

We hope all our readers have had a great summer and a fantastic start to the new school, uni or working year!

- ❖ If you have news items you want covered or stories / resources / events / photos to share, get in touch and we can include them in the next edition of YOURR News
- ❖ We are also always looking for new Your Rheum members - if you know of a young person aged 11-24, living with a rheumatic condition and interested in research, get in touch with us.

Contact us using your.rheum@manchester.ac.uk
OR find us on Facebook, Twitter, or via the website yourrheum.org

Research Round Up

Here are a few highlights of the work Your Rheum members have been involved in this year...

CLUSTER: Childhood arthritis and its associated uveitis; stratification through endotypes and mechanisms to deliver benefit - a £5 million study funded by Medical Research Council (MRC) stratified medicine initiative. This is a 5 year research project following 5,000 children with childhood arthritis in the UK. The goal of CLUSTER is to develop a biomarker test (a characteristic to identify a disease) of childhood arthritis and JIA-uveitis (inflammation of the eye), to enable personalised treatment for patients. To find out more about CLUSTER click [here](#). Eilean was involved in the development of CLUSTER study and continues to be part of the research project team. Eilean has contributed effectively to the study design. Read Eilean's blog [here](#) to find out more about her involvement and experience.

TRANSFER: Understanding the role of psychosocial factors in achieving a successful transfer to adult services - The NHS is split into children's and adult health services. Young people with long-term health conditions (such as arthritis) need to move from children's to adult health services when they reach 16-18 years old. This study aims to investigate if psychological (feeling worried or sad) and/or social factors (feeling supported by friends and family), impact on a young person's decision to attend their rheumatology hospital appointment. At two of the previous Your Rheum meetings, we've discussed the initial study design with the project lead and worked with other members of the research team suggesting ways the we'd like to stay involved in the project, if successfully funded.

NOTICE Board

- ❖ Next Your Rheum Meeting **24th November, 1-4pm, London** (Get in touch if you want to come along)
- ❖ Launch of EULAR's Edgar Stene Prize Competition 2019 - The deadline for UK entries is Tuesday **11th December**. Entries must be sent to projects@arma.uk.net. Click [here](#) for more info.
- ❖ BANNAR meeting **27th November**, Sheffield.
- ❖ New Your Rheum flyers co-designed by group members



SPOTLIGHT - Your Rheum member

Name: Beth Dillon
Least favourite food: wafers and peas
3 words to describe Your Rheum: rewarding, interesting, exciting
Best holiday: interrailing around Europe
Would you rather be a big hamster or a tiny elephant: tiny elephant



Photos from left to right...

Simon Stones, Sophie Ainsworth and Hema Chaplin discussing self-management support research and exploring pain and the impact of JIA in 16-25 year olds, @ EULAR conference 2018 - Dr Janet McDonagh highlighting the importance of involving young people in research and promoting Your Rheum, @ BSR conference 2018 - Laura Lunt presenting research on the vocational experiences of young people with JIA, @ BSR conference 2018.

★ Get Rid Of The Jargon ★

Health transition: a term used to describe the preparation of young people and their families as they grow up and eventually move into adult services. To ensure the young person's physical, psychosocial, educational and vocational needs are met during transition to adulthood.

Stratified medicine (also known as personalised medicine): is based on identifying subgroups of patients with distinct mechanisms of disease, or particular responses to treatments. Allowing scientists to identify and develop treatments that are effective for particular groups of patients. Ultimately stratified medicine will ensure that the right patient gets the right treatment at the right time.

Biomarker: (short for biological marker) is a medical characteristic to help identify a disease or condition.

Young People Have Their Say – A number of us alongside other young people in the UK, living with a rheumatic condition, contributed to a chapter in Adolescent and Young Adult Rheumatology in Clinical Practice. The chapter covers the many different experiences of young people living with a long term health condition, as well as describes their ideal transition service and provides helpful hints and tips for rheumatology health professionals. Publication date to be released soon – keep your eyes peeled!

Library

Arthritis specific: information and support, news and event updates

- **JIA @ NRAS**
<https://www.jia.org.uk/>
- **Arthur's Place (for those 18 year olds and older)**
<http://arthursplace.co.uk/>

National young person advisory groups / networks relating to health and wellbeing

- **VoiceUp - Manchester's Young Person's Research Advisory Group** *an opportunity for all young people aged 11-24 years in Greater Manchester to have their say in health research - find them on Facebook.*
- **Generation R** *a national young persons' advisory group made up of local groups across the UK. They support the design and delivery of paediatric research in the UK.*
<http://generationr.org.uk/>
- **UK Youth Parliament** *provides opportunities for 11-18 year olds to use their elected voice to bring about social change through meaningful representation and campaigning.*
<http://www.ukyouthparliament.org.uk/>
- **NHS England Youth Forum** *aims to give a voice to young people to express their thoughts on the health issues that matter most to them. Ran by British Youth Council (which is another group that aims to empower young people aged 25 and under to influence and inform the decisions that affect their lives).*
<https://www.england.nhs.uk/participation/get-involved/how/forums/nhs-youth-forum/>
<https://www.byc.org.uk/>

Bookshelf

- **What do young people with rheumatic conditions in the UK think about research involvement? A qualitative study**
<https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-018-0251-z>