

# AUSTRALIAN AUTISM BIOBANK

## Access and use of collected information

The information stored in the Australian Autism Biobank will be valuable to the autism research community. In the first instance, the data will be used by the research team specified on Page 2 of this Information Booklet to investigate the causes of ASD. Your biological samples will only be used for bona fide research studies. Some genetic information about you will be obtained and used with other data in your medical records to see how your genes relate to your diagnosis and general health. Your samples will NOT be used for research involving reproductive technology, human embryos or cloning.

Second, we will also make the information available to other researchers around Australia and the world. Where appropriate, your information may be sent interstate or overseas for collaborative research purposes. This can only happen when we are sure that requisite approvals have been obtained and the necessary ethical and privacy safeguards are in place.

Sharing information between research groups is critical to making research advances, and we would like the Australian Autism Biobank to be part of this important process. Importantly, we will never share any of your personal identifying information with these researchers (e.g., name, address). Instead, your data will be labelled with the code number allocated to you at the start of the research. Necessary ethical and privacy safeguards are in place.

Access to the data will be managed by a 'Biobank Access Committee', which will be chaired by Prof Sylvia Rodger from the Autism CRC. Access to data will only ever be granted by this committee when researchers have approval from an Ethics Committee and where the Biobank Access Committee can identify a clear potential benefit of the proposed research to the ASD community.

The law in Australia dictates that you may not be rewarded financially for donating biological samples. We are, however, allowed to profit from research outcomes that are ultimately successfully commercialised. Any money we receive from commercial ventures is always put back into medical research.

## Withdrawing consent

You are free to withdraw your consent to participate in this study at any time. Your decision to withdraw consent will not influence the care your child receives from any of the personnel involved in this study.

If you withdraw consent, we will destroy the hard and electronic copies of the collected information as well as the biological samples.

## What happens to the results of the research study?

We would send you an end-of-year newsletter that gives results of our research. We also plan to publish our findings in scientific journals. We would not normally give feedback about results for individual children to anyone. However, if we found results that might be useful for your child's education, we could write a report that you could show to the school staff if you wished.

## Who has approved the study?

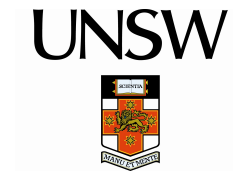
This study has been approved by the Sydney Children's Hospital Network Human Research Ethics Review Committee HREC/14/SCHN/269

## Who to contact if you have any concerns about the running of the study?

If you have any concerns or complaints regarding this study, you can contact the Research Ethics Manager (Telephone No. 02 9845 3017). Your concerns will be drawn to the attention of the Ethics Committee which is monitoring this study.

## Who to contact for more information or if you would like your child to take part in this research?

If you would like to take part in this research study, please contact Feroza Khan at the University of New South Wales on 0491 137 235 or [feroza.khan@unsw.edu.au](mailto:feroza.khan@unsw.edu.au) or Rachel Grove on 9385 0621 or [r.grove@unsw.edu.au](mailto:r.grove@unsw.edu.au)



## The AUSTRALIAN AUTISM BIOBANK Information Booklet

Your family is being invited to take part in a research project that seeks to gain more insights into the causes of autism. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with other family members. Take time to decide whether or not you wish to take part.

Thank you for reading this.

This information Booklet contains the following information:

- Why are we doing this study?
- Who is carrying out the study?
- Why have I been chosen?
- Does my child have to take part?
- What will happen if I give permission to take part?
- What will happen with the blood samples?
- What are the possible disadvantages in taking part?
- What are the possible benefits in taking part?
- Storage of information.
- What happens to the results of the research study?
- Who has approved the study?
- Who to contact for more information about this study?
- Who to contact if you have any concerns about the running of the study?
- What to do next if you would like your child to take part in this research?

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# THANK YOU FOR YOUR TIME



## Why are we doing this study?

Autism is a lifelong condition that affects a person's ability to communicate and form relationships with others. The exact causes of autism remain unknown, but it is becoming increasingly apparent that combinations of genes and environmental factors are involved. Children with autism can be very different from one another. Some children with autism are high functioning, with language and intelligence intact. Others may be nonverbal and/or intellectually disabled. We are now beginning to appreciate that careful observation of both similarities and differences among children with autism will allow us to discover more about the many underlying causes.

The aim of the Australian Autism Biobank is to collect detailed information on Australian children with autism and their families. By understanding how the many genes and gene combinations may result in different types of autism, we aim to learn much more about why autism occurs.

Our knowledge of autism has advanced considerably over the past decade as a result of the worldwide research effort. Recent findings suggest that autism can be diagnosed at an earlier age. There are also now grounds for thinking that biological compounds or medications will eventually be discovered that are able to overcome or reduce disabling autistic characteristics and behaviours. We are taking a long-term approach towards establishing a strong autism research program in Australia that is closely integrated with autism clinical services and also the training of future health care professionals providing services to affected individuals and their families.



We expect that some of the discoveries that will emerge from the Australian Autism Biobank will contribute to international autism research.

