

CREST NEWS UPDATE

November 2004

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Epilepsy is the world's most common brain disorder, affecting some 50 million people worldwide. There is general agreement that stigma and exclusion are common features of epilepsy in both the developed and developing countries and a major contributor to the burden associated with the condition. Reducing the stigma of epilepsy is therefore key to reducing its impact and so improving quality of life.

In order for effective health policy initiatives to be implemented to reduce the stigma of epilepsy, a number of issues first need to be addressed. These include addressing cultural variations in the meaning attached to having epilepsy and hence the way in which stigma is played out; and defining appropriate outcomes and methods for assessing them. The Collaborative Research on Epilepsy and Stigma (CREST) project will address these issues and so inform about the development of culturally appropriate approaches to reducing stigma and discrimination.

The project will involve ethnographic studies to explore prevailing beliefs and attitudes to epilepsy in two developing countries, China and Vietnam. It will define theoretical models of stigma and its link to disease burden. It will develop validated and culturally specific measures of outcome for use in future intervention studies. Through its implementation, the project will enhance social science research capacity in these two countries and facilitate development of strong collaborations for future related research activities.

This is the first newsletter of the Collaborative Research on Epilepsy and Stigma (CREST) Project.

The CREST NEWS UPDATE will focus specifically on activities related to the Project as well as updating you on new initiatives and developments.

If you have any suggestions concerning this newsletter then please do not hesitate to contact us at the correspondence address (see page 2).

The Project is made possible through a grant, which was awarded by the Fogarty

1. Publications
The review article on Stigma in Epilepsy, commissioned by Lancet Neurology, has been submitted. It will now be sent for peer review, but will hopefully be accepted for publication.
An article about the project recently appeared in Red Brick, the new University of Liverpool newsletter, which will receive very wide circulation.

2. Meeting in Bangkok
A very successful meeting took place in Bangkok, Thailand, in late August, which was attended by many members of the research team, including Dang Vu Trung, Professors Li Shi Chuo, Wenzhi Wang and Jianzongh Wu, Ann Jacoby, Gus Baker, Hanneke de Boer, and the chairman of the Advisory Group Professor Jerome Engel Jr.

During this meeting the protocols for the ethnographic studies, which will commence in early 2005, were revised.

Joint site visits to Vietnam and China by Ann Jacoby and Gus Baker have been planned to take place in early 2005.

Furthermore it was decided to produce posters featuring the results of the rapid appraisals and giving general information concerning the project, amongst others about the CREST Team.



The CREST Investigators, sitting in the centre Dean John Coldwell from Liverpool University

The posters were made by Dee Snape and mailed to the entire team.

3. BIEF

Ann Jacoby, Gus Baker and Hanneke de Boer travelled to China on 20th October, to take part in the First International Beijing Epilepsy Forum, organised by Professors Li Shi Chuo, Jianzhong Wu and Wenzhi Wang.



Life was tough in China!??

Ann gave a presentation on "The Stigma of Epilepsy", Gus spoke about "Psychological and Neuropsychological Sequelae of

Epilepsy" and Hanneke presented a paper on "Living with Epilepsy in the Developing world" and she gave an introduction on "The Global Campaign Against Epilepsy".



From left to right: Wenzhi Wang, Ann Jacoby, Gus Baker, Hanneke de Boer, Jiangzong Wu in the Great Hall of the People in Beijing

During their visit to China, Ann, Gus and Hanneke together with Professors Wu and Wang met with anthropologists from Beijing University, who will assist with the training for and execution of ethnographic studies. It is hoped that the training will now commence in both Vietnam and China in January 2005.

4. Networking meeting

Ann Jacoby travelled to Washington DC, USA on 11th October to attend an NIH networking meeting for researchers funded under the 'Brain Disorders' funding call. Ann displayed the two CREST posters and gave a brief oral presentation to the other delegates on the progress of the project.

5. Workshop on Stigma

Ann Jacoby, Gus Baker and Ria Reis will take part in a 4-day workshop on Stigma in Chronic Illness, which will be held in the Netherlands in December. 55 delegates, representing stigma research across a range of chronic conditions, will take part therefore the workshop will represent an important networking opportunity.

6. Update Literature Review

Dee is now a grandmother! Currently she is updating the literature review. If anybody has any further thoughts on appropriate journals for inclusion in the review, please email them to Dee (dsnape@liverpool.ac.uk) as soon as possible.



Grandmother

7. Capacity Building

As part of the capacity-building element of the project, Dee Snape has registered to do her PhD, entitled 'The Differences in Being Different: A narrative study of the nature of epilepsy and stigma'.

Editorial contacts

Mrs. Hanneke M. de Boer
Global Campaign Against Epilepsy

Stichting Epilepsie Instellingen Nederland

P.O. Box 21, 2100 AA Heemstede

The Netherlands

Tel: + 31 23 55 88 412

Fax: + 31 23 55 88 419

Email: hdboer@sein.nl

Prof. Gus Baker

The Walton Centre, Rice Lane

Liverpool L9 1AE

UK

Tel. + 44 151 529 4146

Fax: + 00 44 151 529 5503

Email: g.baker@liv.ac.uk