GRANT REPORT FOR THE WORLD FEDERATON OF NEUROLOGY

TITLE OF PROJECT: Cognitive Clinics Worldwide

SPONSORING GROUP AND LEADERS:

Research Group on Aphasia and Cognitive Disorders (RG ACD) (Dr. Thomas H Bak, Chair, Dr. Facundo Manes, Co-Chair) In collaboration with the Research Group on Motor Neuron Disease (RG MND)

(Dr. Albert Ludolph, Chair)

OBJECTIVES (as in the original grant application)

- 1. To improve the knowledge about cognitive disorders in neurology
- 2. To encourage neurologists to set up cognitive clinics and to offer guidance how to run them
- To promote a better understanding of cultural and linguistic context of cognitive disorders
- 4. To establish robust and lasting structures for the dissemination of knowledge

DEFINITION OF COMPONENTS

- 1. Regional Teaching Courses: The teaching courses are the basis for the dissemination of knowledge. They are jointly designed by the WFN RG ACD, WFN RG MND and the local organisers, with a particular attention devoted to specific features of cognitive disorders in each region.
- **2. Expert Workshops:** Due to take place before or after the Teaching Courses; they allow the national and international faculty to discuss clinical as well as research issues, including the development of collaborative projects. They also lead to the formation of LNE (see below).
- **3. Local Networks of Expertise (LNE):** Bring together regional experts with the aim of taking over the organisation of future teaching courses and offering advice to clinicians. To this end they create websites to provide guidance for clinicians running cognitive clinics.
- **4. Cognitive Clinics Worldwide Task Force:** a representation of the LNE's at the Biennial Meeting of the WFN RGACD will organise a **symposium** updating members of the group about its activities.

ACHIEVED MILESTONES

The first Regional Teaching Course in INDIA

The first of the three planned **Regional Teaching Courses** took place 6-7 January in Kolkata. The international faculty consisted of TH Bak, J Snowden, B Chakrabarti, F Manes and A Ludolph (the president of the WFN RG ALS). The national faculty included A Dutt, A Pauranik, A Biswas, J Rajeswaran, E Ratnavalli, M Tripati, P Mukhopadhyay, S Pal, S Khanna, SK Chengappa, S Alladi, PS Mathuranath and A Ghosh. The programme combined practical sessions on how to conduct and interpret cognitive tests with updates on the latest developments in the field of aphasias, dementias and stroke. The emphasis was put on topics of particular relevance in Indian context, such as linguistic and cultural factors and bilingualism. The course was attended by 221 delegates. The feedback was overwhelmingly positive; some participants wished three-day courses in future. A course report (posted at the WFN RGACD webpage on the WFN website) is attached to this report.

The teaching course was followed by an **expert workshop**, bringing together the international faculty and **LNE for India**. The workshop discussed future courses, joint projects and test adaptations and validations. It became apparent that one of the biggest problems facing cognitive clinics in India is the limited availability of cognitive tests translated into Indian languages and adapted to the social, cultural and linguistic characteristics of the relevant populations. In order to address this issue, the LNE created a **website** providing information about the cognitive materials, tests etc available in Indian versions: http://www.wfnteachcogn.in. The website, which will be constantly updated and extended, also includes a list of relevant publications and information about future teaching courses. The next teaching course is due to take place in spring 2013 in Bangalore. The WFN RGACD is currently negotiating with the Academy of Aphasia the plan of a joint organization of this course.

A member of the LNE for India, Dr. Amitabha Gosh from Kolkata is organizing jointly with colleagues from South America, Asia and Europe a **symposium** about different presentation of dementia across the world. The symposium will be held at the Biennial Meeting of the WFN RDACD in Hyderabad, 9-12 December 2012.

Summarising, the January 2012 meeting in Kolkata has reached all its planned objectives: the dissemination of knowledge to clinicians, an impetus for further research through the expert workshop, the establishment of the website for new cognitive clinics and the planning of the next teaching course next year. The experience of our teaching courses in India has established a well-functioning model, from which we can learn for our activities in other parts of the world.

Further Courses

The second course will take place in two weeks time, 21-23 June in Beijing. All the arrangements for the national and international faculty are in place. The combined representation of the WFN RG's for Aphasia and Cognitive Disorders and for MND will be particularly timely, since we will be able to present and discuss the relevant and much debated recent discoveries of the C9ORF72 gene from the point of view of MND as well as FTD. Apart from its teaching aspect, the meeting is also designed to establish the LNE for China and lead to the establishment of a website containing information and testing material in Chinese. Dr. Suvarna Alladi from Hyderabad, who will be speaking at this meeting, will share the Indian experiences of establishing an LNE and a dedicated website with our Chinese colleagues. This direct connection between the different LNE's was an important part of the grant proposal and we hope that it will help in establishing direct links between India, China and South America. A full report will be sent within few weeks after the teaching course.

The third teaching course will take place in January 2013 in Cali/Colombia. The details will be discussed at the meeting of WFN RGACD and WFN RGMND representatives during the Beijing Teaching Course.

Summarising, the progress in terms of teaching courses and LNE foundation has been very good. The intervals of ca. 6 months between individual courses allow us to evaluate the experiences from previous courses and incorporate them into the planning of the next one. Originally, we were considering having the course in Colombia before the one in China, but although this order has now been changed due to logistical reasons (China: June 2012, Colombia: January 2013), the overall structure of the project remains the same.

CONCLUSIONS/FURTHER STEPS

The establishment of the LNE's and their websites constitutes a lasting contribution to the development of cognitive clinics in the regions we are covering in this project: India, China and South America. The LNE's will form an integral part of the WFN RGACD and will be supported by it.

In terms of securing a lasting future for the teaching courses, our Indian experience shows that with time the local organisers are able to take over more and more organizational and financial responsibility for their continuation. Although small external funds will still be necessary for the foreseeable future, their contribution will gradually decrease. Moreover, we are continuously working to identify other sources of funding, particularly in form of joint courses held together with other organisations (e.g. Academy of Aphasia), a solution which can bring academic as well as financial advantages by brining together the expertise of different organisations.

In 12 months time, in June 2013, we hope to be in situation in which India has already successfully completed its third teaching course (and planning the fourth), while China and South America are preparing the second one. By that time, all three websites will be operational, linked to the WFN website and constantly updating their information. By then, we will be also working to identify further regions for future activities of the cognitive clinics worldwide programme. We will have also consolidated the links between the RG ACD and RG MND, leading to further joint projects.

We are deeply grateful to the WFN to have given us the chance to work on this project

Dr. Thomas H Bak (on behalf of the WFN RG ACD and MND)