

Living with Rare Disease:

The Impacts on your Child and your Family

INSTRUCTIONS FOR COMPLETION OF THE SURVEY

Thank you for your interest in taking part in this research project.

By completing and returning this survey you give consent to participate in this study, and so it is important that you understand what is required and how the information you provide will be treated and used. For this reason ***it is important that you read the information and instructions on this sheet carefully*** before deciding to complete and return the survey. If you have any questions please do not hesitate to contact your Partner Organisation (SMILE Foundation, the Steve Waugh Foundation, the Association of Genetic Support of Australasia and The Children's Hospital at Westmead) or alternatively you can contact Dr Marie Deverell at the APSU (marie.deverell@health.nsw.gov.au; Phone: 02 9845 2200)

How to complete this survey

This survey has a number of sections including:

- About you and your child
- Diagnosis
- Health Related Function
- Treatment
- Health Service Use
- Impact on Family
- Support and Information Needs
- Financial Support.

The questions concern you and your experiences whilst caring for your child or children who have a rare disease. You will need to complete a separate survey for each of your children as each child's transition journey will be different.

We estimate that it will take approximately one hour to complete the questionnaire. Please note that you need not complete it in one session.

Some questions will simply require you to choose an answer out of options we have provided by checking a box; others will ask you to fill in the space provided by typing in text.

Try to select the most appropriate answer to each question. In some instances you may not know the answer, so please select the 'Don't Know' (DK) option. Some questions will ask you to complete them only if you answered yes to the question before it. Please follow the directions in the survey to ensure that you answer all required sections.

Please remember all the data is anonymous, so **please DO NOT write your name, address, phone number or any other information that might identify you on this survey**. Some questions ask about the diagnosis, how this was made and who made it. *To protect the privacy of the health professional(s) who might have been involved in the diagnosis, please DO NOT provide any information that might identify them (e.g. DO NOT provide any health professionals' names, phone numbers or places of work).*

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