



MCRN/BAPN Paediatric Nephrology CSG Meeting; Tuesday 15th March 2011 (11.00 – 14.30), MRC Head Office, London.

Attendees: Moin Saleem (MS), Caroline Jones (CJ), Manish Sinha (MaS), Simon Waller (SW), Kjell Tullus (KT) Larissa Kerecuk (LK), Mine Orlu Gul (MOG), and Andy Lunn (AL), Rodney Gilbert (RG), Sally Johnson (SJ), Karl McKeever (KMc), Nick Webb (NW), Laura Pilkington (LP), Ann Byrne (AB),

Apologies; Wendy Cook (WC), Leah Krischock (LAK), William Van't Hoff (WvH), Mark Woodward (MW)

Additional - Part Attendees via Teleconference: Sabah Attar

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. Apologies were noted, as above.	None.
2. Introduction of new members		Karl McKeever was introduced to the group. Karl is the Devolved Nations Representative (based in Northern Ireland) for the group. NICRN have agreed to cover the cost of Karl's travel expenses to/from meetings	MS to look back at correspondence when the CSG was set up re Welsh representative
3. Review of minutes from previous meeting and matters arising	[Paper 1]	The minutes from the last meeting held on 6/12/2010 were reviewed by the group and were accepted as an accurate record of the discussions that took place. The following matters arising were discussed: Jenny Newman (JN) (MCRN Consumer Liaison Officer) is coordinating consumer activities centrally. JN wants a formal process for widening consumer representation and part of her plan is to increase the number of lay Members on CSGs especially where there are only one or two representatives at present (e.g. Nephrology). The CSG is still waiting for JN's reply regarding the appointment of additional Consumers to assist Wendy. LP reported that JN is working towards getting further consumer membership for the group. It was noted that this has	LP to update JN on issues re consumer involvement CSG members to identify consumer representatives who would be willing to apply

		<p>been on the agenda since last year and that the CSG desperately needs to make at least two appointments sooner rather than later, ideally before the next meeting of the group in July. The CSG also discussed having a pool of consumers, which the group could access either through Wendy and the new representatives or Jenny Newman as required. These representatives would not be formally appointed to the CSG.</p>	
<p>4. Update from MCRN CC</p>	<p>CSG Chair's Forum</p>	<p>MS gave a brief overview from the Chair's Forum held in Liverpool on 10th March. Summary points included: Annual Report – Subject to a review of the information relating to industry studies, all reports will be made available on the website. It was agreed that all CSGs should circulate their report to charities / other groups affiliated with the CSG in order to show what the CSG is about and what they have achieved to date. CSG Leaflets: These should be disseminated via CSG members either electronically or printed in hard copy and distributed to all associates in order to help raise awareness about the CSG(s). The leaflets have been designed for Investigators principally as it is clear that many still don't engage CSGs when developing protocols. It was reported that the leaflets would be available at annual events such as RCPCH, MCRN Annual Stakeholder Meeting etc. The CSG enquired about the possibility of making them available at DGH's and LP agreed to follow this up. Feasibility Questionnaires: These have been developed by AR/LP for CSGs to use when assessing public / commercial studies MCRN Website: The website had recently been re-launched www.mcrn.org.uk. Potential Portal Forum: This discussion group facility would allow CSG Chair's to post topics for discussion with other Forum members as and when required. This was to be piloted by the CSG Chair's Forum in the first instance with a possible roll out to all CSG members over time.</p>	<p>LP to enquire about displaying CSG leaflets in DGH's especially those which do not have an LRN.</p> <p>All members to review the new CSG website and to feedback any comments / suggestions of ways in which it might be improved to LP / AB</p>
	<p>CSG Meeting 'Why Don't Children Take Their Medicines?' [PAPER 2]</p>	<p>This meeting followed the initial meeting held last year to address the question 'why don't children take their medicines?' The meeting took place in January and Veronica Swallow had put a programme together. The outcome of the meeting was that it would be useful to have a systematic review of this area. It would be good to employ someone for a year to do the systematic review and members were asked to let MS know if they would like to be involved / could suggest colleagues who would be interested in collaborating on the project. KMc asked if</p>	<p>MS to pass information regarding Health Foundation</p>

