

BIOLOGICS FOR CHILDREN WITH RHEUMATIC DISEASES

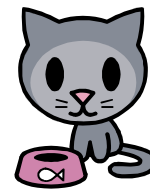
Study participant newsletter

You have received this newsletter because either you or a member of your family is participating in the Biologics for Children with Rheumatic Diseases Study (known as 'BCRD' or sometimes 'the extended biologics study').

Firstly, we would like to offer you a massive **THANK YOU** for being part of this really important research project.

The information that your doctor gives us about what medicine you take for your arthritis and how it affects you is very useful for our team of scientists* here at the University of Manchester to see how well these treatments work and if they cause you to have any side effects.

This newsletter is to give you and your family some information about the study and how we are getting on so far!



* Our scientists are called 'epidemiologists' - pronounced "epp-pee-dee-mee-ol-o-jist" and they are the type of scientists who study disease and why diseases affect some people but not other people. The head scientist in BCRD is called Dr Kimme Hyrich—you can meet her on page 4 of the newsletter!

What does the BCRD study involve?

The Biologics for Children with Rheumatic Diseases study was set up by the charity



who wanted to know how children and young people with arthritis are affected by the medicines that they are prescribed by their doctors.

In particular, they were interested in how types of medicines called 'biologic therapy' affect children and young people.

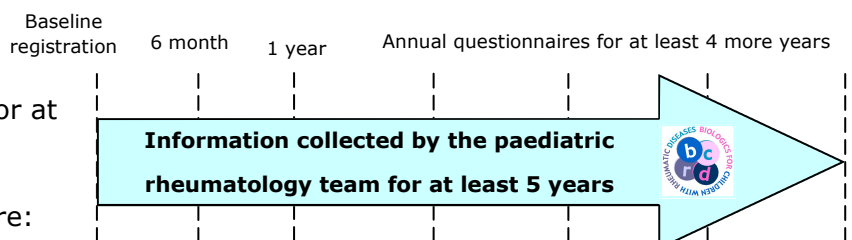
So, Arthritis Research UK awarded a team at the University of Manchester a generous grant of **half a million pounds** to set up a study to register and follow up children who were being prescribed a biologic drug by their doctor.

We do not register children who are starting biologic treatment with Etanercept (also called Enbrel) because there is another study set up to do this, called the BSPAR etanercept study.

The researchers need to be able to see how the biologic therapy affects kids differently to the medicines that were used in the past, so a group of children and young people who are prescribed methotrexate are also being registered and followed up in the same way to those on biologic therapy, so that the two groups can be compared.

This type of study is known as a **cohort** study. We aim to recruit 250 children to each cohort

Once you or your parent/guardian has signed a form saying that you can be involved in the study, the doctor at your centre completes questionnaires about you and the medicines you are receiving at the time-points noted here:



How is the study progressing so far?



The study was set up in 2010

23 paediatric rheumatology centres have registered children and young people with us

The first participant was registered on to the study on 4th May 2010 from Alder Hey Children's Hospital

352 children and young people have been registered so far

Map of centres who are involved in the study across the UK



BCRD registers children and young people with JIA from hospitals throughout the UK. We have a total of 352 patients registered to date. Of this total:

191 are registered in the methotrexate cohort. People registered in this cohort must never have received biologic therapy

161 are registered in the biologic cohort. People who are registered in the biologic cohort may also be taking methotrexate.

It is a team effort for research studies to be successful, and we are very grateful to the doctors and nurses who have been very supportive of this research, as well as the participants who have helped to ensure the study's success at recruitment and follow up. Thank you!



OUR LARGEST RECRUITMENT CENTRE IS THE GREAT NORTH CHILDREN'S HOSPITAL IN NEWCASTLE, WHO HAVE REGISTERED AN IMPRESSIVE 64 PATIENTS WITH US SO FAR!

What have we found out so far?

We started collecting information in 2010 so it is still early days in the study. The longer we collect information, the more we will know about how the medicines affect you and your arthritis so we will be able to tell you more over the next few years.

Our research assistant Lianne has had a look at the information that is sent to us by your hospital when you are first involved in the study. She has found the following information so far:

66% of children and young people registered in the study are female (this means that two out of three people in the study are girls)



The average age at registration on to the study is 9 years old



Polyarthritis: RF negative is the most common subtype of JIA (27% of participants)

→ There are several types of arthritis grouped together under the term of JIA, including oligoarthritis, systemic-onset JIA and psoriatic arthritis. For more information on the different sub types of JIA please visit the Arthritis Research UK website (details on p3)

161 (46%) of participants are registered into the biologic group, 34% of whom are taking adalimumab (Humira)

Representing you in BCRD

Hi! To introduce myself, my name is Sharon Douglas and I am a 'consumer representative' member of the BCRD study steering group. I joined the committee in August 2010. My role is to provide a parent's perspective on the study and its progress. As a family of a daughter who has had JIA for 8 years, we, like many families have had lots of questions and indeed still have as we live with JIA. I remember at diagnosis questioning everything, what it meant and what did the future hold. Subsequently on starting medications we wanted as much information about the short and long term side effects of them.

