

Living with FASD: The impacts on your child and your family

PARTICIPANT INFORMATION SHEET

We invite you to be a part of a research project that looks at the experiences of families like yours, who are caring for a child or adolescent with Fetal Alcohol Spectrum Disorder (FASD). Your participation is important because we have limited information about the impact of FASD on children and their families in Australia.

What is the project about?

We have developed a survey for parents and carers of children and adolescents with FASD to explore your experiences of the assessment and diagnosis process, as well as the impact that caring for your child has had on your family and experiences with health, educational and other support services.

The information regarding impacts of FASD on children and families will greatly increase our understanding of the needs of families like yours. The Australian Paediatric Surveillance Unit (APSU) can then identify the resources required to meet your needs and raise awareness within the health and government sectors. The study also provides a knowledge base about the impact of FASD to guide future research in this much neglected area. This information will assist in planning and advocacy for better diagnostic and treatment services and supports for families like yours.

What will it involve?

You will be asked to complete a survey about your child(ren) **aged less than 19 years** and your family either online or in paper version (postage paid envelope provided).

The survey consists of 15 pages and 8 sections and will take less than one hour to complete. We will ask questions:

- About you and your child
- Diagnosis of FASD
- Health related function
- Treatment
- Health service use
- Impact of FASD on the Family
- Support and information needs
- Financial support

The questions in this survey concern you and your family's experiences whilst caring for your child or children who have fetal alcohol spectrum disorder. You will need to complete a separate survey for each of your children as each child's journey will be different.

We acknowledge that the information we are collecting is of a personal nature and may cause distress to you. In such instances you may contact the study investigator listed at the end of this information sheet or the Social Work Department at the Children's Hospital at Westmead (Lyn Biviano (02)9845 2641).

What will happen to the information collected?

All information you provide is confidential.

The information we collect will be re-identifiable, meaning a unique code will be created to identify your survey response. Your information (your child's name, your name or contact details) will not be used in the research analysis or in any related publications. Only the researchers involved directly in this study will have access to your unique code and it will be kept in a secure database.

All survey responses will be entered onto a password-protected computer, located in a secure building at the APSU, in the Kids Research Institute. Only summary group data will be published. Confidentiality of patient information will be maintained at all times.

Feedback will be provided to you through newsletters informing you of our results and how they have been used to inform improvements to health services, peer support services, educational opportunities and information resources for families such as yours.

Do I have to take part in the study?

Participation in this survey is completely voluntary. If you do decide to be a part of this project, by completing the survey, you will be giving consent for us to use the de-identified information you have provided.

You are able to withdraw from the study at any time and this will not affect the routine health care provided by the FASD Clinic at the Children's Hospital Westmead in any way.

You can also withdraw your data from the study at any time by contacting the study investigators or the APSU. This will not affect your relationship with the FASD clinic.

How do I return the questionnaire (if completed by paper)?

A reply paid envelope is provided for you to return the questionnaire.

How to I complete and return the questionnaire (if completed online)?

To complete the questionnaire online, use the individualized secure link to the survey through REDCap (Research Electronic Data Capture) system. To return the completed questionnaire please clicks the 'submit' icon at the end of survey.

Are there any concerns you have with the study?

If you have any concerns or issues regarding this study or questions asked in the survey please contact:

Dr Marcel Zimmet marcel.zimmet@health.nsw.gov.au

Or phone the APSU on 02 9845 3005 or email us at SCHN-APSU@health.nsw.gov.au

This project has been approved by the Sydney Children's Hospitals Network Human Research Ethics Committee. If you have any concerns about the conduct of this study, please contact the Executive Officer of that Committee on (02) 9845 3066 or via email: SCHN-ethics@health.nsw.gov.au.

