

An update for kids and parents from the CAPS study - Summer 2017

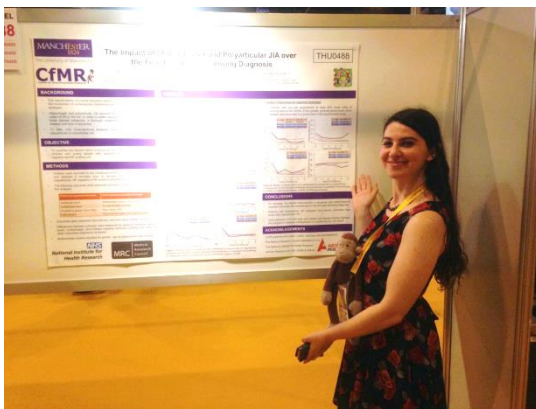
Welcome to the Summer 2017 edition of the CAPS Newsletter! You have received this newsletter because either you or a member of your family is participating in the Childhood Arthritis Prospective Study (known as 'CAPS'). As ever, we would like to thank you for your continued support and provide you and 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 Arthritis Research UK 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 1600 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 in 2017



In June, Stephanie Shoop-Worrall, who is studying for a PhD using CAPS data, attended the European League Against Rheumatism (EULAR) conference in Madrid.

She presented a talk called 'The Impact of Oligoarticular and Polyarticular Juvenile Idiopathic Arthritis over the First Five Years Following Diagnosis.'

Stephanie looked at how people's JIA changes from when they are first diagnosed to how they are doing five years later. In the 832 children included in Stephanie's study, all signs and symptoms measured improved within the first year after diagnosis. She then compared two different groups using the five year information; those who had fewer than five swollen joints when they were first diagnosed were compared with those with five or more swollen joints. The first group did better than the second group, although both groups showed improvement over time. In summary, new treatments for JIA usually mean that children and young people are now doing better than ever before.

Dr Samantha Smith gave a talk at the British Society for Rheumatology (BSR) conference in April about how our DNA could make JIA more likely in some people. Samantha found that having two genes (known as TNFSF15 and TNFSF8) make it more likely for people to get JIA. Targeting these genes further could potentially benefit future patients and additional investigation is required.

Dr Anne Hinks also spoke at the BSR conference. This was about whether the genes of people with one type of JIA (called rheumatoid factor (RF) positive arthritis) are similar to those in people with adult rheumatoid arthritis (RA).

This is important because it might help decide which is the best choice of treatment out of a range of available options. It could even speed up the development of new treatments. Around one in every 20 children with JIA has RF positive arthritis which seems to have a lot in common with adult RA.



CAPS recruits patients from **7 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)

44 participants have been recruited to the study in 2017. Dr Joyce Davidson and the team at **Royal Hospital for Sick Children (Edinburgh)** have recruited the most so far!



Dr Gavin Cleary has joined the CAPS team as Principal Investigator (PI) at Alder Hey hospital.

Gavin says "I have been a consultant paediatric rheumatologist at Alder Hey Children's Hospital since 2003 and consider myself very fortunate to help deliver care to children and young people with JIA. I also have considerable research experience and have recruited patients to CAPS since the study began. I have been PI for 6 clinical trials of biologic therapies in JIA. I also lead the delivery of paediatric education to medical students from the University of Liverpool."

Gavin has taken over from Dr Eileen Baildam, who has now retired after being involved with CAPS from the outset. Dr John Ioannou has also moved on from his position as CAPS PI at UCLH. **We would like to thank Eileen and John for all of their hard work and dedication to CAPS.**

Beads of Courage

CAPS participants at the Royal Hospital for Sick Children (Edinburgh) can now join Beads of Courage, a resilience-based programme designed to support and strengthen children and families coping with serious illness. The programme uses colourful beads as symbols of courage to commemorate milestones met by children along their unique treatment path. Each child is first given a length of string and beads that spell out their name. Beads each representing a different treatment milestone are then given to the child to add to their collection throughout their treatment as determined by the Beads of Courage Bead Guide.



Ongoing evaluation shows that Beads of Courage helps to decrease distress caused by serious illness and provides the tools to support positive coping strategies. It also provides something tangible for children to express regarding their experiences: <http://www.beadsofcourageuk.co.uk/>



#WearPurpleForJIA Day

Friday 9th June was #WearPurpleForJIA day, so we marked the occasion accordingly here at the University's Centre for Musculoskeletal Research. The idea was to raise awareness of JIA and raise funds for the National Rheumatoid Arthritis Society (NRAS), a charity that aims to support all with RA or JIA to live life to the full: <http://www.jia.org.uk/> <http://www.nras.org.uk/>

We invited staff to wear purple and had a cake sale which raised £136 for NRAS. More pictures of our purple outfits can be seen here: <https://twitter.com/CapsieNair>

My Pain Tracker (MPT) update

As mentioned last time, My Pain Tracker (MPT) is a new app that the research team have developed for children and young people with pain. The app 'tracks' pain as children use symbols, faces, words and colour within the app to describe pain on their body. The app also asks questions about what the pain might have stopped you from doing during the day.

We have been testing the app with children who have arthritis, who used MPT on iPads to track their pain at home for one week. We found that children liked using our app because they could track how their pain made them feel, how they could use different symbols to describe their pain and that they could use new technology like iPads to make tracking pain fun. The children thought that MPT made talking about pain with doctors and parents much easier and said it was 'cool' and 'interesting' to use. We also learned what children did not like in the app and we are trying to improve these things.



We are now doing a new study to find out how often children and young people with pain should use MPT. We are going to test whether it is better to track pain once a day, twice a day, once a week or as and when pain is experienced.

Long-term research via NHS Digital

NHS Digital collects information on health outcomes and hospital admissions across the United Kingdom. With your permission, the CAPS researchers can use this information in two ways. The first is through 'flagging' of a study participant's NHS health records to notify the research team of very rare outcomes such as death or cancer. The second way is through linking research data with data routinely collected through hospital records (e.g. when a child is admitted to hospital) so as to provide a more detailed picture of the children's health outcomes that could benefit the research.

We will only do this with your consent and any identifiable data will not be shared with anyone outside the study team, aside from NHS Digital to identify your child on the system (name, date of birth, gender, address and NHS number are used for this). This is a resource that is very 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 normally collect from you as part of the study, which makes our data more complete, stronger and more reliable. You will have opted in (or out) of this system on the consent form when joining the study, though you are free to withdraw consent at any time. Please contact the study coordinator (details below) for more information.



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. Contact us as below and follow CAPSIE, our monkey mascot, to events around the world with our researchers on Facebook and Twitter: <https://www.facebook.com/capsie.nair> <https://twitter.com/CapsieNair>

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