		<p>this could be a project for a PHD student and MS answered this would be an option. JD suggested that the Health Foundation might be interested in funding this type of project, funding was awarded annually from this body up to 400k. MS agreed to pass this information on to VS.</p>	<p>onto VS.</p> <p>Members to let MS know if they would be interested in collaborating with this study</p>
	<p>CSG Objectives Document [PAPER3]</p>	<p>LP confirmed that the document had been produced and the objectives matched the annual report where possible. The objectives were reviewed by the group. MS noted that the CSG needs to think about how it can keep momentum going in terms of developing new studies.</p>	
	<p>MCRN Key Stakeholder Meeting [PAPER 4]</p>	<p>The meeting had taken place on 3rd March in Manchester. The purpose of the meeting had been to show what MCRN do and how they can assist with development of studies and was entitled 'Sharing Best Practice on Widening Participation in Children's Research'. The day included presentations from Anne Greenough, the Chair of the Paediatrics (Non-Medicines) Specialty Group and from Tom Walley of the HTA and involved workshops. The message from the HTA was that if you had a study of sufficient quality which addressed an important health care need for the nation there was funding available. Consumer involvement was also seen as essential to the process. SJ suggested that a Conference be set up inviting families from around the country to take part. Participants would ideally be families who are or have been affected by a nephrotic illness. JD suggested that Sir Ian Chalmers and the James Lind Alliance might be useful as they are closely aligned with consumers of rarer disease conditions and that there might be some overlap. LP reported that JN works closely with Sir Ian Chalmers and the group and that there may be an opportunity to tap into this. It was agreed that LP would follow this up with JN and that SJ, JD would also be involved with the view to providing an update at the next meeting in July.</p>	<p>LP to speak with JN re: Sir Ian Chalmers and the James Lind Alliance/Consumers. Link in with SJ and JD.</p>
<p>5. Update on Consumer Activities</p>		<p>In view of Wendy's absence there was no report on this item. WC has provided a link to the Rare Disease UK Strategy report – http://www.raredisease.org.uk/documents/RD-UK-Strategy-Report.pdf</p>	
<p>6. KKR/CSG Funding Update</p>		<p>MS confirmed that money had now been awarded. Details circulated via BAPN enews</p>	
<p>7. Update on Studies in</p>	<p>a. ACHIEVE</p>	<p>It was reported that the initial data planning had been completed. (Please see appendix 1 which is an update submitted by Rukshana that we received post the</p>	<p>RS to submit a report on progress before the next</p>

Development		CSG meeting)	meeting (MS/LP to remind)
	b. APPROVE	The study had not moved on since the last CSG meeting. The CTU have suggested that the incorporation of a pilot study to the submission would be beneficial. A meeting with CTU Statisticians was to be set up.	JD to arrange a meeting with CTU Statistician(s) and to update the group of progress at the next meeting.
	c. CIQ Antibody	There was nothing further to report at this time.	Study to be merged with MPGN study for future updates
	d. TAUROLOCK	No further progress to report. CJ reported that she would like another Nephrologist to be involved with the application. The group advised CJ to contact Lesley (?) again to see if she would be willing to be a collaborator on the study. NW suggested that the current group has adequate expertise already for submission of a feasibility study before May. Members also agreed to see if anyone in their work areas might be interested and let CJ know. CJ informed members that the MCRN 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.	Members to let CJ know if there are any nephrologists within their units that would like to come on board with the study
	e. RITUXIMAB	There was no update to be given. Although funding had been received it had not been awarded through open, national competition and therefore, the study could not be considered for MCRN support at this time. The funding had been awarded from Guys and St Thomas and this was to be the only recruiting site. The group expressed concerns that patient numbers would not be achieved if recruitment was limited to one site and suggested that multi-centres should be used. MS would follow up with AK. LP suggested that MS might like to involve AR in his communications because he had. A face to face meeting of the working group is urgently needed.	MS to follow up with AK
	g. ARB Study and HotKid Study	Both studies were discussed and there was concern expressed that they may overlap and that there may not be enough patients to take part in both of the studies. Following discussions it was agreed that MaS would revise the inclusion criteria for his study relating to proteinuria.	MaS to revise inclusion criteria for HotKid Study, and continue discussions with the ARB study group.
8. Portfolio Studies		The Chair welcomed Sabah Attar, the MCRN Portfolio Manager, who joined the meeting via teleconference at this point. The Chair noted that studies were doing	

