

Dear SOPHIA-members,

It was good to see many of you at our annual meeting in October in London, along with European partners in the other ALS JPND projects. This was a first attempt to make our research project meetings more efficient and we will organise a similar event in 2015 together with the project coordinators of ALS-CarE (Orla Hardiman & Alice Vajda), STRENGTH (Ammar Al-Chalabi & Anna Kulka) and NEEDS in ALS (Dorothee Lulé). This will be the last official SOPHIA annual meeting, as the project finishes in June 2015. We will need to deliver an annual report over 2014 to JPND by 31 January 2015, and a final report to JPND, for which we will be in touch around April next year.

SOPs

These are the SOPs currently available through the SOPHIA website:

- [Brain dissection](#)
- [Blood & urine sample collection](#)
- [DNA purification](#)
- [ALS Core clinical dataset](#)
- [ECAS](#)
- [MUNIX](#)

Progeny

Now that the core clinical dataset has been confirmed, we are implementing all final adjustments in the templates in the Progeny database, also in the MUNIX and neuropathology templates. We will create dedicated folders for all your organisations, so you can actually start your data collection. We are finalising an updated version of the Progeny guideline to help you when necessary.

The data sharing agreement as drafted by UMC Utrecht will be finalised shortly, so data can be shared following clear rules and guidelines by all partners whenever needed.

TRICALS

As discussed at the annual meeting, SOPHIA needs to think about the continuation of its efforts after the project officially finishes. Funding needs to be secured so a long-term plan needs to be devised (this what work package 4 in SOPHIA is all about). Biomarkers are becoming more and more important, also in clinical research. This goes for imaging (MRI), neurophysiology (MUNE/MUNIX) as well as wet biomarkers (CSF, blood).

In September 2013, Leonard van den Berg presented the idea of establishing a consortium of ALS centres for clinical research (trials) and biomarkers. All participating (European) centres use European standards for EMG, MRI, clinical data, staging in ALS, etc. (as developed by SOPHIA and other efforts) and a structure for continuous quality control as developed by SOPHIA, which can be attractive to companies developing new drugs. The consortium could offer its experience and several services in executing more efficient and enhanced ALS clinical research to the pharmaceutical industry, and this way maintain itself.

At the ENCALS meeting in December 2013 in Milan, Leonard highlighted the idea of a *Treatment Research Institute for the Cure of ALS* once more. 'TRICALS' would become a platform where ALS centres, ALS patients and the pharmaceutical/biotech industry can easily find each other. Through transparent communication and enhanced global collaboration it will speed up the clinical research process and the translation of candidate compounds into clinical trials, in order to find an effective treatment for ALS sooner.

The plans for TRICALS have now been put into action. TRICALS has thus far been developed by Leonard van den Berg, Ammar Al-Chalabi, Orla Hardiman and Adriano Chio and in the summer of 2014 a TRICALS website was launched in The Netherlands (www.tricals.org). The website was built together with Accenture, who offered their services for free.

Patients can fill in and update their personal and medical details and scorecards like ALS-FRS-R regularly. These details can be used to match patients to new trials and the trial criteria. This way TRICALS can immediately show the estimated amount of patients available for a certain new (investigator-initiated or sponsored) trial, and they can be easily contacted through the system. ALS centres can view and communicate with the patients that are connected to them through the platform.

The next steps are to translate the website (currently only in English and Dutch) into Italian and launch the site in the UK, Ireland and Italy, expand further after that. We will keep you posted!

For more details on progress in the different workpackages, please consult the [minutes of the recent annual meeting](#).

Acknowledgement of JPND on your publications for SOPHIA

We have checked once more and the acknowledgements as defined before (see below) should be followed. However, if objections are made by a scientific journal, it would be okay for an individual paper to just include those institutions that correspond to the authors on the paper.

ACKNOWLEDGEMENT (long)

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ACKNOWLEDGEMENT (short)

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Warm regards,
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