

NIHR CRN: Children/Versus Arthritis Paediatric Rheumatology CSG Research Studies Leaflet

JIA Research Studies Leaflet (Completed)

- Juvenile idiopathic arthritis
- JIA-associated uveitis

Autoinflammatory Diseases Research Studies Leaflet (Future)

- Autoinflammatory diseases

Connective Tissue Diseases Research Studies Leaflet

- Juvenile systemic lupus erythematosus (jSLE)
- Scleroderma/systemic sclerosis (SSc)
- Juvenile dermatomyositis (JDM)
- Sjogren's syndrome
- Vasculitis
- Kawasaki disease (KD)
- Behcet's disease
- Mixed connective tissue disease
- Undifferentiated connective tissue disease
- Antiphospholipid syndrome (APS)

Noninflammatory Research Studies Leaflet (Future)

- Noninflammatory musculoskeletal pain
- Joint hypermobility syndrome (JHS)
- Ehlers-Danlos syndrome (EDS)
- Chronic widespread pain syndrome
- Fibromyalgia
- Complex regional pain syndrome

Current/future studies

Disease	Study abbreviation	Study title	Chief investigator(s)	Study description	Study hyperlink	Sites	Status
JSLE	UK JSLE Cohort	UK Juvenile Systemic Lupus Erythematosus Cohort Study & Repository	Michael Beresford	<p>The study is led by the UK JSLE Study Group, a team of UK paediatric rheumatologists, adult rheumatologists, nephrologists, dermatologists, nurses, psychologists and scientists with active patient/parent involvement and close links to the charity Lupus UK.</p> <p>The UK JSLE Cohort Study regularly collects clinical information about patients with JSLE from across the UK, as well as biological specimens (e.g. blood and urine). This has helped us to learn more about how Lupus affects children and look at the treatments they receive. The blood samples collected as part of the study have led to lots of research into the causes of JSLE (looking at the immune system and also genetics of Lupus). We use the urine samples to help better understand the kidney problems seen in Lupus.</p>	https://www.liverpool.ac.uk/translational-medicine/research/ukjsle/about/	Liverpool (Alder Hey, Royal Liverpool hospital, Aintree), Birmingham, Bristol, Glasgow, Edinburgh, Aberdeen , London (GOSH, UCLH, Guy's and St Thomas's, Leeds, Nottingham, Newcastle, Oxford, Manchester, Coventry , George Eliot , Taunton and Somerset,	Open since 2006, recruiting

						Bradford, Southampton, Sheffield, Leicester, Cambridge	
JSLE	JSLE BPSU study	British Paediatric Surveillance Unit study into Juvenile-onset Systemic Lupus Erythematosus	Hanna Lythgoe, Michael Beresford	This study will identify the numbers of children developing JSLE each year and how their disease manifests. It also aims to identify by whom and how these children and young people are looked after, exploring the delay in diagnosis experienced by children with JSLE.	https://www.liverpool.ac.uk/eatc-for-children/research/workstreams/jsle/	Open to the whole of the UK	Open since September 2017, recruiting until September 2019 with as further 12 months follow-up.
JSLE	Living with Lupus	'Living with Lupus' - deriving treatment targets and outcome measures with children and young people with JSLE, to underpin development of the TARGET LUPUS research programme	Eve Smith	This study involves carrying out interviews with patients with Lupus and one of their parents to try to understand Lupus, how patients feel when they are 'well' and what it's like when they are feeling unwell. The study also collect information on experiences of Lupus treatment, and what sorts of questionnaires are best to use to track how patients with Lupus are feeling over time. The findings from this study will help us to decide what treatment goals should be included in a future study comparing two different approaches to Lupus treatment. We know that different doctors have their favorite ways to	https://www.liverpool.ac.uk/eatc-for-children/research/workstreams/jsle/	Liverpool, Birmingham, Leeds, Sheffield, London (GOSH), Bristol, Leicester, Nottingham	Open since March 2019, recruiting until December 2019.

				manage Lupus. In the future project, patients would either be 'treated to target' by following a set plan, or treated in the usual way that their doctor usually treats Lupus.			