Update - March 2024

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Greetings. This simple update is replacing our prior newsletters. Many thanks to newsletter editor Julie Granning!

We have been busy as an organization, and we are proud to share these simple updates with you! Below I've included an anonymous member spotlight interview conducted by our own Mindy Uhrlaub.

Community Summit 2024:

We are so pleased and excited to open up registration to all impacted by Genetic ALS & FTD to our first Community Summit of those impacted by genetic ALS & FTD. The event will be held in Chicago with local host the Les Turner ALS Foundation, from Friday afternoon, June 7th, through Sunday mid-day, June 9th. The summit will focus on informal connections for the dozens of participants, a NEALS Clinical Research Learning Institute, and skill-building panels for a strong Genetic ALS & FTD patient movement. Learn more and sign up here!

Education:

We held a great webinar on Practical Updates in Genetic Testing in ALS and FTD; many thanks to our presenters, Genetic Counselor Tara Jones and Professor Ammar Al-Chalabi. View it here.

We recently debuted our SOD1 Genetic Research Education Series webinar recording with translated captions in French and Spanish. View it here.

Our next educational webinar will be hosting Professor Janice Robertson discussing the role of the Loss of Function of C9orf72 in ALS and FTD on April 11th. Sign up for it here!

We debuted a section on Genetic Testing on our website.

Support

Our peer support hour continues! It's held on the Third Wednesday of the month at 4pm Pacific. Sign up here!

Our weekly community team meeting is held every Friday at 9am Pacific. Reply to this email if you would like to attend, along with why.

Advocacy:

We were proud to share with allies in the UK the news of the public board meeting of the NICE committee that made a wrong decision on Qalsody. We applaud the many clinicians, organizations, and patients standing up against this injustice.

We broke the news of the unjust denial of Qalsody for 22-year-old Shelby in Texas by Blue Cross Blue Shield of Texas, a subsidiary of HCSC. Please condemn these insurers on social media with the hashtag #fightingforshelby and stay tuned for new updates on the campaign.

We are supporting the education of State Legislators across the country on the need for broader genetic non-discrimination protections, including in South Carolina, New York, and Maryland.

Research:

We have been hard at work helping fine-tune the report from the first-ever workshop on clinical advice for those at genetic risk of ALS and FTD - it will be a watershed moment when the final product is released, and we are so proud of our part in making that happen. Expect robust community education from us when that debuts.

We submitted our first new abstract of the year for the ISFTD conference in September. We can't wait to share the important information contained in it. Cheers to Jean, Daniel Brickman, and Jary Larsen for their hard work on it.

Many of us, including Linde Lee, Karen King, Cassandra Haddad, Jean, and others, have been invited to speak on panels in the coming months at different conferences. A few years ago, the voices of the at-risk community were absent from the conversation. We have helped turn this tide mightily.

Member Spotlight by Mindy Uhrlaub

1. What is your connection to FTD?

I am a caregiver for my 57-year-old husband who was diagnosed with behavioral variant FTD. He carries the mutation in the progranulin gene which also is thought to be the cause for his mother's early death nearly three decades ago. At that time, doctors told us she did not have Alzheimer's, but instead had "Pick's Disease". We did not make the connection between my mother-in-law's disease and my husband's because their symptoms were vastly different. It was only after worsening symptoms and a second opinion from a new neurologist that genetic testing was done and this revealed the mutation.

2. What are your feelings about genetic testing?

I would encourage anyone that has a loved one with an FTD diagnosis consider genetic testing for the impacted/sick person. If the FTD diagnosed person carries any of the known genes that cause FTD, family members can have a better understanding of their own risk and can make an informed decision for themselves as to whether or not to test. There are clinical trials ongoing now for patients with the progranulin mutation, and they may slow or potentially even stop progression of disease. The only way to participate is if the patient knows they have the mutation. Genetic testing and participation in clinical and observational trials may offer hope for some FTD patients and their families.

3. Short of a cure, what are your hopes for people (and their families) with genetic FTD?

I can't really focus on anything except a cure for each and every type of FTD. Since the disease is so heterogenous, this is a tough hill to climb, but I hope that bit by bit we will get there. In the meantime, I hope for privacy, fairness, and emotional/financial support for impacted families.

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

I'm an avid gardener and have an extensive collection of cacti and succulents that I've grown from cuttings or from young plants. I am obsessed with all things that grow and it gives me peace and strength to reap the benefits of my hobby. My husband loves to watch me garden and enjoys sitting outside looking at all of our beautiful potted plants.

In Solidarity,

Genetic ALS & FTD: End the Legacy

EndTheLegacy.org