

Who We Are

Founded in 2023, Genetic ALS & FTD: End the Legacy is a patient-led organization dedicated to addressing the unique needs and interests of individuals and families affected by genetic Amyotrophic Lateral Sclerosis (ALS) and Frontotemporal Dementia (FTD). Our mission is to provide educational resources, support, and advocacy to empower our community. We work in partnership with our fiscal sponsor the ALS Hope Foundation.

Our Mission

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 Programs



Research: We connect community members with research studies and emphasize the importance of participation. We also initiate patient-led research to address questions pertinent to our community.



Education: We ensure our community has access to up-to-date information on relevant issues, empowering individuals with knowledge.



Community Support: Recognizing the importance of connection, we offer robust support resources so that no one faces these challenges alone.



Advocacy: We amplify the unique perspectives of those affected by genetic ALS and FTD, ensuring our community's voice is heard in discussions with researchers, industry, and government.



Care: We strive to ensure our community members have access to care related to their risk if they desire it in line with expert guidance.

Get Involved

We invite you to join us in our mission to end the legacy of genetic ALS and FTD. Whether through participation in research, attending events, funding the work, or utilizing our resources, your involvement makes a difference.

Contact Us

For more information, support, or to get involved, please reach out to us:



info@endthelegacy.org

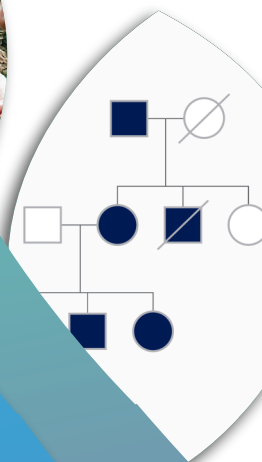


endthelegacy.org



**END THE
LEGACY**
GENETIC ALS & FTD

Empowering the
Genetic ALS & FTD
Community



Together, we can end the legacy of genetic ALS and FTD

ALS Hope
Foundation
Hope is on the horizon