

Dear SOPHIA-members,

It was good to see many of you at our annual meeting in September and again at the International ALS Symposium 2013 and the satellite ENCALS meeting in Milan last week. I hope that you enjoyed the symposium as much as I did. Great to hear about the first the results of the ECAS validation effort from Sharon Abrahams and the ongoing efforts to set up a prospective study on staging in ALS.

#### **JPND projects meeting 24 January 2014**

At our last meeting we discussed combining meetings for SOPHIA and the newly awarded JPND-projects ALS CarE, STRENGTH and NEEDS in ALS, as there is much overlap in project partners and topics. These new projects will start officially in February of the coming year. A final date for the combined kick-off meeting of these projects has now been confirmed, this will be Friday 24 January.

As we recently had our own meeting and we are looking to organise a small satellite meeting again for SOPHIA during the ENCALS meeting in May, we feel it is not necessary to really include SOPHIA in the meeting of January 24th. However, due to the overlap and several of our SOPHIA-partners being involved in the new projects, of course SOPHIA-topics might be discussed at certain moments. In the future we probably will be looking to really include all JPND-projects in one meeting, most likely it will then be a 1.5- or 2-day meeting.

If you have not received an invitation to the meeting in January yet but you are interested and would like to join the meeting in London in January, please do let us know, you are very welcome to!

#### **Progeny**

Payment arrangements for sharing the costs of the Progeny services for the next 3 years have been made. Invoices have been send to all SOPHIA partners except two. I hope to finalise this process before year end, thanks for your cooperation so far.

Progeny has released an update to their system mid-November (Progeny 9). We are working with Progeny to include this update in our set-up. As soon as this has been realised, we will finish the set-up of the database including data tabs for core clinical data, MUNIX, MRI, neuropathology, ECAS, etc. (in collaboration with the respective WP/project leaders) and provide you all with log-in details. I expect this to be mid-January. A SOP for use of the core clinical dataset is currently being written by my colleague Anne Visser together with Jan Veldink and we hope to distribute this along with the login details. Jan Veldink is working on a data sharing agreement which will be distributed shortly as well.

#### **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, 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 Milan last week, Leonard highlighted the idea of a *Treatment Research Institute for the Cure of ALS* once more. 'TRICALS' will 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.

#### **MUNIX training course**

On Friday 22 November Christoph Neuwirth and Markus Weber organised a final full-day MUNIX training course for SOPHIA partners in St. Gallen. After a theoretical part in the morning the focus was on practical hands-on training and demonstration of the most crucial pitfalls and sources of errors in the afternoon. The course was well-attended, very interesting and a lot of fun (so I heard!). Big thanks to Christoph for the organization!

#### **SOPHIA website**

We are a bit behind with launching the SOPHIA website but aim to do so before the end of January next year. We will report all projects within SOPHIA on this site, a link to the Progeny database for SOPHIA partners and we'll upload all available SOPs.

#### **Minutes annual SOPHIA meeting 27 September 2013**

Attached to this email you will find the minutes of the annual meeting on 27 September 2013.

#### **JPND progress report**

We have to report progress by 31 January 2014 to the JPND Joint Call Secretariat. Work package and other project leaders will be approached shortly to provide their updates.

Hope you'll have a great holiday season,

Warm regards,

**Barbara Thuss**