2025-2026 Winter Newsletter

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Director's Letter

Dear End the Legacy Community Members and Supporters:

As I reviewed the last weeks of 2025 and the start of 2026, I am so impressed with the ability of those in our community to get things done. The amazing Dr. Yentli Soto Albrecht's educational series, Search for a Self Cure, and her ambitious research fundraiser, Pushups for ALS, are transforming our community.

The hard work of many End the Legacy volunteers—including Jary, Daniel, Mindy, Wanda, Kerri, Cassandra, Kelsey, and others—has resulted in our At-Risk Care Survey, which is now open. If you are at risk for inherited ALS or FTD, we hope you will take it here.

With our friends at ALS Network, and their representative Dr. Sarah Dougherty, along with a team of volunteer planning committee members, much work is being done to plan for our September Genetic ALS & FTD Community Summit. Registration will open later this month.

In Europe, we have been thrilled to welcome Emma Bouche as our new European Officer, where she is leading European community-building efforts in both French and English.

All of this has been made possible by the successful raising of needed funds, which our community knocked out of the park during our end-of-year appeal, meeting its goal late last year. Together, we can do much.

Mindy interviewed C9 ALS patient Tina Johnson, and her story is powerful. We are glad she found us. Also included are links to other groups, events, and articles we think you may appreciate.

In solidarity,
Jean Swidler
Genetic ALS & FTD End the Legacy

Research
Our inaugural Community Science Liaison, Dr. Soto Albrecht, has attended a number of prestigious academic meetings on the diseases that impact our families with support from End the Legacy. At the Gordon Meeting on FTD Research, she shared a poster on the work of End the Legacy.

At the 2025 ALS/MND Symposium in San Diego, the genetic community had a strong showing, including our own Cassandra Haddad presenting a poster on End the Legacy summits.

On April 8, the Lancaster, Pennsylvania community will be celebrating the life of long-time teacher Brother Frank Albrecht, father of Dr. Soto Albrecht, who died of C9orf72 ALS in 2024. A "Pushups for ALS" challenge will be conducted, raising money for familial ALS and FTD research. You can participate on-site or virtually. Join in and help make this vital fundraiser a success! Learn more and donate here.

We also celebrated the participation of gene-negative siblings in genetic ALS and FTD families as controls in natural history research. We celebrate all who participate, but especially recognize the amazing Maureen!

Advocacy
Ensuring our community's views are heard on important issues is vital to our mission, and we were proud to represent those views in discussions at the biannual Compassionate Use and Preapproval Access Conference.

End the Legacy, with support from our Policy Advisor Tim Bergreen, was proud to push the importance of the ALL ALS / Prevent ALS natural history study in negotiations regarding the reintroduction of the Act for ALS. ALS research needs a well-funded push from the federal budget, and 2027 requests are being finalized now. Join the joint letter from the ALS community, including End the Legacy, in requesting robust ALS research funding from your federal representatives.

Genetic nondiscrimination continues to be a priority for our movement. Bill continues to push the issue in South Carolina, and recently the Insurance Commissioner for California, Ricardo Lara, in partnership with Assemblymember Wilson, has introduced model anti-genetic discrimination legislation. Stay tuned for ways you can help these efforts.

Education

While attending scientific meetings, Dr. Soto Albrecht conducted interviews with many top ALS researchers to help bring their work back to our community, along with other updates, in a new Search for a Self Cure series of videos and blog posts. See the latest and past episodes here. We extend sincere thanks to all working on the series, including ETL member Brooke.

We are excited to have introduced a new way to provide genetic counseling education. Our Genetic Counselor, Shannon Therese Terek, has already conducted two small-group education sessions for a genetic ALS and FTD audience, with a third scheduled for April. Secure one of the few remaining spots here.

In December, Professor Jenna Gregory of the UK presented her lab's work on biomarkers for ALS, and a recording of the webinar with translated subtitles was released last month. See it here.

Care
What we feel passionately about is that those at risk for genetic ALS and FTD should be able to receive care for their own medical benefit related to this risk, if they choose, in line with expert guidance. However, many details are still being worked out. And do you know whose opinion on

this matters? Yours.

To ensure the community perspective on this issue is understood, a survey was developed by committed volunteers, with feedback from over 40 key opinion leaders in ALS and FTD to make it as responsive as possible. That survey is available at this link, and we hope you will take it and share it with others. It is anonymous, so please only take it once.

