

## Frontotemporal Dementia: Genes, Images and Emotions

### Summary

- **Study director:** [Bruce Miller, MD](#)
- **Sponsor:** National Institute on Aging
- **Recruiting?:** Yes
- **Official study title:** Frontotemporal Dementia: Genes, Images and Emotions
- **Conditions studied:** [behavioral variant frontotemporal dementia \(bvFTD\)](#) , [semantic dementia \(SD\)](#) , [progressive nonfluent aphasia \(PNFA\)](#) , [primary progressive aphasia \(PPA\)](#) , [frontotemporal dementia with amyotrophic lateral sclerosis \(FTD-ALS\)](#) , [corticobasal degeneration \(CBD\)](#) , [progressive supranuclear palsy \(PSP\)](#) , [Alzheimer's disease \(AD\)](#) , [amyotrophic lateral sclerosis \(ALS\)](#) and [healthy aging](#)
- **Purpose:** The purpose of this study is to help understand the clinical, genetic, imaging, emotional and diagnostic features of frontotemporal dementia (FTD). The study will collect longitudinal clinical, imaging, behavioral and autopsy data to be analyzed with the goal of improving clinical care for patients with FTD.

### Eligibility

- **Inclusion criteria:** Participants must be between the ages of 35 and 80 and meet criteria for either the [frontotemporal dementia \(FTD\)](#) , [Alzheimer's disease \(AD\)](#) , [corticobasal degeneration \(CBD\)](#) , [progressive supranuclear palsy \(PSP\)](#) , [amyotrophic lateral sclerosis \(ALS\)](#) or [healthy aging](#) group. Participants will need a reliable study partner who has frequent contact with the participant, is available to provide information about the participant, and who can accompany the participant to research visits as needed. Participants must be willing and able to have brain MRIs through the course of the study and have a Mini Mental State Exam (MMSE) score of 15 or greater at time of screening. Anyone not meeting these criteria will need to be approved by the [Study Director](#) .
- **Exclusion criteria:** A history of Korsakoff encephalopathy, alcohol abuse or dependence within 5 years of the onset of dementia, substance abuse, head trauma with a loss of consciousness greater than 30 minutes, brain tumor, multiple sclerosis, epilepsy, Parkinson's disease, communicating or non-communicating hydrocephalus, schizophrenia, bipolar affective disorder, intracerebral hemorrhage, B12 deficiency, hypothyroidism, HIV positive, renal failure, liver failure, respiratory failure requiring oxygen, dementia due to a condition other than those described above, cerebral infarct, large white matter lesions, significant systemic medical illness. Current medication likely to affect CNS functions: benzodiazepines more than three times weekly, no diazepam or triazolam but other short-acting benzodiazepines are fine; no amitriptyline or doxepin, SSRIs and other tricyclics are fine; no lithium; no neuroleptics in the phenothiazine or haloperidol families; no narcotics, codeine is fine but cannot be taken for 24 hours prior to cognitive testing; no anticonvulsants outside therapeutic ranges; and no antihistamines taken more than three times

weekly, cannot be taken for 24 hours prior to cognitive testing.

## What is involved?

- **Testing:** Neurological and physical examinations; interview with study partner; MRIs; cognitive testing; detailed family history; blood specimen collection for genetic testing and cell line generation; behavioral, emotional and personality testing; questionnaires for participant and study partner; pre-consent to obtain a brain autopsy. Participants will be asked to participate in additional studies affiliated with this project.
- **Frequency of visits:** Depending on the individual, there will be 4 to 6 visits over a three month period of time, each year for up to five years. Participants may choose to participate as an inpatient, staying in Moffitt Hospital in the Clinical & Translational Science Institute (CTSI) Clinical Research Center, and complete the visits in one week or as an outpatient and spread the visits out over three months.
- **Materials needed prior to evaluation:** MRI scan and medical records
- **Costs:** No costs will be charged for any of the study procedures. For those who choose to stay in the hospital, there are no costs associated with the stay. Parking will be validated for Millberry Parking Garage for study visit. Participants are responsible for their travel and hotel, should they choose to stay in one.

## Contact information

- **Coordinator:** [Robin Ketelle, RN, MS](#) , 415-514-2058