



Welcome to the  
Paediatric Biologics  
Registers newsletter  
2018!



You have received this newsletter as either you or a family member are involved in the BCRD study and/or the BSPAR ETN 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, many thanks to you and your family for your help!

## What are these studies about?

There are two research studies called "biologics registers" for children and young people being run by a team of researchers at the University of Manchester:



The **BSPAR Etanercept Study (BSPAR ETN)** was set up in 2004 and recruits children and young people from **47** NHS sites across the country. **2027** participants are involved in the study so far.



The **Biologics for Children with Rheumatic Diseases study (BCRD)** was set up in 2010 and has recruited from **38** NHS sites. **1284** participants are involved in the study so far.

Both studies are overseen by a Professor of Epidemiology (the study of disease), Professor Kimme Hyrich. Kimme works with lots of different researchers on projects about both childhood and adult arthritis. She also works as a rheumatologist at Manchester Royal Infirmary, looking after adults who have arthritis.



Both studies look at the long-term effects of "**biologic**" medicines such as etanercept (Enbrel) and adalimumab (Humira), and "**biosimilar**" medicines such as etanercept (Benepali) and Infliximab (Remsima) in people with Juvenile Idiopathic Arthritis (JIA), and compares them with the effects of a therapy called **methotrexate** in separate groups of children and young people with JIA.

### 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.

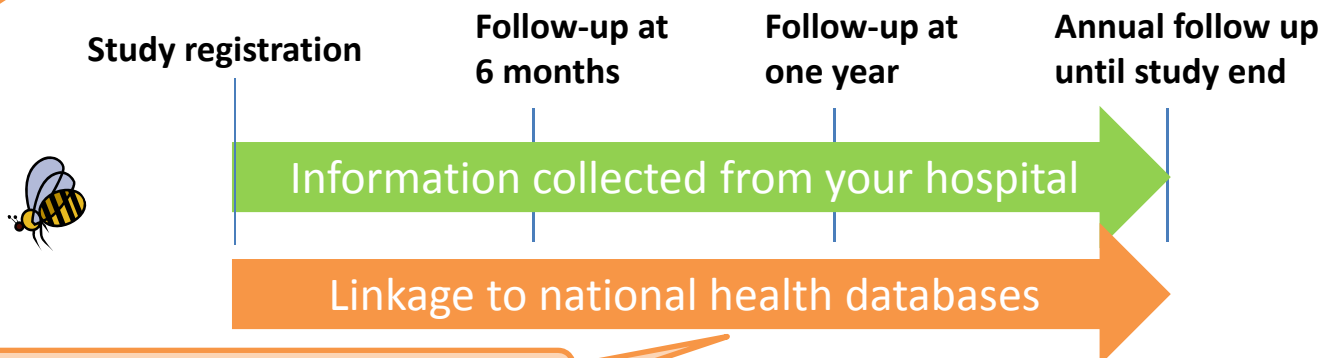
You can scan the QR code with your Smartphone, or follow the link to see a video of Professor Kimme Hyrich explain more about what biologic therapy is:



<https://www.youtube.com/watch?v=nHIScwJJb0>

## Collecting information for the studies

We collect information about you from your hospital on a regular basis (shown below) so that we can build a bigger picture of how the medicine affects you and your illness.



### Linkage to health databases – what does this mean?

When you consent to be involved in the BCRD or BSPAR ETN study you give agreement for some personal information to be shared with national health databases (including NHS Digital in England and Wales, and National Records of Scotland) so that they can match you to their records and place a “flag” on you for our studies.

This “flag” means that if you experience a really serious illness (such as if you develop a cancer) then the research studies will be told of these events directly by the national databases. This is a resource that is really important for research into health and diseases such as JIA, as the information that we get from NHS Digital and other national databases is added to the information that we collect from your healthcare team, which makes our data more complete, stronger and more reliable.



Buzz  
Buzz!

Hello from our study mascot, **Bezz the bee!**

The worker bee has been a symbol of Manchester for over 150 years, due to the industrial heritage of the city.

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



Answer at the bottom of the next page!

## Protecting your information

You may be aware that new data protection laws have been recently introduced in the UK, known as the General Data Protection Regulation (GDPR).

It is important that you know how we use your personal data and what your rights are under the law; a new ‘transparency sheet’ has been developed to explain this further.



You can view this in the '[Protecting your Information](#)' section of the website, or if you would prefer a paper copy you can get this from your rheumatology team the next time you are at hospital. If you have any questions about this please do not hesitate to contact the office and we will be happy to help.



## New discoveries

You can find out about [our discoveries](#) so far– these have been reported in previous newsletters which you can download at the [website](#). Since the last newsletter, our researcher Lianne has been looking at methotrexate use in children and young people with JIA. This research was presented at a European conference in Amsterdam in June 2018.



