British Society for Paediatric and Adolescent Rheumatology (BSPAR) Research Subcommittee: list of current active studies.

Last updated: November 2009

Please note that the order of studies mentioned in no way implies any priority or ranking of importance of projects.

Many of these studies fit into priority areas that have been identified by the MCRN/arc Paediatric Rheumatology Clinical Studies Group: you can find information about the CSG on this BSPAR website
http://www.bspar.org.uk/pages/paed_rheum_CSG.asp
or at-
http://www.arc-research.org.uk/med_director/paedrheumcsg.asp.

1. BSPAR Etanercept Registry. The BSPAR Etanercept study collects detailed information on the effectiveness and safety of Etanercept in children with JIA. In addition to collecting data on children who are taking Etanercept, information from children taking methotrexate (MTX) for JIA is also being collected in order to compare side effects in children taking MTX. The Lead investigators are **Prof T Southwood, Birmingham, and Dr K Hyrich, Manchester.** The study is overseen by an independent Steering Committee, which is chaired by Prof. D GI Scott, and has a Consumer representative involved. Funding from Wyeth.

2. Prevention and treatment of steroid induced OsteoPenia Study, POPS: prevention and treatment of steroid-induced thinning of the bones (osteopenia) in children and adolescents with rheumatic diseases. This study is of children starting steroids, or already on steroids, to investigate the best treatment to prevent thinning of the bones or osteopenia. Children in this study are in one of three groups - 1-alpha hydroxycholecalciferol (1-alpha), Risedronate, or placebo. The Lead investigator is **Dr M Rooney,** Belfast. The study is overseen by an independent Steering Committee and has a Consumer representative. Funded by the Arthritis Research Campaign. This Study is adopted onto the UK MCRN Portfolio see:
http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=2313

3. The Juvenile Dermatomyositis Cohort Biomarker Study and Repository (UK and Ireland), previously known as the Juvenile Dermatomyositis National Registry and Repository, JDRR (UK and Ireland). This is a UK and Ireland wide study and research network, which aims to understand the causes and types, as well as improve treatment and outcomes, of inflammatory muscle diseases in children. The most common inflammatory muscle disease in children is called juvenile dermatomyositis, or JDM. You can find more about this study at the new study website:

http://www.jdrg.org.uk. The lead investigator is Dr L R Wedderburn, London. The study is overseen by an independent Steering Committee, which is chaired by Dr M Friswell, and has a Consumer representative involved. Funded by grants from the Wellcome Trust, Action Medical UK and Myositis Support group UK. The Study is adopted onto the UK MCRN Portfolio see:
http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=7723

4. UK Juvenile Systemic Lupus Erythematosus (SLE) Cohort Study and Repository: The UK Juvenile **Systemic Lupus Erythematosus (JSLE)** JSLE Study Group is a multi-centre, multi-disciplinary collaborative network comprising nearly all of the paediatric tertiary rheumatology centres and most of the paediatric tertiary nephrology centres in the UK. The UK JSLE Cohort Study & Repository aims to define the clinical presentation, severity, extent, prognosis, and disease characteristics of JSLE. The lead investigator of this study is **Dr M Beresford,** Liverpool. The study has an independent Steering Committee has a Consumer representative involved. Funded by grants from Lupus UK and ARC. You can find out more about this study at http://www.liv.ac.uk/ukjsle . The Study is adopted onto the UK MCRN Portfolio see:
http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=3836

5. Childhood Arthritis Prospective Study (CAPS).
CAPS is a prospective observational study of children presenting with new onset inflammatory arthritis. The key aims of CAPS are to find out what happens over time to children with all types of arthritis and to identify the relative contributions of socio-demographic, clinical, psychological, laboratory and genetic factors and treatment in explaining these outcomes. The lead investigators of this study are **Drs W Thomson and K Hyrich,** Manchester. CAPS is undertaken in collaboration with researchers in Manchester, Liverpool, Glasgow, Newcastle, and London. Funded by the ARC. The study is overseen by an Independent Steering Committee, Chaired by Dr E Baildam. You can find out more about CAPS at:
http://www.medicine.manchester.ac.uk/epidemiology/research/arc/inflammatorymusculoskeletal/outcomestudies/caps/

