



MCRN/arc Paediatric Rheumatology CSG

Progress Report

1st October 2008 – 30th September 2009

Written and compiled by Dr Michael W Beresford,
Chair of the MCRN/arc Paediatric Rheumatology CSG
On behalf of the CSG
31st October 2009

Overview of the last year

Background

The past twelve months have been an exciting time and much has been achieved already by the CSG. It has been the fruit of the expertise and strong collaborative ethos of the CSG, integrated closely into the established clinical research community of UK Paediatric Rheumatology, supported by the unique partnership that the CSG forged between the expertise and extensive resources provided by the Medicines for Children Research network (MCRN) and Arthritis Research Campaign (**arc**).

The CSG has demonstrated its role in developing a comprehensive, nationally agreed and scientifically robust research strategy for clinical trials and related studies in paediatric rheumatology. It has proactively engaged with all relevant stakeholders, including patients and families, and its initiatives have been successful in being awarded key enabling grants in priority areas. It is anticipated that the CSG will continue to contribute to major advances in the treatment of rheumatological diseases affecting children across the UK.

Partnership between Arthritis Research Campaign (**arc**) and MCRN

The partnership established between the MCRN and the **arc** has become a model within the MCRN for other paediatric specialties. To date other MCRN Clinical Studies Groups have followed the lead of Paediatric Rheumatology and established collaborative links with funding bodies (www.mcrn.org.uk). This has significantly enabled a proactive research agenda to be developed for these other paediatric CSGs (core MCRN funding supports only a reactive agenda).

The Chair of the CSG was invited to the inaugural meeting of the NIHR Paediatrics (Non-medicines) Specialty Group meeting, May 2009, to present the model of the Paediatric Rheumatology CSG in working with external stakeholders, namely the **arc**.

Role of the CSG

The CSG continues its reactive role of advising both the MCRN and **arc** of research priorities in paediatric rheumatology and its proactive role developing a comprehensive, integrated, long-lasting research programme for paediatric rheumatology in the UK. In summary of its activity in the past 12 months in relation to the established remit of the CS, the following has been achieved:

Remit	Action this year: 2008 - 2009
To be responsible for developing and overseeing a comprehensive portfolio for clinical trials and related studies covering the spectrum of major disease areas in paediatric rheumatology	The CSG carried out a detailed, extensive consultation process over a 12 month period, engaging all relevant stakeholders, resulting in the development and publication of its comprehensive Clinical Research Strategy
To propose and develop protocols for trials and related studies	The CSG actively supports nine “topic-specific groups” to help propose and develop trials and related studies; these have already led already to successful funding in a number of key priority areas (see below)
To provide robust scientific evaluation, expert advice and support to investigators	The CSG, or its Chair, have to date reviewed some 25 study protocols, including seven commercial studies. The CSG gives robust scientific evaluation on all commercial and non-commercial trials submitted to MCRN for adoption
To ensure consumer involvement in all activities.	The 3 consumer representatives, appointed September 2008, are fully integrated into all activities and initiatives of the CSG, and models of patient / family groups established
To uphold the highest standards of Research Governance and Good Clinical Practice	The CSG has emphasised and fostered this across the Paediatric Rheumatology community, both at National meetings and through its website: (http://www.arc-research.org.uk/med_director/paedrheumcsg.asp).

Integration with arc and MCRN Clinical Studies Groups

The Chair of the CSG has monthly one-to-one teleconferences with the Medical Director of the **arc**, monthly teleconferences with the Chairs of the seven **arc** CSGs and bi-annual two-day meetings of the Chairs of **arc** CSGs. At the same time the Chair participates in all meetings of the MCRN CSG Chairs.

Dr Beresford was invited to speak at the NIHR MCRN CSG Chair's Forum to present its "exemplar" Clinical Research Strategy, underlining the role of the **arc** is underpinning this initiative, and in particular it's call to define: "What are the key clinical research priorities that will change clinical practice in Paediatric Rheumatology?"

