



## Children's Health Services

### **Investigators:**

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This information has been put together to help you decide if you would like to donate a sample of blood/DNA for our biobank for future studies about cerebral palsy.

### **Who is setting up the biobank?**

The Queensland Paediatric Rehabilitation Service at is working  
with the Australian Cerebral Palsy Research Group to recruit participants and their families to help build a biobank for cerebral palsy.

### **What is a biobank and why is it important?**

A biobank is a collection of biological samples that are stored for research reasons. Cerebral palsy is a very common disorder, that many people in Australia live with. Approximately one in every 400 children born in Australia has cerebral palsy. We now think that cerebral palsy begins before birth, and we want to investigate this further. The Australian Cerebral Palsy Biobank has been set up to allow important research to be done, which will help us to understand how cerebral palsy develops, and how we can prevent it one day.

### **How will your samples and information be used?**

By participating in the biobank, families agree to the DNA (genes) and medical information they provide being stored indefinitely and used in ongoing and future research. The investigators in charge of this biobank will only use the samples for cerebral palsy research that has been approved by an ethics committee, who will make sure that the research is being done properly.

The area of cerebral palsy research is large and as we develop more advanced technologies, more the future. Some of the current ideas include: investigating families to see if there is anything in their genes that may have caused cerebral palsy, and studies to look into the interactions between genes and the environment to see if there is any connection.

### **Who can participate?**

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

yourself, as a brother or sister (sibling) without cerebral palsy. Your involvement will be important. You will need to be at least 5 years old. If something interesting is discovered in the genes of your brother or sister with cerebral palsy that is not present in your genes, it may help to explain the cerebral palsy in your family.

your brother or sister with cerebral palsy. They will generally be at least 5 years old, but some children as young as 2 years old can also be included if their doctor says they clearly have cerebral palsy.

your mother and your father.

**If you agree to participate, we will:**

1. Collect and store a blood sample (approximately 1 tablespoon) from you - this may be slightly painful and there is a small chance that bruising might occur.

A nurse who is specially trained will take your blood. This nurse can use a special numbing cream very much when the needle goes in. The entire blood sample will be collected with only one try. We will store your blood and DNA in special freezers and they will only be used for cerebral palsy research.

2. Access and store the following information:

Medical records  
(known as perinatal data).

A sample from your newborn blood spot (Guthrie) card, if necessary.

Any other information that may be available to us.

**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. No-