2026 Spring / Mid Summer Newsletter

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Director's Letter

Dear End the Legacy Community Members and Supporters:

Spring/Summer 2026 Update

Thank you for reading our Spring/Summer Update!

There are several actions we hope you will consider taking. Rather than hiding them at the bottom, we are putting them front and center:

1. Register for our biggest Community Summit yet, taking place this September in sunny Sacramento, California. Our main hotel block is nearly full, so register today if you hope to stay alongside the rest of the conference community.

2. Review our growth plan and help bring End the Legacy to the next level.

3. Participate in research, including the new survey from our genetic counselor colleagues described below.

Finally, take pride in knowing that you are part of a movement working to protect our families from falsehoods and distortions that demean us and our loved ones.

A recent example: The New Yorker published false and stigmatizing generalizations about C9orf72 expansion carriers in an article centered on one carrier who committed crimes. Through our community's advocacy, the article was partially corrected. The record has not yet been fully corrected, however, and our work continues.

Stay informed about End the Legacy's activities and help us continue the fight for our families' dignity.

In solidarity,

Jean Swidler
End the Legacy
EndtheLegacy.org

Care





The second phase of an internationally focused working group of academic and community leaders developing care guidance for people at elevated genetic risk of ALS and FTD is moving forward rapidly.

The group held its second in-person meeting in Pennsylvania in May, building upon its first meeting in 2023. End the Legacy was proud to sponsor the event and ensure that the perspectives of impacted families were represented by our Executive Director, Jean Swidler, and our Vice Chair, Cassandra Haddad.

The international working groups are now continuing to refine the proposed guidance using the Delphi method.

At the same time, a parallel initiative is underway in Europe, organized by leaders of the European Network to Cure ALS, or ENCALS.

End the Legacy was invited to provide the community perspective.

Our European Officer, Emma Bouche, and the volunteer leader of End the Legacy Sweden, Anna S., readily answered the call, traveling on short notice to attend an in-person meeting during the annual ENCALS meeting in Madrid in June.

Your donations to End the Legacy allow us to ensure that community leaders can participate in important meetings like this one.

The Madrid meeting produced a commitment to establish additional working groups. We are now placing advocates from Ireland, the United Kingdom, France, Sweden, Iceland, Norway, the Netherlands, and Italy into those groups.

An organized genetic community voice is crucial.

As care programs for people at genetic risk continue to come online in the United States—including programs at Massachusetts General Hospital, Temple University, Northwestern University, the University of Minnesota, Nova Southeastern University, and UCSF—we need institutional support to establish a dedicated End the Legacy staff position overseeing the implementation and standardization of this care.

Learn more about this vision at:

https://www.endthelegacy.org/latestnews

And at risk care here.

Research

Our community responded in force to our At-Risk Care Survey, with more than 200 eligible responses from people at genetic risk of ALS and FTD.

Our survey analysis committee—Daniel Brickman, Mindy Uhrlaub, Jary Larsen, and Jean Swidler—worked hard to review and analyze the responses, with Daniel, who holds a PhD, leading the statistical analysis.

Preliminary results were presented at the care meeting in Pennsylvania in May. A poster presenting the full results will be shared at the International Symposium on ALS/MND in Amsterdam this December.

Following the symposium, we will prepare the findings for publication.



We continue to encourage members of our community to participate in research. Recruiting longitudinal studies for people at genetic risk can be found here:

https://www.endthelegacy.org/recruiting-studies

Push Ups for ALS Fundraiser

This deeply personal fundraiser was succesfully concluded this past April honoring the life of our Science Liasion Dr. Yentli Soto Albrecht's father in partnership with his longtime High School. Stay tuned for news on where the proceeds of this fundraiser are being placed to advance research.

Education

We are proud to announce an upcoming webinar featuring the work of Dr. Ikjae Lee, Associate Professor of Neurology at Columbia University Irving Medical Center.

Dr. Lee’s research focuses on understanding how metabolism may be connected to the manifestation and progression of ALS symptoms among people with genetic risk factors.