He was elected unanimously by the MCRN CSG Chairs to be Chair of their Forum, whose remit includes supporting the development of a comprehensive portfolio of studies across all paediatric disciplines. The **arc**'s Clinical Trials Initiative is thereby informing and influencing the development of a much wider paediatric research agenda than rheumatology, across the UK.

International Profile

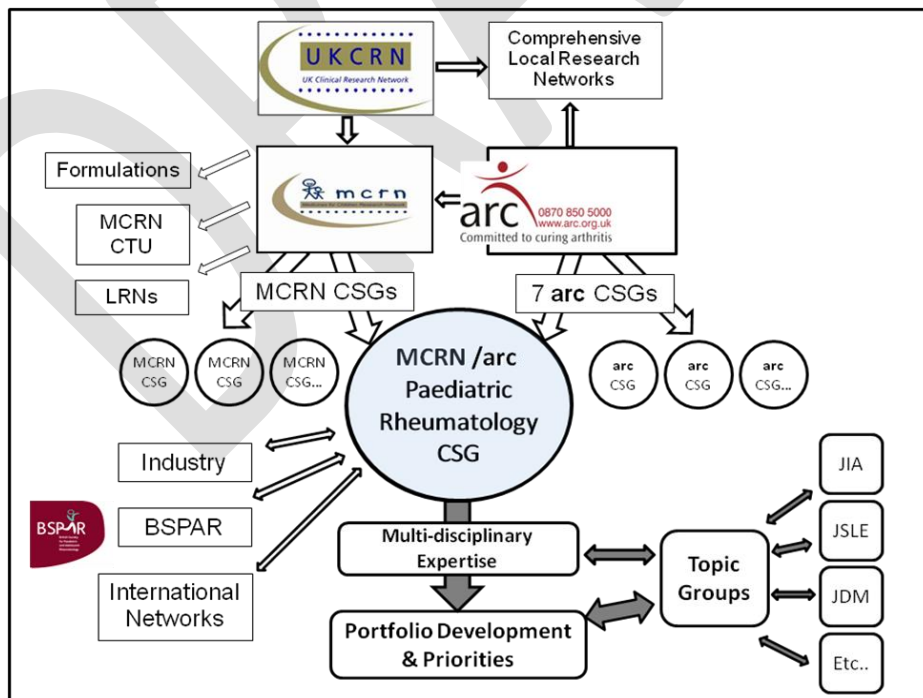
As part of an integrated national research network, the CSG is in an excellent position to collaborate closely with international trial networks while fostering its unique contribution to the transformation of clinical practice by driving both knowledge advance and quality of care of patients with JIA.

This year the CSG's international profile has been consolidated through regular correspondence, discussions and collaboration (e.g. feasibility assessment and intelligence regarding commercial trials) with representatives of the Paediatric Rheumatology International Trials Organization (PRINTO) and the Childhood Arthritis and Rheumatology Research Alliance (CARRA).

Organisation

CSG structure

The figure below outlines the structure of the CSG, its integration into the MCRN and arc's Clinical Trials Initiative, and its links with relevant collaborative organisations:



CSG Membership

Details of all CSG Members and their roles are outlined in Appendix 1, and appear on the CSG's website. Two new members were appointed according to the CSG's Terms of Reference. Ms Sue Maillard was appointed as Allied Health professional representative, and recently Professor Nick Bishop for his expertise in Bone Health and for fostering further links with the British Paediatric and adolescent Bone Group (BPABG).

A number of calls have been sent out for a Clinical Nurse Specialist. No applicants came forward within an extended period of open call. Several have subsequently come forward and have been encouraged to actively engage in topic-specific groups. Agreement is in place with the BSPAR Clinical Nurse Specialists to ensure targeted emails for response to specific queries takes place.

Topic Specific Groups

The Topic-specific groups (TSGs) or sub-groups that were established in embryonic form at the time of last year's Report, have grown and flourished this year. These TSGs have are supported in the task of developing of setting key research priorities, advising on related expressions of interest and Commercial protocols, and fostering collaborative efforts at protocol development and grant application.

