

Paediatric Biologics Registers Newsletter for Participants

Spring 2017



Welcome to the Paediatric Biologics Register newsletter 2017! You have received this newsletter as either you or a family member are involved in the Biologics for Children with Rheumatic Diseases (BCRD) or the BSPAR Enbrel Cohort study (BSPAR EN) about Juvenile Idiopathic Arthritis (JIA). It may have been a while since you've heard from us, so we just wanted to share some information about the study and what we have found out so far. We hope that you find this useful!

What are the BCRD and BSPAR EN studies?

The objective of both of these studies is to follow children with JIA who begin to take "biologic" therapy (such as Enbrel, Humira or Remicade) in order to get a better picture of how these therapies are used and how safe and effective they are. Information from hospital records alongside results from blood samples and data from national databases such as NHS Digital are used to follow each participant over several years. All the data we receive is stored securely within our study database, and no one will be able to identify you from the research that we do.

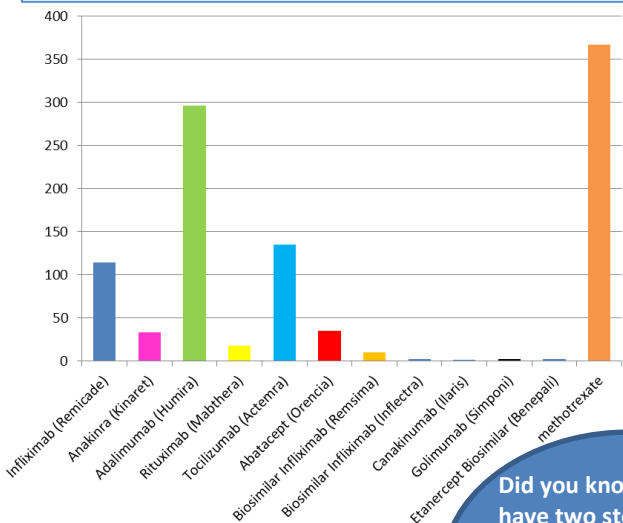
You can see what our researchers have discovered so far on page two!

The **BCRD** study was set up in 2010 and recruits children and young people with JIA who are starting any biologic or biosimilar drug other than Enbrel.

Up to the beginning of February 2017, we have recruited:

- A total of **1015** children and young people across the UK. Of this total:
- **648** participants are in the biologic group
- **367** are in the methotrexate group

The chart below shows the amount of children that were taking each biologic therapy at the time of registration.



The **BSPAR EN** study was set up in 2004 and collects information on the effectiveness and safety of Enbrel in children and young people with JIA. Another group of children and young people with JIA treated with methotrexate are also being recruited in order to compare side effects and long term outcomes between the two treatment groups.

Up to the beginning of February 2017, we have recruited:

- A total of **1703** participants across the UK, of which:
- **1132** participants have been recruited to the Enbrel group
- **571** are in the methotrexate group

When you combine the number of participants in the BSPAR group with the number of participants in the BCRD group, **we have one of the largest groups of children and young people involved in research about JIA in the world!**



Did you know that I have two stomachs?
One for food and another to store nectar to make honey!



Thank you for your help, it really makes a difference!

Our team of researchers have been busy bees examining the data that has been collected, and have published a number of “papers” (this is what we call our results when they get printed in special magazines called “journals”). Below are some key findings which you may find interesting. If you have any questions about anything here, please feel free to contact Becky (rebecca.davies@manchester.ac.uk) or Lianne (lianne.kearsley-fleet@manchester.ac.uk) who will be happy to help (you can find out a little bit more about our researchers on page 3).



We have found **improvement in disease activity of children treated with Enbrel**, with 38% of patients achieving an excellent response, and 48% achieving minimal disease activity after only 1 year.

Patients starting Enbrel were found to be shorter than people who did not have JIA. However, their height significantly improved after 2 years of treatment, suggesting **control of inflammation can help growth in some children.**

Enbrel is the most common biologic prescribed for JIA, however, there has been a shift towards the use of other biologics. This is largely driven by the subtype of JIA and history of an eye condition called chronic anterior uveitis.

Please contact the study team (details on page four) if you would like to see a full copy of any of these papers!

The studies continue!

In Spring 2015 we announced that the BCRD study was awarded funding to recruit children until **December 2019**. We are delighted to confirm that the BSPAR EN study recruitment has been extended to **12th December 2017**, with the intention of seeking further funding beyond this date.

This means that we can recruit more children and young people who are starting biologic treatments to both studies, which will help us gather more information about how your treatment is affecting you.

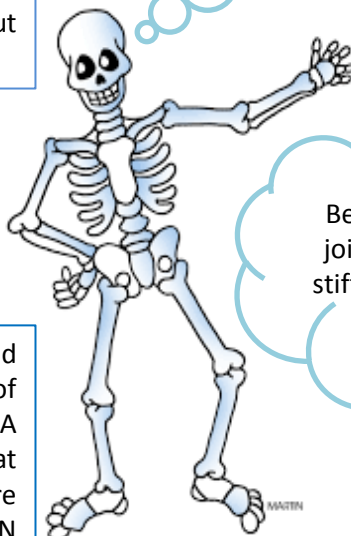


Recommendations for further research by NICE

In December 2015, the National Institute for Health and Care Excellence (NICE) saw that there wasn't a lot of information about the effect of biologic treatments for JIA in the long-term, especially when it comes to looking at how arthritis affects your day-to-day life. They therefore recommend that studies such as BCRD and BSPAR EN continue to collect data of this kind so that more information is available in the future.

