

SOPHIA

SOPHIA aimed to develop optimally informative biomarkers for ALS and establish stakeholder agreements regarding their use. This has been achieved by defining, validating and harmonizing optimal methodologies that can be reliably implemented within a pan-European framework program.

The SOPHIA project resulted in a European web-based data and sampling infrastructure including a Progeny database for a centralised collection of the core clinical data, imaging and neurophysiological biomarker data (MRI and MUNIX) and neuropathology data; harmonized MRI and neurophysiological biomarker protocols and validated procedures, including a repository for MRIa (NiSALS); Standard Operation Procedures (SOPs) for collection and storing of biosamples, and a multi-lingual validated protocol for cognitive screening of ALS patients (ECAS). A consortium of ALS centres for clinical ALS research and biomarkers has been set up (TRICALS), embedded in the existing European Network to Cure ALS (ENCALS) for continuation of the SOPHIA effort beyond its timeframe.

The provision of a common European strategy for the prioritization and selection of candidate biomarker domains for optimization and harmonization provides a solid platform by which existing collaborative structures that are relevant to neurodegenerative disease biomarkers (including academic initiatives, co-funding strategies, biobanks, industrial efforts, private-public alliances) are integrated within an inclusive web-based virtual biobank. The established platform acts as an communication channel between this consortium and the broader international ALS/Neurodegenerative Diseases field, to ensure that the optimization efforts are consistently applied.

The results of SOPHIA offer a solid basis for future pan-European clinical patient-oriented research projects.