



Demographics:

Age
Education
Gender
Race/Ethnicity
Handedness
Visit Number

Clinical Data

Primary Clinical Phenotype and Investigator Confidence Rating
PSP Rating Scale (PSPRS; all items provided)
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)

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)



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 ARTFL/LEFFTDS 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. If you indicate on your data request that your analyses require images, the dataset provided will include information on the availability of scans, scan quality, and temporal proximity (in days) to the clinical data.

Biospecimens

ARTFL/LEFFTDS biofluid specimens are available through NCRAD by request. All samples are distributed blinded and provided with minimal clinical data. If you have completed a biospecimen request and want detailed clinical data once you've returned the results for unblinding, please provide the date of the request along with the project title and PI.