

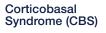
FTLD Syndromes

Behavioral Variant of Frontotemporal Dementia (bvFTD)



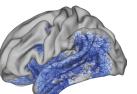
Non-Fluent Variant of Primary Progressive Aphasia (nfvPPA)

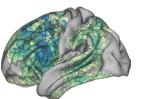
Progressive Supranuclear Palsy (PSP)



bvFTD with Amyotrophic Lateral Sclerosis







Find more information at www.allftd.org/sites.

Study Sites

Alzheimer Center

Mayo Clinic, Jacksonville Mayo Clinic, Rochester

UCLA, Los Angeles

University of Toronto

Contact your site:

Case Western Reserve University, Cleveland

Columbia University in the City of New York

Houston Methodist Hospital, Nantz National

Johns Hopkins University, Baltimore Massachusetts General Hospital, Boston

Northwestern University, Chicago

University of California, San Diego

University of Washington, Seattle Washington University in St. Louis

University of California, San Francisco

University of Pennsylvania, Philadelphia

The University of North Carolina at Chapel Hill

The University of Alabama at Birmingham The University of British Columbia, Vancouver

Cleveland Clinic Lou Ruvo Center for Brain Health,

Sites

Las Vegas

ALLFTD Biofluid Study







approved August 11, 202

ALLFTD is a multisite research 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 in a variety of ways, including a clinical examination, memory and thinking tests, and measuring biomarkers in your blood or cerebrospinal fluid (CSF). These biomarkers are different proteins that we think change in response to disease progression.

If you've been diagnosed with an 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 an 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 cerebrospinal 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 <u>www.allftd.org</u>.

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

Please tell your neurologist that you would like to participate in the ALLFTD Biofluid Study. The contact information for ALLFTD study coordinators is on www.allftd.org. You can also email your site's study coordinator to participate.

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, impulsiveness, 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, or there is difficulty in getting words out so speech seems hesitant and effortful.

Progressive Supranuclear Palsy (PSP)

Those with PSP have stiffness and slowness of the body, poor balance with falling, trouble moving the eyes, and also problems with social skills, judgment, language, and thinking abilities.

Corticobasal Syndrome (CBS)

CBS is identified by worsening stiffness that affects one side of the body (arm or leg) and

similar language and behavioral problems as those seen in bvFTD and PPA.

bvFTD with Amyotrophic Lateral Sclerosis

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