Genetic ALS & FTD: End the Legacy

June 2023 Newsletter

Julie Granning, Editor

A Note from the Chair

With summer here, many minds turn to adventures and excitement in the long, warm days of sunshine the season brings. As adults impacted by genetic ALS & FTD we frequently have had our summers filled up with caregiving. These important memories are central to anyone's identity, more so than even a well-planned trip. But we don't often take photos or share recountings of the time we spend caring for our parents or other loved ones as they suffer from ALS and/or FTD. Often in our families, dwelling on the way this inherited risk has impacted us can be something it doesn't feel OK to talk about.

With the founding of End the Legacy, we have flipped that script. Myself and our whole team of committed volunteers think and talk about our collective risk quite a bit! Would this intentional dive into the topic that may have been forbidden at home leave us feeling worse than if we had never tried? To get some insight into this, we conducted a survey of our most active members, and we are happy to share the results of that later on in this newsletter. A few brief thoughts: 1) Confronting this risk can be beneficial for those who want to do it. 2) We have excellent and growing engagement with a hard-to-reach community. 3) Knowing the context for research drives engagement and volunteering of oneself as a participant.

Happy summer everyone!

-Jean Swidler, Chair

Team Update:

Linde Jacobs, MAPT carrier, has accepted appointment to our Board, joining Jean, our Vice Chair Cassandra, our mentor Dr Terry Heiman-Patterson, and Karen Kornbluh. Congrats Linde and we are so appreciative of all your efforts for our community!

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Mission Statement

The Genetic ALS & FTD community is large and growing. ALS & FTD are terminal conditions, and being at a heightened risk for them can have profound impacts on people and families. We organized Genetic ALS & FTD: End the Legacy to provide educational and support resources to, encourage and promote research about, and advocate for the genetic ALS & FTD community.

Follow us Instagram
Tweet us @End_The_Legacy
Join us Facebook
Watch us Youtube

Join Our Team!
You are invited to join us for our weekly team meetings! If you would like to join our strategy/update sessions held every Friday at 9am Pacific, email us at geneticalsftd@gmail.com.

SUPPORT

Our first Peer Support Hour was held on June 21, 2023, and was a wonderful mix of End the Legacy members and people new to our community.

Join us for our next Peer Support Hour, where informal, peer-led discussions will occur, allowing attendees to meet others impacted and share in a judgment-free space. The next two sessions will take place on Wednesday, July 19, and Wednesday, August 16, both at 6:00pm CST
Sign up here to attend.

ADVOCACY

The 2023 Annual NEALS Meeting is coming up on October 4–6, 2023. **Jean** has been invited to speak on a panel and we have several other members hoping to attend, too.

Board Member **Linde Jacobs** attended and spoke at the Tau Consortium meeting this past week. Having our voices heard in these settings is so important!

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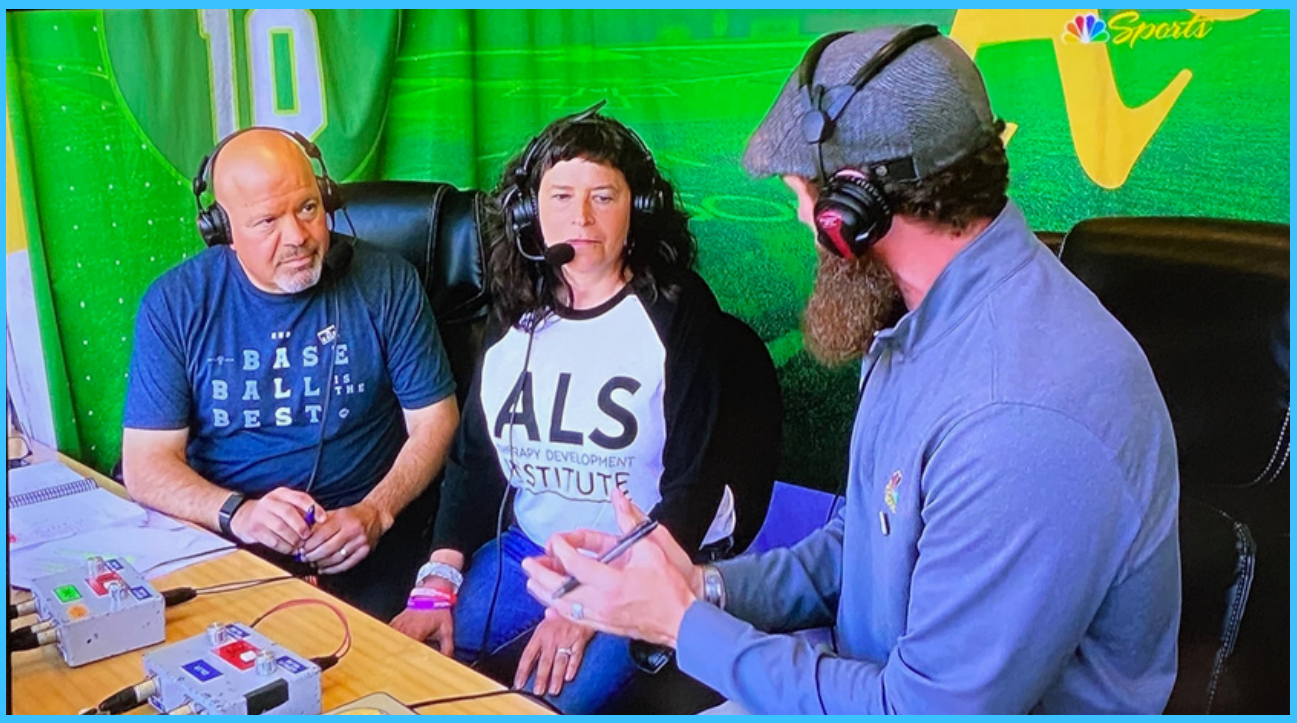
ADVOCACY

