UK JIA BIOLOGICS REGISTER

Newsletter for NHS sites - Summer 2025

This is an update for our colleagues who work on the UK JIA Biologics Register* at NHS hospitals across the UK.

Please contact us with any comments and questions (details are at the end of the newsletter). Have a great summer!

**UK JIA Biologics Register is the collective name for the BCRD Study (UK CRN ID 7725) and the BSPAR Etanercept Study (UK CRN ID 13553)*

In this issue:

CERTIFICATES OF SPECIAL RECOGNITION

Certificates of special recognition have been sent out to sites who contributed data in 2024 - **thank you to all sites who continue to contribute to this (very) long-term study**, it is very much appreciated! Some of the many wonderful photos we received are below. We look forward to seeing more next year!

Northampton General Hospital

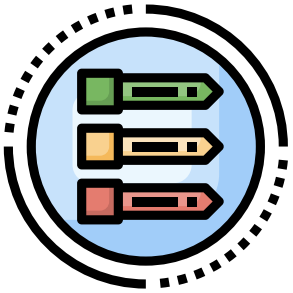
Royal Stoke University Hospital

Freeman Hospital

Sheffield Children's Hospital

STUDY PRIORITIES - 2025 ONWARDS

UK JIA Biologics Register



- Recruitment of **tofacitinib** participants
- Recruitment of all other **biologic, biosimilar and JAKi** treatments
- Completion of all **follow up data**
- Collection of single **blood sample** - a list of any outstanding is within your centre screen on the database

Eligibility:

- Diagnosis of Juvenile Idiopathic Arthritis.
- Under 18 years of age.
- Starting treatment with a biologic, biosimilar or JAK inhibitor.
- Willing to provide consent within six months of treatment start date for new patients and within 2 years for re-registrations (no limit for re-registration for tofacitinib participants).
- Recruitment to BCRD Study only - BSPAR now closed to recruitment.

Funding:

- Please remember: due to a revision of the funding model, we are now able to offer payments for ALL data submitted to the UK JIA Biologics Register (£50 per form, conditions apply).
- Up to £350 is available for each tofacitinib participant recruited.

REGISTER CHAMPIONS

Three sites who have been very successful in their work on the UK JIA Biologics Register have been approached to be new 'Register Champions'. Thank you to the teams at **Oxford**, **Southampton** and **Newcastle**!

They have been kind enough to share their experiences, which have been published on the BSR website - please follow the link below.

Southampton: Ellen Lacey

Ellen's fantastic efforts in both recruiting participants and submitting scheduled follow-ups have earned her the title of 'Register Champion'; this highlights her commitment and impact on the study.

Oxford: Danielle Miller

Danielle is an experienced children's research nurse who has worked on the UK JIA Biologics Register for a number of years at Nuffield Orthopaedic Centre (Oxford) with Dr Kathy Bailey as PI.

Great North Children's Hospital (Newcastle)

The team at GNCH, led by PI Dr Flora McErlane, has had huge success with the UK JIA Biologics Register

Read their stories here:

WWW.RHEUMATOLOGY.ORG.UK/IMPROVING-CARE/REGISTERS/CHAMPIONS

CELEBRATE YOUR REGISTERS!

UK JIA Biologics Register

Data gathered through the **BSR Biologics Registers** has made a significant impact in the management of inflammatory disease. By monitoring adverse events and treatment outcomes over a number of years, the BSR Biologics Registers, including the UK JIA Biologics Register, have helped to identify potential benefits and risks associated with new therapies.

This has enabled healthcare professionals to make more informed decisions when prescribing treatments, ultimately improving patient care.

Important questions answered by your UK JIA Biologics Register data

How are biologics and biosimilars used in the NHS?

- **There was no difference in disease control among children who switched to TNFi biosimilars compared to those who remain on originator TNFi. Switching back to originator from biosimilar was uncommon, suggesting good tolerability following "non-medical" switching** (*Kearsley-Fleet et al*, 2024)

- **About 20% of children with JIA stopped their TNFi for remission, although ~50% restarted within 1 year. Restarting was more likely in those with uveitis history or longer disease duration** (*Kearsley-Fleet et al*, 2023)

- **For many children and young people with JIA, treatment with a first TNFi therapy is not successful. Most children switch to a second TNFi at this stage. There is no evidence that switching to tocilizumab was more beneficial than a second TNFi** (*Kearsley-Fleet et al*, 2020; *Mannion et al*, 2024)

- **Rituximab may be an effective treatment option for children who do not respond to TNFi, with a low rate of serious infections on treatment** (*Kearsley-Fleet et al*, 2018)

View full publications: https://sites.manchester.ac.uk/bcrdbspar/ or scan the QR code

LATEST RESEARCH

Dr Stephanie Shoop-Worrall *discusses her latest research from the CLUSTER consortium (which includes data from the UK JIA Biologics Register). This research looks at how Artificial Intelligence (AI) can help determine which treatment will work best for children and young people with JIA .*

Background:

Methotrexate (MTX) is a common first-choice treatment for young people with juvenile idiopathic arthritis (JIA). However, it only works well for about half of them.

