CAPS

An update for kids and their parents from the CAPS study

Summer 2016

Welcome to the Summer 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.

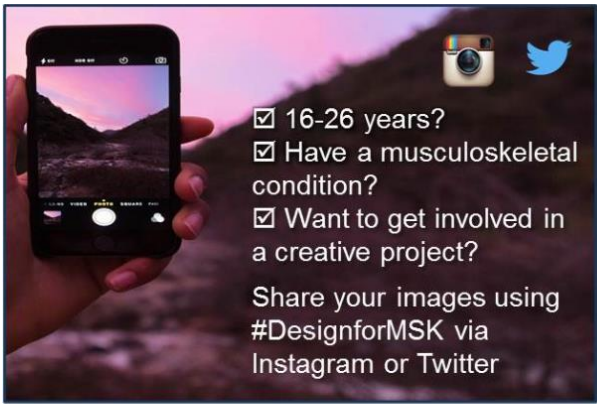
CAPS is based at the University of Manchester, began recruiting in 2001 and has recruited over 1500 patients to date.

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.

Congratulations Dr Ghio!

Dr Daniela Ghio recently gained her PhD with research based on the CAPS study. Daniela was working on developing the PPQ-YP (Pain Perceptions Questionnaire for Young People) measuring pain beliefs. We think that by knowing about young people's pain beliefs we can help with how they manage and deal with their pain.

We are now using the PPQ-YP as part of the study so you may receive it in your next mailing. The PPQ-YP and the information collected are a tool to help communicate about living with pain.



#DesignforMSK project and workshop for 16-26 year olds

The Central Manchester NHS Foundation Trust's **#DesignforMSK** project aims to raise awareness about musculoskeletal conditions such as arthritis in young people. We are asking patients to share pictures of their daily life on social media using **#DesignforMSK** to help others to understand how young people's lives are affected by these conditions; you can post any image that shows how your life is affected. Art students at the University of Manchester will then use these images to inspire new products that could make lives easier and more enjoyable.

Following this, we are looking for patients to work with designers to refine their ideas at a workshop held at **Ziferblat, Edge Street, Manchester on the 12th August**. We hope this may inspire some practical, useful products and even futuristic technology that doesn't exist yet! Some of the product ideas will be displayed at an exhibition later in the year, with a reception for those involved and their friends and family. We hope to take the exhibition to more venues to mix with different groups and discuss what it is like for a young person to have a musculoskeletal condition.

#DesignforMSK is open to anyone aged 16-26 with a musculoskeletal condition. For those interested in the workshop, travel costs will be covered and refreshments provided, plus a shopping voucher as a thank you for taking part. For more details or to sign up, please visit https://designformsk.wordpress.com/, email ginny.smith@cmft.nhs.uk or follow us on twitter or instagram @designforMSK, or find us on facebook.

News and Updates from the CAPS Study

What have we been up so far to in 2016?

In April we attended the BSR conference (British Society for Rheumatology http://www.rheumatology.org.uk/) in Glasgow. We looked at different ways of defining inactive disease in Juvenile Idiopathic Arthritis (JIA). We found that, of over 1400 children studied, around 70% achieved some measure of inactive disease within the first year, however this figure varied depending upon the definition used. This has important implications for future research and for setting the treatment targets used in clinical trials.

Sometimes children with JIA can develop uveitis, which is defined by the NHS as inflammation (swelling) of the middle layer of the eye, called the uvea or uveal tract. Uveitis affects up to 30% of children with JIA and occurs most commonly in those with oligoarticular disease. We used fluorescent dyes to look at how certain patterns of cells of children with JIA can show how likely they are to develop uveitis.

We went to EULAR (European League Against Rheumatism http://www.eular.org/) in London in June to present results on whether depressive symptoms affect future disease activity for adolescent patients with JIA.

You can watch Dr John Ioannou (pictured left), CAPS Principal Investigator at University College London Hospital, presenting this on YouTube: https://www.youtube.com/watch?v=-U_37iXdVn4

This September we will attend the 16th World Congress on Pain in Yokohama, Japan (http://www.iasp-pain.org/Yokohama16/) to discuss our review of chronic pain assessments in children and adolescents. This study, which will be presented by PhD student Rebecca Lee, builds on the research carried out by Dr Daniela Ghio on page 1, along with other researchers.

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)**

200 participants have been recruited to the study since 2013.

Prof Lucy Wedderburn and the team at **Great Ormond Street Hospital** have recruited the highest number of children and young people to the study so far in 2016!

CAPS Website

We are currently redeveloping the CAPS website and are keen to know what you would like to see on there. The current website is in the contact details below 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:

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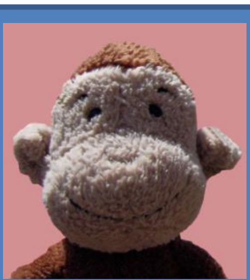

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