

Report on the Current Activities of the WFN Research Group ALS/MND (Chair Prof. Dr. A. C. Ludolph) - 2011

We achieved the following goals and planned the following activities:

1. Collaboration of the WFN Research Group for ALS/MND (Prof. Dr. Albert C. Ludolph) and the WFN Research Group for Aphasia and Cognitive Disorders (Prof. Dr. Thomas Bak, Prof. Dr. Fakundo Manes)

We teamed up with the research group for Aphasia and Cognitive Disorders; this is justified since ALS and FTD now form a spectrum; this is true for both, the clinical and the molecular approach to the diseases. We did the following:

- a. We organized educational programs together (see also 4.) in order to facilitate genetic and epidemiological studies, in particular in the Third World.
- b. We organized meetings to establish educational programs in India, China, Mongolia and South America (Columbia, Cuba). The final goal of this is the formation of local networks of excellence (LNE).
- c. We teamed up to develop a screening test for frontotemporal deficits in ALS patients to facilitate research in epidemiological registers.
- d. We organized a symposium on the next world congress of neurology (Vienna 2013) collaboratively.

2. Establish Guidelines for the Generation and Use of Biological Samples

With financial support of our group, Prof. Markus Otto has gathered a group of neurochemists, CSF specialists and geneticists out of the FTD and ALS/MND field to define guidelines for the preprocessing of samples. This group met twice to establish standard operating procedures and road maps to find “wet” biomarkers for the disease.



These guidelines were published in the journal of the WFN research group of ALS/MND. In Europe, we coorganized a European Program (SOPHIA) for common standards for preprocessing, SOPs and distribution of results on biomarker research; Prof. Marcus Otto will establish a round robin in the important European research labs. This program is cofinanced by the EU. We are in close

contact with our North American colleagues and will distribute the data with the help of the WFN Research Group

3. Established Guidelines for Neuroimaging Biomarker

We also see that the development of Neuro Imaging biomarkers is necessary for our field. Therefore we organized with substantial financial support of our group the NISALS (Neuro Imaging Symposium In ALS). This group met twice in 2011 in Oxford (Leader of the group Martin Turner)



and in Jena (Julian Großkreutz). The goal of this group is financing and establishing imaging markers for longitudinal assessment of ALS patients (for the use in clinical trials) and imaging biomarkers which could be used for early diagnosis. The paper on the published guidelines (Turner et al, Lancet Neurology 20011) is attached. A photograph of the group is attached.

4. Educational Programs for the Third World/Developing Countries (together with the WFN Research Group for ALS/MND Group and Aphasia and Cognitive Disorders)

We have established teaching seminars in the third world and developing countries. This was done together with the WFN research group for Aphasia and Cognitive Disorders. The following seminars have been organized and held:

- a. Kolkata – 8th – 11th of January 2012
- b. Beijing – 21st – 23rd of June 2012
- c. Mongolia – 24th – 26th of June 2012
- d. Cuba – 2012
- e. Columbia – 2012

We originally planned to have a teaching course in Africa to also establish a local network of excellence. Since we wanted to hold this in Mali we regretfully cannot meet this year because of the civil war. We are actively looking for alternatives.

5. Revision of the El Escorial Criteria

We got the finances and made up a roadmap for the revision of the El Escorial Criteria. The goals of the revision include earlier diagnosis improved adjustment to clinical practice, inclusion of electrophysiology and inclusion of the new knowledge of the overlap to frontotemporal dementias. The latter will be achieved with the help of the WFN Research Group on Aphasia and Cognitive Disorders. The milestones (in brief) will be the following one:

- I. Kick-off meeting in Chicago December 2012 (already financed, Symposium organized)
- II. Meeting of the Working Groups in 2013 (most likely in Madrid El Escorial, Spain)
- III. Final Consens Conference in El Escorial, Spain in January/February 2014

6. Support for the ALS Journal

The editorship for Prof. Orla Hardiman who did a very good job for the journal and for the entire ALS community has been renewed. We adjust the title of the journal to the new developments of an association of ALS and FTD.

7. Website of the Research Group

We transferred the website from the US to Europe; not unexpectedly, this met with large difficulties, but we succeeded in late 2011. Now the website of the ALS MND Group is renewed and constantly updated.

8. Meeting of the Board Members

A Meeting of the Board Members of our group took place in Sydney in December 2011. In addition, we organized and financed a symposium to discuss the current progress in ALS research.



Prof. Dr. A. C. Ludolph