

Minutes of Meeting of

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

Tuesday 11th December 2012, 11.00 – 15.30
ICH Neurosciences Unit, 4-5 Long Yard, London WC1

Part A – for publication

Present:

- Dr Richard Chin (by Skype)
- Dr John Coleman (Research Coordinator)
- Dr Mario Cortina-Borja
- Dr Vijeya Ganesan
- Professor Colin Kennedy (Chair)
- Professor Helen Cross
- Dr John Livingston
- Dr Finbar O'Callaghan
- Professor Rod Scott (by Skype)
- Professor Stefano Seri (by Skype)
- Dr Jane Williams (by phone, p.m.)
- Dr Evangeline Wässmer

1. Apologies for absence

- Dr Rachel Kneen

2. Welcome and introductions

Professor Kennedy welcomed all and outlined the programme for the day.

3. Minutes from meeting of 7th December 2011

These were accepted as a correct record except that Part A item 6a should read “transverse myelitis” in place of “inflammatory encephalopathy”. This has been corrected.

4. UKCNRC News

Through UKCNRC efforts the “OMS” study is now fully funded by GOSH Children’s Charity (2011), the Neuroblastoma Society (2012) and Sparks (2012).

The “Vitamin D” amendment to the PUDDLs study was approved by regulatory bodies; the study is now funded and under way.

UKCNRC awarded a grant of £6000 to UCL Institute of Child Health for a pilot study of “The molecular genetic investigation of early onset epileptic encephalopathy”.

The UKCNRC “Research Day” held on 6th October 2012 was attended by 27 delegates and from completed feedback questionnaires was deemed successful: 19/24 said their commitment to research was raised; 20/24 said the day had given them ideas for their own research; 16/24 said they were more likely to engage in research; 24/24 agreed the meeting was worthwhile and would recommend fellow trainees to attend a similar meeting in the future; 21/24 would like to see a follow-up.

The UKCNRC website continues to be further updated; web hosting and webmail have switched to a new provider (eUKhost); the website is averaging about 1000 independent visits per month.

UKCNRC has been awarded £23,000 for 2013/14 from Roald Dahl's Marvellous Children's Charity with an invitation to apply for a further year's funding.

5. The roles of relationship between UKCNRC and other bodies supporting paediatric neuroscience research

Two papers were tabled: Neurosciences Priorities (from ERA-NET); The Research Landscape in the UK – Relevance to Paediatric Neurology (from HC). With reference to these, the roles of UKCNRC RSP, the Neurosciences Clinical Studies Group (CSG) of the Medicines for Children Research Network (MCRN) and other related bodies, and their inter-relationships were discussed. A general problem in the field that government bodies (NIHR) had to recognise is the multiplicity of rare neurological childhood diseases and the problem of case recruitment numbers in clinical trials. The paper by HC noted that the chair of the Neurosciences CSG of MCRN was already an *ex officio* member of the RSP and proposed the following steps:

1. Chairs of respective groups (UKCNRC RSP, BPNSU, BACD Research Strategy Group and Mental Health Research Network) to be co-opted onto the Neurosciences CSG of MCRN (already in process)
2. UKCNRC to continue through RSP to encourage and support development of protocols with regard to neurological disease – later submission to MCRN for adoption on portfolio, and consequent support
3. Priorities for research and key research questions to be brought to the MCRN Neurosciences CSG for submission to NIHR through MCRN.
4. One or two key questions to be addressed by project development from within MCRN Neuroscience CSG utilising its multidisciplinary composition.

The meeting supported these proposals and the following additional points were made:

- UKCNRC RSP is more focused on neurology while MCRN Neurosciences CSG has a broader coverage, including neurosurgery, rehabilitation, mental health).
- MCRN Neurosciences CSG is keen to see UKCNRC develop studies from an early stage and “feed in” to the CSG for steering towards NIHR funding.
- There are several charities in the field of paediatric neurology and we need to be clear about the role of each and how they can mutually support one another.
- UKCNRC RSP might host a charities event at a future BPNA conference or other – to communicate with charities in the field and promote mutual support.
- There needs to be stronger representation of neuroscience within the BPNA structure, including the creation of a scientific meetings committee.
- There are several notable omissions from the ERA-NET priorities, including inflammatory disease, MUNS, genetics, cerebrovascular; all of which have been areas of interest for RSP.
- There may be a case for UKCNRC, in consultation with BPNA Special Interest Groups, and CSG, to work together on a strategic document to list and rank research priorities.

6. New proposals received

- a) Testing the androgen hypothesis in Tourette Syndrome (Hedderly)

RSP decision: 1 = comment only

7. Study updates

- a) Epilepsy in Infancy

A study protocol has been finalised and a first-round grant application submitted

- b) Association between ADEM and vitamin D (Zipitis)
See Item 4 News above.
- c) METCOM - Multinational European Trial for Children with the Opsoclonus Myoclonus Syndrome/ Dancing Eye Syndrome (Pike)
See Item 4 News above
- d) ChiMES (Liverpool Encephalitis study) and developments
This NIHR funded study is underway.

8. Pipeline studies

A number of studies, all at an early stage, were discussed in confidence. For each, UKCNRC RSP has been advising or bringing together potential collaborators.

- a) A clinical trial for acute inflammatory encephalopathy has been taken up enthusiastically by new CIs and a grant proposal is in preparation
- b) UKCNRC is advising on a study of the genetics of cerebral palsy
- c) UKCNRC is bringing together parties interested in a potential study of Medically Unexplained Neurological Symptoms
- d) Research opportunities arising from new NICE guidelines on spasticity will be presented by Drs Paul Eunson and Jane Williams at the UKCNRC Research Fair at the January 2013 BPNA Conference.

9. Research Training – follow-up

RSP is planning a “Research Fair” follow-up to the trainees’ Research Day on Thursday 24 January 2013 at the BPNA Annual Conference, in response to feedback from Research day delegates and with support of the President of the BPNA and UKCNRC Board. This will be an informal “drop-in” session with stalls dealing with specific areas of research planning manned by RSP, and specific topics presented by BPNA Special Interest Groups.

10. BPNA meeting 2013

As at previous BPNA meetings, RSP will review posters and presentations with a look-out for those that offer promise for extension to larger scale collaborative studies. This will be done in partnership with the BPNA and local organisers. The UKCNRC will have a role in the award of a trainee poster prize. Associated with this, and in relation to broader but related issues, RSP Chair will discuss with BPNA President the following: the composition of a scientific meetings committee of the BPNA; the issue of a UKCNRC poster prize and of the mechanism for selecting it.

The UKCNRC stand at the 2013 BPNA Conference will be manned by Research Coordinator and one member of RSP on each conference day; a new banner-poster will be prepared by RSP Chair; a suggestion box will be made available.

11. New UKCNRC initiative: registries

UKCNRC has recently been awarded funds by Roald Dahl’s Marvellous Children’s Charity to support organisational infrastructure, and according to the terms of that award is pursuing a new initiative to support the development over 2 years of case registries in paediatric neurology. This provides an opportunity for RSP to work closely with BPNSU. RSP will prepare an application form with introduction and guidelines and this will be circulated to all BPNA members in early January with a submission deadline of 19th April 2013.

12. RSP guidelines

Those RSP members who had not done so already were reminded to sign the terms of their appointment to RSP.

13. Any other business

The panel was reminded that the term of members and of the chair of RSP was three years with a second consecutive term permissible. Most members were either approaching the end of their first term or were two years into their second term. The chair was approaching the end of his three year term and would seek expressions of interest from the BPNA in joining and also in chairing the RSP.

14. Date of next meeting: 3rd June 2013.