June 2024 - Update

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Greetings - End the Legacy and the genetic ALS & FTD movement had a busy June. We hope these updates, separated into our four pillars, are of interest and provide inspiration. Please pay attention to a few surveys at the bottom shared by others seeking input on important issues.

Support & Education:

Our First Summit:

After years of meeting on Zoom (and Google Meet!) , many of our End the Legacy members met in person for the first time from June 7th to June 9th in Chicago. The Les Turner ALS Foundation and Northwestern University were generous local hosts for a weekend of learning, sharing, and celebrating. We heard from experts in genetic ALS and FTD, researchers, and peers. We learned how to read and dissect a research paper. We listened to stories of others with diseases that can be solved by activism and science. Our panelists – many of them End the Legacy members – validated our feelings, challenged our beliefs, and called on us to do more for our community. One of the most powerful takeaways from our first summit was that we're not alone in the fight against ALS/FTD. We're a wise, plucky community of friends and colleagues, and we're here for each other. May this important first be the first of many!

See our Facebook post for some great photos!

Peer Support Hour

We welcomed new peer facilitators for our monthly peer support hour in June - cheers Mindy, Carolyn, and Lauren! While our weekly meetings are about driving on our mission, our monthly peer support hour is an informal space to connect with others impacted by inherited ALS and FTD without judgment or agendas. Sign up here to attend, the 3rd Wednesday of the month at 6pm Eastern.

Weekly Meetings

Our weekly meetings have been ongoing, and Cassandra recently facilitated an excellent session. Our weekly attendance regularly exceeds 20 individuals—we appreciate everyone's participation!

Advocacy

NASEM Committee Report on ALS

On June 18th, the National Academy of Science, Engineering, and Medicine released its report on making ALS a livable disease. End the Legacy's Mindy Uhrlaub worked for eighteen months with an eighteen-person committee, carrying the flag for the genetic carriers and people at risk of genetic ALS/FTD. Please join Mindy and two other members of the NASEM committee as they discuss the content and writing process of the report: Living with ALS.

Our conversation on Tuesday, July 9 th begins at 3:00PM Pacific/6:00PM Eastern, and you can sign up here. The full report can be forum on the National Academy's website here.

Raising the Issue of Stigmatization of Those at Risk of ALS and FTD

This past month, we ran a series highlighting some statements made by researchers about our community. As we desired to educate on the issue and not shame particular people, we shared summaries of statements without naming our sources. If you would like the particulars for each, please reach out. If our posts were unclear about the fact that they were summaries of statements and not direct quotations, often made in meandering Q&A dialogue, we regret any confusion caused and will strive to be clearer going forward.

Research

C9orf72 Prevention Trial Meeting

In June a one day meeting was held in the Washington DC area hosted by the ALS Association and the Association for Frontotemporal Degeneration and chaired by Drs Boxer and Benatar. Jean and Gail were the only impacted participants and cheered the event and were thankful for their invitations to attend. A summary of the lively and promising proceedings is forthcoming.

Surveys to Consider

FTD Caregiver Survey

Subject: Frontotemporal Dementia Caregiver Survey

Thank you for considering participating in the Frontotemporal Dementia (FTD) Caregiver Survey! Your responses will help Alector, a biopharmaceutical company, better understand your experiences as a caregiver of an individual diagnosed with FTD. The survey will ask questions about your interactions with healthcare providers, use of support services, and day-to-day caregiver challenges. The goal of this survey is to improve overall care and resources for people and families affected by FTD.

We need people who:

• Are or have been a primary caregiver to someone diagnosed with FTD

• Are 18 years or older

• Reside in the United States

• Additional criteria will be reviewed in the survey

We are looking for 50-75 caregivers to complete the survey, after which the survey will be closed. The survey will take about 20 minutes to complete, and the respondents who submit the completed survey will be compensated for their time in the form of a $20 gift card.

LINK TO SURVEY

If you have any questions, please contact the non-profit organization administering the survey, The Center for Information and Study for Clinical Research Participation (CISCRP) at research@ciscrp.org.

ALS Patient and Caregiver Survey

The Lived Experiences Igniting Transformations in Health (LEITH) Lab led by Chelsey R. Carter at the Yale School of Public Health is looking for caregivers of those with ALS and people with ALS to take a survey. The LEITH lab is looking to collect surveys and conduct interviews with caregivers of people with ALS and people who live with ALS. The purpose of this research study is to examine the socio-cultural and behavioral factors influencing care interactions among people with ALS and their caregivers.

The survey will take approximately 20-35 minutes to complete. All responses will be kept strictly confidential, and data will be anonymized in any resulting reports. Our research project is funded by a Seed Grant through the ALS Association. Individuals who meet the criteria and complete the survey will be eligible to receive a $50 gift card of their choosing.

Thank you for your participation!

Best,

Dr. Chelsey Carter

https://www.theleithlab.com/

SURVEY LINK

Caregiver Survey link: https://yalesurvey.ca1.qualtrics.com/jfe/form/SV_bPXKlK8K8GAJsqi

Care Recipient Survey link: https://yalesurvey.ca1.qualtrics.com/jfe/form/SV_8GheZIzI4QRqRzo

Newsletter images