During this presentation, Dr. Lee will:

• Review the scientific literature and what is currently understood

• Summarize recent findings from the ALS Families Project and the MAPS-ALS Study

• Share his current hypotheses

Part of the presentation will be available only during the live webinar, so please register today to join us:

https://www.endthelegacy.org/event-details/metabolic-alteration-in-presymptomatic-and-symptomatic-als

Support

The 2026 Genetic ALS & FTD Community Summit in sunny

Sacramento, California, is drawing closer!

In approximately two and a half months, many of us will gather to reconnect with old friends, meet new ones, learn about the current state of the field, and strengthen our ability to advocate for our families.

The Summit will take place September 24–26, 2026.

For a modest registration fee, any impacted person may attend with hotel accommodations, meals, and conference participation covered.

Learn more and register here:

https://www.endthelegacy.org/communitysummit2026

Please register soon. Our primary Summit hotel is nearly full, and future registrants may need to be accommodated at nearby hotels.

Peer Support Hour

Our Peer Support Hour continues, with the next gathering taking place:

Wednesday, July 15, at 3:00 p.m. Pacific

Register here:

https://forms.gle/xA9ERB74eAVnirqLA

Cheers to our dedicated volunteer facilitators Carolyn

McGraw and Mindy Uhrlaub!

Community Team Meeting

Our community team meetings are also continuing. The next meeting is:

Friday, July 24, 2026, at 9:00 a.m. Pacific

Anyone personally impacted by genetic ALS or FTD is welcome to attend. Email info@endthelegacy.org to be added to the meeting list.

Advocacy

Challenging Stigma in The New Yorker

On June 11, 2026, Dr. Addie Goss published an article in The New Yorker centered on a man with a C9orf72 expansion who had committed crimes.

The article presented a narrow and distorted view of the field, relying heavily on perspectives associated with UCSF's FTD center. It made sweeping claims suggesting that nearly half of C9 carriers have lifelong cognitive or behavioral abnormalities, accompanied by derogatory and implausibly specific descriptions of their personalities.

The article also left readers with the impression that science has established lifelong personality traits associated with C9 and that C9 carriers are particularly connected to criminality or dangerousness.

Our community would not allow those claims to stand unchallenged.

End the Legacy members and allies responded through direct correspondence, public advocacy, and condemnation of the article's stigmatizing generalizations. Following extensive exchanges, The New Yorker made several corrections to the article—an outcome that appears to be unusual for the publication.

The magazine also published commentary from community member Daniel Brickman. Cheers to Daniel for speaking out you can read the letter here.

The record was not fully corrected, however. Stay tuned for further efforts to protect the dignity of our community and ensure that millions of C9orf72 expansion carriers and their families are not portrayed as inherently disordered, criminal, or dangerous.

> *An earlier version of this article mischaracterized the results of a study about the behavioral patterns of F.T.D. patients with the C9orf72 mutation, and did not accurately reflect the current evidence regarding the emergence of personality traits in C9orf72 carriers in childhood.*

The note appended to the article noting the changes made.

California Genetic Nondiscrimination

Legislation to expand genetic nondiscrimination protections in the nation's most populous state continues to move forward.

We expect the legislation to pass, but every expression of support helps. If you live in California, please contact your state senator and urge them to support:

AB 1798 (Wilson): Genetic Nondiscrimination in Life, Disability, and Long-Term Care Insurance
Find your representative here:

https://findyourrep.legislature.ca.gov/

Federal Advocacy: ACT for ALS Reauthorization

We continue to be the only national voice consistently pointing out that the proposed ACT for ALS reauthorization legislation does not provide funding for ALL ALS/Prevent ALS.

Please contact your members of Congress and ask them to amend Section 2 of the bill so that grants may support natural-history studies as well as Expanded Access Programs.

Find and email your representatives here:

https://democracy.io/

Additional Announcements

New Survey on Genetic-Testing Decisions

Genetic counselors Laynie Dratch and Jennifer Roggenbuck are conducting a new study examining genetic-testing decision-making. They graciously sought and incorporated feedback from members of our community while developing the project.

