

RESEARCH STUDY: Childhood Dementia

Dementia-CONNECT: Connecting the dots in Childhood Dementia disorders

Researchers at The Sydney Children's Hospital Network (SCHN) are seeking volunteer research participants to help identify commonalities in the symptomology of childhood dementia disorders.

You are eligible to participate in this research if you are an individual or caregiver/guardian of an individual who has been diagnosed with a genetic condition associated with childhood dementia

What does participating in this research involve?

If you decide to take part you would be invited to complete an online or hard copy survey that comprises of several tools to assess behavioural, cognitive, and developmental characteristics of the individual with childhood dementia. In addition, it asks questions that aim to capture the impact that childhood dementia has on psychosocial outcomes for an individual's family/caregiver(s). This survey should take no longer than 40 minutes to complete.

To learn more about the research study or to enquire about participating, please contact:

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This study has been approved by the Sydney Children's Hospital Human Research Ethics Committee (2022/ETH00240)

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