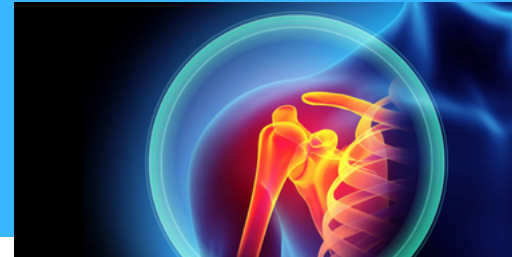


# UK JIA BIOLOGICS REGISTER



Newsletter for NHS sites  
Autumn 2023



Thank you for being involved with the **UK JIA Biologics Register**! This is an update for our colleagues who work at NHS hospitals across the UK.

**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)

The **UK JIA Biologics Register** is coordinated by a small team at the University of Manchester, based at the Bright Building (*pictured*).



**3528**

Children and young people with JIA have been recruited so far

**51**

NHS Hospitals across the UK have recruited participants

## NOW RECRUITING TOFACITINIB PATIENTS!

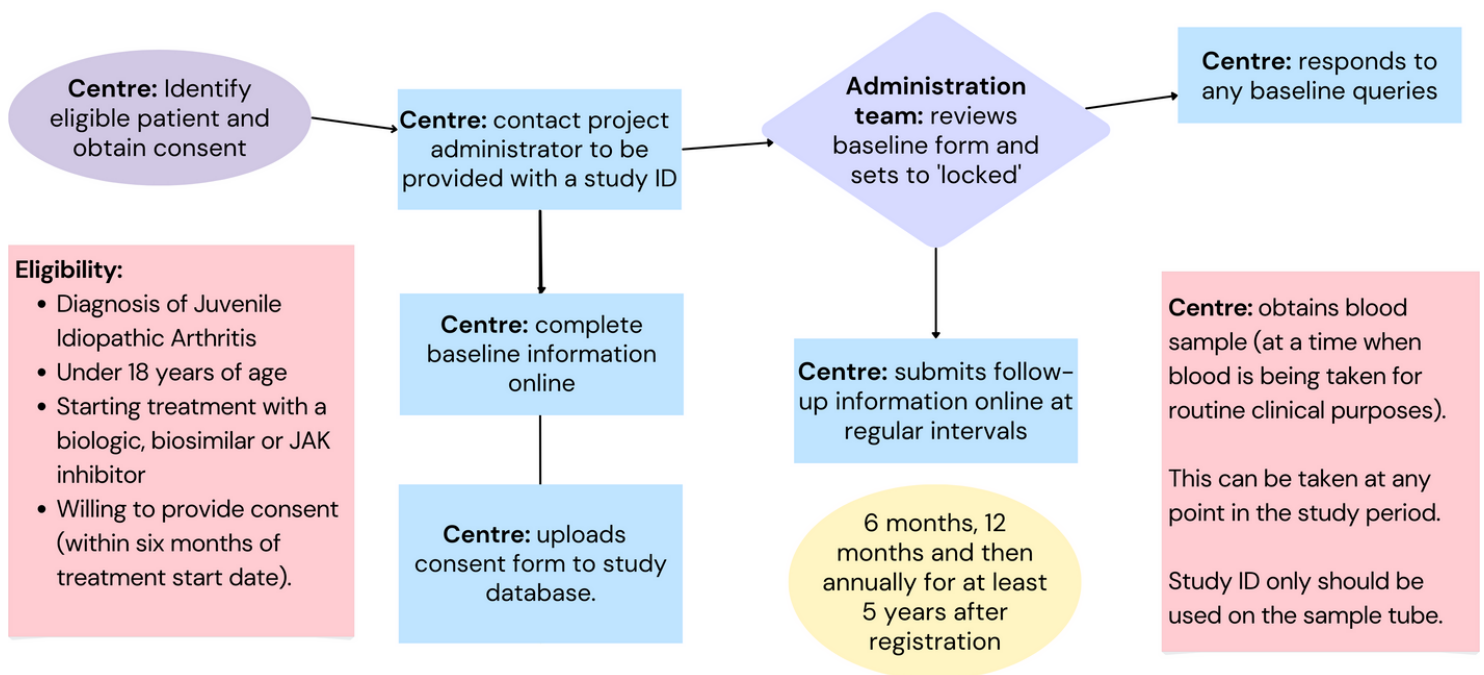
**We aim to recruit all children and young people < 18 years with JIA who are starting treatment with tofacitinib.**

