



# THE BUZZ



## An update for kids and their parents from the UK JIA treatment studies Spring 2015

Both the Biologics for Children with Rheumatic Diseases study (BCRD) and the BSPAR Etanercept Study (BSPAR ETN) are research studies about Juvenile Idiopathic Arthritis (JIA) that are coordinated by the University of Manchester. You may be involved in one of the studies, or maybe even both; this newsletter, which we've called The Buzz, in honour of our Manchester Bee (see the next page for more details), is to provide you and your family with an update on how the studies are progressing so far, and update you on any results we have found.

We would like to thank you for your involvement in these research studies – it is really making a difference and we are proud to have one of the largest groups of children and young people involved in research about JIA in the world!



If you have any questions or comments then please feel free to get in touch – we would love to hear from you! Our details are on the final page.

Both studies recruit children and young people with JIA who are starting treatment with a biologic therapy.

Those starting Etanercept are recruited to BSPAR ETN, those who are starting other biologic treatments are recruited to BCRD.

Both studies recruit another group of children and young people who have started treatment with methotrexate and have never received a biologic therapy.



### Why are there two separate studies that are so similar?



Dr Kimme Hyrich is the Chief Investigator (C.I\*) for both BCRD and BSPAR ETN. She works both at the University of Manchester as a researcher, and at the Manchester Royal Infirmary as a consultant rheumatologist. She oversees both BCRD and BSPAR ETN which each collect the same types of data from the same types of children and young people.

You might be thinking “why are there two studies instead of one big one?”. The answer is a simple one and is purely due to the way that the studies are funded.



**BSPAR ETN** was set up in 2004 when etanercept (Enbrel) was the only licensed biologic therapy for children with JIA. The study is funded by the British Society for Adolescent and Paediatric Rheumatology (BSPAR) and receives some support from Pfizer, the company which makes etanercept.



**BCRD** was established in 2010 and funded by a charity called Arthritis Research UK, who wanted to monitor the safety of less commonly used biologic drugs that were being prescribed to children and young people in clinics across the United Kingdom.



Each research project has a Chief Investigator, who is the person who is responsible for making sure that the project is being run correctly.





## News and Updates from the BCRD Study

The funders, Arthritis Research UK, extend the BCRD study for another 5 years! 

We are thrilled to say that Arthritis Research UK have decided to fund the BCRD study for another 5 years, until December 2019. This means that we can recruit more children and young people who are starting treatment with biologic therapy other than etanercept on to the study, which will mean that we have more information available to us when our researchers look at the effects of biologic treatments.

### What have we found out so far?

Our data has shown that since 2010, biologic drugs other than etanercept such as adalimumab (Humira), tocilizumab (RoActemra) and infliximab (Remicade) are now being prescribed by doctors for children and young people with different subtypes of arthritis in the UK.

For example, if you have systemic JIA or an eye disease called uveitis, you may be more likely to be considered for some of the less common biologic therapies such as infliximab or adalimumab.

These data have been presented at conferences across the world, including at Leeds (UK), Belgrade (Serbia) and Boston (America).   

### 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: [www.bcrdstudy.org/participants.asp](http://www.bcrdstudy.org/participants.asp).

Our YouTube channel can be found by scanning the QR code, or by following the link above.





BCRD has recruited patients from over **30 centres** across the UK, as shown by the red triangles on the map above.

**354** participants have been recruited to the biologic group.

**363** have been recruited to the methotrexate group.

**162** participants were recruited to the study in 2014.

Dr Alice Chieng and the team at **Manchester Children's Hospital** have recruited the highest number of children and young people to the study in 2014!



You might have spotted our friendly mascot Bezz buzzing his way around this newsletter. Bezz is our mascot because the worker bee is the symbol of Manchester. Manchester had an important role in the industrial revolution in the early 1800s; the city was a hive of activity at this time and the bee was used as a symbol of the hard work of Mancunians. There are seven bees in the city's coat of arms, as shown on the right. What is your town or city's coat of arms like?



