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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?

Who can participate?

You will generally need to be at least 5 yrs old, but some children as young as 2 can also be included if their doctor says they clearly have cerebral palsy. If you are a brother or sister without cerebral palsy your involvement will be important as a genetic control and you will need to be at least 5 years old - if something interesting is discovered in the genes of the child with cerebral palsy that is not present in the genes of the brother or sister, it may help to explain the cerebral palsy in your family.

If you agree to participate, we will:

1. Collect and store a blood sample (approximately 1 tablespoon) from you and also from your mother, father, and brother or sister if you have one. This can be painful and bruising can occur. If you are going into hospital for treatment or an operation, the doctor can collect your blood when you are feeling sleepy or asleep. If you are not having any treatment, we will get a nurse who is specially trained to come and take your blood. This nurse can use a special numbing cream and your blood sample will be collected with only one attempt. We will store your blood and DNA in special freezers and we will use it only for cerebral palsy research.
2. Store a sample of your saliva (GRA). People working at GRA have the skill to extract DNA (take it out from your blood) and store it for us. They will do this by using white blood cells from each blood sample we collect, and when you come back and ask you for more blood later. Your parents will be given extra information about this. Your anonymous DNA samples may be used by other researchers for research in any medical condition, with ethics committee approval.
3. Ask your mother to fill in a short questionnaire about things that happened when she was pregnant with you.
4. Access and store the following information:
 - Taken from your birth records (known as perinatal data).
 - Information collected by a Cerebral Palsy Register, if you have been diagnosed with cerebral palsy.
 - A sample from your Newborn blood spot (Guthrie) card, if necessary.
 - Any other information that may be important to cerebral palsy research.If you agree to let us keep this information, we will keep it very safe, and not have your name attached to it. We will use a special code number to store it.

Do I have to take part in the research?

Will anyone know that I am taking part?

No, no-one will know that you have donated blood/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, so that no-one knows who you are.

What will happen to the blood I donate?

The biobank will contain blood samples, DNA samples, Guthrie card spots and medical data that are stored without your name. We will use a special code number to store everything about you, so that no-one knows who you are. The information you tell us 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-one 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