

1st October 2007

To: All BSPAR Members

Dear Colleagues,

Re: MCRN/arc Paediatric Rheumatology Clinical Studies Group

As many of you will know, and as advertised back in May/June via the BSPAR Website / mailings (in addition to the MCRN and ARC websites), a unique and extremely important partnership between the Medicines for Children Research Network (MCRN) and Arthritis Research Campaign (**arc**) has recently been formed with the establishment of the “MCRN/**arc** Paediatric Rheumatology Clinical Studies Group (CSG)”.

For those of you able to make the BSPAR Research Day, an initial overview of the CSG was presented by Dr Poustie from the MCRN and discussed. More details of the establishment of the CSG can be found via the following document: “MCRN/arc Rheumatology Clinical Studies Group” (<http://ctuprod.liv.ac.uk/mcrnweb/images/stories/csg/mcrn-arc%20rheumatology%20csg.pdf>). More recently, following a competitive application process, I was delighted to be appointed Chair of the CSG, to take up position in October 2007.

The CSG has been established by the MCRN and **arc** to support and develop a comprehensive portfolio of clinical studies directed towards and including clinical trials in all areas of paediatric rheumatology, across the UK. It will advise the MCRN and **arc** in defining related research priorities for their support and adoption.

I do believe it is one of the most exciting developments in paediatric rheumatology in the UK in recent times.

It will work in synergy with, and complementary to the wider research portfolio of the entire paediatric rheumatology community. In a preliminary meeting with the Chair of the BSPAR Research Sub-Committee, Dr Lucy Wedderburn, we agreed the fundamental importance of close integration of the work of the CSG with that of all relevant stakeholders, and the incredible opportunity the CSG provides in facilitating research in all areas of paediatric rheumatology.

In view of the importance of this new development, a brief summary will be presented in the Research Update at the BSPAR AGM. In addition, Lucy has kindly suggested that the major part of the Research Sub-Committee in Birmingham will be devoted to a detailed presentation and related discussion about the opportunity and potential the CSG offers us all.

The MCRN and **arc** have a clear framework for the organisation and integration of the work of a CSG into their structures and standard operating procedures, and to ensure open and transparent processes, remit and terms of reference. Our CSG is unique in being the first to be developed in partnership between a UK Clinical Research Network and a Major Research Funder. I will present background information and overview in Birmingham.

The first step for the new CSG is the establishment of its core membership. In keeping with the MCRN / **arc** guidelines, this will comprise experts representing the whole spectrum of paediatric rheumatology who have a strong collaborative ethos aimed at the improved care of children with rheumatological disorders throughout the UK. The responsibilities of the CSG will be:

1. Reactive and Proactive - To support and develop a comprehensive portfolio of clinical studies directed towards and including clinical trials in all areas of paediatric rheumatology across the UK
2. Advisory - To advise the MCRN and **arc** in defining related research priorities in paediatric rheumatology for their support and subsequent adoption

The second step, once the core members have been appointed, will be the development of topic-specific groups. These will be established as required (and subsequently disbanded in a timely manner) for the task of taking ahead development of disease specific or intervention-specific study / trial protocols.

I look forward to meeting as many of you as possible at the Research Sub-Committee. There are many ways in which all of us can be actively involved in this exciting new development, either as core members of the CSG itself, in any of the various topic-specific groups of interest, or by providing suggestions and feedback to either of the above.

Please don't hesitate to contact me to find out more.

With best wishes and kindest regards

Michael

Chair of MCRN/**arc** Paediatric Rheumatology CSG