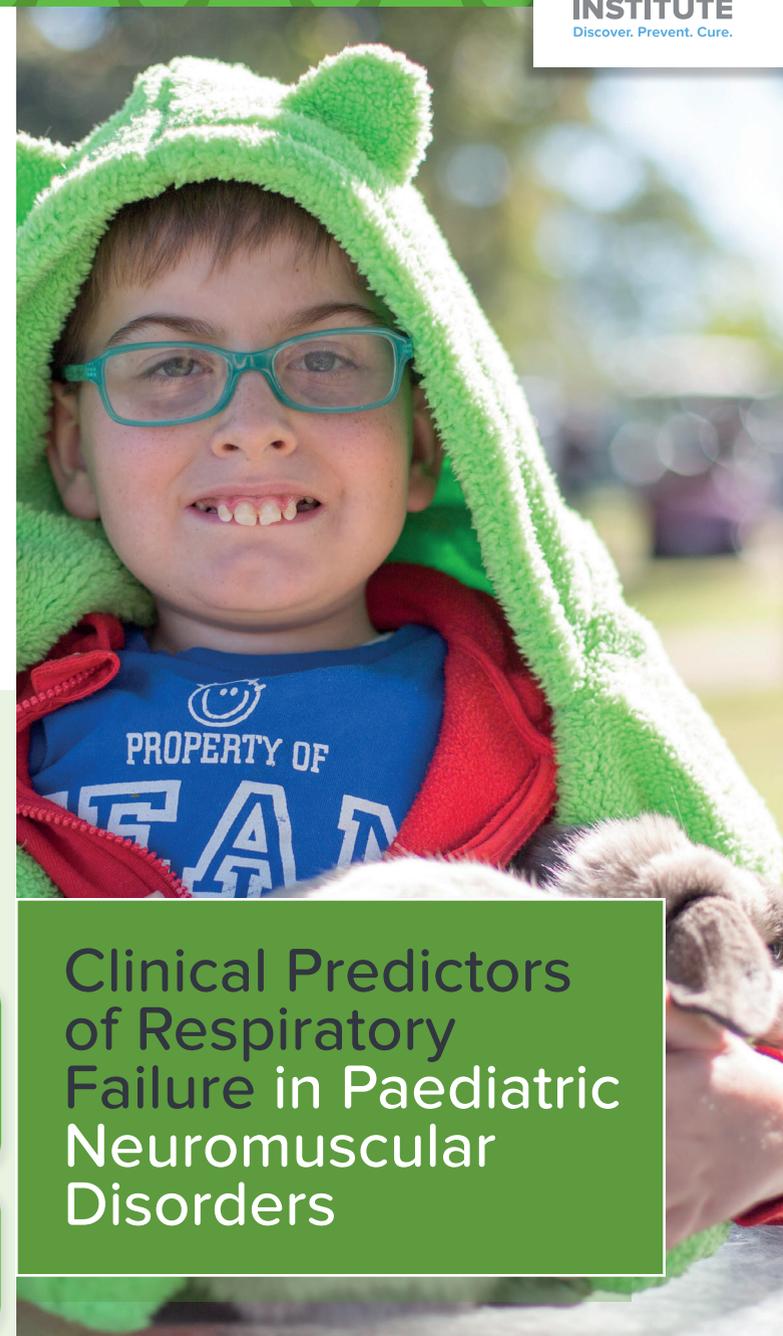




What this project means to the Muscular Dystrophy community

Muscular Dystrophy WA is passionate about improving the quality of life of people living with muscular dystrophy. This research project has the potential to improve clinical care, assist in finding better ways to manage conditions and to better understand the factors that can positively impact the quality of life. In real terms, this project gives hope, it allows people to feel valued, be heard, to know that their experience matters and they have the opportunity to shape future health and social well-being.



What are the possible benefits of this research?

Although your child may not directly benefit from participation in this study, we hope the findings will benefit other children with neuromuscular conditions.

What happens to the results?

We will use the results from this study to determine which tests are best for predicting breathing problems during sleep. These will then help doctors ensure they use the most sensitive tests as part of the normal clinical review.

Want to discuss it further?



If you would like to discuss the project further, please email neuromuscularresearch.SMB@telethonkids.org.au

This research is in partnership with:



This research is funded by:



Clinical Predictors of Respiratory Failure in Paediatric Neuromuscular Disorders

What is the Clinical Predictors of Respiratory Failure in Paediatric Neuromuscular Conditions?

This research project is a collaboration between *Telethon Kids Institute*, *Muscular Dystrophy Western Australia*, *Princess Margaret Hospital* and *Curtin University*.

Why are we doing this research?

We are conducting a study to identify problems children with neuromuscular conditions experience with breathing during sleep, due to muscle weakness. Participants will undergo various tests to see whether we can diagnose this problem early, rather than relying on the current method of simply asking about symptoms. We hope that through earlier diagnosis and treatment of muscle weakness during sleep, we can prevent future lung failure.

Who can be involved?

Any child with a neuromuscular condition who attends Princess Margaret Hospital Neuromuscular Clinic can be involved in the project. Participation in this research is voluntary.



What is involved in this research?

Information for the study will be collected over a 12-month period from the time of enrolment, via lung function tests and questionnaires to be completed during participants' regular clinical appointments with the Neuromuscular Clinic. Some extra visits may be required (eg if the participant requires a sleep study).

What is involved at each visit?

(i) Lung Function Testing

This can include blowing into a tube, taking deep breaths, breathing slowly for several minutes at a time, coughing into a tube, and sniffing through a tube

(ii) Patient Information

General health information of the participant collected during the clinic visit with the doctor

(iii) Motor Function Testing

Includes various tasks such as walking, standing up, climbing and using the hands. These tests will be performed by a physiotherapist or doctor

(iv) Quality of life questionnaire

Information about the quality of life and mood of the participant and main carer, including feelings, worries or concerns, and how your family is coping.