To improve treatment decisions, researchers in CLUSTER used artificial intelligence (AI) to find groups of young people who experienced different patterns in their disease and its impact after taking MTX. They also wanted to see how these AI-based patterns compared to traditional ways of measuring treatment `success'.

What they did:

The researchers studied children and young people who started MTX before 2018 using data from multiple hospitals in the UK. They tracked key disease impacts over a year: joint swelling, how well the doctor thought the young person was, and wellbeing of the young person and a blood marker of inflammation . They used AI to group patients into six response types, based on how their condition and its impact changed over time.

What they found:

The six response types were: Fast Improvers (key impacts all got better six months after starting MTX), Slow Improvers (key impacts took a year to get better), Improve-Relapse (some improvement then worsening), Persistent Disease (little to no improvement), Persistent Doctor Concern (young person felt better, but doctors still thought the disease could be better controlled), and Persistent Parent Concern (doctor thought disease looked well controlled, young person still had issues like pain and issues doing everyday tasks).

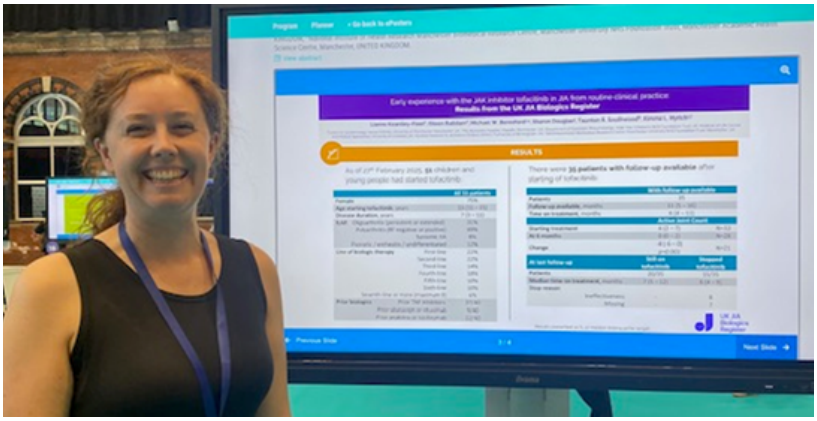
- Factors like age, ethnicity, and initial disease severity influenced which group patients fell into.
- Traditional scoring methods couldn't fully capture how different patients improved or relapsed over time. They also couldn't pick out young people whose disease and its impacts didn't all improve at the same rate.

Why it matters:

This AI-based approach shows that the standard way of judging treatment success (a simple yes/no measure) is too limited. Instead, recognizing distinct response patterns could help doctors personalize treatment plans for children with JIA. This would make sure each young person gets the best possible care, tailored to which part of their disease and its impact are causing issues.

LATEST RESEARCH

Co-Lead of the UK JIA Biologics Register, ***Dr Lianne Kearsley-Fleet****, presented her work on tofacitinib at the British Society for Rheumatolgy conference 2025 in Manchester.*



Early experience with the JAK inhibitor tofacitinib in JIA from routine clinical practice

Within the UK JIA Biologics Register, we have over 50 children and young people who have started the JAK inhibitor, tofacitinib.

These children tend to start this advanced therapy at a slightly older age, having had their JIA for longer and previously tried at least one other biologic therapy.

For those children who had information available 6 months after starting tofacitinib, the number of joints they had with active arthritis appeared to reduce, and over half the children were still on therapy at their last clinic appointment.

Our data suggests that tofacitinib could be a very effective treatment for JIA even after multiple prior biologic therapies.

Please continue to recruit all participants starting (or switching to) tofacitinib to the BCRD Study. Up to £350 per recruit available.

UK JIA Biologics Register

CONTACT US!

Over the summer period the team will be taking some leave, and will get back to any queries as soon as possible. Normal hours will resume early September. Thank you for your patience.

Study Coordinators:

Katy (right) - *BCRD Study - Katy.Mowbray@manchester.ac.uk*

Emily (left) - *BSPAR Study - Emily.Sutton@manchester.ac.uk*

Project administrator Praksha is on hand for all your recruitment, eligibility and database queries: praksha.jariwala@manchester.ac.uk

www.sites.manchester.ac.uk/bcrdbspar/

Thank you!