

Minutes – MCRN/arc Paediatric Rheumatology Clinical Studies Group Teleconference

5th January 2009

Present: Michael Beresford – MB (Chair), Eileen Baildam – EB, Paul Brogan – PB, Sharon Douglas – SD, Helen Foster – HF, Laura Pilkington – LP, Athimalaipet Ramanan – AR, Madeline Rooney – MR, Wendy Thomson – WT, Lucy Wedderburn – LW, Joanna Worsfold – JW and Katharine Venter - KV.

Apologies: Utpal Shah – US, Pat Woo - PW

Item	Subject	Briefing	Action Required
1	Welcome & Introduction	<ul style="list-style-type: none"> • <u>Welcome</u> MB opened the meeting and welcomed all in attendance • <u>Apologies</u> Apologies were noted from Utpal Shah and Pat Woo 	None
2	Review of Minutes from Last Teleconference and Matters Arising	<ul style="list-style-type: none"> • <u>Minutes from 1st December 2008</u> The minutes from the last teleconference held on 1st December were reviewed by the group and accepted as an accurate record of the discussions that took place • <u>Matters arising</u> <ol style="list-style-type: none"> <i>a) New IL1 Antagonist Trial (Novartis)</i> MB contacted Novartis through the MCRN Industry Team to inform them of the 6 UK Centre's that are keen to participate in the trial; MB is awaiting a reply <i>b) Tocilizumab Trial (Roche)</i> MB had a successful meeting with Roche; outlining importance of MCRN and CSG in optimizing recruitment; early engagement with CSG would aide Industry; He also met with MCRN Industry team; meetings with local PI's for Birmingham, Liverpool and Bristol have been arranged 	MB to keep the group up to date with any further developments from Novartis and Roche
3	2009: Our Global Perspective	<ul style="list-style-type: none"> • <u>CSG Strategy Document</u> <ol style="list-style-type: none"> <i>a) Update</i> MB thanked all members for their input into the document to date; The document is now open for peer comment; MB to personally write to the following groups to inform them of the strategy and to invite comment: All BSPAR Members, All Paediatric Rheumatology Nurse Specialists, British Paediatric and Adolescent Bone Group (BPABG), The Paediatric Orthopaedic Fraternity, The Paediatric Nephrology CSG and British Association of Paediatric Nephrology (all of whom have been consulted to date on strategy development); MB to invite the other ARC CSG Chairs to consider the document and to feed back to us on the areas of mutual interest and collaboration <i>b) International Peer Reviewer</i> Need an international peer reviewer of the strategy document; Members put forward their recommendations; It was agreed that an appropriate international peer reviewer would be the current Chair of CARRA; MB to approach the current Chair of CARRA • <u>Key Aims for 2009</u> <ol style="list-style-type: none"> <i>a) Options for May deadline</i> AVN Study; Extension of funding for POPS; Whole area of MTX; Predicted power of ultrasound 	<p>MB to circulate the strategy document to the groups that have been listed to invite comment [actioned by MB]</p> <p>MB to invite current Chair of CARRA to act as the international peer reviewer for the strategy document [ARC advise awaiting end of national peer consultation prior to International – carry forward next time]</p> <p>Members wishing to pursue the May deadline need to move forward quickly and actively and keep CSG informed</p>
4	Face-to-Face Meeting	<ul style="list-style-type: none"> • <u>Face-to-Face meeting (March)</u> <ol style="list-style-type: none"> <i>a) Date</i> The next face-to-face meeting will take place on Monday 9th to Tuesday 10th March 2009 <i>b) Apologies</i> Paul Brogan (trying to attend for part of meeting – to inform) <i>c) Itinerary</i> 	LP to forward meeting details to CSG members; LP to book CSG attendees into hotel unless informed otherwise

