PARTICIPANT INFORMATION SHEET

Title of study: Uncertainty in juvenile idiopathic arthritis.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
We understand that having a child with arthritis can be very worrying for parents and having to deal with areas of uncertainty around your child’s condition can be difficult. The purpose of this research is to gain a better understanding of parents’ experiences of caring for a child or young person with arthritis, the aspects of your child’s arthritis about which parents experience uncertainty and how this affects you.

The research is being conducted by researchers from City University London.

Why have I been invited?
You have been invited to take part in this study because you are the parent/guardian of a child or young person who has been diagnosed with juvenile idiopathic arthritis (JIA). This study has been advertised to parents/guardians via the National Rheumatoid Arthritis Society (NRAS) website, social media channels and direct emailing to parents/guardians on the NRAS database. If your child is aged under 18 years of age, we would like to invite you to take part in an interview for this research. In total 20 parents/guardians of children/young persons with JIA will take part in the research. We would like to interview one parent/guardian per child.

Please note, if lots of parents/guardians are interested in taking part, we may not be able to interview everyone. We will let you know as soon as possible after you contact us.

Do I have to take part?
No, taking part is voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?
If you agree to take part you will be asked to make an appointment for an interview with a researcher. The appointment will be arranged for a day and time that is convenient for you. It can take place either at your home or in a private room at City University London, or can be conducted over the telephone, whichever you prefer. The interview will last around an hour, but some parents may choose to speak with us for longer. The interview will be audio-taped so that it is recorded accurately and will then be typed up.

During the interview, you will be asked some questions about your child’s JIA and issues related to living with it. The conversation will largely be guided by what and how much information you want to
share with us. Please note that you will be free to share only as much information as you wish. You can choose not to answer questions, and you can end the interview at any time without giving a reason.

We can pay for petrol or public transport costs you incur whilst attending this interview. Unfortunately we will not be able to pay for taxi costs. At the end of the interview you will be given an expenses and reimbursement form to fill in before you can be reimbursed.

**What do I have to do?**
If you would like to take part, please contact Caroline Pearce on 020 7040 3269 or Caroline.Pearce@city.ac.uk or Kathleen Mulligan on 020 7040 0889 or Kathleen.Mulligan.1@city.ac.uk who will be able to answer any questions you may have and will be able to arrange a time for the interview.
As the study will ask some questions about your child, we have also provided an information sheet for you to discuss with your child.

**What are the possible disadvantages and risks of taking part?**
It is unlikely that you will experience any harm by taking part in the study. If you do find that taking part causes you any discomfort, distress or concern you are free to stop or withdraw at any time.

If taking part in this research raises any issues with which you feel that you would like more support, the contact details of some organisations that provide support to families of children with arthritis are given at the end of this information sheet.

**What are the possible benefits of taking part?**
Whilst there are no immediate benefits for people participating in this study, it is hoped that this work will contribute to improving support for parents/guardians of children/young persons with JIA. We also hope that you will find it interesting to take part and learn of the results.

**What will happen when the research study stops?**
After the study has ended, all study information will be stored securely at the School of Health Sciences at City University London for at least 10 years. After this time, it will be disposed of securely.

**Will my taking part in the study be kept confidential?**
All the information you provide during the course of the research will be kept strictly confidential. We will use a unique number on all records, rather than your own name. The recording of the interview will be sent for typing up to an external company which provides an assurance of confidentiality. Study information will be securely stored in locked files or on a secure computer database at City University London. Only authorised individuals directly involved with the study will have access to the data. We will comply with the University's policies to ensure confidentiality of the data throughout the process.

However, if you tell us something that gives us concern about your safety or the safety of another person, we may have to pass that information on to the University safeguarding team.
What will happen to results of the research study?
Information from the study will be used in presentations or published in scientific reports. These will not identify any individual taking part. Quotations from interviews may be used in research publications but any quotations used will be anonymous. If you would like to be sent a summary of the results at the end of the study please let the researcher know by initialling the relevant section of the consent form. A report summary will also be available via the NRAS website or a full report can be requested to be mailed to you from NRAS via enquiries@nras.org.uk.

What will happen if I do not want to carry on with the study?
Once you have agreed to take part in the study you may decide that you do not wish to continue. You can withdraw from the study without an explanation or penalty at any time.

What if there is a problem?
If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: Uncertainty in juvenile idiopathic arthritis.

You could also write to the Secretary at:

Anna Ramberg  
Secretary to Senate Research Ethics Committee  
Research Office, E214  
City University London  
Northampton Square  
London  
EC1V 0HB

Email: Anna.Ramberg.1@city.ac.uk

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone’s negligence, then you may have grounds for legal action.

Who has reviewed the study?
This study has been approved by City University London School of Health Sciences Research Ethics Committee.

Further information and contact details
If you would like to discuss the study please feel free to contact the research team:

Caroline Pearce - Email: Caroline.Pearce@city.ac.uk, Tel: 020 7040 3269

Dr Kathleen Mulligan - Email: Kathleen.Mulligan.1@city.ac.uk, Tel: 020 7040 0889
Contact details for some organisations that provide information and support to families of children and young people with arthritis:

National Rheumatoid Arthritis Society (NRAS)
Ground Floor, 4 The Switchback, Gardner Road, Maidenhead, Berkshire SL6 7RJ
Website: http://www.jia.org.uk/
Email: jia@nras.org.uk
Telephone: 0845 458 3969 / 01628 823524

The Children’s Chronic Arthritis Association (CCAA)
Ground Floor, Amber Gate City Wall Road, Worcester WR1 2AH
Website: http://www.ccaa.org.uk/
Email: info@ccaa.org.uk
Telephone: 07958 187 600

Arthritis Care
Helpline / The Source
Floor 4, Linen Court, 10 East Road, London N1 6AD
Website: https://www.arthritiscare.org.uk/managing-arthritis/children-with-arthritis
Email: thesource@arthritiscare.org.uk
Telephone: 0808 800 4050

Thank you for taking the time to read this information sheet.