



CDSS Children with Down's Syndrome Study

PARENT/GUARDIAN CONSENT FORM

Thank you for reading the information about the study. If you think you would like to help, please read and sign this form. Please initial each box if you agree with the accompanying statement:

1. I have read the parent/guardian information sheet and have been given a copy to keep. I have had the opportunity to ask questions about the study and I understand why the research is being done.
2. I understand that participation in this study is entirely voluntary and that I will not receive any payment. I am free to withdraw my consent at any time without giving a reason and without my child's medical treatment being affected.
3. I am willing to complete confidential questionnaires about my child's background and current health.
4. I give permission for a research team member to access, examine and record information from my child's hospital records.
5. I give permission for a research team member to access, examine and record information from my child's GP and health visitor records.
6. I agree to an additional blood sample being taken from my child when they are having a routine blood test.
7. I agree to a mouth swab being taken from my child.
8. I give my permission for my child's samples to be stored and retained for use in future research projects approved by the relevant ethics committee.
9. I understand that all information I give will be treated confidentially and will not be used or released in a way that I or my child could be identified. I am aware that the data and samples will be used anonymously and that I will not receive routine feedback about the results.

Child's name: _____

Child's date of birth: ___ / ___ / ___

Address: _____

Postcode: _____ Telephone number: _____

Parent's name (mother) _____ Parent's name (father): _____

Signature(s): _____

Date: ___ / ___ / ___