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**SURVEY:
DIAGNOSTIC EXPERIENCE OF FAMILIES WITH BATTEN DISEASE.**

Purpose:

Understanding the early experiences of parents of a child or children diagnosed with any childhood onset subtype of Neuronal Ceroid Lipofuscinosis (NCL), more commonly known as Batten disease.

Information Statement:

- A detailed Participant Information Statement about the study can be accessed at www.battens.org.au clicking on the research tab
- Or requested by post from Batten Disease Support and Research Association (BDSRA) Australia (02) *****

Inclusion Criteria:

- This study is open to parents who have previously had a child or children affected by any childhood onset subtype of NCL, and/or parents who presently have a child or children with NCL
- The parent must be a current Australian or New Zealand resident (or temporary absence for a clinical trial or treatment).
- Participants must be fluent in English

Expected commitment time:

- There is an online survey for each individual child.
- Each survey should take approximately a half hour to complete.
- Some families may complete two or more surveys if multiple children are, or have been, affected.
- If applicable to your family, a short and optional Part B of the survey will explore your family's experience with family carrier testing, and genetic testing of other children (with or without symptoms).

Confidentiality:

- All the answers you provide will be kept confidential and secure. You are **not** required to provide your name on the survey, so your identity remains anonymous. The research team intends to present and publish findings, but will do so without identifying your family.

Consent:

- If you proceed to complete the survey after reading the Participant Information Statement, this is understood to mean that you have provided your consent to participate in the study.
- Because the surveys are submitted anonymously, it will not be possible to withdraw your survey from this study once it is submitted.

Thank you for your time and for considering taking part in this survey.

Designated mobile telephone for the study is 0432 354 441
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RESEARCH STUDY

www.newcastle.edu.au