

Thursday

The Neurofilament Surveillance Project (NSP): A biomarker study to sample blood quarterly in familial frontotemporal lobar degeneration

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State of the Art

In familial FTLD plasma levels of neurofilament light (NfL) are elevated at least two years prior to symptom onset and predict future clinical status. The Neurofilament Surveillance Project (NSP) will obtain more frequent sampling of plasma NfL to better understand its clinical utility. The NSP is a pre-competitive collaboration sponsored by the Bluefield Project to Cure FTD and funded by biotechnology and pharmaceutical companies and nonprofit organizations.

Methodology

Participants must be members of families with disease-causing mutations in *C9orf72*, *MAPT* or *GRN* and enrolled in the ALLFTD natural history study. Up to 335 participants will provide plasma quarterly for 3 years to enable the observation of peripheral NfL levels longitudinally during disease onset and progression. Plasma is collected by certified mobile research nurses during remote visits. NfL measurements will be correlated with annual cognitive and neuropsychiatric assessments in the ALLFTD study. Additional plasma aliquots are reserved for future analyses and distribution after the study ends.

Results

As of 23-05-2022, the NSP had enrolled 209 participants, including 88 from *C9orf72* kindreds, 70 from *MAPT* kindreds, and 38 from *GRN* kindreds. 174 participants had completed their initial visit, and 106 had completed more than 3, and up to 7, quarterly blood draws. Enrollment and study visits are ongoing despite COVID-related limitations.

Conclusions

The quarterly blood sampling from this study, combined with annual comprehensive clinical assessments through ALLFTD, will enable a more detailed understanding of when and how NfL levels change during phenoconversion and/or disease progression in f-FTLD.

Conflicts of interest

The author is a clinical research and regulatory consultant and performs services for Meditrina, Inc., Healyx Labs, and multiple start-up clients under Beacon Launch Partners LLC