



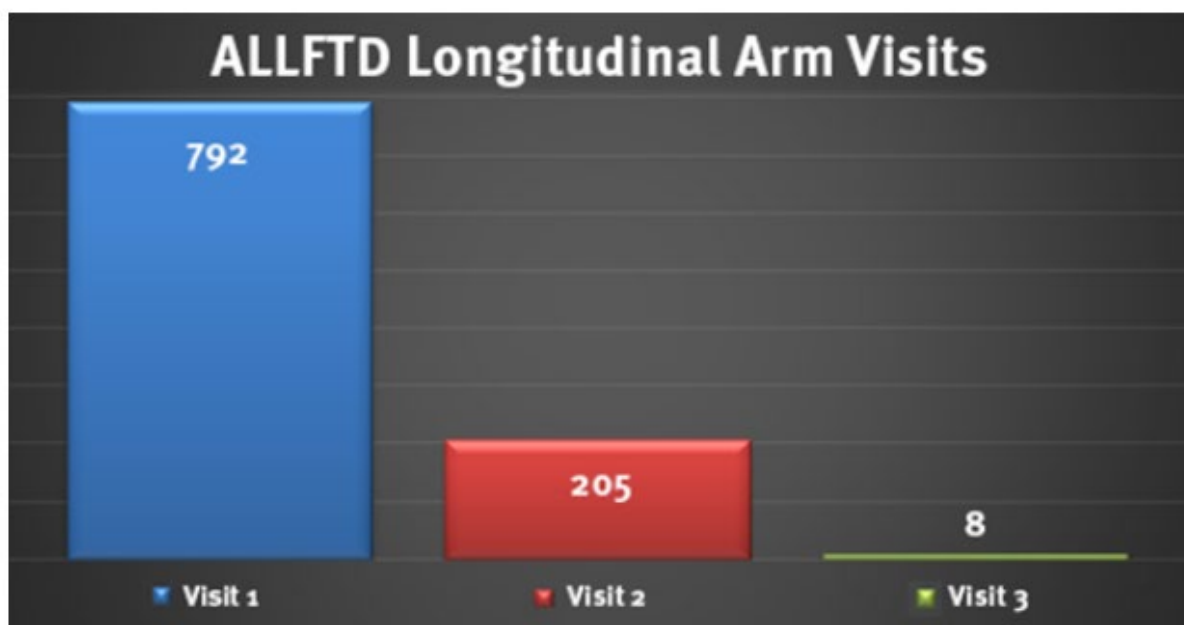
The ALLFTD Study

Summer 2022 Newsletter

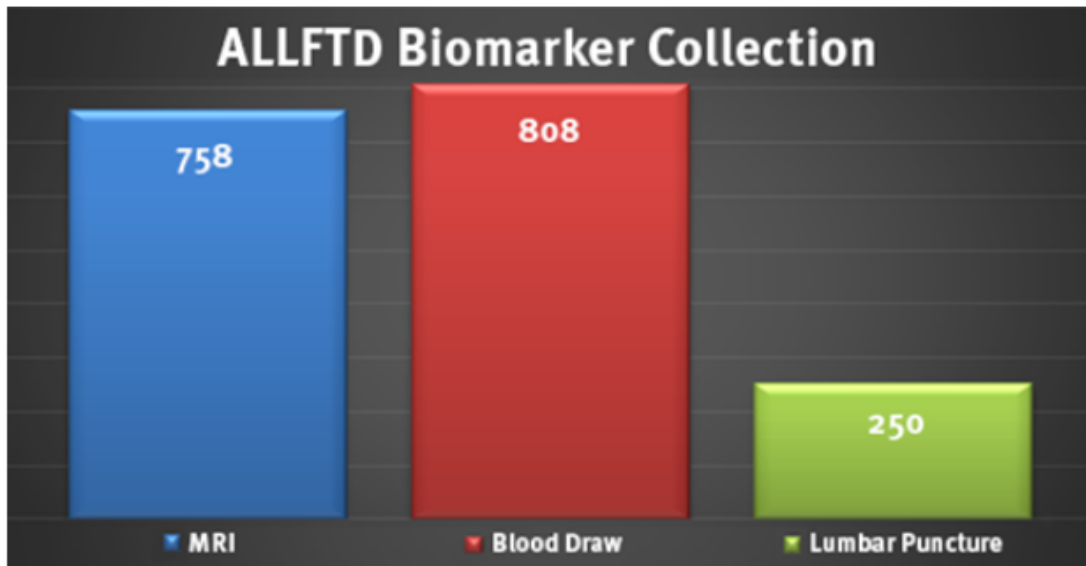
Thank you for being a participant in the ALLFTD Study. Here are some updates we wanted to share with you.

