



CAPS



ARTHRITIS RESEARCH UK

MANCHESTER 1824

The University of Manchester

An update for kids and their parents from the CAPS study - Christmas 2016

Welcome to the Christmas 2016 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) recruits children and young people newly diagnosed with arthritis.

CAPS is based at the University of Manchester, began recruiting in 2001 and has recruited around 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 since July



In November, PhD student Rebecca Lee was invited to present her CAPS PhD research at BSPAR (British Society for Paediatric and Adolescent Rheumatology) in Manchester. Her talk was called "Exploring the prioritisation of pain and its assessment in healthcare professionals managing children and young people with juvenile idiopathic arthritis".

In this talk, Rebecca highlighted how healthcare professionals were reluctant to ask their patients about pain. Rebecca also discussed some of the barriers which healthcare professionals believe make it difficult to ask children about their pain in this long-term condition. We hope that this research is used to make pain a higher priority in JIA clinics.

Stephanie Shoop-Worrall, who is also studying for a PhD using CAPS data, presented a talk called "Comparability of the childhood, adolescent and adult measures of functional ability in Juvenile Idiopathic Arthritis". It is important to understand not only what symptoms young people with JIA experience, but also how they function in everyday activities.

These measures are the HAQ questionnaire and the two versions of the CHAQ, for completion by parents or participant depending on their age. You may have received these in the post during your participation on the study. Ultimately, the adult function questionnaire might be best for teenagers to make sure we measure function in a similar way right from 11 years old into adulthood.

Dr Lis Cordingley also gave a talk entitled "Are you thinking what I'm thinking?" What young people believe about Juvenile Idiopathic Arthritis and why it matters". The aims of the talk were to help healthcare professionals and researchers to gain new insights into young people's beliefs about their JIA, to remind them of how children's thinking processes change as they grow, and to consider how these issues may affect their clinical practice. Further details of our research can be found at:

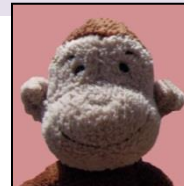
<http://www.caps-childhoodarthritisprospectivestudy.co.uk/>

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)

76 participants have been recruited to the study in 2016.

Alder Hey Children's Hospital, Royal Manchester Children's Hospital and Great Ormond Street Hospital have jointly recruited the highest number of children and young people to the study in 2016!



Win a cuddly CAPSIE!

CAPSIE is our monkey mascot and we have hidden lots of CAPSIE monkeys in this newsletter. If you count them and email how many to the address overleaf then you will enter our prize draw and could win a cuddly CAPSIE of your own! Please include your name, address and telephone number.



More from the world of musculoskeletal research

£28.5m invested in Greater Manchester’s research

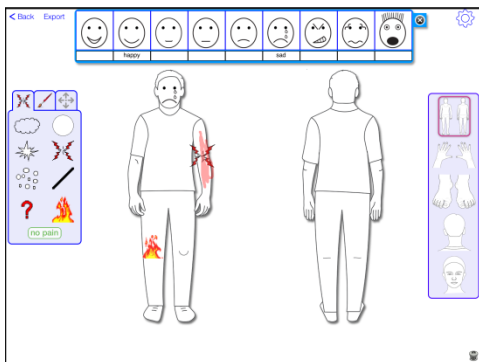
In September, a joint bid from Central Manchester University Hospitals NHS Foundation Trust and the University of Manchester was awarded £28.5m from the National Institute for Health Research (NIHR), bringing lifesaving tests and treatments a step nearer for millions of people. This Biomedical Research Centre (BRC) will drive forward pioneering research into new tests and treatments in the areas of musculoskeletal disease, hearing health, respiratory disease and dermatology and three cancer themes (prevention, radiotherapy and precision medicine). The great news for childhood arthritis research is that it remains a major research area within the musculoskeletal theme.

Introducing YOUR RHEUM

YOUR RHEUM is a group for young people aged 11-24 years, set up by a group of rheumatology professionals who undertake research into rheumatology conditions. The group is funded by the Barbara Ansell National Network for Adolescent Rheumatology (BANNAR). BANNAR itself is funded by Arthritis Research UK, like CAPS.

The aim of this group is to ensure that young people across the UK are involved in rheumatology research so that the research undertaken means something to them, reflecting what’s important to them and not just what is important to the researchers. If you’d like to join the group (which can be either via face to face meetings or online) or find out more, go to <https://yourrheum.org/> or email Katharine.cresswell@manchester.ac.uk

Watch out for My Pain Tracker (MPT)



Watch out for an exciting new CAPS study that you could take part in. Pain is common in childhood arthritis. Understanding who gets pain and how to manage pain long-term is one of the key goals of CAPS. However, pain can be hard to describe and even harder to measure, especially in young children. With this in mind we have been working on developing a new iPad app that is simple and easy to complete, even for younger children. Individuals with childhood arthritis have helped us to develop it so that we can track changes in pain and its impact on day to day activities. It’s called My Pain Tracker (MPT).

We will be looking for people to help us test the app to see how easy it is to use. We will also be looking for people to complete it at differing times over the course of a few weeks to see how well it captures the pain being experienced. Watch out for invitation letters asking if you would like to join this study which will be sent out in the New Year or get in touch with our study coordinator (contact details below).

CAPS website – any ideas?

We are currently redeveloping the CAPS website and are keen to know what you would like to see on there. The link is <http://www.caps-childhoodarthritisprospectivestudy.co.uk/> if you would like to take a look. Email or call us to give us any feedback or suggestions, thanks!

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 via email or telephone as below and follow CAPSIE, our monkey mascot to events around the world with our researchers on Facebook and Twitter:

Andrew Smith (CAPS Study Coordinator)

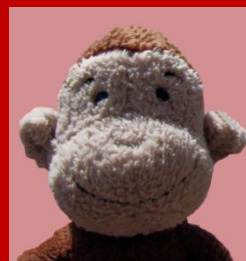
0161 275 1656

Andrew.D.Smith@manchester.ac.uk

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