



**MCRN/BAPN Paediatric Nephrology CSG Meeting; Monday 28<sup>th</sup> November 2011 (11:00 – 14.30), MRC Head Office, London.**

**Attendees:** Moin Saleem (MS) (Chair), Sarah Bryan (SB), Wendy Cook (WC), Sandra Cope (SC), Rodney Gilbert (RG), Mine Orlu Gul (MOG), Wesley Hayes (WH), Sally Johnson (SJ), Caroline Jones (CJ), Andy Lunn (AL), Ania Koziell (AK), Leah Krischock (LAK), Manish Sinha (MaS), Kjell Tullus (KT), Tina Wagnell (TW), Nick Webb (NW), Laura Pilkington (LP), Ann Byrne (AB),

**Apologies;** Jan Dudley (JD), Larissa Kerecuk (LK), Janet Pooley (JP), William Van't Hoff (WvH), Simon Waller (SW), Mark Woodward (MW)

**Additional - via Teleconference:** Sally Feather (SF), Karl McKeever (KMc),

AGENDA ITEM	SUB-TOPIC	KEY DISCUSSION POINTS	ACTION POINT(S)
<b>1. Welcome and apologies</b>	N/A	The chair opened the meeting and welcomed everyone in attendance. Apologies were noted, as above.	None.
<b>2. Introduction of New Members</b>		The new Consumers, Sarah Bryan, Sandra Cope and Tina Wagnell were introduced to the group.	
<b>3. Review of minutes from previous meeting</b>	[Paper 1]	The minutes from the last meeting held on 12/7/11 were reviewed by the group and were accepted as an accurate record of the discussions that took place.	
<b>4. Updates from MCRN CC</b>	MCRN Chairs Forum [PAPER 2]  Working in partnership for	Paper 2 had been distributed to the group for information. Main points from the meeting: Two new CSGs Cleft & Craniofacial Anomalies CSG and Pain and Palliative Care CSG. Recruitment for Chair, Deputy Chair and Members would be undertaken early in the new year.  This was a follow up meeting which was led by CSG Chairs in collaboration with the Non-Meds Specialty Group and was well attended with 20 Charities represented and representatives from Industry and NIHR HTA also present.	

	<p>children 30/9/11</p> <p>Consumer Involvement Day 25/11/11</p> <p>LRN Directors Forum 1/12/11</p>	<p>MS also reported that he had attended the recent meeting held by the Rheumatology CSG with Industry which had highlighted the work of the CSG its strengths and need for close collaboration.</p> <p>WC reported that the event had included presentations from consumers about their experiences within MCRN. Discussions had taken place regarding how to raise the profile of MCRN. There had been a recent recruitment drive and several new Consumer members had been recruited. J Newman would produce notes from the meeting which would be fed back to the group.</p> <p>Members were reminded of the importance of involving consumers at the start of any development discussions and WC confirmed that she was happy to hold a list of consumers that could assist with reviewing work, attending discussion meetings etc.</p> <p>LP explained that if any members had study ideas/protocols that required a review there was a process in place for circulating the information to the groups, which involved a set of questions to be answered. There were different questions for Consumers and Clinicians. LP/AB would be happy to assist with this process.</p> <p>LP reported that the MCRN Executive are keen to improve feasibility and delivery of studies and to encourage collaboration between LRNs and the CSG groups. MS was attending the meeting and would feedback to the group.</p>	
<p><b>5. CSG Annual Report</b></p>	<p><b>[PAPER 3]</b></p>	<p>A copy of the report which was to be submitted to the MCRN Executive next week was distributed to the group who were asked to let LP know immediately if there were any major changes required. Noted: WC had attended Manchester Children's Hospital Parent's Evening and had given advice regarding the PREDNOS study which would be added to the report.</p>	<p>LP to add details to the Consumer Section of the report.</p>

6. Update Consumer Activities		A recruitment drive had taken place to recruit new Consumers to the MCRN and as mentioned earlier, four new members were now part of the group. WC had attended the Manchester Children's Hospital Parents Evening and had assisted with the review of the PREDNOS study.	
7. Update Clinical Research Strategy	<b>[PAPER 4]</b>	MS had drafted a document following discussions at the last meeting which the group reviewed. The group discussed what key items should be included within the document and it was agreed that the previous priorities would be circulated to the group and that members would review and send suggested items to MS <b>by the end of January 2012</b> . MS would circulate the ideas to the group for discussion and final inclusions would be made to the strategy at the next face to face meeting in March. After this is planned to hold a workshop to take forward the prioritised studies. MS explained that once the strategy was finalised it would be included on the website and sent to various groups i.e. KRUK etc. The group would continue to build on the strategy in future years.	Members to review priorities and send ideas to MS <b>by end of January 2012</b> .
8. Update on studies in development	a. APPROVE	SF reported work was ongoing and Liverpool MCRN people had been very helpful and a further teleconference was to be held on 16 December. Although still in development, work was moving forward and SF would keep the group informed of progress.	
	b. TAUROLOCK <b>[PAPER 5]</b>	CJ confirmed that the application made to HTA had been unsuccessful. MCRN CTU was to discuss further with Patient Research for Patient Benefit and CJ was awaiting a response. CJ was congratulated for getting the project this far along. The group felt this was a key clinical question, and a test of whether individual units could set aside their anecdotal experiences to participate in developing a solid evidence base.	
	c. RITUXIMAB	AK confirmed that funding had been given from GSTT Charity for this study looking at the safety and efficacy of Rituximab. Some re-structuring of the protocol had taken place and it was agreed that the protocol should be circulated to the group for comment. Noted that further funding would be required to ensure MCRN support, which would allow wider participation of centres. As it stands it seems most feasible to run the study out of one or two centres.	AK to forward protocol to LP for circulation to the group. Group to comment.

