April / May 2024

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We are proud to share these updates with you! These updates are separated into our 4 pillars - Education and Support for our community, Research about our community, and Advocacy on behalf of our community. We are also glad to share the spotlight of Dr Roubenoff, whose wife, Dr Falk, joined our community as she suffered from ALS. To have received Dr Roubenoff into the team following her passing is a touching reminder of the ever-lasting fight that these genetic diseases imbue into our families. We honor Dr Falk's memory, especially as she participated in the Biogen C9orf72 ASO trial that did not work but provided such valuable knowledge of the disease.

Education

An Amazing webinar explaining the Loss of Function theory of C9orf72 disease was held on April 11th. Presented by the generous Professor Janice Robertson it was extremely informative. Watch it here.

When an amazing development for our community debuted in the new Miami Framework for ALS we shared an analysis for our community breaking down what it meant for diagnosis of ALS in gene carriers. Read it here.

For ALS Awareness month Cassandra designed a great infographic series for us to share about what we do! See it here.

We are eagerly anticipating our first in-person meeting ever - the inaugural End the Legacy Genetic ALS & FTD Community Summit! Taking place in just 7 days we couldn't be more proud and excited that this is really happening!

Advocacy

Jean spoke at the ALS Canada Research Forum on a panel about asymptomatic research. Thanks to the team at ALS Canada for the Invite!

Karen King spoke at the ALS Drug Development Summit on a panel about genetic research.

Jean is preparing to speak at a meeting to prepare for C9orf72 Prevention studies, hosted by the ALS Association and the AFTD. Thanks to them for the invitation!

Research

We had an abstract accepted for a poster presentation at the International Society of Frontal Temporal Degeneration meeting in September - congrats to the authors Jean, Jary, and Daniel.

Jean advised and collated feedback from the group for the ALL ALS asymptomatic study and attended their Investigator training. Thanks to the leaders of the study especially Drs Berry , Harms and Garret for soliciting this feedback.

We are pleased to share that the guidance from the meeting last year on care advice for the at-risk community has been submitted and is pending review.

Support

Our weekly meetings proceeded well throughout April and May, with Cassandra facilitating one of the meetings while Jean was on vacation. Recently, we had our largest Friday meeting to date with over 30 participants.

Our monthly peer support hour announced a time change to 3pm Pacific every 3rd Wednesday. Sign up here. Cheers to newly enrolled facilitators Laura, Mindy and Carolyn!

Member Spotlight: Ronnen Roubenoff, interviewed by Mindy Uhrlaub

1. What is your connection to Familial ALS/FTD?

My wife, Barri Falk, died of C9orf72 ALS in October 2022. Her brother had died of it a year earlier. Her sister has it now. Their mother, in retrospect, probably had FTD, though it was not diagnosed during her lifetime. Barri's 17 year old son is at risk for carrying the gene but has not been tested.

2. These neurodegenerative diseases can make patients and families feel out of control. What gives you agency over ALS/FTD?

Not much, I'm afraid. I'm a physician and have been working in biotech and pharma for over 20 years, including on drugs for ALS. Being involved in research and in patient support groups is the best I can do.

3. Short of a cure for ALS/FTD, what is your hope for the genetic community?

We need better systems for identifying and recruiting patients and carriers for clinical trials. If we're going to find treatments that work, we need to build networks of patients, families, clinicians, and researchers who can openly discuss new ideas and move studies forward faster and more cheaply than today.

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

I was widowed twice before, each time from cancer. ALS is worse, in a way. With cancer, you're always waiting for the next shoe to drop, but you're ok until you're not. With ALS, the screw turns every day, it's a continual retreat.

Any Photos you would like to share?

There's one of Barri at a Red Sox game in August 2022; one of her before she was ill, in 2019; one of her and her sister Lisa at the same time.

In Solidarity,

Jean Swidler

Genetic ALS & FTD: End the Legacy

EndTheLegacy.org

Newsletter images





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