JOHNS HOPKINS MEDICINE

Approved December 17, 2019

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. Some forms of FTLD are genetic, while others are not. ALLFTD is interested in all forms of FTLD.

We can learn about changes in your brain a variety of ways, including a clinical examination, memory and thinking tests, and MR imaging of your brain. We also measure different proteins in your blood or cerebral spinal fluid (CSF) 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 a FTLD syndrome or are at risk due to your family history, please consider participating in our ALLFTD Longitudinal Study.

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.

ALLFTD Longitudinal Study

ALLFTD
ARTFL LEFFTDS Longitudinal Frontotemporal Lobar Degeneration

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Who is eligible to participate in the ALLFTD Longitudinal Study?

You're being asked to participate in the ALLFTD Longitudinal Study because you've either:

1. Been diagnosed with a FTLD syndrome like bvFTD, bvFTD with ALS, PPA, PSP, or CBD
2. Are from a family with a mutation in a gene known to cause FTLD (such as C9orf72, MAPT, and GRN)
3. Have a significant family history of FTLD suggesting a familial genetic mutation.

If you are from groups 2 or 3, you don't have to have symptoms to participate and you don't need to know your mutation status to participate.

What happens in the ALLFTD Longitudinal Study?

The ALLFTD Longitudinal Study is an annual visit to the clinic, each lasting 2–3 days. We will have you complete some questionnaires, meet with a clinician for a neurological exam, have your blood drawn, some memory and thinking questions, and a MRI. If you're willing to do a lumbar puncture, we will also collect your cerebrospinal fluid.

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?

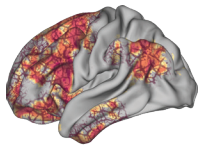
Please tell your neurologist that you'd like to participate in the ALLFTD Longitudinal Study. You can also find contact information for ALLFTD site study coordinators at www.allftd.org and can also email a coordinator to let them know you'd like to join. We suggest you choose the site most convenient for you.

FTLD Genetics

Familial FTLD (f-FTLD) occurs in about 30% of FTLD cases where multiple members of a family are affected. This occurs due to changes in the genetic code called mutations, which are associated with a high risk of developing FTLD during a person's lifetime. These mutations follow an autosomal dominant inheritance pattern, meaning each child of someone with a mutation has a 50% risk of inheriting the mutation. Mutations that cause f-FTLD can present with any FTLD syndrome, and in a given family each affected individual can potentially present with a different syndrome. There are three gene mutations commonly associated with f-FTLD (*MAPT:* microtubule associate protein tau; *GRN:* progranulin; and *C9orf72:* chromosome 9 open reading frame 72), however through research studies like this one we are learning about other mutations that cause f-FTLD.

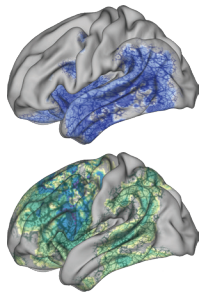
FTLD Syndromes

Behavioral Variant of Frontotemporal Dementia (bvFTD)



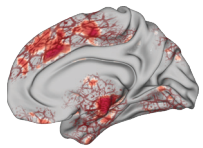
Early symptoms in bvFTD usually include loss of interest in previously enjoyed activities (apathy), loss of empathy, loss of knowledge about how to behave in social situations (disinhibition), and fixations or obsession about certain topics or ideas.

Primary Progressive Aphasia (PPA)



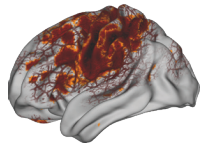
The main symptoms are early and progressive language difficulties. Spoken and written words are affected. Words lose their meaning and there can be issues recognizing objects and people in the semantic variant, or there is difficulty in getting words out so speech seems hesitant and effortful in the non-fluent variant.

Progressive Supranuclear Palsy (PSP)



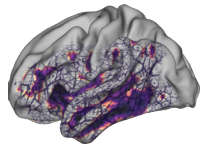
Those with PSP have difficulty moving combined with other problems including social-emotional function, cognitive functions, or language, depending on which parts of the brain are involved. Movement problems include stiffness and slowness of the body, poor balance with falling, and trouble moving the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