**Lianne**  
BCRD/ BSPAR ETN  
Researcher



Methotrexate is an effective and safe drug for children and young people with juvenile idiopathic arthritis (JIA). Our study investigated how many people with JIA on methotrexate might experience an adverse effect. We found that after two years on methotrexate therapy, one-in-four people may experience nausea or vomiting. It is therefore important in the future to identify how we can reduce these effects so that people can receive the full treatment benefit that methotrexate can provide.

## What's it like to be a researcher?



**Have you ever thought about being a scientist when you are older and wondered what it is like?**

We asked our researchers to tell us a bit about why they decided to research diseases like JIA for their career!



**Lianne Kearsley-Fleet**  
Research Assistant

I studied Bioveterinary Sciences at university as I have always loved science and enjoyed learning about all the different animal diseases. I then became a researcher because I love learning about how different medicines affect people.

BCRD and BSPAR-ETN are the largest studies in the UK looking at biologics and methotrexate in children and young people with JIA. I find it very exciting to work with all of the data, and then writing my results up to share at conferences and in journals.



**Rebecca Adam**  
Research Assistant

I studied Psychology at university and enjoyed conducting experiments and making new discoveries. I went into research so that I could continue to do this. I like to investigate things and get answers to problems, so this job suited me perfectly!

Every day is different. Sometimes we might be asked to make posters about our research, other days involve thinking of questions that we want to answer and using the data that we collect to do this. For example, would taking a biologic increase the risk of infection?



**Diederik De Cock**  
Research Associate

I studied Biomedical Sciences at university as I was really interested to see what a human is, from the level of a cell to the whole body. I discovered I was really interested in the effects of medicine on our body, in adults but nowadays also in children as I became a father recently.

I look at how well the drugs for JIA work as part of my job. I really enjoy as it can help people who have questions about the drugs they are given by their doctor.

# The Amazing Bone and Joint Word Search!

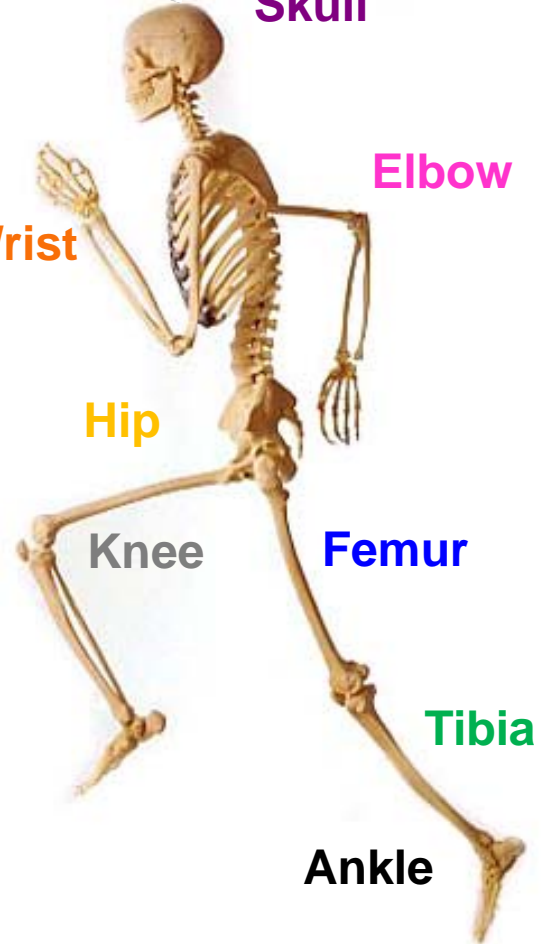
Can you find all of the words listed next to our skeleton in the grid below?

E	J	P	P	E	L	F	S	E	N	E	G
P	N	I	A	T	L	F	H	E	G	H	B
Z	H	O	S	U	U	Y	O	P	E	A	A
L	Q	I	B	A	K	P	L	B	T	N	H
J	R	A	N	Y	S	W	T	Q	I	D	K
W	T	K	L	X	N	F	X	B	B	N	B
O	L	V	B	X	X	N	E	H	I	M	R
E	L	B	O	W	Q	L	U	M	A	H	O
I	O	Q	N	L	G	O	E	F	U	N	B
B	Z	L	M	S	U	D	S	L	I	R	J

DNA

Gene

Skull



Elbow

Wrist

Hip

Knee

Femur

Tibia

Ankle

**BONUS WORD!** When does a skeleton laugh?  
When something tickles their... **Funny bone!**

## Contact Us!



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.

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BSPAR ETN Study Coordinator – Emily Sutton  
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**Find us on the web!**

If you would like to find out more about the studies and the work we do, please visit our new and improved **website**. This can be found at:

[www.manchester.ac.uk/bcrd-bsparetn](http://www.manchester.ac.uk/bcrd-bsparetn)