Here is their invitation:

> Researchers at The Ohio State University Wexner Medical Center are studying decision-making among people who may be at risk for genetic ALS or FTD.
>
> Please consider participating to help us learn how to support members of the at-risk community as they consider options for their individual care.
>
> The study consists of one or two surveys, each taking approximately 10–30 minutes. The first 100 people to complete the study will be offered a $25 electronic Amazon gift card.
>
> Please feel free to share the survey with others who may be eligible.

Access the survey here:

https://redcap.osumc.edu/redcap/surveys/?s=JA89JC3ERWXP973M

Questions may be directed to the Principal Investigator, Jennifer Roggenbuck, at jennifer.roggenbuck@osumc.edu.

Philip Kipngeno Interviewed by Mindy Uhrlaub



1. What is your connection to ALS/FTD?

My connection to ALS is both familial and advocacy-driven. Several members of my immediate and extended family—particularly along my paternal grandmother's lineage—have been affected, placing us at clear familial risk. I lost my brother Jonathan to ALS in 2007 and my brother Andrew in 2023, whose case was genetically confirmed with a SOD1 mutation. Other relatives have also experienced related neurological conditions, suggesting a multigenerational pattern. In response to this lived experience, I chose to go public and founded the Motor Neuron Disease Association of Kenya (MNDAK), where I advocate for awareness, support, and improved access to diagnosis, care, and research.

2. What is presymptomatic ALS care like in Kenya?

Presymptomatic ALS care in Kenya is largely undefined and varies widely depending on awareness, belief systems, and access to healthcare. In many cases, individuals do not take any specific action, either due to limited awareness or the absence of a clear clinical pathway. In some communities, symptoms are interpreted through cultural lenses such as curses or bewitchment, leading families to seek spiritual or traditional interventions.
There is also a longstanding reliance on traditional medicine, including remedies derived from

indigenous plants and forest resources. This reflects a deep body of local knowledge that communities trust and continue to engage with, even though it is not yet formally integrated into ALS care pathways.
For those who enter the formal health system, the journey often begins at local facilities where nurses or clinical officers manage symptoms without a definitive diagnostic framework. Patients who are able may be referred through multiple levels of care, often with delays, before reaching a neurologist. Even then, care remains largely symptomatic, and access to genetic testing, counselling, or structured presymptomatic monitoring is very limited.
Overall, presymptomatic care is not yet systematized. It remains constrained by limited awareness, scarce specialist services, and minimal integration of both biomedical and indigenous knowledge systems—reflecting a broader gap across much of Africa.

3. What are your hopes for the future?

As an individual within a family with a history suggestive of familial ALS, my perspective is shaped by risk rather than confirmed carrier status, recognizing that genetic predisposition does not always result in disease due to variable expression.
My immediate hope is that the disease does not recur within our family—or in any family. ALS carries a significant clinical burden, with progressive loss of function and profound impact on both patients and caregivers, underscoring the importance of prevention and early intervention.
I remain committed to advancing understanding through learning, engagement, and advocacy. I hope to see improvements in diagnostic pathways, multidisciplinary care, and access to emerging therapies in Kenya, across the Global South, and globally, where disparities persist.
Looking ahead, I hope that advances in genetics, clinical trials, and targeted therapies are implemented equitably, including underrepresented populations. There is also value in exploring Africa’s biodiversity within rigorous scientific frameworks as part of broader therapeutic discovery.
Ultimately, my hope is that risk is translated into knowledge, and knowledge into action, improving outcomes and quality of life.

No family should have to learn ALS through loss.

4. Please tell us a fun fact about you that we don't already know.

I can be quite humorous. I enjoy surprising people with jokes or posts that sometimes take a moment to fully sink in. I’m also rarely idle; someone once pointed out that I never seem to just sit and relax without reaching for something to read. I also run marathons and am a gym enthusiast, and I have served as a trustee of the Tegla Loroupe Peace Foundation, founded by renowned Kenyan marathon runner Tegla Loroupe.

2026 Community Summit

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