Mindy's MLB Outreach

On June 12th, as part of Major League Baseball's Lou Gehrig Day, I was interviewed by the play-by-play announcers at the Oakland A's game. It was the top of the fourth inning, and I was seated in the announcers' booth. ALS TDI, a non-profit biotech lab that exists to find treatments and cures for ALS, had asked me to represent them and the broader ALS community. I was pretty nervous, but I kept telling myself that I know enough about familial ALS to speak about it publicly. I'm passionate because it affects my family, and I can articulate that as a genetic carrier, I have skin in the game. It was one thing to out myself as a genetic carrier of C9orf72 on social media or on the End The Legacy webpage. It was an entirely different ballgame (pun intended) to speak over an MLB game and be on camera for thousands of people to see.

I had about ten minutes to speak, so I gave an ALS primer about the causes of the disease. I spoke about the one in 400 people who have ALS. I was on live television, and sometimes we talked over the game. It was hard in the moment to remember to plug all of the nonprofits I love, but I know I urged collaboration among organizations, and I encouraged viewers to educate themselves about ALS and support the search for a cure. I grew up in a family where "the game" was always on, and I knew that if I was in the announcers' booth, people would hear and see me. I made it very clear that if enough eyes were on ALS, together we could find a cure. Before I knew it, the interview was over. I was certain that my message was clear. I was so proud to be able to represent my ALS community, and I was grateful to ALS TDI and the MLB for recognizing that genetic carriers are ALS patients, too.

For clips of the A's game interview, and for more reading on my ALS activism, please check out www.mindyuhrlaub.com.



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EDUCATE

Our education team is working on drafting some gene-specific resource guides. Guides for C9 and progranulin should be finished and posted on our website in the coming month. Each guide will include information on inheritance, penetrance, age of onset, and other material specific to the gene as well as a section on current research. After these first two guides, the team will be working on SOD1 and MAPT.

Webinar: On June 27, researcher Jolien Perneel, a PhD candidate working in renowned genetic FTD researcher Dr. Rosa Rademaker's lab, presented on findings related to genes people may have in addition to ALS/FTD genetic mutations that could alter the risk of developing disease. This webinar focused on the genetics of TMEM106B and also covered its function in the cell and in the brain with specific examples of how it relates to progranulin and C9Orf72. Watch on our Youtube channel here: https://youtube.com/live/yQgqXlBT6Yw

We have more webinars in the works. Follow us on Eventbrite to receive notifications for new events: End the Legacy on Eventbrite.

If you are interested in presenting to the Genetic ALS and FTD community, please reach out! Email us at geneticalsftd@gmail.com.

RESEARCH

Reasearch Study News:

ALS TDI has recently announced the expansion of their efforts to remotely track the als disease course- the new program is called the ALS Research Collaborative or ARC. This will be an open access effort available for all researchers. Participants are tracked via the internet and with mobile things like blood draws and smart watches. With this update ALS TDI also has clarified they are fully recruiting those with an als mutation who are not yet symptomatic. It should be noted, unlike some studies of this nature you must already be positive to enroll.

We applaud this initiative and all who do similar work. And we extend that of course to all who volunteer as participants ! Please see details for the predecessor to this initiative from ALS TDI (it will be updated soon!) and other studies recruiting carriers or those at risk here.

RESEARCH

Patient-Led Research

ETL sent out a survey to 50 of our most engaged members of the group (defined as people who had participated in at least five meetings or webinars in 2023) and received 33 responses in the six-day period it was open. The survey consisted of demographic questions, multiple-choice questions on how the group has impacted the member's mindset, and open-ended questions.

Here are some highlights of the results:
75% of participants felt a greater sense of well-being after being involved in the group.
69% of participants felt more optimistic about the future risk to themselves and/or loved ones
63% of participants reported they are more likely to participate in research

We believe in the power of our community and are pleased to see that the work everyone puts into our group is having a positive impact on its members in return.

Member Spotlight:
is on
Summer Break
😎

Let's keep our growing community strong and informed!

Visit us: https://www.alshf.org/end-the-legacy
Email us: geneticalsftd@gmail.com
Follow us: Instagram
Tweet us: @End_The_Legacy
Join us: Facebook
Watch us: Youtube

In the meantime, to hear from people personally impacted by these diseases, please watch (or re-watch!) our re-creation of the presentation we provided to FDA in our Patient Listening Session. You will see touching personal stories of people impacted by C9orf72, TARDBP, and GRN.
https://youtu.be/O81YU2azUIE

You can also see the summary of the meeting, approved by the FDA, linked to on the FDA Website! View It Here