

NSP FACT SHEET

Neurofilament Light
SURVEILLANCE PROJECT (NSP)

WHAT IS FRONTO-TEMPORAL LOBAR DEGENERATION (FTLD)?

* FTLD is a fatal brain disease that is a common cause of neurodegeneration in people under the age of 60

* FTLD is characterized by a progressive degeneration of the frontal portions of the brain, the regions responsible for language and behavior

* There are currently no approved treatments or cures for FTLD

* Genetic FTLD is passed down in families. The majority of genetic FTLD is caused by a mutation in one of three genes: *C9orf72*, *MAPT* or *GRN*

WHAT IS THE NSP?

• The Neurofilament Surveillance Project (NSP) is a longitudinal biomarker study. The study's goal is to evaluate levels of the protein neurofilament light chain (NfL) in the blood of individuals who are members of a family with genetic FTLD.

• NfL is a protein primarily found in brain axons that is released when neurons are damaged or die. For example, NfL levels in the blood are elevated after traumatic brain injury and in neurological disorders. Prior work suggests that NfL levels in the blood of people with FTLD-causing mutations may rise shortly before symptom onset.

• This is important because being able to identify FTLD and respond before irreversible brain degeneration takes place is critical to giving patients the care they need, and even more importantly, to know when to provide potentially life-saving therapies.

FAST FACTS:

• NSP is an ancillary study to the ALLFTD natural history study (allftd.org).

• Data collected are de-identified to protect participant privacy.

• NfL will be measured using Quanterix's Simoa® neurofilament light chain assay. Further assays to be determined.

• Participating sites include: Columbia University, Johns Hopkins University, Massachusetts General Hospital, Mayo Clinic (Jacksonville and Rochester), University of California, San Francisco, University of Pennsylvania, and Washington University in St. Louis.

• The NSP is a pre-competitive consortium comprising academic researchers, medical foundations and biopharmaceutical companies.

• Study funders include Alector, the Alzheimer's Drug Discovery Foundation, Arkuda Therapeutics, Biogen, the Bluefield Project to Cure FTD, Ionis Pharmaceuticals, Janssen Pharmaceuticals, Inc., Passage Bio and UCB Biopharma SRL. Additional consortium members may join as the study proceeds.

HOW IT WORKS



MORE INFO: nspstudy@bluefieldproject.org



www.allftd.org/nsp