Details of the TSGs and their activities are outlined under "CSG meetings and Activities" below.

Community engagement

BSPAR and Informing the BSPAR Community

The CSG Chair and its members continues to regularly inform all members of the BSPAR community of its activities and initiatives, both through its website (see below) and posting of minutes of all meetings, and through specific e-circulars to all BSPAR members (and / or specific target groups such as nurses, allied health professionals). In this way every effort has been made to inform them and invite them to help in driving the CSG's clinical research agenda, inviting them to participate in every level. The Chair gives regular written updates to the BSPAR Executive which are available via the BSPAR website. Links with the BPABG have been further strengthened with the recent appointment of Professor Bishop to the CSG.

BSPAR Trainee's Meeting and BSPAR Clinical Affairs Committee

CSG members ran a very successful, interactive workshop at the annual BSPAR Trainee's Day, December 2008. As well as outlining the role and remit of the CSG, the workshop engaged trainees in the process of developing the Clinical Research Strategy. Trainees were invited to contribute topics across the spectrum of relevant diseases to identify key priority areas for clinical research. These formed the basis of subsequent discussions at the BSPAR Clinical Affairs Committee in January 2009, where topics were discussed, research questions formulated and priorities set. Open consultation following development of the CSG's Clinical Research Strategy took place with all members of the BSPAR community.

The CSG has also been actively involved in the review taking place of the **arc** Barbara Ansell Fellowship scheme.

CSG Consumer Involvement

The CSG continues to include Consumers in all its activities, actively developed in close collaboration with the MCRN Consumer Liaison Officer. Three excellently qualified consumer representatives representing geographical distribution including a devolved nation's representative, and a range of personal professional experience are integral to the CSG.

Role of Consumers on CSG

- All are fully integrated and participate in all meetings and activities of the CSG
- All were actively involved in development of the Clinical Research Strategy, and indeed a section for Consumer-priority Studies was added.
- A consumer representative is nominated and has participated in protocol and study development for key projects supported by the CSG (e.g. Katharine Venter – uveitis associated with JIA trial being submitted to HTA/ARC bid).
- Consumer representatives sit on, or are being sought for each of the topic-specific groups.

They have represented consumers in a number of ways, including:

- Joanna Worsfold sits on the MCRN Consumer Steering Group panel
- Katharine Venter and Sharon Douglas gave a presentation about consumer involvement at the ERA-NET PRIOMEDCHILD Conference (November 2008)
- Sharon Douglas represented the CSG at the meeting: "Project to develop guidance for Chairs of research groups and committees that include patient and public members" (October 2009)

Pilot Models of Consumer Involvement

Pilot models are being set up for consumer comment on the wider CSG agenda. These include:

- Child / parent consumer groups on issues related to a specific TSG agenda (e.g. JSLE, Scleroderma and JDM TSG)
- Consumer group meetings to discuss the remit and wider agenda of the CSG (e.g. Coventry / West Midlands)
- Fostering existing consumer links / representatives in a range of areas of clinical / research activity (e.g. existing links through the TSG members)

CSG Meetings and Activities

CSG Meetings

Minutes of all meetings of the CSG can be found on the **arc**'s CSG's website or from the CSG Administrator (laura.pilkington@liverpool.ac.uk).

Meetings (teleconferences) of the CSG take place on the first Monday of every month. Twice-a-year, face-to-face meetings also take place. These are residential, starting the evening before with an opportunity to review the year to date, discuss progress and a review of how the CSG is working and integrating with the wider community, and discuss direction and vision for the year ahead. We have also been very grateful to Alan Silman, Medical Director of the **arc** who has attended the last of these evenings in January 2009, and has agreed to attend our next meeting in November. The next day is a full-day meeting where all relevant business of the CSG including its prioritisation, standard operating procedures, expressions of interest and trial protocols are discussed in detail. Sarah Rudkin, CSG Research Manager from the **arc** attended the whole meeting in January. In November, both Sarah and Keith Baker from the **arc**, and Ms Nadia Corp, **arc** Information Officer will be attending.

