

Minutes of Meeting of

The Roald Dahl Child Brain Service (UKCNRC Research Support Panel)

Monday 3rd June 2013, 11.00 – 15.30
ICH Neurosciences Unit, 4-5 Long Yard, London WC1

Part A – for publication

Present:

- Dr Anna Basu
- Dr Richard Chin
- Dr John Coleman (Research Coordinator)
- Dr Mario Cortina-Borja
- Dr Vijeya Ganesan
- Professor Colin Kennedy (Chair)
- Dr Rachel Kneen
- Dr Finbar O'Callaghan (by phone)
- Professor Stefano Seri (by Skype)

1. Apologies for absence

- Prof Helen Cross*
- Dr John Livingston
- Professor Rod Scott
- Dr Evangeline Wässmer*
- Dr Jane Williams*

*Submitted notes in advance

2. Welcome and introductions

Professor Kennedy welcomed Dr Anna Basu to her first meeting as new RSP member.

3. Minutes from meeting of 11th December 2012

These were accepted as a correct record except that ERA-NET (page 2) should be better defined. This has now been changed to read:

“... (from ERA-NET NEURON – the European Research Area Network supporting translational research in disease-related neuroscience); ...”

4. UKCNRC news and study updates

- Association between ADEM and vitamin D (Zipitis)

This study is underway after some problems (now resolved) arose with regard to quality of shipped blood samples

- UMSCOM – UK Multicentre Study of Children with Opsoclonus Myoclonus (Pike)

Now fully funded through 3 agencies. Ethics application has been submitted ahead of REC review later this month. UKCNRC to disengage at imminent appointment of study administrator.

- Genetics of myoclonic astatic epilepsy (Tang)

This is a fully funded and REC-approved study. RSP is supporting the R&D approval process across UK Paediatric neurology centres.

- Study of Medically Unexplained Neurological Symptoms (Various)

No developments. RSP will re-engage with Dr Isobel Heyman and other interested parties to gauge commitment to a study in this area. An academic child psychologist might be appropriate to lead. Dr Jon Stone, Consultant Adult Neurologist in Edinburgh was mentioned as having a research interest in MUNS. Dr Tallur, Consultant Paediatric Neurologist in Edinburgh has a cohort of patients with MUNS, as does Dr. Rachel Kneen. Dr. Kneen voiced a willingness to collaborate. RC will discuss with Drs Tallur and Stone in Edinburgh about possible collaboration with other parties.

5. Registry proposals

The concept and required resources of disease registries was discussed. Input and offers of support had been received from Mr Richard Lynn, BPSU Scientific Coordinator, and from the universities of Newcastle and Edinburgh. Many of the proposals are seeking generic support that could be met with a generic knowledge base. Setting up and managing databases is an ambitious and costly exercise that is a likely constraint on what the UKCNRC can achieve at present. Therefore the RSP should help to develop proposals to enable their authors to obtain funding from other sources when it does not have the resources to fund set up of a database in its entirety.

Eight proposals had been received for consideration by RSP.

- a) Characteristics and outcomes of childhood moyamoya in the United Kingdom (Ganesan, Saunders)
Support
- b) Incidence and spectrum of Neural Tube Defects in the UK (Kamath Tallur, Kandasamy, Eunson, Shetty)
Decline
- c) Improving outcomes for children with Sturge-Weber syndrome: a registry of children with facial port wine stains and Sturge-Weber syndrome (Aylett, Scott, Newsom-Davis, Hawkins, Kinsler)
Decline
- d) MISTT - A registry of acute Management of arterial Ischaemic Stroke using intravenous or arterial Thrombolysis / Thrombectomy in paediatric patients in the UK (Pysden, Chitre, Goddard)
Decline
- e) Outcomes Following Early onset Epilepsy (Cross, Kurian, O'Callaghan, Scott, Eltze, Hughes)
Decline
- f) The Myoclonic Astatic Epilepsy Registry (Tang)
Support
- g) An International Clinical Registry of Panayiotopoulos Syndrome (Ferrie, Pal, Koutroumanidis)
Decline
- h) Rare Epilepsy Registry (Pal)

Decline

6. Research proposal

a) Brain Function in Rolandic Epilepsy (Smith)

RSP decision: 4 = Support

7. UKCNRC in relation to MCRN and other bodies

MCRN Neurosciences CSG had engaged in a priority-setting exercise that had been inconclusive and in which the RSP should become engaged through RC, its representative on the CSG.

RSP discussed further its role in setting research priorities with focus on close interaction and consultation with the BPNA. The BPNA Council has already approved the creation of a 'Scientific Meetings Committee' (SCM) that will include representation from RSP and BPNSU. Its purpose is to organise meetings and raise their scientific quality, rather than setting research priorities for the BPNA. Accordingly, RSP will ask BPNA Council to approve RSP playing a pro-active role in helping the BPNA set research priorities. The latter function is one which UKCNRC could lead and coordinate. Accordingly, RSP will ask BPNA Council to approve RSP playing a leading role in helping the BPNA to set research priorities. The SCM, various SIGs of BPNA, all RSP members, professional bodies with overlapping clinical and research interests, and parent groups might be encouraged to contribute to this process. A RSP working group of RC, VG, FOC and AB will liaise and work together on this. Their remit will cover setting up a survey among BPNA members to help identify research priorities, groundwork for UKCNRC joining the James Lind Alliance as an affiliate (probably easiest achieved with a message signed jointly by the BPNA president, the UKCNRC chair and RSP chair: note BPNA is already a JLA affiliate), and setting up a survey among BPNA members to help identify research priorities. The JLA is considered important because it works with the NIHR to set the clinical research agenda. The NIHR rare diseases programme should be a useful point of reference.

8. Research Training – follow-up

RSP will give thought to this ahead of their next meeting

9. BPNA meeting 2014

RSP will give thought to this ahead of their next meeting

10. RSP membership rotation

AB joins the group. CK is stepping down at the end of two consecutive terms, including one as chair of the panel. JW is also stepping down but has offered to nominate a colleague from the BACD as a replacement. RC as incoming Chair voiced the desire for stability of the RSP to help guide the UKCNRC through a sensitive period of potential change in its focus and responsibilities.

11. Any other business

12. Date of next meeting

To be arranged for December 2104