End the Legacy's Summer 2025 Newsletter

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Notes from the ED

What a summer! While so many of our families are dealing with back to school lets spend a few minutes together in this report reviewing the past few months in the movement for those impacted by genetic or inherited ALS and FTD. So many advocates are raising their voices to share a bit about what living with the risk of ALS and FTD is like, please consider reading these well written efforts! Read their stories linked below.

This weekend a group of 20 (our registration goal!) impacted people will be gathering in Melbourne Australia for the first Pacific Region Genetic MND and FTD community summit. As a small organization bottomlining this event was a lift, but with dedicated community volunteers it is a go! Read about them below. And of course we are still amazed at the great summit we held in the US in June. Finally another interview of a community member will round out this update.

In this brief note I want to again celebrate the amazing achievements of some of our co-founders - the author Mindy Uhrlaub has continued to spread awareness and community in her book tour events for her very well received memoir. The advocate and pharmaceutical industry worker Daniel Barvin was bestowed with the title of “ALS Hero” by the ALS Association at their recent ALS Nexus event. Cheers to both Daniel and Mindy! You inspire us all.

JS

Mission Areas: Education & Support

We are so proud to report our 2025 North American Summit was a success! Many thanks to the planning committee, speakers and sponsors. Over three days many powerful connections were made among over 70 participants impacted by genetic ALS and FTD.

As the feedback makes clear these gatherings are serving a real need.

Pacific Region Summit - We are so thrilled we could make a first gathering happen in Australia this coming weekend! With dedicated intent from volunteers Assunta, Sharon and Paige this event really came together. Stay tuned for the post event report!

Images from the program

French Community Team First Online Meeting - September 25th
With the support of dedicated researchers we are gathering a french speaking community team. We have had a great response. Cheers to volunteers Emma and Neil who have done a lot to prepare for this event!

Mission Area: Advocacy

ALLFTD Support

For those who haven't heard, approval of NIH grants has become mired in strange delays with the new administration. That has unfortunately stopped up the renewal grant for the large multicenter ALLFTD study, which has a very large cohort of people at genetic risk for FTD. We signed an AFTD letter asking for these studies to be approved for FTD a few months ago. But as an ALS and FTD focused organization with many genetic communities under our banner being responsible for both diseases, we knew this study held importance for the ALS community. So we organized a joint letter from many prominent ALS focused organizations on the studies' importance for the ALS community. There has still been no word on the studies approval.

Policy Training
To ensure we have a voice with legislators to ensure science policy and other areas of government meet the needs of our community we had our policy advisor Tim Bergreen provide an insightful training on how to meet with a legislator in our August community meeting. Thank you to Tim! Key areas we need to push with legislators in the United States include:
1) Funding for scientific research - small scale - approve the ALLFTD study renewal - Medium Scale - the Act For ALS Renewal Large Scale - Keep Scientific Funding Strong (the current executive admin is asking congress to cut research funding in half).
2) Genetic Non Discrimination - we need congressional champions to introduce legislation to match laws like Florida's where genetic testing non-discrimination protections have been added for long term care, disability, and life insurances
3) Joining the ALS caucus (this is a group of legislators that are first to respond to requests from the als community).

Speaking up for the rights of Genetic Communities
End the Legacy co-founder Bill spoke to a crowd at the GeneDX conference on a panel about Genetic Non Discrimination - go Bill!

Mission Area: Research

FUS ASO
We were proud to play a part in bringing the story of the dosing of nearly asymptomatic FUS carrier to the wider world with the appearance of Jeff Viestra, PhD at our Summit. His profile was revealed in this Stat News Article: His dosing in a compassionate use context was documented in this paper. We applaud the team at Columbia for innovating in this space. Of note the full controlled trial for this ASO recently completed enrollment. We eagerly await news of results. In the meantime we are reviewing the statement from the companies about this development.

C9orf72 Prevention Trials
We were proud that our Executive Director Jean Swidler was able to participate in the 2024 workshop on designing C9orf72 prevention trials hosted by the ALS Association and the AFTD. The real work of this project was in drafting the report which was recently accepted by a top journal and which required a knowledgeable impacted patient advocate to be involved to spot many items of great importance to those impacted by C9orf72. You can read the accepted but not yet fully proofed manuscript here:

One key permission the report provided is the possibility today of non-pivotal cohorts of asymptomatic c9orf72 carriers in larget trials based on the effect in a symptomatic cohort. We

wrote about this important issue for the whole field of ALS and FTD drug research here.