TSG Meetings

The TSGs gather under disease-specific groupings or themes of intervention. In these environments, multi-disciplinary expertise informs project development. The TSGs have provided a mechanism for proactive development of the CSG's comprehensive strategic portfolio. The CSG has successfully built on existing strengths in the UK Paediatric Rheumatology Research Community while supporting other key clinically important research areas needing development. Each Scientific Member of the CSG has developed their role(s) as "link-person" for these TSGs and facilitates integration of the various activities of the TSGs into the overarching work and strategic portfolio development of the CSG.

Each TSG has an inclusive membership and its activities are publicized via the BSPAR E-Mailing, and regular meetings of BSPAR and the BSPAR Research Sub-Committee, and specifically through the CSG's three websites. The CSG also supports financially all meetings of these TSGs (teleconferences and face-to-face) in as much as their activity specifically relates to the CSG's research agenda and remit.

A summary of the TSGs and their current focus of activity is given here:

Topic Specific Group	CSG link person	Initial developments (see Strategy Document)
Auto Inflammatory Diseases	Prof Patricia Woo	Tocilizumab Trial (systemic JIA) adopted and underway; other Industry trials in consideration; developing links with European collaborators
Bone Health	Dr Madeleine Rooney Prof Nick Bishop	Priority support for POPS Trial. Paediatric Bone-Health meeting linking with British Paediatric Adolescent Bone Group. Initial focus of studies: Bone densitometry and use of bisphosphonates in AVN; many projects under development
Formulations & Pharmacy	Dr Utpal Shah	Scoping exercise indicating Methotrexate key priority for formulation / palatability issues; Project ideas being considered
Juvenile Dermatomyositis	Dr Lucy Wedderburn	Building on JDM Research Group (TSG open to all); Regular meetings; Study of Vasculopathy in JDM approved; working

		towards adoption of Cohort Study; treatment protocol survey being constructed; related studies
Juvenile idiopathic arthritis, and JIA-associated uveitis	Prof Helen Foster, Dr Ramanan Dr Wendy Thomson, Dr Eileen Baildam	Combined TSG: Extended Biologics in Paediatric Rheumatic Diseases study funded by arc . Review of collaborative research issues across BSPAR being undertaken; Link with BSPAR Clinical Affairs Committee; JIA-Uveitis anti-TNF trial protocol submitted; see Strategy
Juvenile-onset SLE	Dr Michael Beresford	Building on UK JSLE Study Group - Main focus on developing a UK-wide cohort and validation of paediatric BILAG; priority trials: biologics in JSLE; MMF and cyclophosphamide in severe JSLE;
Childhood Scleroderma	Dr Eileen Baildam	Developing links with PRES Systemic Sclerosis Study and considering localized scleroderma intervention study
Vasculitis	Dr Paul Brogan	MYCYC Trial adopted with support of CSG; Links with EUVAS; development of biomarkers in childhood vasculitis
Non-inflammatory musculoskeletal disorders	Sue Maillard	Strategy consultation identified need to develop this TSG; areas of focus hypermobility, chronic regional pain

Details of Workshops/Meetings Attended

CSG members have represented the CSG at the following meetings this year:

- BSPAR Trainees' Day – HF/WT/AR/EB (December 2008)
- NICE/arc Workshop – MB (January 2009)
- BSPAR Clinical Affairs Away Day - MB/HF/WT/AR (January 2009)
- JIA International Consortium (MB/LW/WT/MR)
- NICE/HTA Meeting – MB (May 2009)
- Inaugural meeting of the NIHR Paediatric (Non-Medicines) Specialty Group – MB (May 2009)
- BSPAR Research Day WT (July 2009)

HTA Priority Setting Exercise

The CSG has proactively contributed to this process, as part of the joint HTA / arc initiative. It has submitted a number of proposals, identified from its Clinical Research Strategy.

