



ALLFTD Summer 2022 Newsletter - Manuscripts

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. Thanks for participating in ALLFTD and all FTD-related research studies. Recent publications are highlighted below:

The contribution of behavioral features to caregiver burden in FTL spectrum disorders

At each ALLFTD visit, study partners complete the Zarit Burden Inventory questionnaire which is aimed at assessing burden in Care Partners. 558 participants from ALLFTD (or previous studies ARTFL or LEFFTDS) were included in this analysis. The ALLFTD Investigators found that when the clinician indicated that the participant exhibited apathy or depression, the study partner reported feeling more burdened on the Zarit Burden Inventory. Additionally, the investigators found that when a clinician reported the participant having more behavioral symptoms (versus language or motor) the study partner reported feeling more burdened. These are important findings because they better illustrated the challenges FTL-study partners experience, and these are important findings when considering FTL clinical trial design and outcomes.

- [PubMed](#) – National Library of Medicine
- [Alzheimer's & Dementia](#) – Journal of the Alzheimer's Association

Proposed research criteria for prodromal behavioural variant frontotemporal dementia

Prodromal bvFTD, (prodromal is used to refer to the very initial appearance of symptoms) doesn't have very specific criteria for diagnosis. Early diagnosis is important for many reasons, but it's hard to provide a diagnosis if clear criteria doesn't exist. In this publication, a group of ALLFTD investigators reviewed data collected in ARTFL, LEFFTDS, and ALLFTD to try and create diagnosis criteria for prodromal bvFTD. The investigators coined a new term "mild behavioral and/or cognitive impairment in bvFTD (MBCI-FTD). This new diagnosis category will allow clinicians to provide a diagnosis when symptoms (behavioral or cognitive) are very mild and don't qualify for an overt diagnosis of bvFTD. To test their new criteria, the investigators applied it to group of ALLFTD participants and found that the new criteria correctly classified 74% with a false positive rate of less than 10% in a group of controls (participants without bvFTD or prodromal bvFTD). While more work needs to be done to further refine the criteria to be more specific, when tested in a cohort of those with prodromal Alzheimer's disease, the false positive rate of diagnosis was 11%-16% which is really impressive. Stay tuned for more work on this important new diagnostic criteria.

- [PubMed](#) – National Library of Medicine
- [Brain](#) – Oxford University Press Academic publication

Comprehensive cross-sectional and longitudinal analyses of plasma neurofilament light across FTD spectrum disorders

Neurofilament light (NfL) is a measure of neuroaxonal damage, or said differently, it's a measure of distressed neurons. As the neurons in your brain are negatively impacted by the changes associated with dementia, like FTD, they expel NfL into the space around them. These NfL proteins eventually make their way into your blood. This publication measures the levels of NfL in blood collected from ARTFL, LEFFTDS, and ALLFTD participants. This study, and others, have identified NfL as a promising FTD biomarker (see definition below). However, until this recent publication, scientists grouped every FTD syndrome together when analyzing NfL as a possible biomarker for different forms of dementia. The ALLFTD scientists that led this effort found that NfL levels were increased across every FTD syndrome and in those who carried an FTD mutation but were not yet symptomatic. They also found that NfL levels were associated with disease severity. Additionally, they found that before symptoms were identified in participants who carried an FTD mutation, the amount of NfL found in blood was higher than those who don't carry an FTD mutation but were the same age and sex.

- [PubMed](#) – National Library of Medicine
- [Cell Reports Medicine](#) – ScienceDirect