## Who is carrying out the study?

This study is being funded by the Cooperative Research Centre for Living with an Autism Spectrum Disorder (www.autismcrc.com.au), which is a national research program aimed to improve the lives of people with autism and their families.

The Australian Autism Biobank is conducted across four Australian states, and is led by Prof Andrew Whitehouse (WA), Prof Cheryl Dissanayake (Vic), Professor Valsamma Eapen (NSW) and Dr Honey Heussler (Qld). The biological data and samples will be stored at the Wesley Research Institute, Wesley Hospital, Brisbane (WRI). Your samples will be under the custodianship of Autism CRC for the duration of the Autism CRC. If the Autism CRC is finalised, custodianship will pass to WRI.

## Why have I been chosen?

You have been approached because your child has been diagnosed with autism. We are approaching all families of children who have received this diagnosis in WA, Vic, NSW or Qld.

## Does my child have to take part?

It is up to you and your family to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You and your family are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your child's health care in any way.

## What will happen if I give permission to take part?

If you decide to take part, a researcher will contact you via telephone. They will discuss the three parts of the study, which will take around 2 hours all up. These are:

1. Questionnaire: You will be sent via mail a series of questionnaires, which asks about your child's development, as well as pregnancy and birth history and information on the biological parents. The questionnaire asks some questions that could be considered 'personal', such as any illicit drug use. All information is kept strictly confidential and you can choose not to answer any question. These questionnaires can be completed at your home and will take about 2 hours to complete.
2. Clinical assessment: Your child and you will then be invited in to the Children's Hospital at Westmead

for a clinical examination. In this session, your child will take part in various child-friendly games and activities and we will also take measurements of your child's face, arms and legs. We will also conduct an interview with you, asking further questions about your child's development. The session will take around three hours and has been designed to be fun for children. We will also ask parents to complete a structured parent/caregiver interview based upon your family history and child's development, and also complete a short cognitive ability test, taking about two hours in total.

3. Blood sample: To obtain genetic information, we will ask

to obtain a blood sample from your child. The blood sample will be 8 ml (2 teaspoons). The procedure will take around 10 minutes and will be carried out by suitably qualified staff at the Children's Hospital at Westmead. The procedure is as follows:

- i. You and your child will be taken to a 'child-friendly' room at the Children's Hospital at Westmead.
- ii. Your child will be encouraged to sit in a chair.
- iii. A soft rubber band (tourniquet) is placed around your child's arm.
- iv. Blood will then be taken from his/her arm. Your child will feel a small 'prick' sensation as the needle enters the skin. The blood will then fill a test-tube for around 10 seconds.
- v. The needle is then withdrawn from the skin and a cotton wool bud is placed on your child's arm to stop the bleeding.

Importantly, the qualified staff are highly experienced in taking blood from children. If you or your child would like to stop this procedure at any time, you may do so.

We would also request to take a blood sample from the biological parents (approximately 10ml each). This will be done at the Children's Hospital at Westmead. The blood samples will be transported to the Queensland Brain Institute (University of Queensland) and then to the secure facility at the Wesley Research Institute in Qld to be stored for analysis.

**Your family may participate in as much or as little of this study as you would like.**

## What will happen with the blood samples?

Blood comprises many substances and we will be extracting two elements from each sample: DeoxyriboNucleic Acid (DNA) and plasma. Each element will be stored in secure freezers at the Wesley research Institute for later

analysis. DNA is the chemical substances that carries the genetic information required for the reproduction, growth, development and function of the human body, including the brain. The DNA will be analysed in search of genes of possible importance to autism and related disorders. We may also look at the plasma for exposures to common chemicals in the environment.

## What are the possible disadvantages in taking part?

Some discomfort may be experienced when a blood sample is taken. A local anaesthetic cream can be applied beforehand to minimise pain. Afterwards a small bruise at the site of blood collection may develop. The procedures will be carried out by qualified staff at the Children's Hospital at Westmead.

The Family Questionnaire asks some personal information about the pregnancy, your child and your family. You are able to answer as many of the questions as you like. Importantly, all information is kept confidential and secure.

There is no cost for taking part in this study.

## What are the possible benefits in taking part?

The information we get from this study could help design better ways of assessing and helping future generations of people with autism. You and your child could be involved in an important scientific advance.

## Storage of information

The genetics of autism is complex, and these studies often take many years. We will retain all data collected for this study (including genetic information) indefinitely, with annual reviews.

As soon as you enter the study, your child and your family would be identified by a code number. The document matching your code numbers and names will be kept separately from the study data.

The information we collect from the questionnaires and the clinical assessment will be entered immediately into a secure electronic database. The hard copies of this information would be kept in a locked filing cabinet at the University of New South Wales.

The blood samples we collect will be labelled with a code number and will be sent within 24 hours to the University of Queensland. DNA and plasma will be extracted from the samples and then transported to the Wesley Reserach Institute (Brisbane) and stored in a locked freezer at this site.