

Living with Rare Disease: The Impacts on your Child and your Family

INFORMATION STATEMENT

We would like to invite you to be a part of a project that looks at the experiences of families like yours, who are caring for a child with a rare disease or condition. There are approximately 8000 different rare diseases affecting an estimated 2 million Australians, including 400,000 Australian children. Approximately 70% of all rare diseases are of genetic origin; however, some are due to rare infections, injuries or mental health problems.

What is the project about?

For the first time in Australia, this project brings together a number of rare disease charitable organisations, including the SMILE Foundation, the Steve Waugh Foundation, the Association of Genetic Support Australasia and the Children's Hospital at Westmead, to work with a nationally recognised research partner at the University of Sydney, the Australian Paediatric Surveillance Unit (APSU), to adopt a coordinated approach to the provision of better support services, educational opportunities, and information resources for families of children with rare diseases. This approach will greatly increase the awareness of rare diseases amongst the public and government sectors and provide a knowledge base about rare diseases for future research in this neglected area.

We have developed a survey for parents/carers of children with rare diseases to explore your experiences during the diagnosis period, the health related function of your child, the impact that caring for your child has had on your family and your experiences with Health and Support Services.

What will it involve?

You will be asked to complete a survey about your child(ren) **aged less than 19 years** with a rare disease/condition and your family via the online link. The survey will take about 1 hour to complete.

What will happen to the information collected?

All information you provide is confidential.

The information we collect will be anonymous, it will not contain your name, your child's name or contact details. Each survey will have a code attached that will be linked with each family. Only the research team collecting the data will have access to your questionnaire answers but not any identifying information about you. All survey responses will be entered onto a computer protected by a password in a locked office in a secure building at the Children's Hospital at Westmead. Data from the study will be analysed and published, but will not contain any data which could identify individuals, including your child or your family. Only summary data will be published.

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Feedback will be provided to you through our newsletters informing you of results and how they will be used to inform improvements to 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 anonymous information you have provided.

You are able to withdraw from the study at any time and this will not affect your relationship with the partner organisation in any way.

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 the APSU on 02 9845 3005 or the Social Work Department at the Children's Hospital at Westmead on 02 9845 2608.

Other information

If you have any questions, feel free to contact us at any time

If you have specific questions about the survey or the design of this research, please contact:

Dr Marie Deverell marie.deverell@health.nsw.gov.au or phone the Australian Paediatric Surveillance Unit on 02 9845 3005.

This research study has been approved by the Sydney Children's Hospitals Network, Human Research Ethics Committee (HREC reference number 10/CHW/75).



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