

NATIONAL FETAL ALCOHOL SPECTRUM DISORDER (FASD) REGISTRY

PARENT/CARER INFORMATION SHEET

What is the 'Registry'?

The registry is a national database that will collect information on patients and their families that have been diagnosed with FASD.

How to Register?

To be eligible to enrol into the FASD registry your child must have a confirmed diagnosis of FASD.

It is important that you read through this document carefully

Participation in this registry is voluntary. Your decision whether to participate will not change the current or future care that you/your child receive(s) from your paediatrician or staff involved in your care.

To enrol into the FASD registry is easy; you don't need to do anything. If we don't hear back from you within **4 weeks** of receiving this information sheet (see dates below) we will automatically enrol you into the National FASD Registry.

Date information received: _____

However, if you do not wish to participate you must **OPT-OUT** by **[insert date 4 weeks from today]** by either contacting the Registry by:

Phone: 02 9845 3005

Email: SCHN-APSU@health.nsw.gov.au

Why we need you?

Your data is valuable. The Registry is the first of its kind in Australia and the information gathered by this registry will be used to inform better diagnosis, treatment and prevention of FASD. The information will support development of better services and public health policy. The registry will provide you and your family the opportunity to participate in future research projects or clinical trials of new treatments.

What does being part of the registry involve?

Families who register will be placed on our registry database. Information about you and your child will be stored in our registry database and you will be contacted when there is an appropriate research study that you and your family may like to be involved in.

The registry database is stored on a secure computer server at the University of Sydney. Only the Registry custodians have access to the information. Researchers and policy makers can request extracts of de-identified information but information on individuals will never be released to anyone.

We will not publish any individual data. Any reports or publications produced using the Registry will only contain grouped summary data. No individual information will be published.

If you provide us with your email we will also update you about FASD reports, new research projects, and educational events.

Can I withdraw from the Registry?


Yes, you can withdraw from the Registry at any time, including removal of data that you have already provided. However, please note that this will only be for data that hasn't been published.

You do not need to provide a reason. Withdrawing from the Registry will not have any negative consequences and will not impact the care you receive from the Hospital in any way.

You can withdraw from the Registry by contacting the Registry by Phone (02 9845 3005 or via email SCHN-APSU@health.nsw.gov.au).

Questions or Concerns?

If you have any questions or concerns about the Registry or would like some further information please contact us.

 02 9845 3005

 SCHN-APSU@health.nsw.gov.au

This project has been approved by Sydney Children's Hospital Network Human Research Ethics Committee. If you have any concerns about the conduct of this study, please do not hesitate to contact the Executive Office of the Ethics Committee (02 9845 3066) and quote the approval number [insert no. once approved].