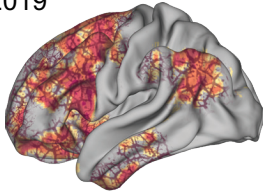
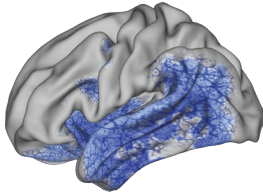


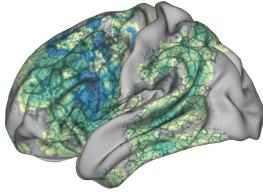
Behavioral Variant of  
Frontotemporal  
Dementia (bvFTD)



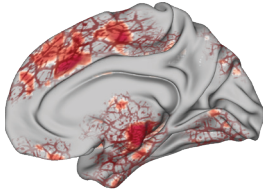
Semantic Variant of  
Primary Progressive  
Aphasia (svPPA)



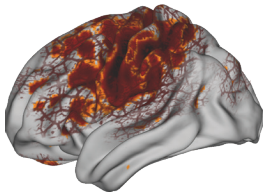
Non-Fluent Variant of  
Primary Progressive  
Aphasia (nfvPPA)



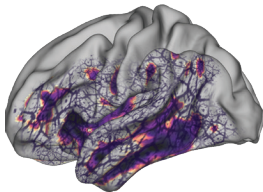
Progressive  
Supranuclear Palsy  
(PSP)



Corticobasal  
Syndrome (CBS)



bvFTD with  
Amyotrophic Lateral  
Sclerosis



## Study Sites

### Sites

Case Western Reserve University, Cleveland  
Cleveland Clinic Lou Ruvo Center for Brain Health,  
Las Vegas  
Columbia University in the City of New York  
Houston Methodist Hospital, Nantz National  
Alzheimer Center  
Johns Hopkins University, Baltimore  
Massachusetts General Hospital, Boston  
Mayo Clinic, Jacksonville  
Mayo Clinic, Rochester  
Northwestern University, Chicago  
UCLA, Los Angeles  
The University of Alabama at Birmingham  
The University of British Columbia, Vancouver  
University of California, San Diego  
University of California, San Francisco  
The University of North Carolina at Chapel Hill  
University of Pennsylvania, Philadelphia  
University of Toronto  
University of Washington, Seattle  
Washington University in St. Louis

### Contact your site:

Find more information at  
[www.allftd.org/sites](http://www.allftd.org/sites).

# ALLFTD Biofluid Study



**ALLFTD**  
ARTFL LEFFTDS Longitudinal  
Frontotemporal Lobar Degeneration

This project aimed at understanding the changes in brain function that occur as a result of Frontotemporal Lobar Degeneration (FTLD) syndromes. FTLD syndromes can include bvFTD, bvFTD with ALS, PPA, PSP, or CBD.

We can learn about changes in your brain a variety of ways, including a clinical examination, memory and thinking tests, and measuring biomarkers in your blood or cerebral spinal fluid (CSF). These biomarkers are different proteins that we think change in response to disease progression.

If you've been diagnosed with a FTLD syndrome and are interested in helping us

learn more about FTLD, please consider participating in our ALLFTD Biofluid Study.

### **Why am I being asked to participate in the ALLFTD Biofluid Study?**

You're being asked to participate in the ALLFTD Biofluid Study because you've been diagnosed with a FTLD syndrome like bvFTD, bvFTD with ALS, PPA, PSP, or CBD.

### **What happens in the ALLFTD Biofluid Study?**

The ALLFTD Biofluid Study is a one-time visit that may overlap with another clinic visit. We will have you complete some questionnaires, meet with a clinician for a neurological exam, and you will have your blood drawn. If you're

willing to do a lumbar puncture, we will also collect your cerebral spinal fluid. After your visit we will follow up with you a few times over the next few years.

### **Where can I find more information about the study?**

You can find more information about the study on our website at [www.allftd.org](http://www.allftd.org).

### **I am interested in participating. What do I do next?**

Please tell your neurologist that you'd like to participate in the ALLFTD Biofluid Study. The contact information for ALLFTD study coordinators is on [www.allftd.org](http://www.allftd.org). You can also email your site's study coordinator to let them know you'd like to join.

## **FTLD Syndromes Described**

### **Behavioral Variant of Frontotemporal Dementia (bvFTD)**

Early symptoms in bvFTD usually include loss of interest in previously enjoyed activities (apathy), loss of empathy, loss of knowledge about how to behave in social situations (disinhibition), and fixations or obsession about certain topics or ideas.

### **Primary Progressive Aphasia (PPA)**

The main symptoms are early and progressive language difficulties. Spoken and written words are affected. Words lose their meaning and there can be issues recognizing objects and people in the semantic variant, or there is difficulty in getting words

out so speech seems hesitant and effortful in the non-fluent variant.

### **Progressive Supranuclear Palsy (PSP)**

Those with PSP have difficulty moving combined with other problems including social-emotional function, cognitive functions, or language, depending on which parts of the brain are involved. Movement problems include stiffness and slowness of the body, poor balance with falling, and trouble moving the eyes.

### **Corticobasal Syndrome (CBS)**

CBS is identified by movement difficulty combined with other problems including

social-emotional function, cognitive functions, or language challenges. Early symptoms are worsening stiffness that affects one side of the body (arm or leg) and similar language, cognitive, or social-emotional changes as those seen in bvFTD and PPA.

### **bvFTD with Amyotrophic Lateral Sclerosis**

Often referred to as *motor neuron disease*, ALS (sometimes called Lou Gehrig's disease) is caused by degeneration of nerves in the brain and spinal cord that control muscles. The main symptoms are weakness, twitching, and atrophy (shrinking) of the muscles in the limbs, torso, neck and face, usually starting in one part of the body and spreading to others.