

Wales Dementias and Neurodegenerative Diseases Research Network - NEURODEM Cymru

Notes of second Steering Group meeting held at the Welsh Institute of Sport, Cardiff on Tuesday, 3rd October 2006

Present

Mr Tom Woods	NHS Trusts in Wales
Dr Tony Bayer	Cardiff University
Professor Johannes Thome	University of Wales Swansea
Mrs Elizabeth Morgan	Cardiff & Vale NHS Trust
Professor Bob Woods (Chairman)	University of Wales Bangor
Dr Olivia Handley	Cardiff University
Dr Huw Morris	Cardiff University
Dr Charles Twining	Carers Wales
Mr Gareth Morgan (Coordinator)	University of Wales Bangor

1. Apologies

I Thomas, J Gallagher, M Warner, J Meara, D Seddon, A Rosser, D Linden, C Thomas-Wylie, L Clare, S Hatch, R Williams.

2. Notes of Steering Group meeting held on 22 February 2006

2a. Accuracy.

These were accepted as a correct record subject to including the following amendment:-

Item 8 – Identification of other interested parties. It was decided to make enquiries about the possible inclusion of the MS Society on the Steering Group. **Action GM**

2b. Matters arising.

Item 3a: Constitution.

It was noted that the constitution for the European Huntington's Research Network could provide useful guidance for new studies to be run on the NEURODEM Network. The NEURODEM Cymru Steering Group meetings would be convened and organised as described in the original submission (previously circulated) to WORD.

Item 7: Title for the network.

Professor Woods thanked everyone who contributed to the debate and decision making process and confirmed that NEURODEM Cymru had been nominated by a large proportion of members, and subsequently adopted as the brief title for the network.

Item 8: Identification of other interested parties.

Old Age Psychiatry. Awaiting response from all Wales group.

Pharmaceutical Industry. There was concern about liaising with the Wales Industry Group which focused on marketing, and it was decided that the "prescribing" members of the group should consider more appropriate means of establishing contacts, with a view to acquiring some additional and appropriate support for NEURODEM Cymru.

Action: AB/HM to lead

Local Health Boards. Awaiting nomination to replace Alan Lawrie, CEO, Denbighshire LHB who had recently taken up a new post in Scotland.
Pathology. Dr Jim Neal to be invited to attend future meetings.

Action: GM

3. Brain Bank

Professor Thome gave an overview of the meeting he had convened on 3 August 06, Chaired by Dr Huw Morris. Dr Morris outlined the contents of a discussion paper, currently in draft form, which had subsequently been circulated to those present for further comment. During the meeting it had been evident that there was much support for the concept of establishing a Brain Bank for Wales. However, it was appreciated that such a development would incur significant infrastructure costs, some of which may relate to the needs of NEURODEM Cymru and/or the Epilepsy Research Network. It was agreed that the discussion paper would be circulated to members of the Steering Group as soon as it had been approved by all members present at the meeting on 3rd August.

Action: HM

4. Work Programme

Professor Woods introduced the quarterly progress report for the period 1 June to 31 August 2006 inclusive. The following were highlighted during discussion:-

a) Activity 2 - User and carer participation. Mr G Morgan introduced the outline agreement which had been developed in consultation with Alzheimer's Society Wales. There was broad support for the initiative and the following amendments were approved during discussion:

- Key principles, no. 2 - MS Society to be included with the other named voluntary sector partners.
- General aims, no. 4. Adopt and broaden the Alzheimer's Society QRD process in order that lay people, primary care-givers and service users are able to establish priorities for research projects.....
- Objectives, no. 5. Arrange adequate training and support for service users and care-givers

Action: GM

b) Activity 3 - Web site: www.neurodem.org.uk . This had been developed by Lesley Prendergast, NEURODEM Cymru Information Officer (e mail: neurodem@bangor.ac.uk) and was live as from 30 June 2006. Dr Morris made reference to the potential of providing information/newsletters for specific patient groups. All members were invited and encouraged to submit any suitable information for inclusion: text, photographs, links to other sites

Action: All members

c) Activity 5 – Protocol for patient participation in projects.

