

## Minutes of Meeting of

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

Wednesday 27<sup>th</sup> June 2012, 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 Mario Cortina-Borja
- Professor Colin Kennedy (Chair)
- Professor Helen Cross
- Dr Rachel Kneen
- Dr John Livingston (by phone)
- Professor Rod Scott (by Skype)
- Professor Stefano Seri (acting Chair for items 1-5)
- Dr Evangeline Wässmer

As observer: Dr Kirti Patel, SPARKS

##### **1. Apologies for absence**

- Dr Finbar O'Callaghan
- Dr Vijeya Ganesan
- Dr Jane Williams

##### **2. Welcome and introductions**

Professor Seri as acting Chair for items 1-5 welcomed all. Those present self-introduced. Professor Cross was welcomed to her first RSP meeting in *ex officio* capacity as Chair of the MCRN Neuroscience Clinical Studies Group as replacement for Dr Tim Martland. Dr Martland was thanked for his services to the RSP.

##### **3. Minutes from meeting of 7<sup>th</sup> December 2011**

These were accepted as a correct record.

##### **4. UKCNRC News**

Since the December 2011 meeting the RSP had awarded its first research grant (item 7d) and received three new research proposals (item 5). The new UKCNRC website is up-and-running with regular news and content updates. UKCNRC continues to raise funds through our Development Officer. Currently £4000 is available for research funding.

##### **5. New proposals received**

a) Randomised trial of IVIG as add-on therapy in acute inflammatory encephalopathy (Pike)

RSP decision: 3 = Provisional support

Lead panel member going forward: Dr Rachel Kneen

b) Autoantibodies in Childhood Epilepsy (Wright)

RSP decision: 2 = Comments and invitation to resubmit

Lead panel member going forward: Dr John Livingston

c) Whole exome sequencing in children presenting with spasticity presumed to be due to cerebral palsy (Kumar)

RSP decision: 2 = Comments and invitation to resubmit (following external review)

Lead panel member going forward: Prof Rod Scott

## 6. Other potential studies

- a) A proposal for a clinical trial of combination immunotherapy for childhood acute inflammatory encephalopathy from Dr Pike (Oxford) had been taken up enthusiastically with UKCNRC support by national paediatric neurology colleagues who had refined the study design and are currently at the stage of seeking funding. UKCNRC has invited but not received a formal proposal relating to the revised study but is keeping in close contact with the new study team.
- b) After a review of work presented at the January 2012 BPNA meeting by UKCNRC, Dr Kneen had raised the need for a clinical study of Medically Unexplained Neurological Symptoms (MUNS) as presented in an abstract by Vijayakumar *et al.* The panel agreed that there is a pressing need for such a study and suggested a number of national colleagues who might wish to be involved, some of whom had already expressed interest. The panel suggested the study be broadened to include input from other disciplines, e.g. rheumatology; training of support staff is important in this area; health economics should be covered; it may be too soon for a full clinical study pending a pilot surveillance/economics type study. UKCNRC is currently seeking expressions of interest from national colleagues with an interest in this area.

## 7. Study updates

a) Association between ADEM and vitamin D (Zipitis)

Lead panel member going forward: Rachel Kneen

The panel was updated on progress: the study plan has been revised and submitted by Dr Wässmer as an ethical amendment to the PUDDLs study. Funding for the study, covering biosample handling and laboratory tests has, with UKCNRC support, been granted from research funds at the Royal Manchester Children's Hospital.

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

Lead panel member going forward: Helen Cross

Funding has, with UKCNRC support, been obtained from two sources (the Great Ormond Street Hospital Research Fund and the Neuroblastoma Society). The outcome of a third funding application is awaited to complete full funding for the study. Professor Cross will take over from Tim Martland as UKCNRC clinical lead and advise specifically on governance issues relating to drugs to be used in this trial.

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

Lead panel member going forward: Vijeya Ganesan

Dr Pysden is keen to pursue this study on her imminent return from maternity leave.

[Post-meeting note: Dr Pysden's survey of variations in the management of children with cerebral venous sinus thrombosis in the UK and Ireland has now been published (Dev Med Child Neurol, 2012, 54: 770-7710)].

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

Lead panel member going forward: John Livingston

This pilot study is under way and the results will be used to support applications for funding of an extended study. The investigators are not seeking further UKCNRC support.

e) Response to treatment in the early onset epilepsies of childhood (Cross/ BPNA EIG)

Lead panel member going forward: Stefano Seri

This has evolved with UKCNRC input into primarily a database study of disease incidence and long term progression, building on the current North London cohort study that is being extended geographically. Professor Cross is to trial certain databases for application to this study. The study will retain active links with UKCNRC.

### **8. Trainees' Research Workshop**

The programme has been finalised by RSP working with the trainees' representative, Dr Daniel Lumsden. The meeting will be held at Aston Conference Centre on 6<sup>th</sup> October 2012. Dr Chin will provide further guidelines to contributing RSP faculty.

### **9. RSP guidelines – sign up**

RSP members were requested to sign up to the revised “Guidelines for the *modus operandi* of the Research Support Panel of UKCNRC” as tabled, signed copies to be archived by Research Coordinator.

### **10. BPNA meetings – study look-out and lessons learned**

RSP had adopted a joint strategy with the organising committee at the BPNA 2012 Conference for seeking abstracts/poster presentations with potential for further development with UKCNRC support. This led to several promising leads (e.g. item 6b). Ahead of the 2013 conference, Helen Cross is to investigate the previously agreed proposal that a Scientific Advisory Panel of wider membership be established. She will feed back to the RSP chair, so that he can explore whether the UKCNRC can be represented on the Abstract Review Panel and whether there is scope for a UKCNRC-sponsored poster prize.

### **11. Any other business**

The relationship of UKCNRC to other support structures in paediatric neurology was discussed. The panel concluded that there are complementary roles for UKCNRC and the Neurosciences CSG of the MCRN; the MCRN remain largely a “medicines” group and focus is on clinical trials that recruit large numbers of cases; UKCNRC focus is not necessarily so “medicines” oriented and focusses rather on rare diseases requiring multi-centre involvement, often for relatively low case numbers.

### **12. Date of next meeting**

11<sup>th</sup> December 2012