

Minutes of Meeting of

The Roald Dahl Child Brain Research Development Service

(UKCNRC Research Support Panel)

Monday 13th December 2010, 11.00 – 15.30
Wolfson Centre, Mecklenburgh Square, London WC1

Present:

- Dr John Coleman (Research Coordinator)
- Dr Paul Eunson
- Dr Vijeya Ganesan
- Professor Colin Kennedy (Chair)
- Dr Rachel Kneen (by telephone)
- Dr John Livingston
- Dr Finbar O'Callaghan
- Professor Stefano Seri
- Dr Evangeline Wassmer (by telephone 14.00 onwards)

Observer: Mrs Ann Marie Barnard (UKCNRC Fundraising Officer)

1. Apologies for absence

- Dr Richard Chin
- Dr Rod Scott
- Dr Jane Williams
- Dr Tim Martland

2. Welcome and introductions

Professor Kennedy welcomed all and introduced Mrs Ann Marie Barnard, newly appointed UKCNRC Fundraising Officer. Efforts to connect to Dr Rod Scott by Skype were unsuccessful.

3. Minutes from meeting of 2nd June 2010

These were accepted as a correct record.

4. Meeting report: MCRN Funders/AMRC Member Charities meeting and Paediatric Non-Medicines Document

The aim of the AMRC meeting was to develop links between medical charities and NIHR research organisations (Paediatric Non-Medicines group, MCRN etc.). This would help charities achieve their aims and allow researchers to set priorities compatible with the funding bodies' aims.

The tabled document (Beresford and Greenough) dealt with how the newly established NIHR Paediatric (Non-Medicines) Specialty Group might better interact with other Clinical Studies Groups (e.g. the Neuroscience CSG of the MCRN). It proposed that the CSGs might have satellite topic-specific groups (TSGs) which could work jointly with the charities through AMRC and report to the CSGs. UKCNRC RSP might evolve into a TSG. Some TSGs had established research priorities in partnership with relevant charities (e.g. Arthritis Research UK).

Comments arising from RSP discussion:

- Overall the problem of research support in Paediatric Neurology was not so much lack of structures or bodies but shortage of funds for pilot studies of rare diseases. This might be an area where UKCNRC could provide support not available elsewhere.
- Many local funding bodies, e.g. hospital or NHS trust-based, were not registered charities and therefore their resources might be available only to local researchers rather than nationally; nevertheless these are potentially a useful source of start-up funds.

5. Meeting report: ‘Supporting paediatric neurology research’ meeting convened by MCRN

The above meeting was held (26 Nov 2010) with representatives from the strategic group of the BACD, BPNA, Epilepsy Research Network, MCRN, MCRN Neuroscience CSG, Paediatric Non-Medicines Group, MHRN, BPNSU and UKCNRC. The overall message from the meeting was that the various networks and other supporting bodies such as UKCNRC should work closely together to support research in paediatric neurology research without increasing committee work and researchers’ administrative time. The Neuroscience CSG of MCRN could act as a central coordinating body and UKCNRC would be represented on this body. A more specific proposal document would be forthcoming from MCRN Neuro CSG.

The following comments were made by RSP members:

- The question of the role of UKCNRC in relation to MCRN Neuro CSG will be raised at the forthcoming UKCNRC Board meeting. In the meantime CK would communicate further with Professor Allan Colver, as Non-Medicines Paediatric Specialty Group representative on the Neuroscience CSG, who had been unable to attend the meeting of 26 Nov, for clarification of the possible role of the Non-Medicines Network in the proposed MCRN Neuroscience CSG.
- Returning to the question of research priorities: in arthritis research for example, the research programme is more coherent than for rare diseases in paediatric neurology, and may not be a valid precedent; a priority setting exercise had been successful in nephrology and might provide a model for UK paediatric neurology support bodies coordinated by Neuro CSG.
- On questions of strategy for supporting research and setting priority areas: UKCNRC aims to be democratic in inviting and supporting proposals from an early stage; we perhaps should seek views of client groups e.g. funding agencies; the “Campaign” element of UKCNRC should be brought to the fore as a means to attract proposals – this would add to the special / unique dimension provided by UKCNRC; we would be helped by positive outcomes e.g. practical benefit arising from UKCNRC supported studies; UKCNRC is open to approaches from non-established sources; overall RSP is reserved about top-down priority setting but certainly UKCNRC needs to maintain close links with Neuro CSG and other NIHR network structures.
- The RSP should note that the MCRN also is involved with studies from an early stage and helps to solicit and develop them pre-funding.

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.

Proposals for discussion (Part A)

7. 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)

RSP decision: 2 = Comments and invitation to resubmit by new CI or steering group.

Lead panel member going forward: [Evangeline Wassmer](#)

- c) Childhood ABI (Forsyth)

RSP decision: 2 = Comments and invitation to resubmit pending outcome of outline funding application

Lead panel member going forward: [John Livingston](#)

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

This study has part funding in the UK and is at an advanced stage of planning across 8 European countries; RSP has been working with proposer on the research protocol and IRAS submission for ethics.

RSP decision: 4 = Support

Lead panel member going forward: [Tim Martland](#)

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

RSP decision: 2 = Comments and consider resubmission after Dr Whitehouse and his consortium have discussed further with other relevant parties

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

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

RK was not present for the discussion.

RSP decision: 3 = Provisional support

Lead panel member going forward: [Richard Chin](#)

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

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

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

RSP decision: 3 = Provisional support (alongside Fry study (7i) below).
Lead panel member going forward: Stefano Seri

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

RSP decision: 3 = Provisional support (alongside Cross study (7h) above).
Lead panel member going forward: Stefano Seri

- j) Oral therapy in severe dystonic cerebral palsy (Fairhurst/Lundy)

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

- k) Upper Airway Obstruction due to VNS in children with epilepsy (Singh)

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

8. New study proposals received

- a) The genetics of cortical malformations (Fry)

RSP decision: 3 = Provisional support
Lead panel member going forward: Paul Eunson

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

RSP decision: 2 = Comments and invitation to resubmit
Lead panel member going forward: John Livingston

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

CK and FOC left the room because of potential conflicts of interest.

RSP decision: 3 = Provisional support
Lead panel member going forward: John Livingston

- d) Multicentre study of paediatric cerebral sinus thrombosis (Pysden)

RSP decision: 3 = Provisional support
Lead panel member going forward: Vijeya Ganesan

9. Matters arising from meeting of 2nd June 2010

- a) Approaches to seeking new proposals

As before, PE will monitor BPNA poster presentations for studies that might be extended with UKCNR support; RSP members will collectively do likewise for oral presentations

- b) Composition and *modus operandi* of the RSP

In future we might seek to engage service users and/or charities that represent them. It is not considered appropriate to invite study proposers to present their case at RSP meetings.

c) The UKCNRC network of regional and centre link persons

It might be better to engage with current Deanery Advisors rather than the current network that has been somewhat underused and hence unengaged.

d) Research nurses; neurological outcome team

In addition to above, a statistical advisory service could be valuable, with expertise already available within the RSP

10. Any other business

None

11. Date of next meeting:

June 2011