		quite well but emphasised the need to maintain this.	
	RADAR (MS) RADAR The SRNS	Overall doing well. The study has two arms: SRNS and MPGN. Approximately 100 patients have been recruited to date. DNA analysis has started using next generation sequencing. The data of 12 patients has been analysed to date. . The website was undergoing re-development, it is planned that there will be automatic data collection soon, using direct electronic linkage to Renal Patient View. Also looking at International patients from 3 big centres in India and Iran. A rare Disease Committee had been set up with Mark Taylor as the Chair. The committee will put out a call for new Disease Renal groups and there has been overall £500k awarded for 5 years development to set up, up to 10 new working groups within the RADAR framework. The group would need to think about how this can link in with MCRN working groups.	MS to send details of working groups to SA
	MPGN	Portfolio studies are normally funded through open, national competition. MS to update SA on the funding process re setting up the disease working groups so she can get clarification on whether or not studies from these groups will be able to seek MCRN adoption. SJ reported that the study had initially been started by CI in Birmingham but had now been moved to Newcastle. The role of CI has been transferred to SJ. The study had been able to recruit but not take samples and this aspect had been amended and was awaiting IRAS approval. It was now moving forward. MS thanked SJ for her involvement and congratulated her on the progress made.	CSG members to disseminate information regarding call for new working groups
	KKR [PAPER 5]	Veronica Swallow had provided an update. All was going well and thanks were given to the group and to Evelina and GOSH hospitals for their support. VS requested that anyone with similar studies get in touch with her.	VS to provide a report on progress in advance of the next meeting (MS/LP to remind)
	PREDNOS	NW gave thanks to everyone for their input. The study was ready to go, more than 80 sites had been set up however, there had been a minor drug manufacturing issue to be sorted relating to one of the excipients and this had caused a delay with the start date. MOG requested the information regarding the problem be sent to her and NW agreed to send all email correspondence through.	NW to send email correspondence regarding pharmacy issue to MOG.

	Non-Meds Portfolio Report [PAPER 7 –tabled]	<p>LP explained that the Paediatrics (Non-Medicines) Specialty Group receive a monthly report of the studies on their Portfolio that for the purpose of this meeting she had selected the Nephrology studies which might be of interest to the CSG. The report was colour coded i.e. green studies doing well, red not reaching targets. LP explained that the specialty group members role incorporates following up with CI's to check on studies and to see if they are able to help in any way.</p> <p>JD commented that the DUTY study was shown in red which was surprising as three centres were doing really well and it was thought that all of the recruitment data had not been uploaded possibly.</p> <p>SA emphasised the importance of early engagement with CSGs/MCRN regarding trial design and with LRN research staff.</p> <p>Also highlighted was the fact that NIHR are keen to fund studies that include a pilot stage moving onto a larger study at a later stage.</p>	JD to contain Alastair Hay to ask him to make sure his accrual uploads are up to date
9. Any Other Business			
10. Date, Time and location of next meeting		The next meeting will take place on Tuesday 12 July 2011 at MRC Head Office, 13th Floor, One Kemble Street, London WC2B 4AN and will commence at 11.00 a.m.	