When the BCRD steering group meets, as I contribute to discussions I always try to think representatively of what would be helpful to parents, how they might feel reading the information sheets, what their concerns might be and what are the difficulties when participating in the study?

It's incredibly important to me that good research like this is happening in the UK and beyond and that relevant and important information is collected. There is a lot of hopeful, positive, collaborative work with families and researchers, we all have the same wish for greater knowledge leading to treatment decisions based on understanding and evidence.



Sharon Douglas

Consumer representative member of the study steering group, who meet every 6 months.

The steering group ensures that the study is being carried out properly and make decisions on any changes that might need to be made. They also decide how to look at the information that is collected.


This information can only be gained by the practice of good research with results fed back to all. In the UK there is a network called the Medicines for Children/ Arthritis Research UK Clinical Studies group. One of the group's aims is, by providing an expert collective view, to prioritise what research questions are important to paediatric rheumatology. Again, as consumer members our efforts are focused on providing the patient view on and how can we ensure the research being discussed is an acceptable design and the question being asked is important to patients. More information about the MCRN can be found at www.mcrn.org.uk.



I have enjoyed watching the BCRD study be successful at recruitment but also am pleased with its success at follow up, ensuring the required information is collected at the right time in order for the final results to be as complete as possible. It matters hugely to us parents as we administer medications that information is being collected about their short and long term safety and efficacy. This study will provide helpful information for rheumatology teams and future families to have.



Information and Support Organisations





There are a number of organisations that you can contact for information about your arthritis, the medicines you take, or just to find out a bit more about other people who may share the experiences that you have had.



National Rheumatoid Arthritis Society (NRAS) www.nras.org.uk
 @NRAS 

Arthritis Care www.arthritiscare.org.uk
 @arthritis_care 

Kids Like Us www.kidslikeus.info
 (West Midlands)
 @kids_like_us 

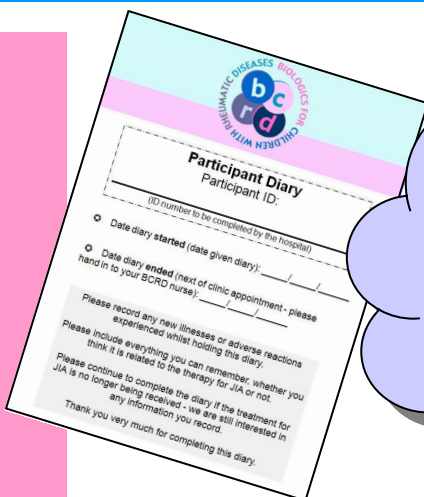
Arthritis Research UK
www.arthritisresearchuk.org
 @ArthritisRUK 

Scottish Network for Arthritis in Children (SNAC) www.snac.uk.com
 @SNAC_JIA 

Children's Chronic Arthritis Association (CCAA) www.ccaa.org.uk
 @CCAA_org 

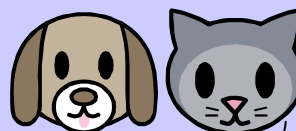
You may have been given a study 'diary' by your nurse at your hospital appointment so that you or your parents can write down if you are poorly for any reason.

Please remember to bring back your study diary to your nurse at your clinic appointments (even if you have not been ill between clinic appointments) so that they know how you have been feeling.



DID YOU KNOW....

It's not just humans who can get arthritis— animals can be affected too, particularly cats and dogs.



Meet the team!



Dr Kimme Hyrich
BCRD Chief Investigator

Fun Fact!

I grow vegetables in my garden, and this year I have been struggling with potato blight!



Katy Mowbray
BCRD Study Coordinator

Fun Fact!

I am very scared of spiders, but faced my fear whilst on holiday this year when I volunteered to hold a massive tarantula at a zoo in Devon!



Lianne Kearsley-Fleet
Research Assistant

Fun Fact!

I have 2 naughty cats; a fluffy black girl called Mog who watches the birds in the garden, and a big tabby boy called Rum Tum Tugger who likes eating Mog's dinner!

Contact us!

BCRD Study

Biologic Studies Group

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Follow us on Twitter for news and updates about the study

@BCRD_Study



Please feel free to contact us if you have any comments or suggestions for the next edition of the newsletter.



We would appreciate any contact, but if you require any medical advice please remember it is best to contact your GP or rheumatology specialist team in the first instance.