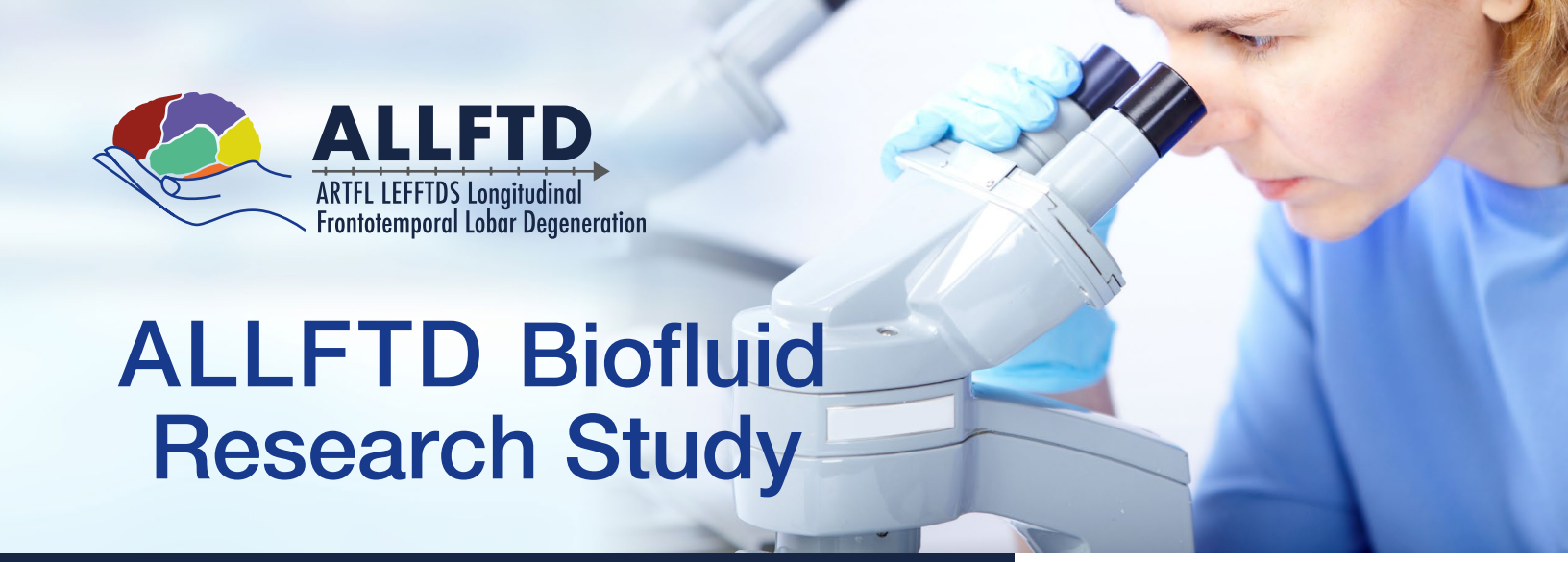


ALLFTD
ARTFL LEFFTDS Longitudinal Frontotemporal Lobar Degeneration

ALLFTD Biofluid Research Study

ALLFTD is a multisite research study 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 are interested in helping us learn more about FTLD, and you've been diagnosed with an FTLD syndrome or are at risk due to your family history, please consider participating in our ALLFTD Biofluid Research 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 www.allftd.org.

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.

Study Sites

Brown University
Case Western Reserve University/University Hospitals Cleveland Medical Center, Cleveland
Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas
Columbia University in the City of New York
Emory University, Atlanta
Houston Methodist Hospital, Nantz National Alzheimer Center
Indiana University
Johns Hopkins University, Baltimore
Massachusetts General Hospital, Boston
Mayo Clinic, Jacksonville
Mayo Clinic, Rochester
Mt Sinai, New York City, New York
National Institutes of Health (NIH), Bethesda
Northwestern University, Chicago
University of Alabama at Birmingham
University of British Columbia, Vancouver
University of California, Los Angeles
University of California, San Diego
University of California, San Francisco
University of Colorado Denver
University of Michigan
University of North Carolina at Chapel Hill
University of Pennsylvania, Philadelphia
University of Texas Health Science Center at San Antonio
University of Toronto
University of Washington, Seattle
Vanderbilt University
Washington University in St. Louis

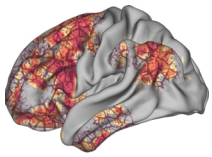
Contact your site:

University of California Los Angeles, Los Angeles
Alexander Sheppard
ASheppard@mednet.ucla.edu
(805)338-2858

More information at www.allftd.org/sites.
Contact us at info@allftd.org.
IRB00227492. Drs. Boeve, Boxer, and Rosen.

FTLD Syndromes

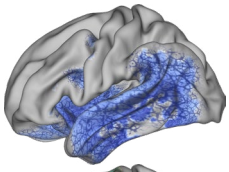
Behavioral Variant of Frontotemporal Dementia (bvFTD)



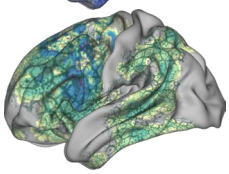
Behavioral Variant of Frontotemporal Dementia (bvFTD)

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.

Semantic Variant of Primary Progressive Aphasia (svPPA)



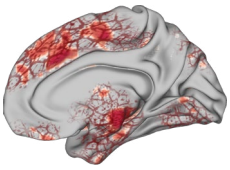
Non-Fluent Variant of Primary Progressive Aphasia (nfvPPA)



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.

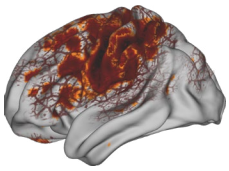
Progressive Supranuclear Palsy (PSP)



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.

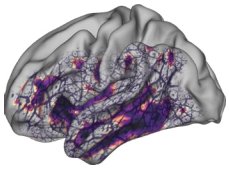
Corticobasal Syndrome (CBS)



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



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.