The Sydenham Chorea Study

Information Sheet

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

Who is conducting the research?

The research is being carried out by the departments of Psychiatry liaison and Neurology (Fraser of Allender), Royal hospital for sick children (RHSC), Yorkhill, Glasgow. We will also have help from colleagues in the Institute of Health and Wellbeing at the University of Glasgow.

What is the purpose of the study?

We hope to find out more about the psychiatric symptoms that manifest in children with Sydenham’s chorea.

Why have I been invited?

You have been invited to take part in this study as you have a child with Sydenham’s chorea.

Do I have to take part?

It is up to you and your child to decide. This information sheet will provide details of the study, but should you have further questions before deciding to take part, we will be pleased to answer them. You will be asked to sign a consent form to show you have agreed to take part. You and your child are free to withdraw at any time, without giving reason. This would not affect the standard of care your child receives or your child’s future treatment.
What does taking part involve?

If you decide to have your child take part in the research study, you and your child will be invited to RHSC to take part in a structured interview.

► Parents/carers will be asked about your child’s development, the sydenham’s chorea and any psychiatric symptoms and how this affected your child at home, school and socially. We will ask you about your family history. You will be interviewed on your own and with your child. The session will last from 1-4 hours.

► Teachers will be phoned (with your permission) asking about how their school performance varied before, during and after their illness.

► Children will be interviewed and asked to carry out a few simple movement tests to identify any choreic movements. The session will last around one to four hours.

► Video. We would like to video the whole assessment so we can look at it afterwards and take our time understanding the psychiatric symptoms and the movement test.

There will be regular breaks during the session. Snacks and drinks will be available throughout the session. You can leave at any time you wish.

What happens to the information?

Your identity and personal information will be completely confidential and known only to the researcher. All the information obtained will remain confidential and stored within a locked filing cabinet. The data are held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission. Your data will be used only for the purposes of the research, unless there are concerns about child safety. With your permission, we would let your child’s GP know of the family’s involvement in the study but would not pass on any study information to the GP.

What are the possible benefits of the study?

- Better understanding of the psychiatric complications of Sydenham’s chorea.
- Health professionals may be more able to detect symptoms early and treat them.
- Better help for children with Sydenham’s chorea could improve their functioning at school, home and socially
- Helping to improve the information and services available to other children and their families who are diagnosed in the future with the condition
What are the possible benefits of taking part?

- It is hoped that by taking part in this research, you will be providing valuable information about the psychiatric symptoms that can present in children with Sydenham’s chorea.
- Getting your voice and experience heard.
- An update of your own medical information and physical exam
- An opportunity to meet other families with children with Sydenham’s chorea, network and share experiences.
- An opportunity to discuss and reflect upon any challenges you faced as a family with a child with Sydenham’s chorea.
- We would be happy to share with you the results of the study on completion.

What are the possible limits of participating in the study?

The interviews can take from one to four hours, requiring a significant time commitment from families during a working week. We are here to help make the process as smooth and enjoyable as possible, regular breaks can be taken and families can leave at any point during the session if they do not feel they can stay the whole time. We would also be happy to provide a letter for workplaces if required in order to enable time off.

On occasions in a structured psychiatric interview, difficult topics and personal questions may be touched upon. It is always your choice what you would like to discuss or not and interviewers will respect your wishes in this regard.

If you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanisms is also available to you.

Who has reviewed the study?

This study has been reviewed by the West of Scotland Research Ethics Service.

If you have any further questions?

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study and wish to speak to someone linked to the study, please contact Dr. Mallika Punukollu at mpunukollu@nhs.net or Nadine Mushet at Nadine.Mushet@ggc.scot.nhs.uk.
Contacts:

If you have any questions about the study, please don’t hesitate to contact the research contact.

Research contact

_Irene O’Neill_

Institute of Health and Well Being

Caledonia House
Child and Adolescent Psychiatry
Royal Hospital for Sick Children
Yorkhill, Glasgow, G3 8SJ
Tel: 0141 201 9239

More information at:
www.sydenhamschorea.org.uk

_Thank-you for your time and co-operation_