



Biologics for Children with Rheumatic Diseases

Study Participant Newsletter!

Issue 2: Spring 2014

Welcome to the second newsletter for people involved with the Biologics for Children with Rheumatic Diseases (BCRD) study, which is coordinated by the Biologic Studies Group at The University of Manchester.

You have received this newsletter as either you or a family member are involved in the study, so we thought we would let you know a bit about where we are up to and how we are going to use the information we collect.



We are really grateful that you are involved in our research, thank you to you and your family for your help!

The BCRD study looks at the long-term effects of medicines such as adalimumab (Humira), infliximab (Remicade), tocilizumab (Actemra), anakinra (Kineret), abatacept (Orencia) and rituximab (Mabthera), **known as biologic therapy** in people with Juvenile Idiopathic Arthritis (JIA), and compares them with the effects of a therapy called methotrexate in separate group of children and young people with JIA.

We collect information about you from your hospital on a regular basis so that we can build a bigger picture of how the medicine affects you and your illness. BCRD was set up in 2010, so has been running for quite a long time now. We have some exciting updates for you on the next few pages.

What is biologic therapy?



Biologic therapies are fairly new and work by suppressing the immune system to reduce the pain, swelling and stiffness associated with arthritis. These therapies are used if you don't respond to drugs such as methotrexate.



You can scan the QR code with your Smartphone, or follow the link to see a video of Dr Kimme Hyrich explain more about what biologic therapy is:

<http://www.bcrdstudy.org/videos.asp>

BCRD Showcased in Parliament!

We are thrilled to have been put forward by Arthritis Research UK (the charity who funds us) as a good example of research at a meeting between all the political parties in the government, which was held at the House of Commons in London.

The meeting's aim was to discuss the challenges that are faced in understanding health and disease in children and young people, and it is hoped that the meeting will kick start some action in this important area, and speed up the development of new treatments for children and young people suffering from difficult medical conditions.



Arthritis Research UK



More funding from Arthritis Research UK!

The enthusiasm and support that we have received from people involved in the study across the UK has been remarkable, and we have reached our recruitment targets well ahead of schedule.

We are thrilled to announce that we have been awarded another £75,000 by Arthritis Research UK to recruit more children and young people like you on to this important study.



The study in numbers



The study was set up in 2010

29 paediatric rheumatology centres have registered children and young people with us, shown in the map on the right

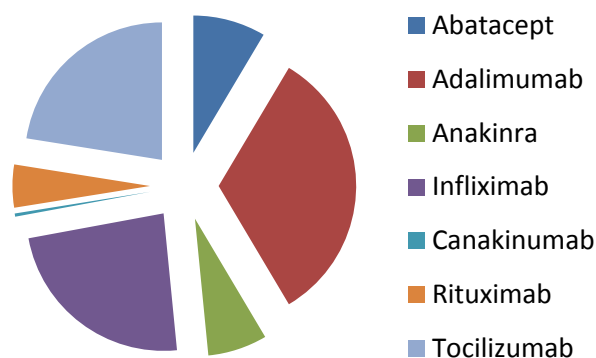
534 children and young people have been registered so far. Of this total:

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

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

We have a sister study based in the same group at The University of Manchester (the Biologic Studies Group), called the **BSPAR Etanercept cohort study** which some of you may also be involved in.

It is exactly the same as BCRD but they only recruit children/young people starting etanercept/Enbrel (rather than all other biologic therapies like BCRD). They do however, recruit the same type of young person starting methotrexate, and have recruited 252 participants in this cohort so far. This means that when combined with the BCRD methotrexate group, **we have one of the largest comparison groups of its kind in the world!**



The pie chart above shows the numbers of children recruited in the study split by which drug they were receiving at the time of registration.

As you can see, the three most frequently reported drugs being taken by participants at the time of registration are:

1. Adalimumab (Humira) = 33%
2. Infliximab (Remicade) = 24%
3. Tocilizumab (RoActemra/Actemra) = 22%

If you wanted to know more about the BSPAR Etanercept Cohort Study, then you can contact the study coordinator Dr Emily Sutton at:

0161 3061918
Emily.sutton@manchester.ac.uk



What have we found out so far?



Our research assistant Lianne's job is to look at the information that we collect and see what it all means. Although we are now four years in to our study, we are still at a very early stage to begin answering any questions. It is really important that we continue collecting data so that we can look at a wider range of questions in the future.



BCRD Research Assistant Lianne, preparing to do a bungee jump!

The average age of participants at registration with our study is 9.3 years old

There are seven relatively unique patterns of JIA known as ILAR subtypes, developed by the International League of Associations for Rheumatology. The most frequently reported ILAR subtype of JIA in our study is polyarthritis rheumatoid factor negative (28%)

67% of the children and young people that we've registered are girls

The average age at which children in our study are diagnosed with JIA is 6.9 years old

In our biologic cohort, 55% of our participants were recruited when they were starting their first ever biologic treatment, but 45% were recruited when they had started a biologic that was not their first exposure.

How will the data in the study be used?

With the data BCRD are collecting, we hope to look into the safety and benefits of using biological drugs in children with JIA. Although we don't quite know how the data will be used specifically just yet, we have a lot of experience within the other studies of the Biologic Studies group here at the University of Manchester and it is likely that similar topics will be looked at. For example, the analysis team could look at the rates of infection and other illnesses between the two groups in the study, or they could look at the growth and height of children in the study compared to the general population.

What do we want to find out in the future?

We are going to introduce some new questionnaires to our study:

A questionnaire called the 'Child Health Utility' which asks about how you feel.

Your nurse will give you or your parent a copy of this when it needs completing.

A questionnaire for older teenagers who are moving to an adult rheumatology clinic. This will ask questions about your growth, education and social life and will be given to you when you move to an adult rheumatology clinic.

You will receive this questionnaire again at around the time of your 21st birthday, and there will be the option for you to complete these online using our secure database.

Your study nurse will speak to you once we are able to start collecting this data (if they have not spoken to you already).



If you have any questions about this then please contact the study coordinator Katy, her contact details on page 4.

Do you want to be involved in other types of research?

If you are interested in helping with other research studies, you should speak with your nurse to see if there are any other projects going on in your hospital that you might be able to get involved with. Some hospitals have their own young peoples support group, and sometimes part of this group can include some involvement in research and research projects.

This is really useful to researchers, as it can give a different point of view, and makes it clear if what the study is about is important and worthwhile looking at.

You can also find out more about involvement in research in general on the NHS site INVOLVE <http://www.invo.org.uk/> and the 'OK to Ask' campaign, which says it is OK to ask about being involved in research.



Contact Us!

Katy Mowbray, BCRD
Study Coordinator



We would love to hear from you if you have any questions about the study, or suggestions for anything you would like to see in future newsletters.

Email: katy.mowbray@manchester.ac.uk

Telephone: 0161 306 1917

Twitter: @BCRD_Study



Find us on the web!

If you would like to find out more about the BCRD study, the team and the work we do, we have a special section on our website for you and your parents. This can be found at: <http://www.bcrdstudy.org/participants.asp>

We have a YouTube Channel! Please subscribe and keep an eye out for more information videos. Follow the link or scan the QR code for more info

<https://www.youtube.com/channel/UCTy5bvCQdOLFdDmpFII4XPw>



You might have spotted Bezz, our friendly bee mascot, buzzing his way around this newsletter. The worker bee is the symbol of Manchester, so we thought he would like to make an appearance here!

How many bees can you spot on this newsletter?

