



The ALLFTD Study

Summer 2023 Newsletter

Update on Study Participation

As of September 1st, we have completed 2,180 visits. Wow! We are so excited and impressed by everyone's willingness to participate in ALLFTD. Here is a breakdown on some details about what we've collected from participants so far:

26 Sites	2,180 Total Visits	1,716 visits with Blood Collected	464 visits with a Lumbar Puncture	1,683 visits with a MRI
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What does the Second "L" in ALLFTD Stand For?

We always welcome new participants in the study, but it's really important to have return visits because we learn so much from seeing changes over time. In fact, the second "L" in ALLFTD stands for Longitudinal because follow-up visits are so important. 😊 If you know someone trying to enroll in ALLFTD, they may be facing longer "wait" times because our sites are prioritizing bringing people back in for their annual visits.

139 Biofluid Focused Arm Visits	1,244 Baseline Longitudinal Arm Visits	564 Cycle 2 Visits	181 Cycle 3 Visits	21 Cycle 4 Visits
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ALLFTD Investigators' Meeting (IM)



Over 100 members from ALLFTD teams met in-person in Denver, Colorado April 13-14 for an Investigators' Meeting (IM). Most research studies, including clinical trials, host an Investigatros' Meeting about once a year for the people working on the study to get together and do some training and generally discuss how things are going . The last time ALLFTD teams met in-person was November 2019! In addition to ALLFTD study team members, colleagues from the [AFTD](#), [FTD Disorders Registry](#), [CurePSP](#), and other groups were able to join as well. The meeting focused on sharing important study-wide updates about what's happening during in-person visits and what we're learning scientifically. We also discussed what the future of ALLFTD might look like because in 2024 we plan to submit a renewal grant to continue the study– we're currently funded through June 2025.

We discussed potential changes to the study like adding more technology to hopefully shorten in-person study visits, collaborating with our international colleagues more so that we can further our understanding about FTD around the world, and how to better accommodate participants who don't consider English to be their first language.

We welcomed presentations from our FTD partners the AFTD and the FTD Disorders Registry about how things are going for them and some exciting changes coming in the short and long-term future. Specifically, AFTD is expanding their offerings to those impacted by FTD and we highly encourage you to learn more by checking out [their website](#).

Engagement Board Co-chair update on the ALLFTD Investigators' Meeting

A perspective from Bradford Grems, Co-Chair of the ALLFTD Participant and Family Engagement Board



I had the privilege to attend the 2023 ALLFTD Investigator' Meeting in Denver in April. There was such a wonderful group of doctors, investigators, and study coordinators. I have been able to interact with some of them in the past with my participation in ALLFTD and my work on the ALLFTD Participant and Family Engagement Board, but this took it to another level. I was inspired by the latest advancements on projects and research from the experts. My confidence is renewed that we are all driving towards the mission to cure FTLD.

During the meeting, I was able to present information about the Participant and Family Engagement Board to the whole group there. This led to many follow up conversations with individuals that were attending the meeting. To be able to have a candid open conversation with someone while enjoying a meal together or walking outside was so impactful. The building of relationships that came from that has had a great impact of my collaboration with other people involved in ALLFTD.

The ALLFTD Investigator Meeting was a monumental event for all of us that attended. The mix of science, collaboration, fun activities, and the concentration on our mission was amazing. We truly have wonderfully dedicated people in the ALLFTD community, and I am happy to be a part of it.

ALLFTD Participant and Family Engagement Board

The ALLFTD Participant and Family Engagement Board (Board) was launched in 2022 to provide a platform that allows for sharing of information between ALLFTD study staff and study participants. The Board is comprised of current ALLFTD study participants and caregivers of study participants nominated by study site staff. The Board meets quarterly to advise on participant and family priorities and assist with the creation or improvement of public information about FTLD and the ALLFTD Study. If you have questions about the Board, you may reach us at info@ALLFTD.org.

Ever wondered what it's like to work on the ALLFTD study?

Read a perspective from one of our Research Study Coordinator's Ralitsa Kostadinova



My name is Ralitsa Kostadinova, and I am the Study Coordinator for the ALLFTD study at the Indiana Alzheimer's Disease Research Center. David Clark, MD, and I welcomed the ALLFTD study at our site in Summer 2021 and since then, we have been fortunate to meet a wide range of participants from across the United States. He and I have borne witness to substantive changes in ALLFTD that have crafted it to be a unique and useful opportunity for all of us to gain and spread our collective knowledge on FTLD.

I am a keen fan of reading the manuscripts in my free time and exploring what the ALLFTD researchers have most recently found. One of my favorite parts of the ALLFTD visit is the administration and grading of the neuropsychological assessments, even though they are lengthy. Each test has a distinct purpose. Testing cognition and behavior, this evaluation is a key asset to determine how an individual may carry out certain tasks and how cognitive functioning changes over time. This part of ALLFTD has inspired me to pursue a career in neuropsychology.

Outside of the visit session, several participants have called to ask for advice. Most calls have requested suggestions for long-term care facilities. In these situations, I connect them with our social worker and I check back with them to see if all matters have been resolved. I am very grateful to be surrounded by team members that help at a moment's notice. The passion to help families, whether they are part of ALLFTD or not, runs strongly at our facility.

On the first Tuesday of every month, Dr. Clark and I hold an FTD Caregiver Support Group meeting for caregivers to talk through any issues they've faced and to offer each other guidance and support. These caregivers find the support group to be a great way to connect with peers who really understand what they are going through. Our support group has been remote since the Covid-19 pandemic, but Dr. Clark and I are working to add an in-person factor. This support group reminds us that the FTD community is a strong-bonded group of individuals, leaning on each other for guidance.

Being a study coordinator for ALLFTD has been a great honor. I am very fortunate to work in tight collaboration with a physician as dedicated to this field of medicine as

Dr. Clark. The dedication to understand, diagnose, and eventually cure FTD is exhibited by every member of ALLFTD beyond the grounds of research.

Looking for more information about FTD?

Breaking Down the Science

Do you enjoy reading scientific publications? Use [this link](#) to review all publications related to ALLFTD. None of these important scientific works would be possible without your contributions.

RECENT PUBLICATIONS

AFTD Educational Seminar

Did you miss the AFTD 2023 Education Conference? Don't worry! You can watch all or some of the recorded sessions by visiting [their website](#).

Get in Touch with an ALLFTD Study Site

Interested in learning more or participating in ALLFTD? You can email our team at info@ALLFTD.org or you can check our list of sites on the [website](#) and reach out directly to a study team.

Thanks!

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

We hope you had a wonderful summer!

The ALLFTD Study Team

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.

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