6. PRINTO JDM treatment trial.
The Paediatric Rheumatology International Trials organisation (PRINTO) trial in juvenile dermatomyositis (JDM) is taking place in may countries, both in Europe and beyond, including the UK. The study aims to compare 3 standard methods of treatment of newly diagnosed JDM. In the UK the lead investigator is **Dr C Pilkington** London. Funded by PRINTO via EU grant funding. For more information see the PRINTO website: http://www.printo.it/

7. Tocilizumab (Anti IL-6R) in active sJIA phase III. This is a 12-week randomized, double blind, placebo-controlled, parallel group, 2-arm study to evaluate the efficacy and safety of the drug Tocilizumab in children with active systemic juvenile idiopathic arthritis (sJIA), with a 92-week single arm open-label extension to examine the long term use of Tocilizumab. The study involves two centres in the UK, and has now finished recruiting. Lead investigator is **Prof P Woo** London. The study is funded by Roche. The Study is adopted onto the UK MCRN Portfolio see:
http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=4497

8. Tocilizumab (Anti IL-6R) in polyarticular JIA. This is a multi-center international study to evaluate the efficacy and safety of the drug Tocilizumab in children with active polyarticular-course juvenile idiopathic arthritis; followed by an open-label extension to examine the long term use of tocilizumab. The lead investigator is **Dr A Ramanan** Bristol. The study is funded by Roche. The Study is adopted onto the UK MCRN Portfolio see:
http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=7050

9. Improving musculoskeletal clinical skills in medical students. This is a multi-centre study incorporating 3 UK medical schools and BSPAR members. The aim is to determine the musculoskeletal learning outcomes (including clinical skills and knowledge) that medical students need to know, and develop a teaching resource pack aimed at clinical teachers who may or may not be experts in the area. This study is ARC funded. The lead investigators are Dr S Jandial, and **Prof H Foster,** Newcastle.

10. Musculoskeletal problems in children from a primary care perspective. What does the General Practice Registrar need to know and how should this be taught? This study has determined paediatric musculoskeletal learning outcomes for GP trainee, based on evidence and consensus opinion derived from GPs, GP trainees and secondary care specialists. Many BSPAR members took part in the initial survey. The data from this study has been integrated into the revised ARC GP Learning Guide (due 2009) and used to devise pMSK modules in the RCGP e-learning project (launched August 2009). The results from this study will facilitate the development of further supportive educational materials aimed at GPRs. Lead Investigators are Dr D Boyd, Sunderland and **Prof H Foster,** Newcastle. This project is ARC Funded.

11. Exploring barriers to care for children with JIA. This project will *identify, define and understand* factors that promote or inhibit referral, and understand how these are mediated through different health care and social networks. This work will lead to strategies to facilitate access to care for children with JIA. The lead investigators of this study are **Prof HE Foster** and Prof C May, Newcastle. This project is ARC Funded.

12. SPARKS CHARMS: the Childhood Arthritis Response to Medication Study. This is a large study of the mechanisms of response to methotrexate and anti TNF medicines, in JIA, at genetic, biological, immunological and psychological levels. The lead investigator of this study is Dr L R Wedderburn, London. The study is based in London with collaborating partners in Birmingham and Utrecht. The study is overseen by an Independent Steering Committee chaired by Dr R Leech and has a Consumer representative involved. Phase 1 of the study was funded by a Lottery (Community Fund Research) grant in partnership with SPARKS UK, and Phase 2 is funded by SPARKS UK. This Study is adopted onto the UK MCRN Portfolio see
http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=3227

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Thank you to all those who contribute information for this list
We are always keen to hear details of studies going on within BSPAR.

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