Who can participate?

We are inviting families with cerebral palsy to participate in this study, and this includes: you.

Will anyone know that I am taking part?

No, no-one will know that you have donated blood and DNA for this biobank. Our biobank will contain blood samples, DNA samples, blood spots taken from Guthrie cards and medical data that are stored without your name

. We will use a special code number to store everything about you and them, so that no-one knows who you are.

What will happen to the blood I donate?

The blood samples, DNA samples, Guthrie card spots and medical data will be stored in the biobank using a special code without your name, and will only be used by researchers who are linked with The Australian Cerebral Palsy Biobank to help them do more research in the area. Noone else will be allowed to use this information. The information could be used with information from other young people in reports or papers about the research. You will not be able to be identified in these reports or papers.

any results from this biobank.

We have a website (www.adelaide.edu.au/cerebralpalsy) which gives information on projects that we are working on if you would like to know more about what your samples are being used for.

If you would like any more information about this biobank, please talk to your parents first. They can help you to contact the local study co-ordinator in Brisbane on (07) 3068 2950 or a member of the Biobank Team in Adelaide. They will be happy to answer any of your questions:

Chief Investigators Prof Alastair MacLennan, Prof Eric Haan and Prof David Adelson

The Australian Cerebral Palsy Research Group, The University of Adelaide

Phone: (08) 8313 1404

Princip al Investigator Dr Lisa Copeland,

Queensland Paediatric Rehabilitation Service

Phone: (07) 3068 2950

The Biobank Team Kelly Harper and Jessica Broadbent

Phone: (08) 8313 1404

Email: cerebralpalsy@adelaide.edu.au
Website: www.adelaide.edu.au/cerebralpalsy

This project has been approved by The

n Research

Ethics Committee (HREC). If you have any worries or questions about the study or your rights as a participant, or if you wish to make a confidential complaint, at any time, please call the Coordinator of the Ethics Committee on (07) 3636 9167. If this phone is unattended, please leave a message and your call will be answered as soon as possible.

This information is for you to keep.