

Poster presentation

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UK paediatric rheumatology and its clinical trials network

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Background

There is striking paucity of a rigorous evidence-base for the treatment of paediatric musculoskeletal diseases. The Medicines for Children Research Network (MCRN) improves coordination and quality of clinical trials and related studies across the UK. It has joined in partnership with the Arthritis Research Campaign (arc), the major UK charitable funder of musculoskeletal research, to form the MCRN/arc Paediatric Rheumatology CSG.

Methods

The MCRN has extensive expertise in supporting non-commercial, pharmaceutical-sponsored and investigator-led studies. The CSG is a multi-disciplinary group comprising clinicians, academics, basic scientist, pharmacy, and clinical trials unit support. Through consultation with stakeholders, its remit includes: developing a comprehensive portfolio for clinical trials/related studies covering the spectrum of paediatric rheumatology; ensuring consumer involvement; upholding Good Clinical Practice.

Results

The CSG has developed topic-specific groups (TSGs) outlined in Table 1. Key "themes" across TSGs include: acceptability of intervention; quality of life; health economics; cardiovascular risk; skeletal health; rare diseases; orphan drugs; international collaboration. Key "tools" include: characterised phenotype cohort studies; biomarkers; genotype/phenotype/proteomics; pharmacogenomics; pharmacokinetic studies; mechanism of disease;

Phase II and III studies. Strategic development of protocols is underway. Regionally based networks assist with feasibility, site selection, financial, ethical and governance arrangements, staff recruitment, training, participant recruitment and trial monitoring. Table 2 illustrates studies already MCRN adopted and supported in this way.

Conclusion

An integrated national research network provides an excellent infrastructure to collaborate closely with international trial networks (e.g. CARRA, PRINTO) while fostering a unique contribution to the transformation of clinical care of children.

Table 1: Topic-specific Groups

Topic Specific Group
Auto Inflammatory Diseases
Bone Health
Juvenile Dermatomyositis
Juvenile idiopathic arthritis (JIA)
Juvenile-onset SLE
Rare disorders (Initial focus on Scleroderma)
Uveitis in JIA
Vasculitis
Formulations & Pharmacy

Table 2: Studies recently adopted by MCRN

Acronym	Study Title
POPS Study	Prevention and treatment of steroid-induced osteopaenia in children and adolescents with rheumatic diseases
UK JSLE Cohort Study and Repository	UK Juvenile-onset Systemic Lupus Erythematosus Cohort Study epository: Clinical Characteristics and Immunopathology of Juvenile-onset SLE
MYCYC	A randomised clinical trial of mycophenolate mofetil versus cyclophosphamide for remission induction in ANCA associated vasculitis
SPARKS CHARMS	A study of the immunological and genetic mechanisms of response, and psychological response to, standard disease management in juvenile idiopathic arthritis (JIA)

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