



# Perspectives on Research Plenary: Research Coordinator

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# Overview

- ▶ Why participate in FTD research?
- ▶ Common participation concerns
- ▶ Types of research opportunities available for FTD patients and their caregivers
- ▶ What to expect during a typical research visit
- ▶ How look for research studies
- ▶ Questions



# Why do we do FTD research?

- ▶ FTD research provides the opportunity to understand the disease, its symptoms, its changes and how it affects family and caregivers.
- ▶ It is necessary in advancing treatments, services and technology.
- ▶ For participants– it may provide sense of meaning and purpose within this devastating disease.
- **Many of our research participants often state that they want to help others and contribute to science**



# Common Concerns and Questions

- ▶ What is the purpose of the study?
- ▶ What are the study's procedures?
- ▶ What can I expect on the day of a research visit?
- ▶ How long will the research last?
- ▶ How do I benefit?
- ▶ Will my information be kept confidential?
- ▶ How will the results be disseminated?
- ▶ How will the investigator benefit ? conflicts of interest ?
- ▶ Why should I volunteer?
- **Research Consent form**, provided with most research studies usually addresses many of the concerns by participants



# Types of Research Opportunities

- ▶ There is a wide range of studies that you can participate in
- ▶ Research studies range in time intensity or personal burden
- ▶ The primary clinical studies include:
  - ▶ Observational clinical studies
  - ▶ Clinical trials
  - ▶ Registries
    - ▶ **FTD Disorders Registry** [www.FTDregistry.org/](http://www.FTDregistry.org/)
- ▶ Brain Donations



# What to expect on the day of the visits

- ▶ Not much preparation before the visit is needed
- ▶ There is travel time– most studies take place at study sites.
- ▶ There is time investment– depending on the type of research study the visits may be from 1-4 hours.
- ▶ Examples of study procedures include cognitive testing, caregiver/study partner questionnaires, brain scans, lab collection, ECG
  - ▶ *Some studies request that participants fast prior to labs*
- ▶ Participants are provided breaks in between procedures and as requested.
- ▶ Meal breaks are provided
- ▶ Additional support staff is available to assist with impaired participants
- ▶ **Not every question or procedure has to be completed** – most times participants can ask to skip a question or task that makes them uncomfortable/frustrated
- ▶ The research visit can be stopped at any time if the participant no longer wants to participate or does not feel well
- **Not every situation is the same—most visits are tailored to address specific needs of research participants.**



# How do you find research opportunities?

- ▶ Ask your providers
- ▶ ClinicalTrials.gov
- ▶ Association for Frontotemporal Degeneration ([theaftd.org](http://theaftd.org))
- ▶ Research Institutions (e.g., universities, industry research sites)
- ▶ Community events
- ▶ Internet/ Social media
- ▶ Support groups



# Research Opportunities at UCLA Behavioral Neurology FTD participants & Study Partners

## FOXY ➤ *Interventional*

*Intranasal Oxytocin for Frontotemporal Dementia*

- bvFTD
- FTD semantic
- FTD progressive nonfluent aphasia

## ARTFL ➤ *Observational*

*The Advancing Research and Treatment for Frontotemporal Lobar Degeneration*

- frontotemporal dementia (FTD)
- primary progressive aphasia (PPA)
- corticobasal degeneration (CBS)
- progressive supranuclear palsy (PSP)

## Biogen 992FD001 ➤ *Observational*

*Cognitive Change in behavioral-variant FTD*

- bvFTD

## ALLFTD ➤ *Observational (upcoming)*

*ARTFL + LEFFTDS (Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects)*

- FTD
- PPA
- CBS
- PSP

- FTLD related gene mutation: *MAPT*, *GRN* or *C9ORF72*

## EOAD Phenotypes ➤ *Observational*

*Early-onset AD Phenotypes*

- Healthy controls