**How many times does Bezz appear in this newsletter?**

**Tell us your answer by 31/08/2015 (contact Katy Mowbray - details on the final page) and all correct answers will be entered in to a prize draw to win a cuddly bee!**

## News and Updates from the BSPAR ETN Study



BSPAR-ETN has recruited patients from over **45 centres** across the UK.

**299** have been recruited to the methotrexate group.

Professor Taunton Southwood and the team at **Birmingham Children's Hospital** have recruited the highest number of children and young people to the study in 2014!

**133** participants were recruited to the study in 2014.

**916** participants have been recruited to the etanercept group.

## What have we found out so far?



Our research assistants Becky and Lianne have been looking at the information that has been collected so far. We thought we would tell you a little bit about what they have found out about some of the areas they have been researching.



**Name:** Rebecca Davies  
**Nickname:** Bex  
**Favourite Food:** Chocolate  
**Fun fact:** Bex recently white-water rafted down the River Anduin from the Lord of the Rings films

Becky looked at the rates of serious infections in the two groups within the BSPAR ETN study: the children treated with etanercept and the children being treated with methotrexate. She found that although those treated with etanercept were more likely to get some infections, there was no difference in the rates of more serious infections that needed a hospital stay.



**Name:** Lianne Kearsley-Fleet  
**Nickname:** La-La  
**Favourite Food:** Pizza  
**Fun fact:** Lianne has bungee jumped from the very first bungee to be built in New Zealand

Lianne wanted to look at how young people grow when they are being treated with biologic therapies. She found that children and young people with JIA who had started etanercept were, in general, shorter than other children and young people without JIA of the same age and gender. However, she found that the height of these children improved a lot after two years of treatment with etanercept, which might suggest that controlling the inflammation that is experienced in JIA will help growth in some children.

## BCRD and BSPAR Etanercept Study contribute to NHS England policy

When a doctor prescribes a treatment for a patient, they are often following guidelines that have been created by a government body called the National Institute for Health and Clinical Excellence (NICE). For JIA, many of our treatments don't yet have NICE guidance. At the moment, there are new guidelines being written for prescribing biologic therapies to children and young people with JIA.

In the meantime, the NHS has produced interim guidelines for biologics in children and these include evidence taken from our two biologics registers for children with JIA. The guidelines recommend that all children starting biologic treatment should be registered in the studies in order to capture and understand the long term benefits and safety of these drugs.





## Did you know.....

...it is thought that dinosaurs could have had types of arthritis too?



**Sue the T-Rex** – Displayed at the Field Museum, Chicago, USA.

Sue is one of the largest and most complete Tyrannosaurus Rex fossils in the world.

BCRD study coordinator Katy Mowbray visited the natural history museum in Chicago, USA whilst on holiday in November 2014 and discovered that the palaeontologists (the people who are experts in dinosaurs at the museum) thought that their resident T-Rex (called Sue!) had suffered from a form of inflammatory arthritis called gout.

Gout is the most common type of inflammatory arthritis and causes times when joints are swollen, hot and painful. It is not known how Sue had got attacks of gout, but examination of her fossilised bones showed signs of this disease. The experts agreed that this was probably a rare disease in dinosaurs, and that Sue had just been unlucky.

## Links to Support Organisations

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.

[www.centre-for-adolescent-rheumatology.com](http://www.centre-for-adolescent-rheumatology.com)



The **National Rheumatoid Arthritis Society** has recently launched their JIA services called JIA@NRAS. They have annual information days that are free to attend, in 2014 they had a 'tea on the beach' day which looked like a lot of fun!

[www.nras.org.uk/jia](http://www.nras.org.uk/jia)



## Contact us!

We would love to hear from you if you have any questions or if there is anything you would like to see in future newsletters.



BSPAR ETN contact  
Emily Sutton  
[Emily.Sutton@Manchester.ac.uk](mailto:Emily.Sutton@Manchester.ac.uk)  
0161 3061916



BCRD study contact  
Katy Mowbray  
[Katy.Mowbray@Manchester.ac.uk](mailto:Katy.Mowbray@Manchester.ac.uk)  
0161 3061917



L: BSPAR ETN study coordinator Emily Sutton  
R: BCRD study coordinator Katy Mowbray