

Minutes of Meeting of

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

Wednesday 7th December 2011, 11.00 – 15.30
ICH Neurosciences Unit, 4-5 Long Yard, London WC1

Part A – for publication

Present:

- Dr Richard Chin (by telephone 11.00-11.30)
- Dr John Coleman (Research Coordinator)
- Dr Mario Cortina Borja
- Dr Vijeya Ganesan
- Professor Colin Kennedy (Chair)
- Dr Rachel Kneen
- Dr John Livingston
- Dr Finbar O'Callaghan
- Dr Evangeline Wassmer
- Dr Jane Williams

1. Apologies for absence

- Dr Paul Eunson
- Dr Tim Martland
- Dr Rod Scott
- Professor Stefano Seri

2. Welcome and introductions

Professor Kennedy welcomed all. Dr Chin introduced and welcomed Dr Mario Cortina Borja to the panel.

JC reported that Dr Paul Eunson, whose term on the panel, since joining as a founding member in 2008, had extended through a three year period, had expressed willingness to step down, consistent with the RSP policy of staggered terms of office for founding members. This was accepted by the panel with sincere thanks to Dr Eunson for his valuable service to the RSP. CK suggested that consideration should be given to adding to the panel types of expertise that it currently lacked, including expertise that might come from outside paediatric neurology.

3. Minutes from meeting of 28th June 2011

These were accepted as a correct record.

4. UKCNRC News

A UKCNRC news update letter was sent by email to BPNA members in October 2011 and this was followed in November 2011 by an email from CK, both drawing attention to funds of up to £10,000 that the RSP has available for research support.

5. New proposals received

- a) Hypoxic-ischaemic encephalopathy diagnostic criteria validation study (Harijan)

RSP decision: 1 = Comment only

Lead panel member: [Vijeya Ganesan](#)

- b) The molecular genetic investigation of early onset epileptic encephalopathy
(Kurian, McTague)

RSP decision: 2 = Comments and invitation to resubmit

Lead panel member going forward: John Livingston

6. RSP end of year report and updates on active studies

i. Main achievements in 2011:

- The RSP has considered 26 research proposals since its first meeting in February 2009, all of which had received feedback from RSP discussions. Of these, 12 had received support in one form or another from UKCNRC.
- In 2011, UKCNRC had received four research proposals, three of which were for research funds.
- UKCNRC was instrumental in bringing together parties representing the funded encephalitis study and the proposed ACAES study, and thus helped to resolve a potential conflict.
- The study of the genetics of epileptic encephalopathy was withdrawn by Dr Andrew Fry in the light of the fact that genetic expertise in this field was now available to ICH from within its own resources and also to release more time to pursue the (UKCNRC-supported) study of the genetics of cortical malformations.
- RSP contributed patient info sheets and consent forms to the VIPS study of Professor Kirkham.
- RSP completed the UK protocol, info sheets and consent forms, and submitted a successful grant application for the outcomes component of Dr Pike's OMS study to the GOSH Charity Fund (£27,397 awarded); submitted a preliminary application for administrative support to SPARKS that was approved for a full submission; and continued links with EU group on protocol and procedures.
- RSP established links between the Vitamin D / ADEM disease and the UKCNRC-supported PUDDLs study; helped to resolve questions over controls and assay choice and costs; and helped procure provisional funding from Manchester Children's Hospital.

ii. Current RSP active engagement

- PUDDLs - Paediatric UK Demyelinating Disease Longitudinal Study (Wassmer)
Lead panel member going forward: Finbar O'Callaghan
- METCOM - Multinational European Trial for Children with OMS (Pike)
Lead panel member going forward: Tim Martland
- GOCM - Genetics of cortical malformations (Fry)
Lead panel member going forward: Richard Chin
- Association between ADEM and vitamin D (Zipitis)
Lead panel member going forward: Rachel Kneen
- Multicentre study of paediatric cerebral sinus thrombosis (Pysden)
Lead panel member going forward: Vijeya Ganesan

iii. Steps taken to improve UKCNRC effectiveness

- Questionnaire sent to previous proposers
- Proposal form revised
- Role of UKCNRC explained to BPNA members in newsletters etc.
- Research training day for trainees planned
- Website upgraded

7. The way forward for the RSP – open discussion

This was covered under item 6 iii above. There was extended discussion and approval for promoting a research ethos among trainees and organising a trainees' research training day that would be open to trainees (but not consultant grades) in paediatric neurology and related specialties (see item 9e below).

8. Revised RSP guidelines and membership

The revised "Guidelines for the *modus operandi* of the Research Support Panel of UKCNRC" were tabled. The attention of RSP members was drawn specifically to the terms of appointment, the rules governing conflict of interest, and the signed declaration of research interests. JC will contact RSP members to ensure that the latter is up to date and signed.

9. Matters arising from previous meetings

a) UKCNRC in relation to other research support structures

RSP agreed broadly that UKCNRC is in a unique position in that it:

- ✓ Can develop plans iteratively from early stage
- ✓ Operates in response mode rather than setting priorities
- ✓ Can adopt/support studies
- ✓ Can contribute to the funding of studies
- ✓ Can provide hands-on staff time
- ✓ Is an independent, non-government organisation
- ✓ Can steer studies in any direction

b) Responses to RSP feedback questionnaire

The responses of 8 responders, out of the 16 study proposers who were approached, were tabled. Notably, 6/8 respondents reported that it was "very easy" to obtain information about the service UKCNRC offers; 7/8 reported that the efficiency of UKCNRC responses to proposals was either "good" or improved; 5/8 reported that UKCNRC was "of real benefit in enabling formulation or activation of the study". A wide range of potential services that UKCNRC might be able to provide were ticked. Of these, in particular the provision of 1) a statistical and 2) a neurological outcomes advisory service were discussed. It was concluded that through MCB and CK these services could be made available by RSP.

c) Revised proposal form

The research proposal form has been revised to emphasise the flexibility of the RSP response according to the demands of the proposer(s).

d) BPNA January - Study look-out

Plans are in place to work alongside the Nottingham team hosting the meeting to select posters and presentations for a trainees' prize. RK will be a member of that team, representing the RSP, and will also pass to JC the views of other members of that team regarding work, presented as posters, that offers scope for multicentre studies potentially supportable by UKCNRC. The RSP will also undertake its own review of posters, dividing the task among RSP members who will then feed their views on to RK. RK will synthesize those reviews and take them into account in her contribution to the discussion of the team that will be awarding the trainees' prize.

e) Trainees' research workshop (RC)

Members of the RSP, namely Drs Chin, Ganesan and Scott, have been working closely with Dr Daniel Lumsden, the trainees' representative, to plan a trainees' research training

day for 2012, in place of the usual clinical training day. RSP approved UKCNRC engagement in planning and presenting the proposed meeting.

10. Any other business

None

11. Date of next meeting

June 2012