

Report on the Activities of the WFN Research Group ALS/MND 2013

Chair: Prof. Dr. A. C. Ludolph

We achieved the following goals and performed the following activities:

 We continued the close 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. Facundo Manes)

The following activities were done collaboratively:

- a. Organization of educational programs worldwide (see also 4).
- b. We established local networks of expertise for MND in Beijing and Ulaanbaatar. The next step is a joined effort with the WFN Research Group for Aphasia and Cognitive Disorders at these respective places (Network for ALS and FTD).
- c. A screening test for frontotemporal deficits in ALS has been developed collaboratively (Abrahams S, Newton J, Niven E, Foley J, Bak TH. Screening for cognition and behaviour changes in ALS. Amyotroph Lateral Scler Frontotemporal Degener. 2013 Jun 19. [Epub ahead of print]).
- d. A collaborative Symposium on the World Congress of Neurology was performed.
- e. A collaborative educational program was performed in Columbia August 2013.
- f. We build up a group in Europe in the framework of the European Academy of Neurology, which combines the efforts of the ALS and FTD group.
- 2. The NISALS-Group was further organized (Neuro-Imaging in ALS).

The group continued their efforts for the standardisation of Imaging Biomarkers in ALS. In December 2013, the group met in Milano to discuss standards and guidelines for imaging in ALS.

Educational programs for developing countries, together with the WFN Research Group for ALS/MND and the Group for Aphasia and Cognitive Disorders. a) We performed an educational course in Columbia at the location of the yearly meeting of Colombian Neurologists in Cartagena in August 2013. The workshop was

organized with the support of Prof. Gustavo Roman.

b) We are still interested in performing workshops in Africa. The political circumstances

did not permit this during 2013.

4. Revision of the El Escorial Criteria

We are in the process to revise the El Escorial Criteria. For that purpose

a) We met in Chicago December 2012, had lively discussions and wrote up a paper

which identifies strengths and weaknesses of the criteria. This paper which

summarises the discussions is currently under submission.

b) The WFN Research Group on MND met in Frankfurt on the 4th of May 2013 to

discuss the weaknesses identified in Chicago and produced a paper, which

should be the bases of further discussions.

c) At the MNDA- Meeting in Milano a further discussions of these revisions took

place. We concluded that we have a public discussion for the suggestions made

in Frankfurt on the website of the ALS MND Group.

5. Support for the ALS Journal

In 2011 the Editorship for Prof. Orla Hardiman has been renewed. We replaced Prof.

Reinhard Dengler with Prof. Thomas Bak, who represents the close relation of ALS to

the FTDs. We changed the name of our journal to "Journal for ALS/MND and FTD".

6. The Website of the research group is in place and is working.

7. A Meeting of the board members of our group took place in Milano in 2013.

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Prof. Dr. A. C. Ludolph