



CDSS Children with Down's Syndrome Study

INFORMATION SHEET FOR HEALTH PROFESSIONALS

What is the purpose of the study?

To follow a group of children with Down's syndrome from birth onwards to investigate their health.

Who is doing the study?

The study is a collaboration between paediatricians and haematologists at St James' University Hospital in Leeds, and the Epidemiology & Genetics Unit at the University of York. It has been developed with the support of the Down's Syndrome Association and the Down's Syndrome Medical Interest Group. We are also working with other health professionals who, like you, are directly involved in the care of children with Down's syndrome.

When can children be entered into the study?

All babies born from March 2006 onwards are eligible. Most children will be entered into the study as newborns, but older children with Down's syndrome can also take part in the study.

What will be collected?

For babies joining the study as newborns, we will ask families for consent to have access to a blood sample taken shortly after their baby's birth. In most cases we will be able to use one that has already been taken. If a suitable sample is not available, we will seek permission to take another. However, if families don't agree to this it does not prevent them from taking part in the study.

If parents agree to participate in the study we will write to them with more information about what will happen next. This will include sending parents a short questionnaire before their child's first birthday, and then once a year after that; looking at medical records; collecting blood samples from the child when they are having routine tests and collecting buccal (mouth) swabs from parents and children.

What will happen to the data and samples?

All data will be stored and managed by the Epidemiology & Genetics Unit at the University of York. This information is stored confidentially and kept in accordance with the Data Protection Act.

A full blood count will be carried out on the blood samples. Results from the neonatal samples will be sent to the team managing the baby. If any of the full blood count tests reveal a serious abnormality, advice will be sought from a Paediatric Haematologist at the Regional Centre for Paediatric Haematology in Leeds. The remainder of the samples will be stored and used for research purposes only.

If you want any more information or have any questions about the study, please contact us on:

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