HTA Vignette Review

The CSG has been asked to review and give advice on HTA vignettes which are being considered for prioritisation. These include:

- Role of anti-TNF therapy in JIA-associated uveitis
- Exercise therapy in JIA

CSG Websites

The CSG has three websites that are all linked and updated regularly. These ensure its activities are as widely publicised and inclusive as possible to all relevant stakeholders. Significant updates of the websites are advertised by an e-mailing to all BSPAR Members.

- MCRN Website: <http://www.mcrn.org.uk>
- arc Website: http://www.arc-research.org.uk/med_director/paedrheumcsg.asp
- BSPAR Website: http://www.bspar.org.uk/pages/paed_rheum_CSG.asp

All minutes of meetings, standard operating procedures for the CSG, and contact details for each of the TSGs are provided, along with links to the CSG's Clinical Research Strategy.

CSG Publications and Presentations

Since its last report, the role, activity and remit of the CSG has been noted in the following publications / presentations:

- Paediatric Rheumatology European Society: MW Beresford, , EM Baildam, PA Brogan, HE Foster, AV Ramanan, ME Rooney, UU Shah, W Thomson, LR Wedderburn, P Woo., on behalf of the "UK MCRN/arc Paediatric Rheumatology Clinical Studies Group (CSG)". UK Paediatric rheumatology clinical trials network. Pediatric Rheumatology 2008, **6**(Suppl 1):P150

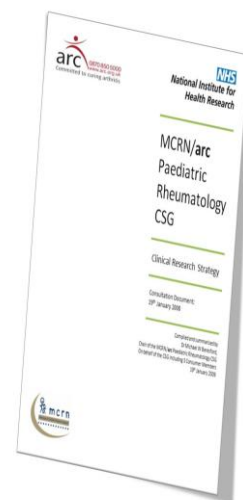
- Beresford MW, Baildam E. New advances in the management of juvenile idiopathic arthritis - 2: The Era of Biologicals. Arch Dis Child Educ Pract Ed 2009;94:151-156
- Hill H, Kelly J, Kemp S, Baildam E, Cleary AG, McCann L, Beresford MW. "To find the right answers, you need to ask the right questions." Consumer involvement in setting our research agenda. Accepted for BSR 2009. Rheumatology 2009; 48 (Suppl 1): i93(213)
- British Society of Paediatric and Adolescent Rheumatology Autumn Scientific Meeting 2009: "Challenges and opportunities – Driving the agenda"
- NIHR Paediatrics (Non-Medicines) Specialty Group: "Involving External Stakeholders: Experience with the ARC" May 2009
- NIHR MCRN CSG Chair's Forum: Clinical Research Strategy, May 2009
- British Society of Rheumatology: "Paediatric Rheumatology Research in the UK," April 2009
- West of Scotland Rheumatologists Meeting: Challenges & Opportunities facing UK MCRN/arc Paediatric Rheumatology CSG," Nov 2008

Prioritisation and the CSG's Clinical Research Strategy

This was the major activity of the CSG in the latter half of 2008, and early 2009 until publication of its final Clinical Research Strategy in May 2009 (http://ctuprod.liv.ac.uk/mcrnweb/index.php?option=com_content&task=view&id=87&Itemid=37).

The CSG has been noted as "exemplar" across all MCRN paediatric CSGs in this initiative. The web-link to its Clinical Research Strategy on the arc website is on the MCRN's own website and all MCRN CSGs have been encouraged to carry out a similar process (see: Integration with arc and MCRN Clinical Studies Groups).

Full details of prioritisation process are given in detail in this document, which remains the primary reference document for all activities and supported studies of the CSG. It will undergo a review process in the Spring of 2010 to ensure it is current and still reflects key priority areas.



