

Alder Hey Clinical Academic Department

Paediatric Rheumatology

Information about our services for parents and carers

Overview of the Department

The Liverpool Clinical Academic Department of Paediatric Rheumatology is based at Alder Hey Children's NHS Foundation Trust and the University of Liverpool, in the new 'Alder Hey in the Park' and 'Institute in the Park'. The department is recognised as one of the leading paediatric rheumatology units in the UK, providing the highest level of specialist care to children and young people across the region with an ever growing international profile. It was recently recognised by the European League Against Rheumatism as one of Europe's outstanding "Centres of Excellence", in close collaboration with adult rheumatology services here in Liverpool.

We are a major centre for paediatric rheumatology and musculoskeletal research, linking with all major rheumatology centres across the UK and internationally. Our team is trying to improve the care and understanding of rheumatic disorders in children and young people.

Paediatric Rheumatology Department

Our department is one of the largest paediatric rheumatology units in the UK. It provides the highest level of tertiary multi-disciplinary rheumatology expertise to children and adolescents in Liverpool, North Wales and the North West.

UK's First Ever 'Centre of Excellence for Childhood Lupus'

Since 2011 we were made the UK's first ever "Centre of Excellence for Childhood Lupus" by LUPUS UK. LUPUS UK is the major UK charity supporting patients and their families with Lupus. This fantastic status was awarded to us as a result of the excellent clinical care and research we provide to help children with Lupus.

UK's First and only "Experimental Arthritis Treatment Centre for Children"

Since 2014, Arthritis Research UK made us the UK's first and only "Experimental Arthritis Treatment Centre for Children". This national research centre is dedicated to testing better and more effective drug treatments for children with arthritis and other related disorders. The Centre aims to improve the health and wellbeing of children with these conditions by developing the very latest better, safer medicines for children and young people.

One of three National Centres of Excellence for Behcet's Syndrome

In 2012, three NHS National Centres of Excellence for Behcet's syndrome were created in Liverpool, Birmingham and London. Alder Hey provides the paediatric arm of the Liverpool Centre linking closely to Aintree. The aims of the centres are to provide holistic and equitable care to children with Behcet's syndrome, including appropriate timely access to biologic drugs.

Training and Education

- **Departmental Education**

Our team are involved in teaching students. Teaching occurs during ward rounds, clinics and team meetings. Sometimes our patients are invited to assist the team with teaching others.

- **Trainee Rheumatologists**

Alder Hey is a main UK centre for training future paediatric rheumatology doctors and general paediatricians with an interest in rheumatology.

- **Multi-Disciplinary Team**

Our Rheumatology Department is a large team made up of different health professionals. Together, we emphasise the importance of working together to provide the best possible care.

Within the team there are consultants, nurse specialists, research nurses, physiotherapists, occupational therapists, pharmacists, psychologists, junior doctors, play specialists, secretaries, scientists and data managers.

Clinical Excellence

Clinical Care in Paediatric Rheumatology

We care for patients with severe chronic inflammatory conditions affecting joints, bones, muscles and tissues as well as other body systems. Some of these conditions are life-long and can have an enormous impact on the child or young person, as well as the wider family. Many conditions can affect different parts of the body, which are rare and difficult to diagnose.

We work closely with other specialists at Alder Hey to provide accurate diagnosis. Treatments include a wide range of drugs and therapies provided by an expert team.



We believe that patients have a right to be involved in research and clinical trials to address gaps in knowledge that exist about their condition.

We are a leading clinical research department and provide all patients with this opportunity.

Clinical Rheumatic Disorders

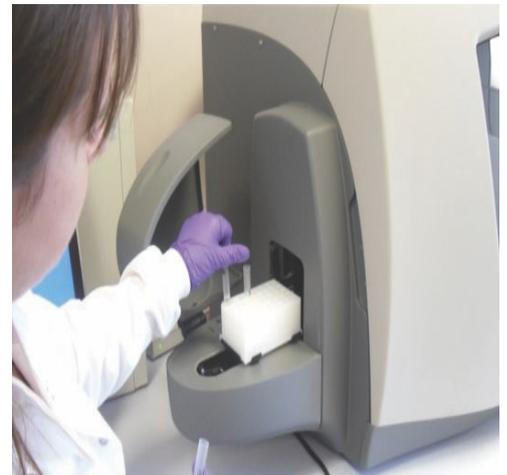
Our department looks after children with conditions including:

- Juvenile idiopathic arthritis.
- Juvenile-onset systemic lupus erythematosus.
- Juvenile dermatomyositis
- Childhood scleroderma
- Systemic vasculitis
- Behcet's Disease
- Auto inflammatory disorders
- Periodic Fevers
- Complex regional pain syndrome
- Chronic musculoskeletal pain syndromes.
- Mechanical disorders affecting the musculoskeletal system.