Participants should be recruited to the BCRD Study in the usual way  
(*reminder on p2*)

**THERE IS UP TO £350 AVAILABLE FOR EACH PARTICIPANT REGISTERED WHO IS STARTING TREATMENT WITH TOFACITINIB. THIS PAYMENT IS FOR THE PROVISION OF BASELINE REGISTRATION AND FOLLOW-UP DATA**

# STUDY REMINDERS

## Registering a participant with either BCRD or BSPAR Study



- Register participants starting **Enbrel and etanercept biosimilars** (eg Benepali) with the **BSPAR Etanercept study**.
- Register participants starting **all other biologic, biosimilar, JAKi** therapies (eg Amgevita, Tofacitinib) with **BCRD**.

**\*NEW FEATURE\*** - *you can now upload consent forms directly on to the online database*

Contact: **Praksha.jariwala@manchester.ac.uk** to obtain a study ID number or if you have any questions about eligibility

## Entering follow up data

You can log in to the study database, which will give you a list of which follow-up forms are now due at your centre.

**<https://sites.manchester.ac.uk/bcrdbspar/information-for-healthcare-professionals/>**

If you need your account un-locking/password re-setting please get in touch and we can do this for you.

# LATEST RESEARCH

*Dr Lianne Kearsley-Fleet asked the question....*

***"If you stop biologic therapy because your arthritis is well controlled, are you likely to remain off treatment?"***



## What is already known?

Sometimes, treatment for JIA might be reduced or stopped for patients when their arthritis is well controlled. This might be due to worries about the effects of taking these treatments for a long time.

## This UK JIA Biologics Register research aimed to see:

1. How many children/young people stopped biologic therapy because their arthritis was well controlled
2. How many later needed to re-start therapy
3. Who was more likely to have to re-start treatment

## What was discovered?

**1451**

children/young people with JIA were included in this research

**55%**

of those who stopped started the same therapy again after 4 months.

*Those less likely to need to re-start therapy were those who had started biologics earlier in their disease.*



One in five stopped therapy after around **2** years of being on treatment due to feeling well

*Those more likely to need to re-start biologic therapy were those who also had an eye disease called uveitis (which may have been the reason for needing to restart).*

## Why is this important / what is the benefit to patients?

This research has found that many children and young people can stop biologic therapy when their arthritis is well controlled and remain off therapy. More research is needed to identify **which** patients will successfully be able to reduce the dose of their biologic therapy or stop treatment altogether in the future, without being at risk of their disease becoming active again.

The full article can be found here: <https://doi.org/10.1093/rheumatology/keac463>

# PUBLICATIONS

Please follow the link below to see all of the publications from the UK JIA Biologics Register

<https://research.manchester.ac.uk/en/projects/uk-jia-biologics-registers-the-bcrd-and-bspar-etanercept-studies/publications/>


## Topics of publications include:


- Growth
- Disease activity
- Choice of biologic therapy
- Biologic switching
- Uveitis


2022

## Successful stopping of biologic therapy for remission with juvenile idiopathic arthritis (JIA).

UK JIA Biologic Registers, 7 Aug 2022, (Accepted/In press) In: Rheumatology Research output: Contribution to journal > Article > peer-review

 Open Access

 Biological Therapy

 Young People


 Spontaneous Remission


2021


## Burden of comorbid conditions in children and adolescents with juvenile idiopathic arthritis: a collaborative analysis of 3 JIA registers

Kearsley-Fleet, L., Klotsche, J., van Straalen, J. W., Costello, W., D'Almeida, M., Lunt, M., de Roock, S., Ruperto, N., Schoemaker, C., Vijatov-Djuric, M., Hyrich, K., Minden, K. & Swart, J. F., 6 Oct 2021, In: Rheumatology Research output: Contribution to journal > Article > peer-review

 Open Access

 Analysis

 Juvenile Rheumatoid Arthritis

 Young People

# CONTACT THE TEAM

Please contact the study team if you have any questions:

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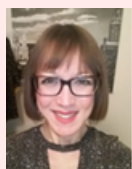
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We would **LOVE** to hear from you if you have any questions you would like to see answered, or any other suggestions for our research!



Emily



Katy



Praksha

