End the Legacy’s Spring 2025 Newsletter

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Notes from the ED

We are preparing this weekend with eager anticipation for the highlight of our year - our 2nd annual in person community summit in Philadelphia with local host the ALS Hope Foundation! The spirit of community and solidarity is so special for all who attend, and we are proud to manifest the establishment of this community of shared interest.

We also must thank the Les Turner ALS Foundation for recognizing myself and Mindy Uhrlaub for our work on behalf of the genetic ALS and FTD community at their annual gala dinner in April. Truly neither of us would be able to have had as much impact as individuals without all our ETL advocates pushing alongside us.

Recently our community had a serious discussion regarding the assertion by some of the establishment of a lifelong cognitive impairment for all impacted by the C9orf72 expansion. We are evaluating this claim with scrutiny and are developing a community response. Join us if you want to have a meaningful interaction with the fields making pronouncements about our families.

We are proud of the efforts on our mission areas shared below, and we hope you appreciate them.

Jean Swidler

Mission Area: Education

Webinar

We were so pleased to welcome Dr Richard Bedlack in May as he presented on his learnings about some off label or alternative treatments that may reduce the risk of developing genetic ALS from his ALS Untangled project. The webinar recording with translated captions if available on our website at EndtheLegacy.org/ETLWebinars

C9 Resource Page

Thanks to the suggestion of a patient advocate we have collated some of the C9orf72 specific content on our website here. https://www.endthelegacy.org/c9orf72info

Genetic Counselling Education

We continue to offer this free resource staffed by the amazing Shannon, a licensed genetic counselor. She has affirmed the sessions she has led have all been well received and productive. See more about it and sign up here. https://www.endthelegacy.org/genetic-counseling-education

Mission Area : Advocacy

DC Lobbying

We were pleased to have 4 End the Legacy advocates stalking the halls of congress pushing for both robust research funding in coalition with all major ALS advocacy orgs, as well as educating on the promise and possibility of further genetic non-discrimination protections. You can see the letter on research funding and our flier on genetic protections here: https://www.endthelegacy.org/policy-efforts

C9 Science Meeting

A few End the Legacy advocates were invited as individuals to a meeting hosted by Barrow Neurological Institute on the current state of C9orf72 research. We will be in touch with the organizers to secure a formal End the Legacy invite in any future iterations.

ADRD Summit

The biannual Alzheimer's Disease Related Dementias summit hosted by the NIH occurred in April. ETL friend and CureMAPT co founder Linde gave a powerful personal testimony to open the meeting. Advocates were able to meaningfully participate in the discussion following various presentations. See our statement to the summit organizers here https://www.endthelegacy.org/_files/ugd/810dd7_a08b7ee782a247d08afebaf3e263d0a7.pdf

UK FTD Meeting

We firmly believe that there should be nothing about us without us so when the UK FTD Research meeting was announced we were glad a volunteer advocate based in the UK agreed to attend and report back. We are proud to help ensure impacted voices are present wherever our community is discussed.

Mission Area: Research

Recruitment

We continue to ensure our community knows the best way to make progress against the diseases that haunt our families is by participating in research. See studies recruiting here: https://www.endthelegacy.org/recruiting-studies

All ALS

We are proud that Jean is serving as an advisor to this study and will be attending their in person investigator training next week.

Survey on Presymptomatic Care

We are still hard at work on our community survey for presymptomatic care. Look for more news on that effort in the coming months.

Mission Area : Support

Summit

We are so glad our summit this weekend is shaping up to be a powerful event. Cheers to our planning committee for really drilling down the details of this summit, our largest yet!

Peer Support Hour

We continue to have meaningful conversations every month led by dedicated peer facilitators. If you would like to be involved sign up here https://forms.gle/ySNjr3GyVA5VKmeq5

Mission Area: Care

We have a new informational sheet on the existing care guidance for those at risk of genetic ALS and FTD. See it here https://endthelegacy.org/care

Newsletter image

