



MCRN/BAPN Paediatric Nephrology CSG Meeting; Tuesday 12 July 2011 (11:00 – 14.30), MRC Head Office, London.

Attendees: Moin Saleem (MS), Wendy Cook (WC), Rodney Gilbert (RG), Mine Orlu Gul (MOG), Wesley Hayes (WH), Sally Johnson (SJ), Larissa Kerecuk (LK), Manish Sinha (MaS), Kjell Tullus (KT), Mark Woodward (MW) and Laura Pilkington (LP), Ann Byrne (AB),

Apologies; Jan Dudley (JD), Caroline Jones (CJ), Karl McKeever (KMc), William Van't Hoff (WvH), Simon Waller (SW),

Additional - via Teleconference: Andy Lunn (AL), Leah Krischock (LAK), Nick Webb (NW),

AGENDA ITEM	SUB-TOPIC	KEY DISCUSSION POINTS	ACTION POINT(S)
1. Welcome and apologies	N/A	The chair opened the meeting and welcomed everyone in attendance. Wesley Hayes, new Trainee representative was introduced to the group. Apologies were noted, as above.	None.
2. Review of minutes from previous meeting and matters arising	[Paper 1]	<p>The minutes from the last meeting held on 15/3/11 were reviewed by the group and were accepted as an accurate record of the discussions that took place, with the exception of the date at the top which would be amended. The following matters arising were discussed:</p> <p>CSG Leaflets – LP reported that there was a link now available on the website for the leaflet which had also been distributed to LRNs, CLRN's etc. In addition to the leaflet a short flyer outlining how the CSGs can assist had been developed and this was also available on the website and would be distributed to DGH's. LP asked the group to think of other ways that the information might be distributed and to let the Coordinating Centre know.</p> <p>Website – The group had been asked to look at the website and provide comments. WC had taken a look and thought it was very good, reads well, navigation was easy and good information was included.</p> <p>LP explained that the Coordinating Centre were currently working to improve the website and reminded the group of the address www.mcrn.org.uk for review.</p> <p>WC reported that a lot of parents still did not know what MCRN is and MS asked for</p>	<p>AB to amend date on minutes. (Actioned)</p> <p>Group to review website and provide LP with comments/ suggestions of ways in which</p>

		<p>volunteers to assist with pulling information together for the website and MS/LAK/WC agreed that they would take this forward. WC enquired if a lay persons summary for studies could also be provided.</p> <p>SJ/JD to speak to Jenny Newman regarding how to get Consumers involved.</p>	<p>it might be improved</p> <p>MS/LAK/WC to coordinate information for website</p> <p>SJ/JD to speak to Jenny Newman.</p>
3. Update from MCRN CC	<p>Annual Report [PAPER 2]</p> <p>Follow-up meeting with AMRC member Charities NIHR Research Funders and Major funding Councils [PAPER 3a –b]</p> <p>Neonatal Topic Specific Groups [PAPER 4]</p> <p>NIHR Case Studies</p>	<p>MS confirmed that he had received a very positive acknowledgment from the Executive following the submission of the Annual Report. The Nephrology CSG was performing well and he congratulated the group on their achievements to date. KJ commented that there was not a great deal to show for studies under development and MS stated that some studies took a long time to develop and gave PREDNOS as an example. MS encouraged the group to keep meetings as robust as possible.</p> <p>LP explained that the document “Points to consider when assessing the feasibility of research” had been produced following last years’ meeting and asked the group to encourage people to use it when designing studies. The document was available on the website.</p> <p>There was to be a further meeting on 30 September but there had been no response from the Nephrology Charities as yet. A reminder would be sent out shortly. MS reported that Sally Feather should be invited instead of J Tizzard.</p> <p>It was reported that the Neonatal CSG had developed 6 Topic Specific Groups and were keen to engage in cross collaboration. Contact details were included in the document.</p> <p>LP explained that Sarah Whiteside (MCRN Communications Officer) had now returned from maternity leave and was pulling together some case studies regarding studies i.e. PREDNOS. MS/SJ suggested RADAR and would put something together. The group were requested to let LP/SW know if there were any other</p>	<p>LP to forward invitation to SF.</p> <p>MS/SJ to put document together re: RADAR study.</p>

