

## Plain Language Statement for survey

*Project: Finding the gaps – Access to Australian government funding support for children with undiagnosed or rare genetic conditions*

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### Co-investigators:

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Heather Renton – CEO, Syndromes Without a Name (SWAN) Australia

### Participant Information

The University of Melbourne and Syndromes Without A Name (SWAN) Australia are collaborating on a study funded by the Melbourne Disability Institute. We want to hear from the parents or caregivers of children with undiagnosed and rare genetic conditions about their experience in accessing and maintaining sufficient government funding support (e.g. NDIS, Carers Allowance, Carer Payment), and how this impacts on these children and their families.

We want to understand more about this to know what is working well, what are the barriers and what could be done better.

We are sending this survey to all members on the SWAN Australia database, and wish to hear from parents and carers of children with an undiagnosed or rare genetic conditions who are living in Australia.

The survey should take approximately 15-20 minutes to complete. Participation is voluntary and you may choose not to answer any question and skip to the next.

### *Are there any risks to me?*

There are no risks involved in your participation in this study. Your name will not be associated with responses in this survey and your data will be de-identified and the data will only be available to the research team. The responses of this survey will be kept safe on a secured, password protect database at the University of Melbourne. Any report we publish will not include information that would make it possible to identify you in any way. Research records will be kept filed and sorted by number codes and not by names. You are free to withdraw from the survey at any time without obligation. You can ask us to withdraw any information you give us up until the time that the final report is written. The survey data will be destroyed after five years.

This project will not necessarily result in changes to government funding support schemes.

If you wish to participate in this study, please proceed by clicking on the survey link provided in email or in SWAN's social media.

If you have any questions before proceeding, you can contact Fleur Smith (lead researcher) [smith.f@unimelb.edu.au](mailto:smith.f@unimelb.edu.au) or Heather Renton (SWAN CEO, co-investigator) [heather@swanaus.org.au](mailto:heather@swanaus.org.au).