	d. ADHERENCE <b>[PAPER 6]</b>	Notes from the meeting held in September were distributed to the group. MS confirmed that a further meeting was being held in December. MS reported that minutes from this group would continue to be circulated to Nephrology members and should anyone wish to be involved they would be welcome and should make contact with Veronica Swallow.	
	e. ARB Study	KT reported that due to lack of assistance the project had not been submitted as planned. Birmingham CTU was now onboard and assisting. KT had also managed to contact some Consumers for advice and had met with the Young Persons Group in Liverpool. KT was keen for input of the group during further development. KT was congratulated on his progress to date.	
	f. Hot Kids Study	MaS confirmed that the funding application had been successful and that the study would commence in the new year. MaS thanked everyone for their input and support. MaS was congratulated.	
<b>9. Update on Portfolio Studies</b>	<b>[PAPER 7]</b>	The paper outlined studies that were currently on the MCRN Portfolio and members were asked for brief updates.	
	RADAR (MS) RADAR The SRNS	MS reported that several new groups were coming on board and that 5 new groups had been approved during the summer, and 3 more this month. Things were progressing and a meeting of all group leaders would take place next week. MS also confirmed that SRNS was moving along with 180+ patients now recruited. Plasma exchange specimens are required as part of the study. Good results are being produced on genetic screening, and reports to clinicians are being prepared. MS asked the group to encourage clinicians who may not have registered for RADAR logins to do so.	
	MPGN	Confirmation was given that this study was now open and 6 sites were up and running. 8 patients had been recruited to date. There had been a working group meeting held in October with three consumer members on the group. A Patient and Family Conference was planned for Autumn next year.	
	KKR	It was reported that this was Veronica Swallow's study which had now closed. 124 patients had been recruited and families were being followed up for a 6 month period. It was hoped that there would be some publications/abstracts from the study. LP would make contact with VS to see if there had been any.	LP to contact VS regarding publications/abstracts.
	PREDNOS	NW reported that the study was up and running with over 100 centres now	

		<p>participating. Newsletters would be produced and circulated shortly. NW gave thanks to everyone for their input and support. NW was congratulated on successfully starting this landmark study.</p> <p>NW confirmed that he had responded to a rapid HTA call for a further study (PREDNOS 2) and would call upon the group for input and advice should the application be accepted.</p> <p>A further discussion ensued about a separate response to the same HTA call (from SJ and MS) for a trial into Eculizumab in D+HUS. The group broadly supported this area of research as topical and necessary.</p>	
<b>10. Industry Studies – rationalisation of studies across a limited patient pool</b>		<p>Members expressed concern regarding the number of enquiries that were received from Industry. LP explained that if members were approached by Companies they should be flagging this to MS or Andrew Rose (AR), at the Coordinating Centre. A reply should be given to the enquirer that the study needs to go via the CSG route. It was agreed that when AR or Carla Owen (CO) send out feasibility requests to a CSG member that MS should also be copied in. The group agreed that there was a need to be realistic about the type and number of studies that could be conducted and that there was a need to be more coordinated.</p>	LP to ask AR/CO to copy MS into feasibility requests to members.
<b>11. Membership</b>	<p>Chair</p> <p>Deputy Chair</p> <p>Membership</p>	<p>LP confirmed that the Chair had completed the required term of office and it was explained that should the group wish the Chair to remain in post for a further year agreement was required and the MCRN Executive would be asked for ratification.</p> <p>The group were in agreement that MS should remain as Chair for a further year. AB to seek ratification from the MCRN Executive regarding the tenure of the Chair.</p> <p>LP reported that KT had been appointed to the Deputy Chair role within the group.</p> <p>It was also noted that tenure of a number of members was also close to completion and therefore it would be necessary to commence rotation of members early in 2012. It was felt important that all units continue to be represented, and that the MCRN should allow some flexibility in order to permit the most appropriate member from each Unit to be on the committee.</p>	AB to seek ratification from the Executive.
<b>12. Any Other Business</b>		There was no further business to discuss and the meeting was concluded.	

<b>13. Date, Time and location of next meeting</b>		The next meeting is scheduled to take place on <b>Friday 9 March 2012 at MRC Head Office, 13<sup>th</sup> Floor, One Kemble Street, London WC2B 4AN</b> and will commence at <b>11.00 a.m.</b>	
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