Clinical Research within the Department

Our department is a world class centre of excellence for research into child and adolescent rheumatic diseases.

Each member of our team helps with research as we believe that it is an important part of our patients' care.



UKJSLE Study Group

Alder Hey is the lead centre of the UK Juvenile-onset Systemic Lupus Erythematosus (JSLE) Study Group. This group is exploring why Lupus occurs in children by collecting information about children with Lupus across the UK. Laboratory research also takes place in our dedicated laboratories.

National and International research

Our department works closely with all major research centres within the UK, along with international colleagues, to support research in paediatric rheumatology nationally and around the world.

Overview of current Research Activity

The following information summarises just some of the current research taking place in our department.

Research Portfolio

Our department is active in a wide range of local and multi-centre collaborative research involving all members of the multi-disciplinary team.

NIHR CRN: Children / Arthritis Research UK Paediatric Rheumatology Clinical Studies Group

The Institute in the Park hosts the the National Institute of Health Research (NIHR) Clinical Research Network (CRN) National Co-ordinating Centre for Children and supports the coordinating of the UK's Paediatric Rheumatology Clinical Studies Group. The group co-ordinates UK wide programme of clinical trials and clinical studies across the entire spectrum of paediatric rheumatology. Professor Beresford is the NIHR Clinical Research Network: Specialty Cluster Lead for Children, Reproductive & Childbirth, Musculoskeletal, Ophthalmology and Haematology. Dr Baildam is the co-chair of the Paediatric Rheumatology Clinical Studies Group (CSG) and Dr Pain is chair of the scleroderma topic-specific group aligned to the CSG.



Biologics and New Drugs Registry.

Our department is one of the main contributors to the national registries, looking at the long term safety and effectiveness of new medication.



Childhood Arthritis Prospective Study (CAPS)

We are a major centre providing data to the Childhood Arthritis Prospective Study (CAPS) which looks at children who present with new onset of inflammatory arthritis.

Juvenile Dermatomyositis Registry and Repository

The work for this study includes collecting detailed clinical data and samples to help research. Our department has been involved with this study since it began. In addition, Dr McCann has led an international study developing a core set of data for children with JDM.

British Paediatric Surveillance Unit national study of Behçet's syndrome in children.

This national study aims to understand how many children in the UK are affected with Behçet's syndrome and how they are treated. It is led by Dr Pain.

Clinical Trials in Paediatric Rheumatology

Alder Hey is a major centre for clinical trials in children and young people with rheumatic disorders. The Department works closely with the NIHR Alder Hey Clinical Research Facility in providing excellent care for children participating in this research.

Vision for the Future

Our aims for the next five years include:

- **Clinical excellence**
To continue to work as a team to deliver world-class care to children, young people and their families within Alder Hey.
- **Clinical and Basic Science Research**
To continue to combine medical treatment with research to improve the care of children in the future.
- **Expansion of services**
To expand our team and allow others to learn from our excellent work.
- **National and international collaboration**
To continue to work closely with others across the UK, Europe and beyond to help all children with rheumatological conditions.

The Clinical Academic Team

Consultants

Dr Gavin Cleary
Dr Liza McCann
Dr Clare Pain
Dr Kamran Mahmood
Professor Michael Beresford
Professor Christian Hedrich



Rheumatology pathway co-ordinator
Database Manager
Blood Clerk
Rheumatology Nurses
Chronic Fatigue/Pain Nurse Specialist
Lead Rheumatology Pharmacist

0151 282 4521
0151 282 4521
0151 282 4521
0151 293 3556
0151 293 3544

0151 282 4811

(Mondays and Tuesdays via pathway co-ordinators.)

Occupational Therapists **0151 252 5236**
Physiotherapists
Play Specialist
Clinical Psychologists
Extended Scope Practitioner

0151 252 5236

0151 252 2027/2744

0151 252 5586/5879

0151 282 4811

(via pathway co-ordinators.)

If you would like further information about Childhood Lupus please visit our website at www.alderhey.nhs.uk

Other useful contact details

UK JSLE Cohort Study and Repository

0151 293 3566

This fact sheet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

Alder Hey Children's NHS Foundation Trust

Eaton Road

Liverpool

L12 2AP

0151 228 4811

www.alderhey.nhs.uk

RhAC/Lupus ©Alder Hey 2017 Date of next review August 2019

PIAG 50