

Minutes of Meeting of

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

Tuesday 28th June 2011

11.00 – 15.30

ICH Neurosciences Unit, 4-5 Long Yard, London WC1

Part A – for publication

Present:

- Dr Richard Chin
- Dr John Coleman (Research Coordinator)
- Dr Vijeya Ganesan
- Professor Colin Kennedy (Chair)
- Dr Rachel Kneen
- Dr Tim Martland
- Dr Finbar O’Callaghan (by telephone)
- Dr Rod Scott
- Professor Stefano Seri (by telephone 11.00-13.00)
- Dr Evangeline Wassmer (by telephone 14.00 onwards)

Observer: Ms Donna Treanor (UKCNRC Development Officer)

1. Apologies for absence

- Dr Paul Eunson
- Dr John Livingston
- Dr Jane Williams

2. Welcome and introductions

Professor Kennedy welcomed all and introduced Donna Treanor.

3. Minutes from meeting of 13th December 2010

These were accepted as a correct record.

4. UKCNRC News

Donna Treanor has taken over as UKCNRC Development Officer from Ann Marie Barnard who has taken a CEO post elsewhere.

A news update letter, as tabled, was sent by email to BPNA members in March 2011.

The UKCNRC website has been updated professionally with funds obtained by Ann Marie Barnard. These funds cover future edits and updates.

5. Research Support Structures

The MCRN and UKCNRC both presented stands at the BPNA January 2011 meeting. The MCRN Neurosciences CSG is consolidating its strategy after feedback from the MCRN executive. The MCRN continues to strengthen links with the NIHR Paediatric (Non-medicines) Specialty Group. A meeting convened by NIHR and AMRC on “Working in partnership for children: Supporting development and delivery of the very best paediatric research across the UK” will be held on 30th September 2011 at the RCPCH. The first such meeting was held in September 2010 and was attended by VG. CK is unable to attend the 2011 meeting but UKCNRC should be represented. The UK

Epilepsy Research Network (UKERN) is establishing an annual research forum, the first of which will take place on Wednesday 21 September 2011 at Aston University. UKCNRC intend to be represented.

6. Funds available for research support

The situation is unchanged since June 2010 with an amount slightly in excess of £10,000 potentially available and ring-fenced to support research proposals.

7. Responses to RSP feedback questionnaire

Email letters with UKCNRC feedback questionnaire as attachment were sent out on 13th June 2011 to 20 proposers of studies submitted so far to UKCNRC. Five questionnaires have been returned to date. JC will send out reminders to proposers and collate responses for circulation to RSP. RSP will make particular note of answers to question 5 "What specific resources or areas of expertise do you think UKCNRC might provide that you would find useful?" The question of providing statistical support to researchers was discussed, since this is frequently requested on research proposals; specifically whether RSP should provide an advisory service and/or direct provision of a statistical service. This would be considered again in the light of questionnaire responses, but in the meantime a statistician will be appointed to RSP. A suggested candidate will be approached for this role. The possibility of RSP providing an "outcomes assessment" team, again either advisory or service provision, was discussed and will be considered again. The UKCNRC website would provide a useful way of bringing such services to the notice of those who might use them.

8. New study proposals received

- a) ACAES - Acute Childhood Autoimmune Encephalopathies Study (Lim and Whitehouse)

RSP decision: 1 = comment only
No lead panel member required

- b) Peripheral neuropathy in children & adolescents with mitochondrial disease (Nesbitt)

RSP decision: 1 = comment only
No lead panel member required

9. Studies previously supported or under consideration

- a) Paediatric UK Demyelinating Disease Longitudinal Study (Wassmer)

Dr Wassmer was not present during discussion of this item.

RSP Decision 4 = Support
The study is adopted by UKCNRC and running; RSP to provide further support as requested.

Lead panel member going forward: [Finbar O'Callaghan](#)

- b) Immuno-modulatory agents in childhood acute transverse myelitis (Pike)

Note: this proposal has been revised as "Randomised non-inferiority parallel unblinded trial of intravenous immunoglobulin versus plasmapheresis for the treatment of acute severe transverse myelitis" by Drs Absoud, Wassmer and Lim.

