

ALLFTD

ARTFL LEFFTDS Longitudinal
Frontotemporal Lobar Degeneration

Demographics:

Age
Education
Sex
Race/Ethnicity
Handedness
Visit Number

Clinical Data

Primary Clinical Phenotype and Investigator Confidence Rating
PSP Rating Scale (PSPRS)
UPDRS
Schwab & England (SEADL)
Clinical Dementia Rating (CDR): see section below
Clinician's Global Impression –Severity (CGI-S)
Clinician's Global Impression – Change (CGI-C; when available)
NPI-Q
FAQ
Family Gene (if known)
Cortico-Basal ganglionic Functional Scale (CBFS; select participants only)

If your analyses require it, individual item scores can be provided for most ratings. Please inquire if you need detailed item scores.

FTLD Module (included in clinical data)

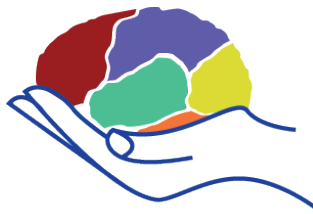
Social Norms Questionnaire
Social Behavior Checklist
Behavioral Inhibition Scale
Interpersonal Reactivity Index
Revised Self Monitoring Scale

Neuropsychology

Diagnostic: NACC UDS 3.0 Neuropsychology Battery

- MoCA
- Craft Story 21
- Benson Complex Figure
- Numbers forward and backward
- Category Fluency
- Trail Making Test (A&B)
- Multilingual Naming Test (A&B)
- Phonemic Fluency (F-words; L-words)





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Neuropsychology (continued)

Experimental: NACC UDS 3.0 FTLD Module Neuropsychology Battery

- Word Reading Test – Regular and Irregular Words
- Semantic Word-picture Matching
- Semantic Associates Test
- Northwestern Anagram Test
- Sentence Repetition Test
- Noun and Verb Naming Tests
- Sentence Reading Tests

Experimental: NIH EXAMINER – selected tasks and executive composite scores

Genetic Information

All participants are genotyped for mutations in FTLD-associated genes. The research results of this testing may be requested as part of the data set but require additional explanation of the necessity for your planned analyses.

Imaging Information

MRI scans are stored at the Laboratory for NeuroImaging (LONI) for a subset of participants. Access to images can be requested through [LONI](#). Images come with a minimal dataset. If these minimal data are not sufficient for your analyses, you may request additional clinical data following the [clinical data request process](#) and should provide a list of IDs you have selected for image download.

Biospecimens

Biofluid specimens are available through [NCRAD](#) by request. All samples are distributed blinded and unblinding occurs once the results are returned. The unblinding provides a minimal clinical data set; if you want more detailed clinical data after unblinding, please provide the date of the request along with the project title and PI in your [clinical data request](#).