The results of the survey will be presented at an upcoming meeting hosted by Drs. Heiman-Patterson and Benatar to further refine the Guidance for Carriers that emerged from the first meeting on this topic in 2023. End the Legacy is proud to sponsor and participate in these deliberations.

Support

Our 3rd Annual North American Genetic ALS and FTD Community Summit will be held in Sacramento, California, on September 24–26. Our volunteer planning committee has been working hard to finalize the agenda, iron out details, and invite speakers. Registration and initial agenda highlights are coming later this month. Registration is capped at 100, so be sure to register early.
Our monthly Peer Support Hour and our biweekly Community Team Meetings have continued and welcomed many new participants.

In Europe, Emma has led the formation of a French Community Team, which has conducted three successful experience-sharing sessions in 2026, as well as a first community team meeting last week. A first English Community Team Meeting was held in January, with a second scheduled for April 2 at 7 PM UK time. If you would like to join the French or European English community team lists, please email us at info@endthelegacy.org.

Member Spotlight Tina Johnson, interviewed by Mindy Uhrlaub

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What is your connection to ALS/FTD?

My uncle, Ronnie Winters, was like a second father to me and he worked for many years at 3M. One day, he noticed he could not sign a paper. He was diagnosed with ALS. I saw him periodically as he declined, walking with a cane, then in a wheelchair, and having difficulty eating. Six months later, I was there in the hospice room when he took his last breath. Never did I think I would get diagnosed with the same terminal disease. The shock of the diagnosis had my mind going everywhere.

When I first Googled “slower and slurred speech,” which was my first symptom, I read that dysarthria stemmed from various neurological diseases, like stroke, brain injury, MS, Lyme disease, Parkinson's, or ALS. I was calling doctors and going to the urgent care and the emergency room because I knew something wasn't right. My family doctor saw me, and he noticed my speech and ordered an MRI of my brain and spine. The results were inconclusive. He told me to make an appointment with a neurologist, but the earliest appointment was approximately ten months out. By that time, my left hand was weak, and swallowing food

became more difficult.

The words, "There is no way to say this, but I think this is ALS. There is a test to confirm, called an EMG…" will forever be engraved in my mind. The end result was that I had both upper and lower motor neuron ALS. By this time, I was searching for documentaries on ALS. I found Steve Gleason and Brian Wallach. Deep down, I did not want to believe it, but I knew. Then, after genetic counseling, the test came back positive for the C9 gene.

If you could change anything about the way genetic carriers (patients) of FTD/ALS were treated, what would it be?

My change would be a swifter diagnosis. This could be attained by having more access to practicing neurologists, so patients don't have to wait so long to see them. Also, knowing my uncle passed away from ALS, I wish someone would have told me to get genetic counseling when I was in my college years. I have an aunt on my paternal side who is living with MS, so that always concerned me. But I always thought I would get breast cancer instead, since both my maternal and paternal grandmothers had that. I started getting mammograms when I turned 30. I have always been focused on my health and wellness. Working out was another passion of mine throughout my life, especially after I had a miscarriage. Speaking and writing were also strengths for me, but my C9 ALS diagnosis has terrified me in every way.

What gives you a sense of purpose, even with C9 disease?

All my adult life, I have loved helping others, especially when I'm mentoring paralegals or doing health and wellness coaching. I know that being "present" in life is key; finding joy when all hope is gone. I know I can find joy in each day, but it is very hard. I have my one and only son, Eli, who is my world. I am so sad that I won't get to see him get married, and I'll never hold a grandbaby. My emotions and fear take turns bursting out every day. I am six months into my diagnosis, so I'm thinking of my Uncle Ronnie each day. I just want to smile and share my compassionate self with the world. Another thing that gives me a sense of purpose is bringing ALS awareness to the world, by passionately educating people and doing everything I can to help find a cure.

Please tell us some fun facts about you that we don't already know.

A fun fact is that my paralegal career is the essence of my being. I was so honored when my law firm and the MN Paralegal Association created an award in my name, the "Tina M. Johnson Legal Service Impact Award." I am also a passionate gal who collects frogs and wears patchouli. My favorite artist is singer/songwriter Bobby Long, whose song, "Dead and Done," is my funeral song. The first line goes, "Heaven is a place where people die pretty."