		studies that could be included.	
4. Update on Consumer Activities		<p>WC reported that at the joint AMRC & RDUK meeting in December there were a few researchers there, but mainly people working for charities. It had been a valuable meeting for WC not just to learn what RDUK AND AMRC impact they are having on government policies and raising awareness through many activities, but also meeting other fellow charity workers too. WC also attended the Why don't Children take their medicines workshop and this had made her more aware of the different issues involved with children.</p> <p>On reviewing various websites WC felt that some could be improved and were not updated very frequently. Although the willingness and ideas were there, it was time to be able to do these that was an issue. WC suggested that a support taskforce might be useful. WC was aware that JD had applied for some funding to assist with this but was unsure where that was up to. BAPN patient information was being reviewed by Sally but again WC was unsure where this was up to. There did not appear to be a strategy for getting information to enough parents/patients. Information regarding conferences etc was quite ad.hoc.</p>	
5. Clinical Research Strategy		<p>The group discussed the production of a document outlining the key research priorities of the group and how to maximise the research output. How to demonstrate to people the purpose of the group and how to benefit from using the CSG. A number of headings were suggested; Biologics, Urology, Genetics, Cardiovascular. MS would set out a document and group members would populate /contribute information under headings giving specific examples. MS reminded the group that it was important to remember the Consumer theme throughout the document. The aim would be to have draft document for the next meeting in November which would be discussed and finalised at that meeting.</p>	<p>MS to draft outline document. Members to contribute details under headings. Draft to be available for meeting in November at which it will be finalised.</p>
6. Update on Studies in Development	a. ACHIEVE	<p>An update had been received. The single centre study was recruiting and had 47 patients. There was potential for the study to go wider. The group congratulated the study team on the achievements to date. A message of congratulations would be sent and the offer of CSG support for the next stages should it be required.</p>	<p>Message of congratulations and continued support to be sent.</p>
	b. APPROVE	<p>A meeting with CTU Statisticians had taken place and the study had been revised. Although work was ongoing it was felt that this was a worthwhile study and should be taken forward. LP offered to distribute it to the Neonatal and General Paediatrics CSGs for comment.</p>	<p>JD/KT to send the protocol to LP for circulation to the Neonatal & Gen Paeds CSGs.</p>

	c. TAUROLOCK	No further progress report had been received from CJ. CJ would be asked to provide an emailed update and an update regarding the May deadline issue that was highlighted at the last meeting. "CTU will withdraw assistance if a submission is not completed by May. The CSG are fully supportive of this study and encouraged CJ to work to the May deadline."	CJ to provide emailed update.
	d. RITUXIMAB	A final protocol had not been seen to date. It was unclear if this study had received MCRN support or if it had gone through the CSP route. MS would email AK again for an update.	MS to follow up with AK. LP to check if gone through CSP.
	e. ADHERENCE	MS explained that this was following on from MCRN initiative looking at adherence etc. VS hoped to do a systematic review of literature a further meeting was organised for September. MS confirmed that members would be welcome if they wished to get involved.	
	f. ARB Study	KT reported that good progress had been made during the last 3-4 months to refashion the study and to answer the 5 questions raised when funding was not given at the last submission. The study would be submitted in October.	
	g. Hot Kids Study	MaS reported that the BHF application had been submitted which addressed the issues that had been raised last time. 8 centres were confirmed for taking part with the possibility of a further 2 centres. As the study would begin during the later part of this year this minimised the possibility of a recruitment issue with the ARB study.	
7. Portfolio Studies	[PAPER 5]	The paper included Industry studies and studies in the pipeline and would hopefully include updates of both in future.	
	RADAR (MS) RADAR The SRNS	MS reported that the Rare Disease Committee had held a first meeting and approved the working renal group. The website would be merging with Renal patient view and will look the same but some of the workings would be different. Pump priming money had been received and there was a call out for new working groups to form. The group would need to think about how this can link in with MCRN working groups. It is also planned to ask for funding for a Project manager to facilitate entry of up to 10 new working groups in the next 12 months. SRNS – is run from Bristol collecting patients, 150 recruited so far and DNA collected from most.	
	MPGN	Still awaiting SSI's Local centres signed off.	

	KKR	Veronica Swallow had provided an update. Researcher had been appointed a further meeting was taking place with VS in Manchester shortly.	
	PREDNOS	NW gave thanks to everyone for their input and support. The study was up and running. Future updates would be given under Any other Business. NW was congratulated on successfully starting this landmark study.	
	Non-Meds Portfolio Report [PAPER 6]	The document was reviewed for information. LP explained that accrual was monitored very carefully.	
8. Membership	Deputy Chair Appointment of Additional Consumer Representatives	LP explained that applications that had been received for Deputy Chair posts within the CSGs had gone to the Executive on 11 July and the outcome of the applications was awaited. LP reported that a national advertisement had been produced and disseminated with an end of July deadline. Interviews would be held shortly and JN would be in touch with Chair's regarding this issue.	
9. Any Other Business		There was no further business to discuss and the meeting was concluded.	
10. Date, Time and location of next meeting		The next meeting will take place on Monday 28th November at MRC Head Office, 13th Floor, One Kemble Street, London WC2B 4AN and will commence at 11.00 a.m.	