Did you know...

Arthritis is actually one of the oldest diseases known to human kind. It has even been discovered in the remains of people living more than 500,000 years ago!



Did you also know...

Bee venom *may* help ease joint swelling and morning stiffness... **but please do not try this at home!!**



Professor Kimme Hyrich



Kimme is Chief Investigator for both BCRD and BSPAR EN. This means she is the person responsible for making sure that the project is being run correctly. As well as working as a researcher on the studies, Kimme also works at Manchester Royal Infirmary as a consultant rheumatologist.

Fun Fact: Kimme grew up in Canada. She speaks with a strong Canadian accent and loves maple syrup and snow .



There are a number of busy bees working on the BCRD and BSPAR EN studies. We thought you would like to know a little bit more about them and what they all do whilst they're not making honey...



Emily Sutton



Emily is the Study Coordinator for the BSPAR EN study, and also coordinates a study for people with a condition called lupus who are taking biologic therapy.

Fun Fact: Emily loves to run, and ran a whole 26.2 miles in the Manchester Marathon!

Katy Mowbray



Katy is the BCRD study coordinator, and has worked on the study since it began in 2010. She also works on another study called the BSRBR-RA, which looks at the safety of biologic therapies in adults with rheumatoid arthritis.

Fun Fact: Katy spends a lot of time singing nursery rhymes to her son Arthur (aged 1) – Incey Wincey Spider is the current favourite!

Praksha Jariwala-Rawsthorne



Praksha is the Paediatric Project Administrator who works across both studies.

Fun Fact: Praksha has two very naughty cats! A Persian/Tabby girl called Nala who likes to chew everything and a Tabby/Bengal boy called Nugget who wakes her up in the middle of the night by scratching and singing at the door! They are both great friends...most of the time!

Diederik De Cock



Diederik is a researcher working on both studies. He studies the impact of the disease.

Fun Fact: Diederik is a Belgian sport enthusiast who loves Nutella! He says that he eats Nutella with a sandwich and not a sandwich with Nutella!

Lianne Kearsley-Fleet



Lianne is a research assistant who works on both of the paediatric biologics registers. She works with Diederik and Becky to look at the data and write up the results.

Fun Fact: Lianne has recently been on holiday to Las Vegas, where she took a helicopter trip over the Grand Canyon!

Becky Davies



Becky is a research assistant who works on both of the paediatric biologics registers with Lianne and Diederik.

Fun Fact: Becky has a degree in psychology, and does sports psychology work with Warrington Wolves rugby league team in her spare time!

A new questionnaire

In 2016, we introduced a new questionnaire to both BSPAR EN and BCRD - this is called the **EQ5D**, which we would like you to complete alongside the usual 'Child Health Utility 9D'. This questionnaire asks you to describe your health and includes questions about your movement and how well you're able to care for yourself.

There are different versions of the EQ5D to be completed by different ages but don't worry - your nurse will give you or your parent the most appropriate copy of this when it needs completing.

- Age 0-3 = no form completed
- Age 4-7 = parent completes the EQ5D-Y PROXY 1
- Age 8-11 = participant should complete EQ5D-Y
- Age 11-18 = participants should complete either EQ5D-Y or EQ5D-3L, as deemed appropriate by the research nurse/study team at the hospital
- Age 18 and above = participant should complete EQ5D-3L



Information and support organisations



The **National Rheumatoid Arthritis Society** has launched a JIA service called JIA@NRAS. They have annual information days that are free to attend, and lots of events such as 'Wear Purple For JIA 2017' which will be held on Friday 9th June. For more information on NRAS, please visit <http://www.nras.org.uk/>

The Arthritis Research UK **Centre for Adolescent Rheumatology** in London has a website that has been created by young people with rheumatic diseases, including JIA. This website includes real stories from young people with JIA on topics such as avoiding flare ups, side effects of medication and getting older/the future. For more information on this, please visit <http://www.centre-for-adolescent-rheumatology.org/>

The **BSPAR parents group** has been set up to represent the views of the parents of children and young people with JIA within the BSPAR (British Society for Paediatric and Adolescent Rheumatology) community. If you would like further information about this group, please contact Shane Kirrane (parents@bspar.org.uk), or see their latest news here: http://www.rheumatology.org.uk/bspar/patient_and_parents/default.aspx

Competition time!



You may have spotted Bezz, our friendly bee mascot, buzzing his way around this newsletter. The worker bee represents the hard work of Mancunians (people from Manchester) during the industrial revolution in the early 1800s, so we thought he would like to make an appearance here!

In order to take part in this years competition, we would like you to answer the following question:

How many times does Bezz appear in this newsletter?

Tell us your answer by 31/06/2017 (contact Sonia at sonia.khanom@manchester.ac.uk) and all correct answers will be entered into a prize draw to win a cuddly bee!

Contact us

We would love to hear from you!

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