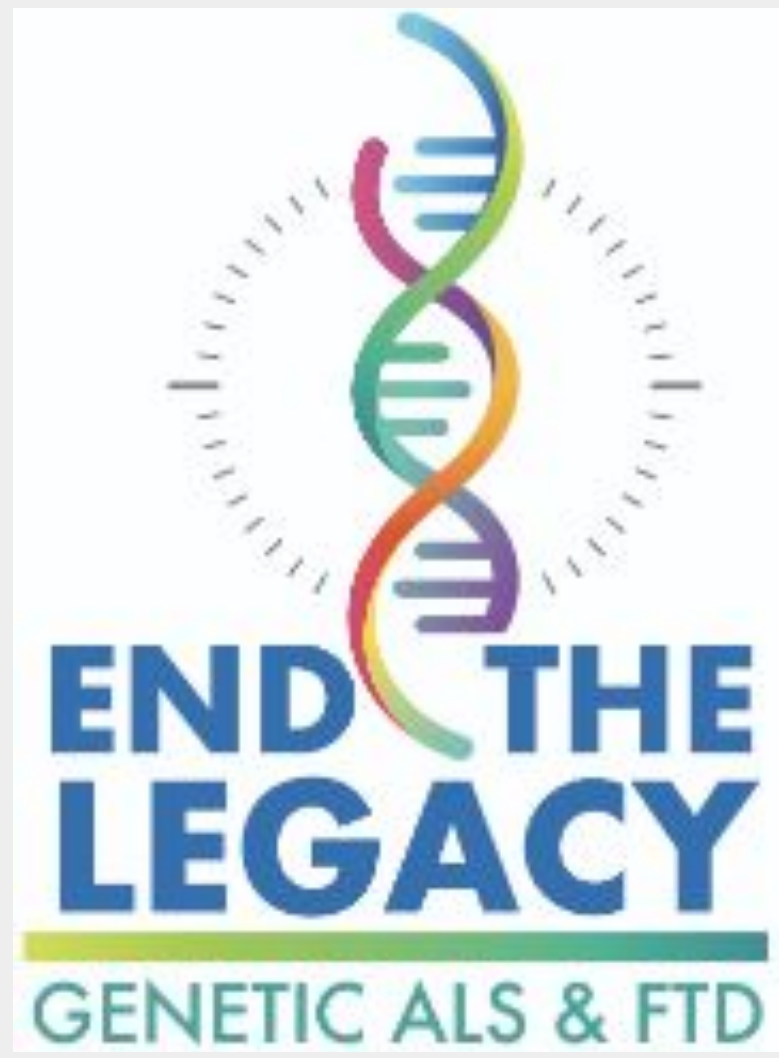


Genetic ALS & FTD: End the Legacy, An Introduction

ETL - By the Numbers

Leadership		Jean Swidler, Chair Cassandra Haddad, Vice Chair Terry Heiman-Patterson Karen Kornbluh Linde Jacobs
Board	5	
Core Volunteers / Supporters	25 / 104	Sod1 C9orf72 MAPT GRN TARDBP CHCCHC Unknown
Newsletter + Social Media	1600	Many in scientific and industry fields.



Our Mission Statement

*The Genetic ALS & FTD community is large and growing. ALS & FTD are terminal conditions, and being at a heightened risk for them can have profound impacts on people and families. **We organized Genetic ALS & FTD: End the Legacy to provide educational and support resources to, encourage and promote research about, and advocate for the genetic ALS & FTD community.***

Our Impact on our Members

Here are results of a survey of 33 of our most active members in 2023.

Confirmed Asymptomatic Mutation Carrier/ At Risk / Loved One / Symptomatic Carrier	55% / 9% / 24% / 10%
Increased Feeling of Overall Well Being	76%
Increased Optimism When Considering Risk	70%
More Likely To Participate in Research	64%

How we will transform these diseases:

Many people impacted by Genetic ALS & FTD want nothing to do with thinking or talking about the subject. We believe that providing a way for our communities to plug in, have a voice on the issues that impact them, and access information easily will draw more and more into the discussion. This engaged and empowered community will be enthusiastic research participants, bringing out of the shadows many of those participants who will be needed to best validate pheno-conversion biomarkers, and allow testing of drugs at early disease stages as routinely happens in Alzheimers. This community will also be eager and sympathetic advocates for additional sound research.

What we do

We strive to ensure the voice of the Genetic ALS & FTD community is heard both by the government and the research and clinical fields (calling for increased or better distributed federal dollars is very much a part of this) (advocacy). We link community members to research studies, and conduct community led research when it is needed, for example surveying our peers (research). We bring information on Genetic ALS & FTD back to our community and host webinars on topics of interest (education). We have launched a [peer run support group](#) effort and plan on peer mentoring programs (support). We have further work planned under each of our pillars as well.

Selected Accomplishments

- Jean Swidler appointed Patient Advisor to the Steering Committee for the Critical Path for Rare Neurodegenerative Diseases.
- Team Member Mindy Uhrlaub appointed a Member of the National Academy of Sciences "Making ALS Livable" committee.
- FDA Patient Listening Session for the Pre-Diagnosis Genetic ALS & FTD Community resulted in FDA approval of [written summary](#), linked on the FDA's website. Posted [public re-creation](#) of the private Listening Session
- Jean Swidler's "Abstract on C9 Estimates", advised by Dr. Al-Chalabi, accepted for 2022 ALS MND Symposium abstract published in the journal [Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration](#)
- Helped shape the NIH ALS Strategic Plan by first engaging with the NIH to change the stakeholders for the plan that was first announced from "ALS Patients and caregivers" to one that included ALS Genetic carriers. We engaged our community to help nominate Jean to the Quality of Life Working Group, and their continued engagement ensured many community members participated in the Public Workshop in October.

- Semi-regular research webinars for the Genetic ALS & FTD Community: Dr. Aaron Gitler, Dr. Matt Disney, Dr. Claire Clelland, Dr. Martina Borchetta, Scribe Therapeutics, Professor Guillaume Hautbergue, Katie Irwin the first author on the Cryptic Exon in C9, Dr Matthew Kiernan, and others.
- [Youtube](#), presence, hosting recorded webinars
- [Letter the Editor](#) published in the Journal Brain

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Email us geneticalsftd@gmail.com

Our very [bare bones website](#), we are revamping this.