		<p>Arrive at venue (to be confirmed; location – Manchester City Centre) at approximately 5.30pm on Monday 9th March for a 6pm meeting followed by an informal working dinner (Alan Silman will be in attendance); On Tuesday 10th March there will be a meeting from 9.00am to 4.30pm; Agenda items include: Discussion of future plans for the CSG; Reflection on the work undertaken to date and how we can better facilitate certain processes</p>	<p>All members to email their agenda items and discussion points at the face-to-face meeting to MB ASAP</p>
5	JIA TSG Qualitative Survey	<ul style="list-style-type: none"> • <u>Update</u> <p>HF and Carl May plan to undertake the web-based survey without applying for a small grant; They have found some one in house who has agreed to carry out the survey; A pilot study may be carried out in early February prior to the launch of the web-based survey; MB congratulated HF on her fantastic work in taking this forward on behalf of the CSG</p>	<p>HF to provide an update at the next teleconference</p> <p>MB / HF to update the BSPAR Executive meeting</p>
6	AHP and Nurse Representation for CSG	<p>Unanimous agreement that these positions are to be <u>fully representative</u> of the respective healthcare communities; their main role is to <u>facilitate engagement within their profession</u> the activities of the CSG and <u>promote participation</u> of their colleagues in all activities of the CSG; their role is <u>representative, fostering mechanisms to ensure consultation and input</u> to general and specific activities of the CSG</p> <ul style="list-style-type: none"> • <u>AHP Update</u> <p>Important to link with the AHP community; only 1 application has been received prior to close (5th Dec: 1 year) for the position of AHP; this application was circulated for review by JW, SD, KV, HF, WT, AR, EB and MR; **Members from GOSH were excluded from this process as there was a potential conflict of interest** The notion was taken to appointment the applicant i.e. Sue Maillard; MB to notify MCRN Board and subject to their final ratification inform Sue of her appointment to the CSG</p> <ul style="list-style-type: none"> • <u>Nurse Update</u> <p>Closing date for applications for Clinical Nurse Specialist (CNS) (5th Dec) – agreed to close at this point as no applicants after 1 year despite MB engaging with CNS community; MB to email Pam Whitworth (PW) (BSPAR CNS representative) when information is required from the nurse perspective</p>	<p>Chair and CSG Members to inform and support post holders (as appointed) of these roles.</p> <p>MB to seek final ratification from the MCRN Board regarding AHP appointment [actioned and passed]</p> <p>MB to inform Sue Maillard and invite her to attend forthcoming meetings [actioned]</p> <p>MB to update PW [actioned]</p>
7	Applications to the CSG	<ul style="list-style-type: none"> • <u>Shaw – Bone density</u> <p>CSG to review proposal and to provide comments via email by Tuesday 13th January to MB; MB to provide feedback at the next meeting</p>	<p>CSG to review proposal and to provide comments via email by Tuesday 13th January to MB; MB to provide feedback at the next meeting</p>
8	Supporting Research Training	<ul style="list-style-type: none"> • <u>Ansell Consultation Scheme</u> <p>LW informed the group Barbara Ansell left a large legacy (approx £1 million) which was specifically for encouraging research in Paediatric Rheumatology; The ARC established a Fellowship scheme for Clinicians wishing to gain experience in Research in Paediatric Rheumatology, offering 1-year fellowships for research, which may then act as a springboard for those who wish to go on to a higher degree; The scheme has no specific deadline and no interview is held; The Ansell Fellows then compete with all other fellowship applications for further funding for MD/PhD studies, but have had a unique one-year opportunity in which to experience research and gain pilot data for a fellowship application; To date there have been about 6 applications and 5 successful fellows (2 of which were Adult trainees); Three of these have applied for further research funding, one successful, one not funded, while the third is awaited;</p> <p>This uptake is far less than hoped for by the ARC and therefore the money is still largely unspent; The ARC are keen to see how we can address this and use the money more fully; LW asked members to provide their comments about how to increase the use of this scheme and/or ways to use the money in alternative ways, while staying true for Barbara's wishes; LW to circulate current proposal to members and members to feedback to LW.</p>	<p>LW to circulate a copy of the current proposal to members and members to provide their comments/suggestions to LW [auctioned]</p> <p>LW to feedback at the next meeting</p>
9	Biology of JIA	<ul style="list-style-type: none"> • <u>International Consortium</u> 	<p>MB to circulate revised deadline</p>

		MB found out more information about the consortium from Rae Yeung/LW; MB circulated this information to BSPAR members on 22 nd December 2008; 1 expression of interest has been received to date; MB to extend deadline to Monday 19 th January	[Actioned] Unless >10 applications, all to be forwarded to RY for selection (without CSG input to this process)
10	AOB	<ul style="list-style-type: none"> • <u>BSPAR Executive Report</u> MB tabled a copy of the CSG report that he has written to the BPSAR Executive; CSG members to provide their comments; MB thanked all members again for the contribution to the CSG	Members to provide their comments on the BSPAR Executive report to MB
11	Dates for Next Meeting	<ul style="list-style-type: none"> • The next teleconference will take place on Monday 2nd February January 2009 at 4.30pm • The Face-to-face meeting will take place on Monday 9th March to Tuesday 10th March 2009 (venue to be confirmed; location- Manchester City Centre) 	

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