Member Spotlight Interview - Kelsey, interviewed by Mindy Uhrlaub

1. What is your connection to ALS/FTD?

I am a carrier of the C9orf72 gene mutation, which was passed down from my mom who has semantic variant PPA FTD. This unusual manifestation of the C9 gene (which is typically the behavioral variant for those who get FTD) shows us that we still have so much to learn. My grandmother probably carried the gene as well. She was diagnosed as schizophrenic in her late 30s and then lived for another 30 years in a care home.

2. What makes you nervous about the future as a genetic carrier?

By far the worst part about finding out that I am a genetic carrier is the possibility that either, or both, of my beautiful children may inherit the gene. The rest of my life will be spent fighting for a cure so that one day I may say, "it doesn't matter". Cuts to funding for ALS and FTD research in the US also delay our future treatments, which is a great setback.

3. What makes you excited about the future as a genetic carrier?

Many things! Big pharma is starting to turn its eyes increasingly towards neurodegenerative diseases. New technologies like ASOs and CRISPR offer hope for gene-targeted drugs. Physician scientists, like Claire Clelland, work tirelessly on breakthrough drugs in ALS and FTD. Above all, we need advocacy to amplify patient voices, make ourselves heard to policymakers and the public, and fight for resources to be funneled into treatment avenues for us. End The Legacy brings me this hope because we are a team, we work hard, and we will get there!

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

I am quite sure this probably does not fall under "something we don't already know," but my passion is definitely distance running!! I am an ultra-marathoner and have raced up to 50 miles. My next race is a road marathon, Avenue of the Giants, through beautiful redwood trees.

Recommended Links

A touching essay by community member Brooke was hosted by the AFTD : https://www.theaftd.org/posts/help-and-hope/gf-familial-ftd-b-teweles/

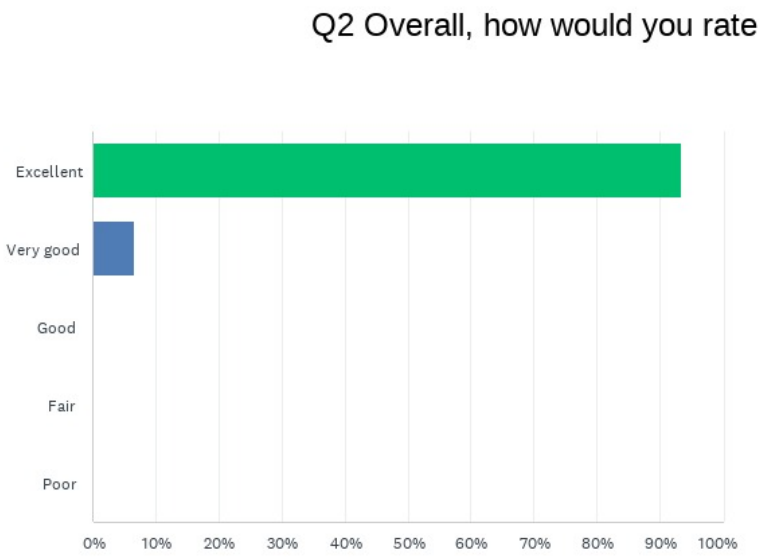
Read about Mindy's book and her book tour: https://www.mindyuhrlaub.com/

Learn more about Daniel's ALS Hero award https://www.als.org/blog/2025-als-hero-daniel-barvin

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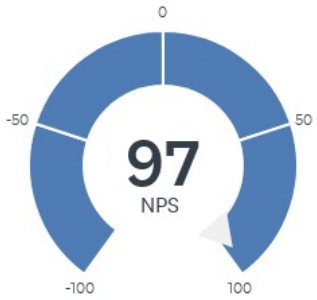


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Q1 How likely is it that you would recommend an End the Legacy community summit to a friend or colleague?



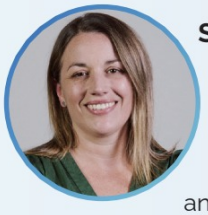
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PLANNING COMMITTEE



Assunta

Assunta founded Racing for MNDi after losing several family members to MND. Driven by this personal loss, she has dedicated her time to supporting research in the hope that fewer families will have to endure the same heartbreak. Beyond her advocacy, Assunta finds time to appreciate her love of art and treasures time spent with her partner and two sons.



