Child Information Sheet

The Australian Cerebral Palsy Biobank

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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 Rehabilitation and Orthopaedic Departments at Sydney Children's Hospital (Randwick) are 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 research ideas will be explored. We don't know exactly what research ideas will be investigated in 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 your genes and the environment to see if there is any connection.

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 on your arm, so that it won’t hurt very much when the needle goes in. The entire 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 DNA at a research building called ‘Genetic Repositories Australia’ (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 growing them to ensure an ongoing supply of DNA. This means that we shouldn’t need to 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:
   - Medical records collected at the time you were born, and about your mother’s pregnancy (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?

No you don’t. If you say no, that is ok. It is up to you.

Even if you take part at the beginning and change your mind later on and don’t want to be a part of the biobank, that is okay as well. All you need to do is tell your parents to tell the researcher that you don’t want to take part anymore.

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 identified in these reports or papers.

We can’t give you 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 Cerebral Palsy Biobank Study Co-ordinator on (02) 9382 1757 or a member of the Biobank Team in Adelaide. They will be happy to answer any of your questions:

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This project has been approved by Sydney Children’s Hospitals Network Human Research Ethics Committee. If you have any worries or questions about the biobank, please call the Executive Officer of the ethics committee on (02) 9845 1253.

This information is for you to keep.