Summer 2024 Update

Archived October 23, 2026 · Source: End the Legacy past newsletters

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Support & Community Engagement

Support Hour / Meetings

Through the dedication of a new volunteer team of peer facilitators, our monthly peer support hour program is going strong. A special shout-out to our August facilitator, Carolyn! To sign up to attend, please visit here.

Our weekly meetings continue to draw dozens each week to connect and share perspectives on issues important to us. Email info@endthelegacy.org if you would like to join our weekly meeting list. Even if you can't make the Friday meeting at 9 am Pacific, we send out detailed notes- often with the assistance of volunteer note keeper Jesse. Cheers to her for the brilliant summaries!

Planning for In-Person Next Year

We are still glowing thinking of the amazing weekend in June when we had our first in-person gathering in partnership with many generous allies. We are starting planning for next year's event in 2025 - join our weekly meetings to weigh in on planning if you would like to be involved! See this wonderful social media video of our June event created by Rod Malloy.

End the Legacy Board Addition

We are so pleased to announce that the accomplished ALS advocate, Dr. Nadia Sethi, has joined our End the Legacy Board. Nadia was a caregiver for her late husband who had TARDBP ALS. She had this to say "Genetic ALS & FTD: End the Legacy is an organization close to my heart. End the Legacy advocates for those genetically at risk or affected by ALS and FTD, driving advancements in care and research that benefit everyone facing these diseases. They've made remarkable strides in amplifying the voices of this community and encouraging vital research and care." This increases the number of pathogenic variants our board personally represents to 4.

Advocacy

Mindy Keynote

Our own amazing author and advocate Mindy Uhrlaub provided a prominent key-note address discussing the position of being at risk for genetic ALS and FTD at the 2024 National Institute of Neurological Disorders and Stroke annual Non-Profit Forum. Go Mindy!

Convo with Mark Harrington

Like all patient advocates, we take inspiration from the HIV/ AIDS movement and especially those who participated in ACT UP and Treatment Action Group (TAG). We shared a recorded conversation between noted HIV Advocate and patient researcher Mark Harrington and our own Jean Swidler. Watch here as they compare notes about different diseases but with similar stakes.

Testimony on Adcoms

A debate is occurring within and outside the Food and Drug Administration about the role of Advisory Committee Meetings in the drug approval process. Jean shared at a public hearing that “Ad-Comm” votes wrongly imply that the FDA serves the academic heavy advisory committees. While the academic field do provide the expertise of science, the FDA must balance that view with responsibilities to the people as a government agency. Their special role must not be compromised. Jean will be attending a special meeting held by the American Federation of Scientists on the topic later this month. You can view her comments from the Ad-Comm on Ad-Comms here.

ALS Nexus

The ALS Association held their first ALS Nexus event brining together many different ALS stakeholders in July. Jean spoke on a panel along with Shelby and Stacey Kinsey about the broad effort to push Bluecross BlueSheild to cover Tofersen for Shelby. Cheers to the Association for the success of the event.

Take ETL Out to the Ballgame

End the Legacy had a spotlight at a Sacramento Baseball game due to Rod Malloy who shared about the group in a special interview broadcast to the whole stadium! Cheers Rod!

Education

Tardbp Webinar Thursday September 12th

Our 2024 Genetic Research Education Series continues with another session focused on the genetic variant of TARDBP which encodes the protien TDP-43. Hear from Dr Neil Shneider and genetic counselor Elizabeth Harrington from Columbia University about research available for those impacted by TARDBP , and from people with the variant about how participating in research fits into their life. The event will be held this Thursday the 12th at 5:30pm Eastern. Sign up here.

NASEM Report Webinar

In July we hosted a wonderful talk reviewing the recently released National Academies of Science report on “Making ALS Livable “ with speakers who participated in the development of the report including the amazing Mindy and Dr Rita Sattler. Watch it here.

ALS ONE Biomarker Panel

Jean was honored to be invited to participate in an August panel discussion on biomarkers in ALS by ALS ONE for their Research Publication Review meeting. The presentation can be viewed here .

Research

ALL ALS Prevention Study Recruiting

We are pleased to share that there is a new location and area of the country being served by a longitudinal study for those at risk of genetic ALS. The Prevent ALS arm of the ALL ALS study has begun recruiting at Barrow Neurological Institute in Arizona. See more details on our recruiting studies page.

ISFTD

Jean will be attending and presenting a poster at the bi-annual International Society for Frontal Temporal Dementia symposium in Amsterdam the week of September 16th. Following the poster session we will share the poster, on the topic of possible risks of the use of informants in studies of those at genetic risk of FTD. Jary and Daniel are additional authors on the poster. Cheers to them all!

Australia Research Symposium

All meetings discussing ALS and FTD should have public representatives impacted by genetic ALS and FTD. End the Legacy was proud to provide some small financial support to allow research librarian Taryn Hunt from a family impacted by genetic ALS to attend the 2024 MND Austrailia Research Symposium. She had a warm welcome and shared reflections on the experience here. Go Taryn!

Member Spotlight Michael Cosgray - Interview by Mindy Uhrlaub

1. What is your connection to ALS/FTD?

My connection to ALS goes all the way back to 1970. My grandfather first noticed he was having difficulty gripping a golf club the day before my parents were married. ALS took him months before I was born. (Michael's mother pictured here also passed from ALS)

2. How did you feel when you found out you carried the C9orf72 mutation for

ALS/FTD, and what did you do about it?

I felt a sense of relief to finally know. The 50/50 cloud was beginning to get dark in my mind. I told my loved ones, had some tough conversations with family, scheduled a baseline visit with a neurologist, and began enrolling in observational research.

3. What made you decide to participate in a drug trial when you are an

asymptomatic patient?

NADALS was the first ever interventional study for presymptomatic gene carriers. As the first in my family to know their genetic status, I was blessed enough to qualify, and in a position where I could participate. I have lots of friends to thank here. Without them my participation would not have been possible.

4. Please tell us something about yourself that we don’t already know.

My friends often refer to me as “Coz”- the same nickname my father had.

Newsletter images





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