



# ALLFTD

ARTFL LEFFTDS Longitudinal  
Frontotemporal Lobar Degeneration

## Happy 2024 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 2,400 people have enrolled in ALLFTD's Longitudinal Arm and we completed a total of 950 visits in 2023. Incredible! Thank you all for participating and returning for your follow up visits!

### **Participant and Family Engagement Board**

The ALLFTD Participant and Family Engagement Board has had a busy year! They made a public comment in support of FTD research at the National Alzheimer's Prevention Act (NAPA ) council meeting this summer. Helped provide review and comment on some ALLFTD study informational materials. Recently, they finished a short video on ALLFTD, and you can watch it [here!](#)

As a study leadership team, we are so thrilled to have the support and guidance of our Engagement Board Members.

## AFTD Support Groups

We wanted our participants to know about an opportunity offered by the Association for FTD (AFTD). The AFTD is starting a new support group for persons at Genetic Risk. The peer support group will offer attendees a community, connection, and a safe place to share their experiences living with and managing their feelings around their genetic risk. The group will meet the first Wednesday of the month 5-6pmEST via Zoom. If you or someone you know might be interested in joining, contact the AFTD HelpLine at 1-866-507-7222 or [info@theaftd.org](mailto:info@theaftd.org).

The AFTD also has other support group options for Care Partners and those living with a diagnosis. To learn more, call the AFTD HelpLine 1-866-507-7222.

## Neurofilament Surveillance Project

The Neurofilament Surveillance Project (NSP) is pleased to announce that the enrollment goal for the study has been met, and enrollment has been closed! The NSP is a longitudinal biomarker study that is a sub-study of the ALLFTD observational study, sponsored by the nonprofit Bluefield Project to Cure FTD. The study's goal is to evaluate levels of the protein neurofilament light chain (NfL) and other potential biomarkers in the blood of individuals who are members of a family with genetic frontotemporal lobar degeneration caused by a mutation in *C9orf72*, *MAPT*, or *GRN*. NfL is a protein found inside neurons and normally not present in the blood of healthy individuals. Participants in the study receive four study visits per year for three years in their home or another convenient location, where blood is drawn and brief questions regarding their health are asked. Currently, more than 1200 samples have been analyzed. The NSP would like to thank all the enrolled participants for being a part of this important research effort. If you have questions or comments related to your study participation, please contact Study Manager Rachel Acuña-Narvaez at [rachel.acuna-narvaez@bluefieldproject.org](mailto:rachel.acuna-narvaez@bluefieldproject.org).

## 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're ever having challenges reaching your ALLFTD site SC, check the [website \(www.allftd.org/sites\)](http://www.allftd.org/sites) to see if your site has a new SC.

## Breaking Down the Science

Enjoy reading scientific publications? Use [this link](#) to review all the publications related to the ALLFTD study.

## 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*

**ALLFTD Study**  
[www.ALLFTD.org](http://www.ALLFTD.org)

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

FTD Disorders Registry  
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