacy*

## Community Support

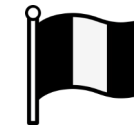
### Online Connection



Two Regular Offerings:  
*Community Team Meetings*  
*Monthly Peer Support*



Hundreds of  
individuals served



2025 French Meeting  
*2025 Innovation*

### In-Person Summits

Our 2<sup>nd</sup> 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](http://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





# Education

## Webinars by the Numbers

**1** French webinar

**4** webinars for a genetic ALS and FTD audience to date with a **5<sup>th</sup>** 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](https://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.

# 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.



# 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.



### 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*



# 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.



# 2026 Planning

Stay tuned for these exciting initiatives planned for 2026:

- Further international specific meetings
- End the Legacy's 3<sup>rd</sup> 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.

2<sup>nd</sup> Annual Community Summit

# Call to Action

**We have the chance to take every dollar raised in this appeal and double it from the support of generous anonymous donors. Up to \$20,000 raised for End the Legacy services will be matched dollar for dollar in this end of year push. For our relatives lost too soon, and for those of us who are healthy but at great risk let's work together to end this legacy.**

**Return the enclosed envelope, visit [bit.ly/ETLgive](https://bit.ly/ETLgive) or scan the QR code below.**







**END THE  
LEGACY**  
GENETIC ALS & FTD

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