Links

An op-ed from team member and author Mindy Uhrlaub in Stat News.

The UK Oxford MND Research Team is hosting an education day for the Familial ALS community in late April. Learn more here.

End the Legacy Board Member Nadia Sethi and others have debuted a new organization for ALS patients and Families to better understand research: NorthstarALS.

Newsletter image

Patient-Led Advocacy Transforming Presymptomatic Research and Clinical Care in Genetic ALS/FTD: The End the Legacy Model

Yentli E. Soto Albrecht, PhD[1-2], Eugene Cha[2], Moses Zeidan[2], Pierre Younes[2], J. Swidler[1]

[1] End the Legacy; [2] Perelman School of Medicine, University of Pennsylvania

Introduction

Genetic determinants of frontotemporal dementia (FTD) and amyotrophic lateral sclerosis (ALS) affect hundreds of thousands of presymptomatic carriers. Yet perspectives from these carriers—who typically face symptom onset in their fourth to seventh decade with no therapies that meaningfully alter disease trajectory—**remain systematically excluded from research design and clinical care development.** This exclusion impedes both scientific advancement and therapeutic translation.

End the Legacy, established in 2023 as the first patient-led organization dedicated to genetic ALS/FTD, demonstrates that centering carrier voices fundamentally transforms research paradigms. Through strategic FDA engagement, multi-institutional collaboration, and community mobilization, we have elevated presymptomatic carriers from research subjects to research partners.

Mission



Why This Matters:
The current system is structured for people who are experiencing symptoms now, not for preventing disease in those who will develop it tomorrow.

Narrative

Personal Journey

Yentli Soto Albrecht, PhD, is a MD-PhD student at the University of Pennsylvania and serves as Community Science Liaison for End the Legacy. Her grandmother died of what was initially thought to be Pick's disease in 2004, later categorized as FTD based on pathology. In 2016, her aunt developed ALS at age 56 and died three years later. Shortly after, her father was diagnosed with ALS.

Recognizing the high likelihood of a genetic cause, she advocated for her father to pursue genetic testing, revealing a C9orf72 repeat expansion. In October of that same year, she tested positive for the same mutation.



Figure 1. Yentli Soto Albrecht, MD-PhD student at the Perelman School of Medicine and Community Science Liason at End the Legacy. Photo courtesy of Aurora Golden-Appleton, from PennMed Trainees Against ALS/FTD.

The Advocacy Gap

Yentli's experience illuminates a critical gap in the research landscape: **presymptomatic genetic carriers have fundamentally different needs than patients with active disease, yet the system fails to address them.** While organizations focus on finding treatments for those currently suffering, carriers like Yentli face a paradox—knowing their genetic fate offers no path to prevention or early intervention.

The barriers are systemic:

- **No preventive trials exist** for C9orf72 carriers, despite the gene being identified in 2011
- **Knowing genetic status provides no clinical advantage**—carriers must wait until they develop measurable motor symptoms to access trials, even when biomarkers indicate disease is approaching. Symptomatic trials are limited to ALS
- **The ALS-FTD divide creates redundancy and inefficiency**—carriers must participate in separate trials for each disease, undergoing duplicate testing and procedures despite having a single genetic mutation that causes both

Events and Initiatives

Research

- Community-led research defining unmet needs, monitoring priorities, and care gaps for presymptomatic genetic ALS/FTD carriers
- Presentations at ALS/MND, NEALS, and ISFTD meetings
- Promotion of participation in observational and interventional studies (e.g., C9orf72, SOD1, GRN)

Education

- Open-access webinars with clinicians and researchers on genetics, penetrance, biomarkers, trials, and at-risk care
- Gene-specific educational resources for families affected by ALS/FTD;
- Search for a Self Cure video series--science for patients

Community

- Annual in-person Genetic ALS & FTD Community Summits
- Ongoing peer support spaces and community forums

Advocacy

- Coalition-based policy advocacy supporting sustained funding for genetic ALS/FTD research
- Engagement with NIH, Congress, and national advisory efforts to elevate presymptomatic carrier perspectives

Care

- Connects at-risk patients to clinics to receive monitoring services.



Figure 2. Photoshoot of 2025 North American Community Summit in Conshohocken, PA. Yentli moderated a panel.