CSG and Pharma-Industry Links

Links with the Pharmaceutical industry

The CSG engages with the pharmaceutical/biotech industry to maximise the development of safe and effective medicines and formulations for children. It carries out this role through the MCRN Industry Team. The CSG has reviewed and advised on the following industry trials which have been adopted onto the UK CRN Portfolio:

Acronym	Title	Status
MCRN049 (WA19977A) Roche	A multi-center international study to evaluate the efficacy and safety of tocilizumab in subjects with active polyarticular-course juvenile idiopathic arthritis; followed by an open-label extension to examine the long term use of tocilizumab	Open
MCRN011 (WA18221) Roche	A 12-week randomized, double blind, placebo-controlled, parallel group, 2-arm study to evaluate the efficacy and safety of tocilizumab in patients with active systemic juvenile idiopathic arthritis (sJIA); with a 92-week single arm open-label extension to examine the long term use of tocilizumab	Closed

Other Commercial studies have been considered by the CSG on behalf of the MCRN, and have either been suspended following adoption, or not adopted due to design issues or not a priority / appropriate to the UK Paediatric Rheumatology environment. These include:

MCRN Study No.	Company	Agent / Disease	Outcome
MCRN027 (CZOL446H2337)	Novartis	Zoledronic acid/Osteoporosis	Initially adopted but trial suspended
SD097 (CCA2000)		Fibromyalgia	Protocol not applicable to UK practice
SD077 (3338)	Wyeth	Etanercept	in Concerns re protocol design; not adopted in view of

polyarticular JIA design issues

The CSG has also been asked to give advice and comment at various stages of Paediatric Investigational Plan development and protocol design. These include:

Company
Glaxo Smith Kleine
Roche
Kingfisher Healthcare/ Worldwide Clinical Trials/Italfarmaco
Novartis
Pharmanet
Parexel
Johnsons and Johnson
Abbott

All CSG Members carry out this advisory role under the MCRN's Industry Liaison guidance and receive no specific or personal remuneration for this work. All trial protocols are considered under UK CRN Confidentiality Agreements in place with relevant companies.

Studies Reviewed

Reactive Role of the CSG (Studies Reviewed by the CSG):

The following table outlines the specific "expressions of interest" or applications to the CSG (**in addition** to those included in other sections of this report) where investigators have come to the CSG for advice, or wanting to develop studies in line with the Clinical Research Strategy. Many of these are under on-going development and will be submitted in due course for funding applications to relevant bodies. Specific details of the expression of interest are not always given here for confidentiality reasons, unless they have been formally reviewed by the CSG:

Study	Investigator (where applicable)
To evaluate the therapeutic effect of mirror therapy in children with CRPS	Jacqui Clinch (May 2009)
To evaluate the therapeutic effect of gabapentin in childhood complex regional pain syndrome (CRPS) –	Jacqui Clinch (May 2009)
MYPAN – Polyarteritis Nodosa trial	Paul Brogan (September 2009)
Validation of Paediatric Vasculitis Scores	Nick Wilkinson (September 2009)
AVN and Bisphosphonates	Simon Thomas (November 2008)
Hypermobility Study	Kim Thomas (February 2009)
MTX Adherence and Polygluts -	James McElroy (May 2009)
Etanercept Registry	BSPAR and CIs – 2009
TREAT Trial	CARRA – December 2008
Genome-wide study	PW - 2009
JDM Cohort, Biomarker and Repository	LW - 2009
Steroid induced AVN and bisphosphonates	1 expression of interest
Bisphosphonates in Duchennes	1 expression of interest
Bone density in chronic inflammatory disorders	2 expressions of interest
Normative range for measuring Bone Mineral density	4 expressions of interest
Vitamin D deficiency and complications	3 expressions of interest
Prevention and treatment of low bone mineral density on children	1 expression of interest
Hypermobility and chronic pain	3 expressions of interest

Applications Submitted

Proactive Role of the CSG (Studies Developed by the CSG)

From its establishment, the CSG has seen its major role in fostering the proactive development of a comprehensive portfolio for clinical trials and related studies covering the spectrum of major disease areas in paediatric rheumatology. The CSG does this in an inclusive, open and collaborative way with all potential stakeholders through its TSGs. It achieves this through its ethos, structure and the wide publicity of its activities and initiatives summarised in also in this Report. Applications that have been submitted during this last year include:

Study Title	Summary	Awarding Body	Outcome
Vasculopathy of JDM	The vasculopathy of Juvenile Dermatomyositis: A Pilot study	Arthritis Research Campaign	Awarded £30,108
Extended Biologics Study	The Long-term Safety and Efficacy of Biologic Therapies in Children with Rheumatic Diseases	Arthritis Research Campaign	Awarded £520,527
POPS Trial – Additional Funds	Prevention and treatment of steroid-induced osteopaenia in children and adolescents with rheumatic diseases	Arthritis Research Campaign	Awarded (£154,000 approx – final sum pending)
Uveitis in JIA Trial	Phase III randomised controlled trial of the clinical effectiveness, safety and cost effectiveness of adalimumab for the treatment of juvenile idiopathic arthritis associated uveitis	Health Technology Assessment / Arthritis Research Campaign	Shortlisted from Outline Application; Full application submitted Sept 2009 - pending

Funded and Adopted Trials

MCRN Adopted Trials/ Studies

The following non-commercial Trials / Studies have now been adopted into the UK CRN (and MCRN) portfolio with the support / input of CSG Members and are relevant to the CSG's strategic development:

Acronym	Study Title / Summary
POPS Study	Prevention and treatment of steroid-induced osteopaenia in children and adolescents with rheumatic diseases * (in particular its ongoing extension)
MYCYC Trial	A randomised clinical trial of mycophenolate mofetil versus cyclophosphamide for remission induction in ANCA associated vasculitis
UK JSLE Cohort Study & Repository	UK Juvenile-onset Systemic Lupus Erythematosus Cohort Study & Repository: Clinical Characteristics and Immunopathology of Juvenile-onset SLE *
SPARKS CHARMS	A study of the immunological and genetic mechanisms of response, and psychological response to, standard disease management in JIA *
SPARKS CHARMS-II	Second Phase of this study
Extended Biologics Study	ARC-funded: Pharmacovigilance and efficacy of biologics (other than etnaercept) in paediatric rheumatic diseases, with collection of Biobank

* Indicates studies already on the UK CRN (and MCRN) Portfolio by the time the current MCRN/arc partnership established the current CSG but which had the backing of the preceding "RANII CSG"

Future Work Plan for 2009/2010

It is just over 18 months since the inaugural meeting of the MCRN/arc Paediatric Rheumatology CSG and two years since its Chair was appointed. It has been an intense and extremely productive two years that has initiated a process that has already integrated itself firmly within the UK Paediatric Rheumatology community. Despite this growth, the

activity and outreach of the CSG will continue to mature and develop over the next year. The future work plan of the CSG includes the following:

Area	Detail
Standard Operating Procedures	The CSG has come a long way in developing its Standard Operating Procedures to enable activities of the CSG to work smoothly and quickly, especially when investigators approach the CSG (commercial and non-commercial). These will continue to be refined and new ones developed as the work of the CSG extends
Topic-Specific Groups	Many of the TSG's have developed significantly this past year; all CSGs will strive to develop further, including their outreach multi-disciplinary expertise, and above all their proactive activity
CSG Strategy	The CSG's Research Strategy will be reviewed in Spring 2010
Membership	The CSG has undertaken a careful process of appointing members to the CSG which has been strengthened with two additional members this year. The CSG awaits clarification from the NIHR MCRN and Paediatrics (Non-medicines) Subspecialty Group as to whether additional members will be needed to address a potential wider remit of the CSG to include non-medicines paediatric research
Awareness of the CSG in the wider research community	This Report outlines the mechanisms by which the CSG is attempting to achieve this. These will be reviewed and audited on a timely basis
Proposals for linking into existing RCPCH research groups	This has already taken place with the major relevant group (BSPAR). Links have been established at various levels with the British Association Paediatric Nephrology (BAPN) and the BPABG, which we will strengthen and foster this year where possible. Other developments will include reaching out to Paediatric Orthopedics, and other MCRN CSGs where applicable. Links with the other arc CSGs has been established in certain specific areas (bone health, autoimmune disease) and these links will also be fostered further in collaboration

Summary

This Report has outlined the work of the MCRN/arc Paediatric Rheumatology CSG over the past year. From an embryonic CSG a year ago, it has matured into a much more robust and extremely active CSG.

