



Welcome to the Christmas 2018 edition of the CAPS Newsletter! You have received this newsletter because either you or a member of your family is participating in the Childhood Arthritis Prospective Study (known as 'CAPS'). As ever, we would like to thank you for your continued support and provide you and your family with an update on how the study is progressing so far, and let you know about our current areas of research.

The Childhood Arthritis Prospective Study (CAPS) is funded by Versus Arthritis and recruits children and young people newly diagnosed with arthritis.

CAPS is based at the University of Manchester, began recruiting in 2001 and has recruited over 1700 patients to date.

The aim of the study is to find those things that may help predict how patients will manage over the long-term. Better understanding of the course of the illness will help in choosing the best treatment for children now and in the future.

News and updates from the CAPS Study



We're delighted to say that Dr Rebecca Lee and Dr Stevie Shoop-Worrall gained their PhDs this year with research based on the CAPS study. Both Rebecca and Stevie have now joined the team here at the Centre for Musculoskeletal Research as Research Associates.

Rebecca's PhD was about new ways to improve pain assessment and communication for children and young people with Juvenile Idiopathic Arthritis, using new technologies. As part of this work, we developed 'My Pain Tracker', which is an app-based pain assessment tool completed at home by children and young people (see update overleaf).

There are 7 CAPS centres across the UK:

- Alder Hey Children's Hospital (Liverpool)
- Royal Hospital for Sick Children (Edinburgh)
- Great Ormond Street Hospital (London)
- Royal Manchester Children's Hospital
- University College London Hospital
- Royal Hospital for Children (Glasgow)
- Great North Children's Hospital (Newcastle)

Each CAPS centre makes a valuable contribution to the study by providing research data for the participants they have recruited.

Stevie's PhD explored which young people will achieve remission of their JIA. Stevie is now funded by the Medical Research Council on their new CLUSTER programme (Childhood arthritis and its associated uveitis: stratification through endotypes and mechanism). CLUSTER brings together world-leading clinical, academic, scientific, statistical and industry expertise in childhood arthritis and its associated eye inflammation uveitis, in partnership with children, young people and their families. Its aim is to improve the lives of children living with these life-changing, complex conditions.

Rebecca is funded by the National Institute for Health Research (NIHR) via the Manchester Biomedical Research Centre (BRC). The NIHR BRC connects world-leading researchers based at The University of Manchester and three NHS Trusts in Greater Manchester, with a joint vision to drive forward the transformation of scientific breakthroughs into life-saving treatments and care for patients.

CAPS research



Stevie had a research paper published this year. She found that children whose disease was clinically inactive according to both doctors and themselves/parents did the best over the first five years after coming to hospital with JIA. Stevie compared their results with a group whose disease was clinically inactive according to doctors only.

Both groups did equally well in their joint movements, but the first group had better quality of life and everyday function. Stevie found that information from both doctors and patients/parents should be used to better treat joint and non-joint symptoms in young people with JIA.

This year, Stevie has presented her research at EULAR (European League Against Rheumatism) in Amsterdam and BSR (British Society for Rheumatology) in Liverpool. Her presentations included the difficulties of predicting which young people will achieve remission. She also looked at how the CHAQ and HAQ (questionnaires you may receive from us as part of the study) can be combined to continuously measure physical function as a young person moves from paediatric to adult rheumatology. We expect both areas of research to be published as research papers in 2019.



CAPS research (cont.)



Rebecca has also been presenting her research at various conferences, including at the PICH2GO (Pain in Child Health) event in Toronto in November. Rebecca was presenting some findings about a timing study in which we investigated how often children and young people with JIA would like to report pain.

Rebecca was also awarded funding from the Wellcome Trust for a research visit to Professor Tonya Palermo's pain research laboratory in Seattle, USA. Professor Palermo is an expert in paediatric pain management and has developed cognitive behavioural therapy for young people with long-term pain.

Here, Rebecca will learn more about different types of pain management and new ways of researching pain with children and young people.

How your genetics can affect your JIA

We have continued looking at genes and how they affect JIA. We have had three scientific research papers published to help advance this subject and we are contributing to large international collaborative studies. For example, systemic JIA is one of the rarer types of JIA and can be more severe than the others. Current treatments of this disease often involve drugs used in other types of JIA. However, we have found that systemic JIA is genetically very different to the other types of JIA and should be considered a unique condition. This should hopefully lead to new, more effective treatments for this severe form of JIA.

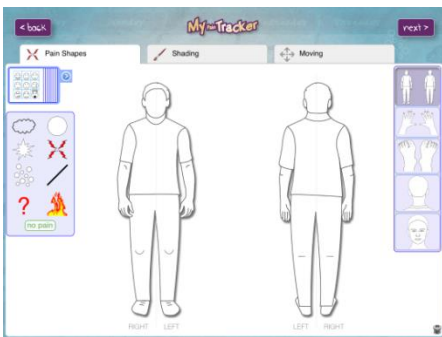


Another type of JIA is known to be similar to adult rheumatoid arthritis (RA). This type, called Rheumatoid Factor (RF) positive polyarticular JIA, is rare and so far only small genetic studies have been performed on it. Our research has shown that RF-positive polyarticular JIA looks genetically more similar to RA than it does to other forms of JIA. This genetic similarity may give us a greater understanding of the causes of this disease. It could also mean that potentially useful treatments developed for use in adult RA could be used for this type of JIA, as well as the development of new treatments.

There are a number of different types of JIA. A system created by the International League of Associations for Rheumatology (ILAR) has been developed to help us describe these different types of conditions that make up JIA. This system is based on clinical data but we felt that including genetic data too could improve it. We have found that, as well as RF-positive polyarticular JIA being genetically similar to RA, the two most common types of JIA (Oligoarthritis and Rheumatoid Factor (RF) negative polyarthritis) are also genetically similar to each other. This may help improve the way these diseases are classified and help us to better understand how these diseases are caused, as well as develop new treatments.

'My Pain Tracker' update

My Pain Tracker (MPT) is an app that the research team at CAPS have developed for children and young people with pain and JIA. The app 'tracks' pain through the use of symbols, faces, words and colours. The app also asks questions about what the pain has stopped you from doing during the day.



In October we had a stand at the British Society for Paediatric and Adolescent Rheumatology in Southampton to demonstrate MPT. We wanted to know how doctors and health professionals would like the data from the app presented in clinic. We received lots of valuable feedback and had a lot of interest in the app being used in clinics, which we will use to develop MPT further.



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. We are also currently developing our new website (see below link), please let us know if you have any feedback or suggestions.

Andrew Smith (CAPS Study Coordinator) 0161 275 1656 Andrew.D.Smith@manchester.ac.uk
<http://www.caps-jia.org.uk/>