SOPHIA

Sampling and biomarker OPtimization and Harmonization In ALS and other motor neuron diseases

Project lifespan: 2012-2016

WHY?

Amyotrophic Lateral Sclerosis (ALS) represents a promising model for the study of neurodegenerative conditions, as it has a characteristic phenotype, rapid progression and the correlation between diagnosis during life and autopsy diagnosis is close to 100%.

However, validated neurochemical biomarkers for monitoring disease activity, for generating earlier diagnoses and for defining prognosis are lacking. Standardised protocols for clinical data and sample collection are required for optimisation and harmonisation of biomarker development.

OBJECTIVE

SOPHIA aimed to develop optimally informative biomarkers for ALS and establish agreement regarding their use by defining, validating and harmonising optimal methodologies that can be reliably implemented.

ACHIEVEMENTS

SOPHIA established a new European web-based data and sampling infrastructure, resulting in:

- A Progeny database for the centralised collection of core clinical data, imaging and neurophysiological biomarker data (MRI, MUNIX) and neuropathology data
- Harmonised MRI and neurophysiological biomarker protocols and validated procedures, including a repository for MRIa (NiSALS.org)
- Standard Operating Procedures for the collection and storing of biosamples
- A multi-lingual validated protocol for the cognitive screening of ALS patients (ECAS)
- A common European strategy for the prioritisation and selection of candidate biomarker domains for optimisation and harmonisation

This “virtual biobank” functions as a communication channel with the broader international ALS/Neurodegenerative Diseases field, ensuring that optimisation efforts are consistently applied.

NEXT STEPS

A consortium of ALS centres for clinical ALS research (TRICALS.org) was set up and embedded in the existing European Network to Cure ALS (ENCALS.eu) for the continuation of the SOPHIA project beyond its timeframe.

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This is a JPND-supported project.
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