Sharon

MND has impacted my family and may one day impact me – but until then there is hope, education, advocacy and the wonders of the scientific community that may save us. I am here for the journey and to share these values and perspectives with others.



Paige

As a genetic carrier from a family impacted by MND, I work to connect our community with research and contribute to national and international projects improving support and guidelines.

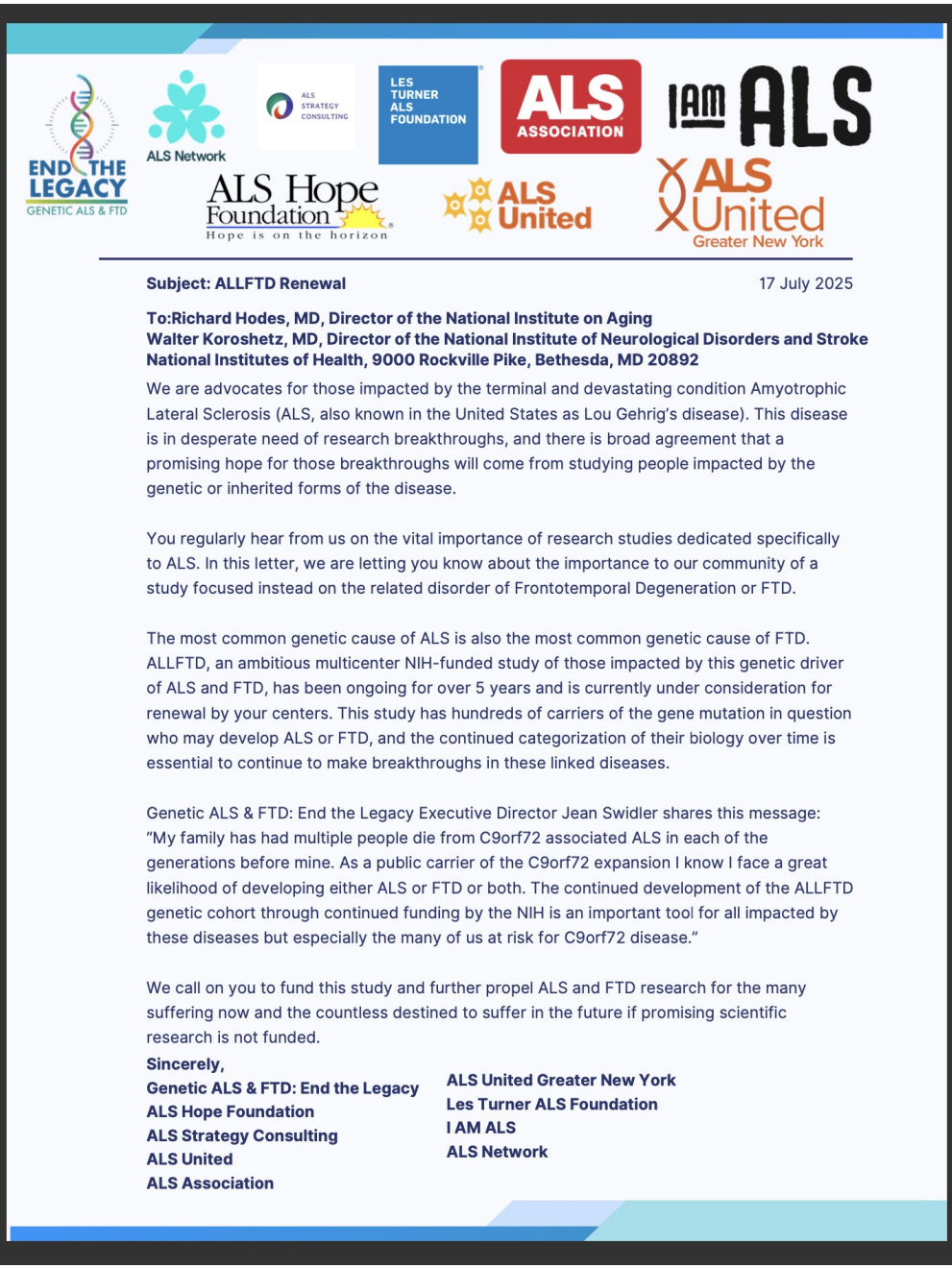
Jean

After witnessing her grandmother, mother, aunt and uncle die from C9orf72 ALS , Jean used her skills as a trade union organizer to help found Genetic ALS & FTD: End the Legacy and was appointed it's first Executive Director.

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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

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