JOHNS HOPKINS MEDICINE

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NSP FACT SHEET

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.

HOW IT WORKS

1 Participants enroll at their ALLFTD study site

2 A research nurse visits at a place of partipant's choosing and draws a blood sample for the study

3 Thirteen visits happen over three years

4 Blood samples are analyzed for levels of NfL and other biomarkers

Neurofilament Light
SURVEILLANCE PROJECT (NSP)

FAST FACTS:

• **NSP is an ancillary study** to the ALLFTD natural history study (all-ftd.org).

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

• **Participating sites include:** Columbia University, Johns Hopkins University, Massachussetts 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.

RESEARCH STUDY

Application No. IRB00232792

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