



MCRN / arc Paediatric Rheumatology Clinical Studies Group Teleconference 4th August 2008

Present: Michael Beresford (Chair), Eileen Baildam, Jennifer Blakeburn, Sharon Douglas, Laura Pilkington, Athimalaipet Ramanan, Madeline Rooney, Utpal Shah, Wendy Thomson, Katharine Venter, Lucy Wedderburn, Patricia Woo, Joanna Worsfold.

Welcome, Introductions and Apologies

MB opened the meeting and welcomed all in attendance. Apologies were received from Paul Brogan and Helen Foster.

Minutes from the Face-to-Face Meeting on 08/07/08 and Matters Arising

The minutes were approved by the CSG as being an accurate record of the meeting held on 8th July 2008.

Matters Arising

Consumer Roles on the CSG:

JW informed the group that the consumer representatives plan to meet via teleconference, in the next couple of weeks, to consider the ways in which they will be able to contribute to the activities of the CSG. ACTION: SD/KV/JW to liaise with JP/LP regarding setting up a teleconference and to provide feedback to the CSG in due course.

LW expressed a keen interest for the consumer representatives to be involved in commenting on patient information leaflets and SD/KV/JW informed the CSG that they were happy to participate in this process.

ACTION: LW to circulate patient information leaflets to the consumer representatives for comment.

Bone Health:

MB informed the group that a new list of provisional dates will be circulated as none of the previously circulated dates were convenient with the key members.

ACTION: LP to circulate a new list of provisional dates.

Biologics and Adoption:

MB informed the group that he has been to several meetings regarding the adoption of the biologics registry into the MCRN portfolio and that further discussions are due to place take place at the next meeting of the MCRN Executive.

ACTION: MB to provide feedback at the next CSG meeting.

ERA-NET PRIOMEDCHILD:

JB highlighted the importance of engaging in the ERA-NET PRIOMEDCHILD work package and asked all members of the CSG to disseminate the link to the Delphi Survey, as widely as possible.

ACTION: MB to send details for the main contact person at PRES to JB.

JIA TSG – Biologics (Qualitative Survey of Requirements and Process Update)

The group discussed a draft proposal, to survey BSPAR membership about collaborative data collection to facilitate clinical studies, which was submitted by HF. The CSG agreed to send any comments including

examples of possible questions/lists of people who could be involved in the survey to EB, HF and WT at their earliest convenience.

ACTION: JIA TSG to collate comments and provide feedback to the CSG at the next meeting

Uveitis and JIA TSG (Adalumimab Trial – Update)

AR informed the group that he was waiting for a response from the Liverpool MCRN Clinical Trials Unit regarding the type/amount of support that they might be able to offer. AR informed the group that he has contacted Caroline Dore's at the MRC regarding statistical support and that she has since provided some extremely useful comments to include.

ACTION: AR to wait to hear from the MCRN CTU and then liaise with LP about arranging a convenient time to visit the Coordinating Centre.

JDM TSG

Feasibility Survey for PRINTO JDM Trial:

The group discussed the feasibility survey for PRINTO JDM, written by Professor Pilkington and agreed to feedback any comments to LW.

Vasculopathy in JDM – Update:

LW informed the group that they will need to undertake a pilot study in the preliminary stages. MB informed the group that there are small pots of money available to fund pilot studies on approximately 20-30 patients.

ACTION: LW to circulate a copy of the protocol to the CSG for comment.

Teleconference Update:

LW informed the group that the JDM TSG teleconference was open to all members and was scheduled to take place at the end of the week. LW explained that the main purpose of the teleconference was to discuss which centres would like to take part and contribute approximately 3-4 patients.

Genetics and the CSG

WT, LW and PW informed the group that they have had a meeting. It was reported that there are international/verbal collaborations for a whole genomic analysis in JIA.

MB informed the group that he has spoken to Alan Silman regarding funding:

- ARC have already funded genome analysis in osteoarthritis
- Up to 2 million pounds is available for sites/teams

PW and WT plan to submit a draft proposal/outline to the ARC.

ACTION: PW and WT to circulate a copy of the protocol to CSG members for comment before the next teleconference in September.

ACTION: Put on agenda for next meeting.

The Next Face-to-Face Meeting

ACTION: LP to re-circulate list of proposed dates for a face-to-face meeting in October.

CSG Members – Nurse and AHP – Update on Applications

MB informed the group that no applications had been received to date. The group agreed that the deadline for applications should be extended until end of September after PRES/BSPAR.

ACTION: LP to update information on the MCRN website.

AOB

MB/LP will circulate the MCRN/arc Paediatric Rheumatology CSG progress report for comment before the next teleconference.