RSP decision: 2 = Comments and invitation to resubmit
Lead panel member going forward: Rachel Kneen

- c) Association between ADEM and vitamin D (Zipitis)

RSP decision: 3 = Provisional support
Lead panel member going forward: Rachel Kneen

- d) Childhood ABI (Forsyth)

RSP decision: 1 = Comments only
No lead panel member required

- e) Carbogen in treatment of status epilepticus (Forsyth)

RSP decision: 1 = Comments only
No lead panel member required

- f) METCOM - Multinational European Trial for Children with the Opsoclonus Myoclonus Syndrome/ Dancing Eye Syndrome (Pike)

RSP has been working with proposer on grant applications, study protocol and related documents required for IRAS submission. The study now has part funding in the UK from the DES Support Trust and provisional funding from the GOSH Charity.

RSP decision: 4 = Support
Lead panel member going forward: Tim Martland

- g) ACEAR - Acute Childhood Encephalopathies with Antibodies Registry (Whitehouse)

This study has been submitted and reconsidered as item 8a.

- h) Understanding and improving the outcome of viral encephalitis (Kneen)

RSP decision: 3 = Provisional support
Lead panel member going forward: Richard Chin

- i) Response to treatment in the early onset epilepsies of childhood (Cross/ BPEG)

RSP decision: 3 = Provisional support
Lead panel member going forward: Stefano Seri

- j) Genetic basis of infantile epileptic encephalopathy through exome sequencing (Fry)

This study has been withdrawn by Dr Fry

- k) The genetics of cortical malformations (Fry)

RSP decision: 4 = Support
Lead panel member going forward: Paul Eunson

- l) Genetics of brain abnormalities and learning disabilities (Kini)

RSP decision: 2 = Comments and invitation to resubmit

Lead panel member going forward: John Livingston

m) VIPS - Vascular Effects of Infection in Paediatric Stroke (Kirkham)

RSP decision: 3 = Provisional support

Lead panel member going forward: John Livingston

n) Multicentre study of paediatric cerebral sinus thrombosis (Pysden)

RSP decision: 3 = Provisional support

Lead panel member going forward: Vijeya Ganesan

10. Matters arising from meeting of December 2011

a) Approaches to seeking new proposals

No poster or oral presentations from the 2011 BPNA meeting had been selected by RSP members for follow-up. At the 2012 BPNA, the work will be divided among the panel so that they can make a collective effort to seek out early stage studies that might offer potential for extension with RSP support.

b) Composition and *modus operandi* of the RSP

- As discussed under item 7, a statistician will be sought to join the RSP.
- The research proposal form will be modified such that proposers will make clear what type of service or support they are seeking from UKCNRC, e.g. scientific review, support with funding applications, statistical advice, preparation of documents, publicity, case or centre recruitment etc.
- RSP study leads are encouraged to interact with proposers, specifically to give proposers the opportunity to respond to RSP questions or concerns ahead of RSP meetings.
- The RSP might organise a “Research Navigation / Workshop” symposium, either as a standalone meeting or at the annual BPNA or RCPCH meeting. Topics could include funding, governance, research support structures etc. This had been proposed for the BPNA in previous years meeting but had faced difficulties with scheduling in a packed timetable. The website might provide a vehicle for such advice but this would not be a light undertaking.

c) The UKCNRC network of regional and centre link persons

In future UKCNRC will communicate directly to BPNA members and as appropriate to Deanery Advisors. This change would therefore render the existing network of link persons redundant.

d) UKCNRC led initiatives

In addition to those discussed under item 7, UKCNRC will sponsor a prize for the best poster at the 2012 BPNA meeting. This will enhance the profile of UKCNRC as well as contribute to item 10a above.

11. Any other business

In the field of childhood stroke and other areas of paediatric neurological research, certain charities have funds available and wish to publicise these to the professional community. Such information will be collated and publicised on the UKCNRC website as

information for professionals and also as promotion of those charities. RSP members will forward any information on charitable sources of research funds to JC.

12. Date of next meeting:

Early December 2011