Requests for Carrier Testing in Children: 
exploration of current practice and views of 
health professionals’ and parents of children 
with genetic conditions in Australia

Presented by

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Danya completed a Bachelor of Behavioural Science at LaTrobe University with a double major in psychology and genetics before embarking on her honours project in genetics. She then worked as a research assistant at the Epilepsy Research Centre for 8 years researching the genetics of epilepsy. Danya completed her Master of Genetic Counselling degree through the Department of Paediatrics at the University of Melbourne, which inspired her to investigate ethical aspects of genetic testing in children for her PhD.

Abstract

Guidelines for genetic testing in children have been developed to help health professionals decide when testing is appropriate. These guidelines recommend carrier testing, where ‘carriers’ of gene changes have no medical complications but may pass the condition on to their children, should not be performed in children. These guidelines are recommendations rather than regulations and it is unclear how these are interpreted and used in clinical practice. This study will investigate both the current practices in genetic health services in Australia for genetic carrier testing in healthy siblings of children with genetic conditions and the views of both health professionals receiving these requests and parents who request testing for their children.

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