Professor Woods reported that NEURODEM Cymru had succeeded in acquiring special project funding for one year from CRC Cymru in order to employ a Data Manager. The purpose of the role holder would be to prepare a data base to register patients /carers consenting to be approached about approved research, but with no obligation to participate in any particular project. The initial opt-in procedure would involve the minimum of demographic information and diagnosis etc. It was envisaged the work would build on the achievements of the European and UK Huntington's disease registries. The Data Manager would work with the Brain Repair Group, Cardiff University and take up post early in 2007.

Action BW/AR

Members were pleased to receive notice of this development. Following discussion it was considered prudent to seek agreement about the basic demographic details for inclusion in the proposed register, which would be required in order to apply for ethical approval. It was agreed that draft demographic criteria be prepared and circulated for comment.

ACTION: BW/GM

e) Activity 7 - Develop working relationship with DeNDRoN UK

It was noted that an exploratory teleconference had been arranged at end of October between Mr G Morgan, Coordinator, NEURODEM Cymru and Piers Kotting, General Manager, DeNDRoN UK.

Action: GM

f) Activity 8 - Representation on DeNDRoN Clinical Studies Groups

Reference was made to the applications from Wales in respect of CSG membership. Professor Rosser had been nominated the Chair/Lead of the Huntington's Disease CSG. Professor Woods had recently received notification of his membership of the Dementia CSG and details of other successful appointments from Wales were anticipated shortly.

g) Activity 9 – Work with CRC Cymru and other Thematic Research Networks (TRNs)

Dr A Bayer and Mr G Morgan had represented NEURODEM Cymru at the launch of CRC Cymru in June.

Mr G Morgan, on behalf of NEURODEM and Mental Health Research Network Cymru, had contributed to the development of the Clinical Study Officer job description during August. The CSOs would constitute the Research Practitioner Network and, over time, up to 6 posts would be dedicated to support NEURODEM Cymru, MHRNC and the Learning Disabilities & Autism Research Network. The CSO job description was currently subject to “Desk top matching / Agenda for Change” procedures within Velindre NHS Trust, and CRC Cymru Coordinating Centre were hoping to advertise for the first phase of recruits in the near future. As from July Professor Woods and Mr G Morgan had been engaged in regular meetings of TRN Leads/Coordinators and CRC Cymru Coordinating Centre staff. Professor Woods tabled copies of the Coordinating Centre Organisational Chart (Sept 2006) to illustrate the complexities of infrastructure support. Other meetings has also been held with representatives from staff from the Involving People Team, Training Section and the Language Awareness Infrastructure Support Service (LLAIS).

Dr A Bayer reported on his involvement with the Older People & Ageing Research Network (OPAN) which was planning:

- representation at the Wales Stroke Conference (November 2006)
- to coordinate an ESRC New Dynamics of Ageing submission involving several TRNs, including NEURODEM Cymru, by June 2007.

5. Wales Office for Research and Development in health and social care (WORD)

a) Contract monitoring arrangements

It was noted that the Network Lead and Coordinator were required to prepare quarterly and Annual reports for WORD, and to attend regular quarterly meetings with WORD's Contract Manager to discuss progress.

b) Research Fellowships

Professor Woods reminded colleagues of his recent e mail communication regarding possible funding, subject to competition, for Research fellows to work in support of TRNs. Dr Bayer and Dr Morris had responded indicating that NEURODEM Cymru should consider working on the early onset of dementia as its priority. This was supported by members and it was agreed that an appropriate submission be prepared as soon as confirmation of funding is received.

ACTION: BW/AB/HM

6. Any other business

a) Animal research.

A brief discussion was initiated following a general query raised by Professor Thome. In essence, NEURODEM Cymru, as part of the Clinical Research collaboration, would not envisage that research involving animals would be part of its portfolio. However, translational research was part of the network's remit and members recognised the potential clinical benefits arising from some animal research studies.

7. Date of next meeting

The next Steering Group meeting would be held on **Thursday, 8th March 2007** at a mid Wales venue.

It was also agreed to organise a workshop/seminar with invited speakers on the same date, and to investigate the possibility of dinner / speaker on the previous evening, **7th March 2007**.

Action: BW/GM