ENROLLMENT UPDATE

As of July 1, we have completed 1,097 visits: 1,005 in the Longitudinal Arm and 92 in the Biofluid-Focused Arm. Wow! We are so excited and impressed by everyone's willingness to participate in ALLFTD. Here is a breakdown of the number of Longitudinal Arm Visits completed so far:



Each Longitudinal Arm Visit generally includes a blood draw, MRI, and if you are willing, a lumbar puncture. Of the 1,005 Longitudinal Arm visits completed, we've collected the following:



Nearly 200 MRI scans were missed for Visit 1, mainly due to pandemic-related restrictions. We look forward to having more biomarkers* collected at upcoming visits.

***Biomarker Definition:** The National Institutes of Health (NIH) defines a biomarker as “a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacological responses to therapeutic intervention.” More simply stated, biomarkers are measures of what is happening inside the living body, shown by the results of laboratory and imaging tests. For example, an elevated PSA level may indicate prostate cancer; an elevated blood pressure reading may indicate high blood pressure. In dementia (in this case FTD), biomarkers are measurable markers in the blood, spinal fluid, levels of amyloid or tau pathology in the brain, and patterns of brain activity on functional MRI or PET scan.

Want to learn more about Digital Biomarkers? Review the summary of AFTD’s Summit on Digital Assessment Tools for FTD [Part 1](#) and [Part 2](#).

APP UPDATE

The ALLFTD Mobile App is a smartphone tool designed to remotely measure clinical manifestations of FTD through a brief battery of cognitive, motor, and speech/language tasks. ALLFTD is the first study to use a mobile app for remote data collection in sporadic and familial FTD.

ALLFTD participants who choose to participate complete 3 “Chapters” each including 10-12 tasks every 6 months. The study team estimates that each Chapter of tasks takes about 30 minutes total to complete.

In June 2020, participants at UCSF started enrolling in a pilot study using the App. Participants at other ALLFTD sites started enrolling about a year later. To date, 256 participants across 18 sites have enrolled. 107 participants have completed 6-month tasks, and 42 participants have completed 1-year tasks. So far:

- 70% of participants have completed all of the available tasks
- 70% of participants thought the Mobile App task instructions were very clear
- 12% of participants thought the instructions were mostly clear
- 98% of participants thought the time allowed to complete the tasks was acceptable
- 44% of participants reported completing the 30-minutes of tasks all at once
- 44% of participants reported completing the 30-minute tasks in the 3-day window for each Chapter
- 98% of participants reported the Mobile App text was large enough to read comfortably

When asked how difficult the tasks were, participants experienced a range of perceived difficulty:

- 14% reported the tasks as very easy
- 16% reported the tasks as somewhat easy
- 30% were neutral
- 35% reported the tasks as somewhat difficult
- 4% reported the tasks as very difficult

Although this is the first time a mobile app is being used for remote FTD data collection, these results are very encouraging. Thanks to our participant feedback within these reports, the ALLFTD Mobile App has been successfully launched as a tool to collect data among participants recruited from the UCSF Brain Health Registry. This initiative will help our future interpretations of ALLFTD Mobile App test results. Overall, we hope using remote smartphone tasks will help with challenges in FTD research, including early diagnosis and longitudinal monitoring.

Stay tuned as we continue to learn more! And thanks to those already using our Mobile App!

BUSINESS UPDATES

Due to the delayed start at many sites caused by COVID-19, the study will be extended.

To help with enrollment, we are expanding the ALLFTD network! During the next 12 months, the following new sites are expected to join the ALLFTD consortium:

- Emory University - Atlanta Georgia
- University of Texas Health Science Center at San Antonio
- National Institutes of Health (NIH) - Bethesda, Maryland

Enjoy Podcasts? The [Remember Me Podcast](#) produced a mini-series on ALLFTD. During June, two podcast episodes were released per week. One episode covers an ALLFTD visit procedure and the other discusses the science behind that procedure. Tune in to learn what it was like to participate: www.RememberMeFTD.com/listen

ALLFTD MANUSCRIPTS

Enjoy reading scientific publications? Use [this link](#) to review all of the publications related to the ALLFTD Study. You can read the summaries of recent publications by accessing the PDF file below:

RECENT PUBLICATIONS

None of these important scientific works would be possible without your contributions!

Thanks for participating in ALLFTD and all FTD-related research studies.

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ALLFTD Study
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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.