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Happy 2023 from ALLFTD!



Thank you for participating in the ALLFTD study! We wanted to give you some highlights and updates from the study.

ALLFTD LONGITUDINAL ARM

Over 1,023 people have enrolled in ALLFTD's longitudinal arm! This represents people from 48 states, as well as from Canada. Excitingly, over 347 have returned for their annual follow-up visits, with 49 completing their 3rd visit. Thank you all for your willingness to contribute your time.



ISFTD MEETING

After being cancelled in 2020 due to COVID, this year saw the return of the *International Society for FTD* (ISFTD) research conference, an exciting opportunity to share new research and reconnect with other scientists and clinicians who care about FTD.

Roughly 600 researchers attended the conference in France, and there were 30 posters and presentations involving research in the ALLFTD consortium. These included presentations on rare genetic findings, updates on brain imaging, and exciting work on "disease progression modeling", which is a technique to help understand what features of FTD start earliest in familial FTLD and how those might inform clinical trials.

At the ISFTD meeting, ALLFTD Participant and Family Engagement Board Director Katie Brandt presented on the creation and activities of the Engagement Board. It was a terrific opportunity to highlight the voices of patients and families in FTD research. In its inaugural year, the board helped create new recruitment materials and delivered a public comment to NIH.

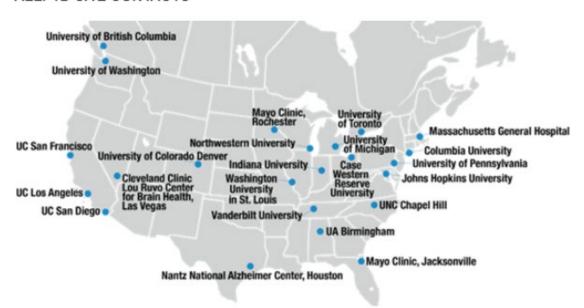


REMEMBER ME PODCAST - ALLFTD Mini-Series

We would like to know, did you listen to the Remember Me Podcast mini-series about ALLFTD? <u>Tell us here.</u>

Missed the news about the series and want to check it out? Go here.

ALLFTD SITE CONTACTS



ALLFTD site personnel can change from one visit to the next. We do our best to update the ALLFTD website when site personnel change. If you ever have challenges reaching your ALLFTD site study coordinator, <u>check the website</u> to see if your site has a new one.

BREAKING DOWN THE SCIENCE

Enjoy reading scientific publications? Use <u>this link</u> to review all the publications related to the ALLFTD Study.

Prefer Science Shorts? Learn more about what we're learning in ALLFTD and how it impacts you by reading brief summaries of some of our recent publications.

READ SCIENCE SHORTS

Want to learn more about how we are using computational modeling to help learn more about familial FTLD disease progression? <u>Click here</u>.

Want to learn more about FTLD fluid biomarkers? <u>Watch this brief interview</u> with Dr. Julio Rojas-Martinez.

THANKS!

Thank you for participating in ALLFTD and all FTD-related research studies. None of this would be possible without your contributions.

We hope you have a blessed New Year!

The ALLFTD Study Team

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ALLFTD Study www.ALLFTD.org

As a participant of the ALLFTD Study, you have been enrolled into the FTD Disorders Registry.

FTD Disorders Registry www.FTDregistry.org



Join the Registry. Tell your story. Advance the science.