



Newsletter for Participants in the UK JIA Biologics Register



Autumn 2021

WELCOME TO THE
UK JIA BIOLOGICS
REGISTER
NEWSLETTER 2021!

In this issue:

Update on Research

A note from the Chief
Investigator regarding
COVID-19

ABOUT THE STUDIES

The Biologics for Children with Rheumatic Diseases (BCRD) study and the British Society for Paediatric and Adolescent Rheumatology Etanercept cohort study (BSPAR-ETN) track the long-term safety and effectiveness of biologic and biosimilar treatment for Juvenile Idiopathic Arthritis (JIA). The Studies are jointly funded by Versus Arthritis and the British Society for Rheumatology, and are managed by a team at the University of Manchester.

You have received this newsletter as either you or a family member are involved in the BCRD study and / or the BSPAR-ETN study (collectively known as the UK JIA Biologics Register), 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. Thank you for being a part of the UK JIA Biologics Register!



SEASONAL COLOURING IN!



What is JIA?

Juvenile idiopathic arthritis (JIA) is an "umbrella term" used to refer to 7 slightly different types of the same illness. All types involve pain and swelling of one or more joints in children starting before the age of 16 years old, but there are some differences too.



If you have JIA it is likely that your doctor has told you that you are part of one of these groups:

1. Systemic-onset JIA (sJIA)
2. Seronegative polyarticular JIA
3. Seropositive polyarticular JIA
4. Oligoarticular JIA
5. Juvenile psoriatic arthritis (JPsA)
6. Enthesitis-related arthritis (ERA)
7. Undifferentiated JIA

The Versus Arthritis Website has some excellent information about these different types:

<https://www.versusarthritis.org/about-arthritis/conditions/juvenile-idiopathic-arthritis/>



A Note from Professor Kimme Hyrich



Professor Kimme Hyrich
Chief Investigator, UK JIA Biologics Register



An update from 2020: Our research and the COVID-19 pandemic.



BSPAR
ETANERCEPT
COHORT
STUDY



Thank you one and all for your continued participation in our JIA research programme.

March 2020 saw a dramatic change in all our lives that none of us could have predicted. Whilst we all have dealt with COVID-19 on our own personal levels, it has also had a profound effect on medical research. The UK JIA Biologics Register was no exception. As our hospitals cancelled face to face appointments, they also closed many research departments. Their staff, including their doctors, nurses and research support staff, were either redirected to supporting COVID-19 research or were moved to focus to managing patients admitted to hospital with COVID-19. Many had not treated patients admitted to medical wards for many years and an all-hands-on deck approach was taken. For the last 18 months, our university JIA research team has worked from home, only communicating through our computer monitor on video calls.

How has this affected children?

Luckily, children and young people have, for the most part, not developed serious COVID-19 infection and few young people have died nationally; however, from the outset there has been a concern about whether children and young people with JIA, especially those receiving medications that suppress the immune system (such as biologics), might be at an increased risk for worse infection. Therefore, in March 2020, whilst our biologics register work came to a grinding halt, we instead worked with colleagues at the European Alliance of Associations for Rheumatology (EULAR) and the Paediatric Rheumatology European Society (PRES) and also turned our attention to COVID-19 research, studying the outcomes of COVID-19 in children with JIA and other rheumatic diseases.

What new research was started?

We established the EULAR COVID-19 database where rheumatologists could report the outcomes of COVID infection in adult and paediatric patients with rheumatic diseases. As expected, the database primarily holds anonymous data from adult patients but has also captured information about a small number of children. For the overwhelming majority of children receiving immunosuppressive drugs for JIA, the outcomes have been extremely favourable, with a very mild illness in most. We are continuing to analyse these data and hope to publish our final report soon.

What may the future hold?

As the vaccine roll out continues and overall number of serious cases of COVID has declined, our research into all things non-COVID is picking up again. We are seeing hospital sites open their research departments again and data are slowly being captured from our participating hospitals.

A year of COVID research has been both stressful but also rewarding but in reality, I want to get back to my real passion which is researching the long term outcomes among children and young people with JIA.

I wish you all health and happiness and remember to please continue to stay safe.



I looked at people stopping their medicines for arthritis if they were feeling better. I also looked at if the medicine was started again later on.



Dr Lianne Kearsley-Fleet PhD
(Research Associate)



Biologic therapy and remission

What did we already know?

JIA is painful and may stop children and young people from doing what they want to do. Sometimes JIA is treated with a type of medicine called "biologic" therapy. If someone's arthritis is getting better, doctors may decide to stop using this type of medicine, or perhaps use less of it. It wasn't known if this is the best decision and whether the medicine may need to be started again in the future if the arthritis gets worse - Lianne looked at the information collected to find out more!

What questions did we have?

- 1) How many participants stopped their medicine because their arthritis was getting better?
- 2) How long participants stay on biologic therapy before they stop?
- 3) How many participants have to later re-start biologic therapy, and after how long?

What was discovered from our studies?

Lianne's work included 878 children and young people with JIA starting their first biologic therapy in the UK JIA Biologic Registers from 2010 up to February 2021.