Figure 3. Photoshoot of 2024 Genetic ALS & FTD Community Summit in Chicago, IL.

Future Directions

- **3rd Annual Genetic ALS & FTD Community Summit** (Sacramento, CA; Sept 24–26, 2026),
- Expansion of international **gene-specific consortia** (including presymptomatic C9orf72)
- **Redesigned research opportunities portal** to help families identify gene-specific studies.

Newsletter image

IN-PERSON CONNECTION IS A CRITICAL SUPPORT NEED FOR INDIVIDUALS IMPACTED BY INHERITED ALS & FTD: EVALUATION OF TWO COMMUNITY-LED SUMMITS

Authors

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Background

Approximately 10% of ALS is familial, and more than 40 genes have been implicated in inherited ALS and frontotemporal degeneration (FTD). With expanded access to genetic testing and growing recognition of hereditary risk, an increasing number of individuals now know they are genetically at risk for neurodegenerative disease.

While clinical research and therapeutic discussions largely center on individuals living with ALS, the psychosocial and support needs of those who are at genetic risk — but currently unaffected — remain far less understood. Members of this emerging community report complex emotional and existential experiences, including uncertainty about health, concerns related to family planning, stigma, and anxiety surrounding the possibility of future disease onset.

End the Legacy (ETL), in partnership with the ALS Hope Foundation, was established to support this population. Although digital education and virtual programming have expanded, consistent feedback from community members highlighted a strong need for in-person connection to reduce isolation, share lived experience, and foster



Methods

Two in-person community summits for individuals at genetic risk for ALS/FTD were held in 2024 (39 impacted attendees, 60 total) and 2025 (72 impacted attendees; 20 returning, 100 total). Events featured expert speakers, shared lived experience discussions, and facilitated peer support sessions.

Following each summit, impacted attendees received a voluntary, anonymous online survey designed to understand the value of in-person connection. Measures included satisfaction ratings, perceived relevance, likelihood to recommend, and open-text reflections on emotional and social impact.

Results

Survey respondents across two summits (N=43) reported uniformly high satisfaction (95% rating 5/5; 5% rating 4/5) and

Discussion

These findings highlight a significant, unmet psychosocial need for in-person engagement among individuals at genetic risk for ALS/FTD. While virtual connection offers accessibility, participants strongly valued physical presence, emotional bonding, and shared vulnerability in person.

This is one of the first systematic evaluations of community-led psychosocial programming developed for and by genetically at-risk individuals in ALS/FTD.
Results support:

- The importance of peer networks in high-risk populations
- The role of community organizations in complementing clinical care
- Expanding psychosocial infrastructure alongside genetic testing availability

Limitations

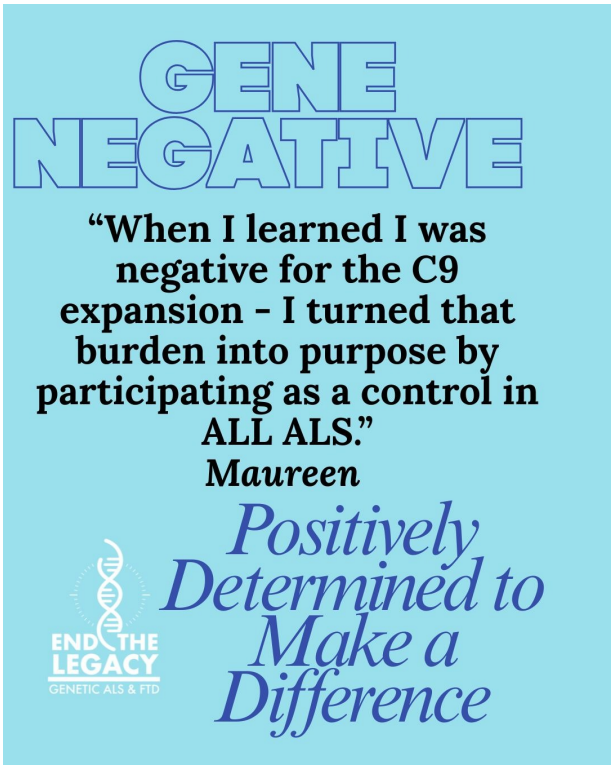
- Small sample size reflective of a rare community
- Self-selected participants, possible positive-response bias
- Surveys differed between years; full harmonized dataset planned

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