It has already succeeded in setting a comprehensive Clinical Research Strategy, supporting both reactive and proactive clinical trial and related clinical study initiatives, both commercial and non-commercial, and developed protocols which have achieved funding through the competitive peer-review process.

Above all, it has successfully started to integrate effectively into the Clinical and Research communities of UK Paediatric Rheumatology. In this way, the goal the CSG set itself following its consultation process in developing the Clinical Research Strategy is becoming a common goal of all, that:

“All children and young people in the UK with a rheumatological condition may be given the opportunity to be enrolled in a clinical trial or well conducted clinical study from point of diagnosis onwards, and in so doing improve the care and outcome of them and patients with similar conditions in the future; and to have the option of contributing towards a related, fully informed and consented Biobank (e.g. DNA and Serum) for subsequent investigation into the cause of their condition”

It has been an exciting time and much has been achieved already, yet much needs still to be consolidated and developed. In this way the CSG will continue to contribute to major advances in the treatment of rheumatological diseases affecting children right across the UK.

Appendix 1 - Members of the CSG – September 2009

Name	Job Title and Institution	Role Within CSG
Dr Michael Beresford	Senior Lecturer (Clinical) in Paediatric Medicine /Honorary Consultant in Paediatric Rheumatology at the University of Liverpool, Liverpool	Chair JSLE TSG
Dr Eileen Baidam	Consultant Paediatric Rheumatologist	Scientific Member Scleroderma TSG
Professor Nick Bishop	Professor of Paediatric Bone Disease, Head of Academic Child Health, University of Sheffield Division of Child Health, Sheffield Children's Hospital	Scientific Member Bone Health TSG Link with BPABG
Dr Paul Brogan	Senior Lecturer/Consultant in Paediatric Vasculitis at Great Ormond Street Hospital, London	Scientific Member Vasculitis TSG
Mrs Sharon Douglas	Consumer Representative	Consumer Representative
Professor Helen Foster	Professor of Paediatric Rheumatology at Newcastle University, Newcastle	Scientific Member JIA TSG
Sue Maillard	Clinical Specialist Physiotherapist in Paediatric Rheumatology, Great Ormond Street Hospital, London	Allied Health Professional
Ms Laura Pilkington	MCRN Coordinating Centre	CSG Administrator
Dr Athimalaipet Ramanan	Consultant Paediatric Rheumatologist/Honorary Senior Lecturer at the University of Bristol, Bristol	Scientific Member Uveitis in JIA TSG
Dr Madeline Rooney	Senior Lecturer in Rheumatology at Queens University, Belfast/Consultant Rheumatologist at Musgrave Park, Belfast	Scientific Member Bone Health TSG
Dr Wendy Thomson	Reader at the arc Epidemiology Unit, the University of Manchester	Scientific Member JIA TSG and Basic Science / Genetics Advisor
Dr Utpal Shah	Formulations Research Fellow for the MCRN, Liverpool	Formulations Research Fellow
Dr Katharine Venter	Consumer Representative	Consumer Representative
Dr Lucy Wedderburn	Reader /Honorary Consultant in Paediatric Rheumatology at Great Ormond Street Hospital, London	Scientific Member JDM TSG BSPAR Research Chair
Professor Patricia Woo	Professor of Paediatric Rheumatology/Head of the Centre for Paediatric and Adolescent Rheumatology, Institute of Child Health at the University College London/Honorary Consultant at Great Ormond Street Hospital	Scientific Member Auto-inflammatory TSG PRINTO link
Mrs Joanna Worsfold	Consumer Representative	Consumer Representative