



## **Report on the Activities of the WFN Research Group ALS/MND 2012**

Chair: Prof. Dr. A. C. Ludolph

We achieved the following goals and planned 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)**

We teamed up with the Research Group for Aphasia and Cognitive Disorders. The following activities were done collaboratively:

- a. Organization of educational programs worldwide (see also 4).
- b. We started 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 (S. Abrahams et al. in press).
- d. A collaborative Symposium on the next World Congress of Neurology (Vienna 2013) is organised.

**2. Guidelines for the generation and use of biological samples in ALS/MND:**

The guidelines for the generation and use of biological samples in ALS have been published by Prof. Otto in 2012. The guidelines were financed by our RG.

**3. The Neuro-Imaging Group for ALS/MND has been constituted the NISALS-Group (Neuro-Imaging in ALS).**

The group continued the efforts for the standardisation of Imagery Biomarkers in ALS. In December 2012, the group met in Miami to discuss standards and guidelines for imaging in ALS.

**4. Educational programs for developing countries, together with the WFN Research Group for ALS/MND and the Group for Aphasia and Cognitive Disorders.**

We have performed teaching seminars in the 3<sup>rd</sup> World and developing countries.

- a) The first teaching course took place in Kolkata between the 8<sup>th</sup>- 11<sup>th</sup> of January 2012. The meeting was attended by more than 200 people. On the basis of this meeting we tried to establish a local network of expertise.

However currently there is not enough financial support for a ALS/MND Registry in New Delhi, as this has been planned with Prof. Gourie-Devi. To obtain funds collaboratively, Prof. Gourie-Devi visited Ulm in October 2012.



- b) A second educational course took place in Beijing between the 21<sup>st</sup> -23<sup>rd</sup> of June 2012. Prof. Cui Liying hosted the meeting. On the basis of this meeting we were able to establish a local network of expertise with support of the Sino-German-Science-Centre. A registry with a common data basis will be in place in late 2013. We are planning to make the data comparable with other places in the world.



- c) A teaching course took also place in Ulaanbaatar, Mongolia between the 24<sup>th</sup> -26<sup>th</sup> of June 2012. On the basis of this teaching course we established a registry for ALS starting its work on the 1<sup>st</sup> of January 2013. This uses similar questionnaires as the EURALS- consortium in Europe and is comparable with the Beijing Registry. However, at writing there is no definite financial support.



- d) We are planning an educational course in Columbia at the occasion of the yearly meeting of Columbian Neurologists in Cartagena in August 2013. This will also be done together with the WFN Group for Aphasia and Cognitive Disorders. The workshop was organised with the support of Prof. Gustavo Roman.
- e) We had to postpone our workshop in Africa because of the civil war in Mali. Originally we planned to meet in November in Mali, as supported by Prof. Moussa Traòre. We are currently in contact with Prof. Moussa Traòre to reorganise a teaching course.

## **5. Revision of the El Escorial Criteria**

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

I, We met in Chicago December 2012, had lively discussions and wrote up a paper which identifies strength and weaknesses of the criteria.

II, the WFN Research Group on MND will meet in Frankfurt on the 4<sup>th</sup> of May 2013 to discuss how to improve the identified weaknesses.

III, at the next MNDA- Meeting in Milano, there will be a discussion to reach consensus about the weaknesses.

## **6. 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".

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

**8. A Meeting of the board members of our group took place in Chicago in 2012.**



Prof. Dr. A. C. Ludolph