She found that around 1 in 5 children had their biologic stopped after their arthritis had got better ("remission"), usually after 2 years of treatment. Our study followed what happened to these patients for an average of one and a half years after they stopped their biologic medicines. During this time, many (3 in 5) did not need to start their biologic therapy again. Of those who did have to re-start biologic therapy, they did so relatively quickly (around 4 months) after initially stopping, and usually re-started the same biologic.

Why is this important?

This information suggests that it might be better to explore lowering the dose of biologic therapy rather than stopping it completely if a patient goes in to remission. It is thought that this would reduce the exposure to the biologic drug without the arthritis symptoms to flare up.

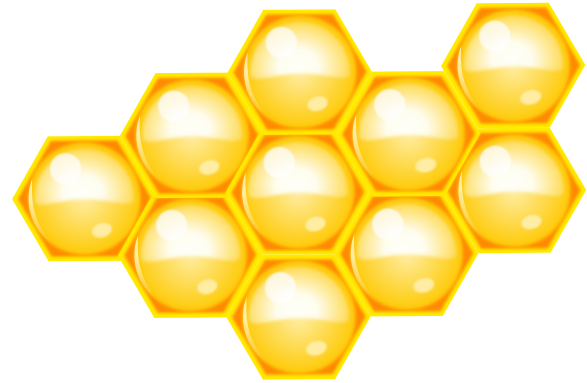
The future? Ideally this should be studied in a clinical trial where some children are asked to reduce their dose and others continue on the same dose to understand how many children will have a flare of their arthritis. This would give more information about what is best to do.

Word Search!

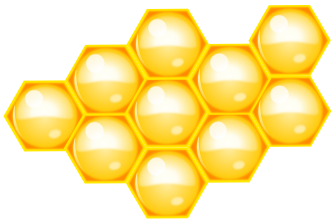
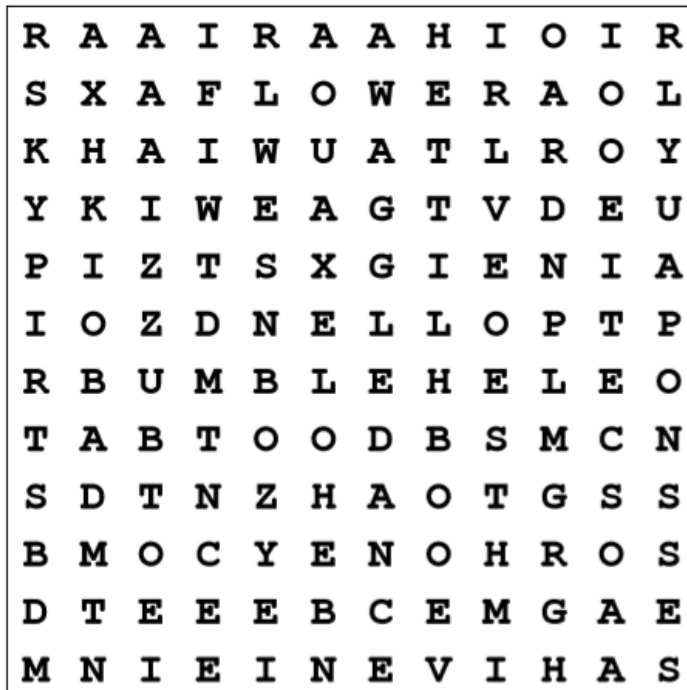
The mascot for our studies is a bee named Bezz!



The studies are based at the University of Manchester and the worker bee is an important part of our city. We can see bees everywhere as we walk down on our streets - the image of a bee is on the bins, bollards and in lots of street art. If you visit Manchester see how many bees you can spot!



We need your help to find the bee-related words in this word search!



BEE

BEESWAX

BUMBLE

BUZZ

FLOWER

HIVE

HONEY

HONEYCOMB

NECTAR

POLLEN

STRIPY

WAGGLEDANCE



Study continuation

We are delighted to confirm that recruitment to the UK JIA Biologics Registers has been extended to at least 31st December 2024. This means that we can continue to recruit more children and young people who are starting biologic or biosimilar treatments to both studies. As this is a long term study, participants are involved for the whole time that the study is running - this extension means that more information can be collected from your hospital doctors and from linking with other national databases, such as NHS Digital. Some participants have been involved for over ten years already!

Once you turn 16 years of age, please speak with your rheumatology team about signing a new consent form. Please feel free to get in touch via the details below if you have any questions!

Is there anything that you would like to see being researched? If you have any ideas we would love to hear them - it may be that the area has already been looked at and we can let you know what was discovered, but it may be an idea that we have not heard before!

You are the people who are living with JIA every day so we would be so interested to know what is important to you and what you would like to see research on. Thank you!

Thank you so much for being a part of these important studies! We really appreciate you being involved - without you our research wouldn't be possible.



Contact Information

We value your input and would appreciate any feedback or suggestions you may have for what you would like to see in future newsletters. Feel free to use any of the following details to keep in touch with us, we would love to hear from you!

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Check out our website: www.sites.manchester.ac.uk/bcrdbspar/for-participants

You can view previous newsletters for participants here: www.sites.manchester.ac.uk/bcrdbspar/for-participants/our-discoveries/



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