



Report on the Activities of the WFN Research Group ALS/MND 2014

Chair: Prof. Dr. A. C. Ludolph

We achieved the following goals and performed the following activities:

1. 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 (including activities in India, Ecuador and Europe (EAN)).
- b. We established local networks of expertise for MND in Beijing and Ulaanbaatar. The next step is a joint 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.* 2014;15:9-14).
- d. A collaborative group for ALS and FTD at the European Academy of Neurology was established. The first meeting of the group will be in Berlin 2015.
- e. A collaborative educational program was planned for Quito Ecuador in January 2015.

2. The NiSALS-Group expanded its activities (Neuroimaging Society in ALS).

The group for Neuroimaging in ALS finished its first multicenter study for diffusion tensor imaging. In December 2014, the group met in Leuven to discuss options and guidelines for imaging in ALS.

3. Educational programs for developing countries, cooperation with the WFN Research Group for ALS/MND and the Group for Aphasia and Cognitive Disorders.

- a) We performed an educational course in Quito Ecuador January 2015.
- b) We tried to establish workshops in Africa, however like in 2013, the political circumstances did not permit this. In addition, sadly Prof. Moussa Traore died unexpectedly in 2014.

4. Revision of the El Escorial Criteria

The process to revise the El Escorial Criteria has been finished.

- a) After meetings in Chicago (December 2012), Frankfurt (May 2013) and Milano (December 2013) a discussion on the internet (Webpage <http://www.wfnals.org/>; from WFN ALS MND group) took place.
- b) After this public discussion the new criteria were finished, they were written up and distributed to the members.
- c) The final discussion took place in Brussels in December 2014, resulting in the proposal that the not-attending members of the WFN group should have the opportunity to discuss them again on the internet (01.01.2015 until 15.03.2015). After this has taken place, the new El Escorial Criteria were submitted and accepted at our Journal (Journal for ALS/ MND and FTD- Webpage: <http://www.wfnals.org/Downloads.html>).

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". We also added some members to the editorial board, who work in close relation to FTD.

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

7. Internal matters

- a) A Meeting of the board members of our group took place in Brussels in 2014.
- b) Sadly, our elected board member, Prof. Imaharu Nakano, died in July 2014. Prof. Ryuji Kaji (Japan) will step into his place.



8. Other business

We initiated an initiative for Staging of ALS / MND. These staging efforts

- follow clinical rules and are headed by Prof. Ammar Al-Chalabi, London and Prof. Adriano Chio, Turino.
- follow the neuropathological rules – established by Prof. Brettschneider and Prof. Braak in 2013.

9. Listing of active members

- **Albert Ludolph:** University of Ulm, albert.ludolph@rku.de, since 2010-today.
- **Orla Hardiman:** Beaumont Hospital & Trinity College, oral@hardiman.net, since 2010-today.
- **John Ravits:** Research University of California, jravits@ucsd.edu, since 2010-today.
- **Jeremy Shefner:** St. Joseph's Hospital and Medical Center, Jeremy.Shefner@DignityHealth.org, since 2010-today.
- **Liyang Cui:** Peking Union Medical College Hospital, pumchcuily@sina.com, since 2014-today.
- **Ryuji Kaji:** Tokushima University Hospital, rkaji@clin.med.tokushima-u.ac.jp, since 2015-today.
- **Adriano Chio:** Universita di Torino, achio@usa.net, since 2014-today.



Prof. Dr. A. C. Ludolph