



# Research Funded in 2018

HeartKids Grants-in-Aid Program will provide \$273,000 to support a range of new Australian research projects into congenital and acquired childhood heart disease in 2018.

The seven grant recipients selected this year will undertake research into the causes, treatment and management of congenital/childhood heart disease, for which there is no known cure, helping to better understand the mysteries behind it.

Here is a list of the ground-breaking research currently underway:

**1) PROJECT:** Investigating Neural Correlates of Outcome in Fontan Patients Using Advanced MRI Techniques

**Principle Investigator:** Associate Professor Mark McKay

**Project Institution:** Royal Children's Hospital, Melbourne

**Project Description:** Children with complex heart defects are at increased risk of physical, learning and behavioural problems. This project will assess the use of advanced MRI brain imaging techniques to investigate brain structure and function, in people with a single ventricle chamber, palliated with a Fontan operation. It will assess volumes of different brain structures, and the microstructural organisation of white matter fibre tracts, which are the brain's

information highways. Subjects with better outcomes will be compared to those with worse outcomes. Understanding of imaging contributors to outcomes may help develop ways to optimise management strategies, including the timing and type of surgery

**2) PROJECT:** Establishing the Queensland Paediatric Cardiac Service CHD LIFE program database

**Principle Investigator:** Associate Professor Robert Justo

**Project Institution:** Lady Cilento Children's Hospital, Brisbane

**Project Description:** Children with Congenital Heart Disease (CHD) are surviving into adulthood with little known about their development over time. Each year over 100 Queensland children undergo open heart surgery before 12 months of age, placing them at risk of poorer developmental outcomes. The CHD LIFE (Long term Improvement in Functional hEalth) Program provides targeted developmental services, and developed a state-wide model of care to meet the developmental needs of these children. The project will establish a centralised database to support long-term follow up and research activity, measure state-wide model success, and inform local and international registries.

**3) PROJECT:** Identifying the Underlying Genetic Cause of Inherited Arrhythmia Syndromes In Early Childhood

**Principle Investigator:** Dr Jodie Ingles

**Project Institution:** Centenary Institute, Sydney

**Project Description:** Heart disease in children results in significant symptoms and can ultimately lead to arrhythmias and premature death. One form of heart disease in children relates to abnormalities in the electrical activity of the heart, many of which are inherited. Inherited arrhythmia syndromes can be difficult to diagnose on standard clinical tests, making clinical screening of family members challenging. Better understanding of the genetics may be useful in predicting clinical outcomes of affected children, but most importantly, can more accurately

determine risk to other family members. The proposed study will use the latest genetic technologies to identify the genetic causes and to use these results in clinical care.

**4) PROJECT:** Cord Blood Cell Therapy for Babies With Hypoplastic Left Heart Syndrome

**Principle Investigator:** A/Prof Salvatore Pepe

**Institution:** Murdoch Children's Research Institute

**Project Description:** This study tests the novel 'first in human' heart treatment with placental cord blood cells in 12 babies with hypoplastic left heart syndrome (HLHS), during the first of three surgical operations (at day three of life). The strategy is to stimulate heart muscle growth as early as possible, and strengthen heart function to avoid the high incidence of heart failure and death that occurs before the second operation at three months. Demonstrating the safety of this new therapy will facilitate larger multicentre clinical studies to determine improvements to immediate and long term post-operative recovery, with fewer life-threatening complications.

**5) PROJECT:** Royal Children's Hospital Cardiac Specimen Collection Cataloguing and Re-classification

**Principle Investigator:** Dr Bryn Jones

**Institution:** Royal Children's Hospital, Melbourne

**Project Description:** The use of heart specimens for teaching paediatric cardiology and cardiac surgical trainees is well established, and widely regarded as an essential component of education and training. The cardiac specimen collection at RCH has been accumulated over more than fifty years. Cataloguing and classification will ensure the specimens are properly preserved as an invaluable resource for research into, and the teaching of the pathology of congenital heart defects.

**6) PROJECT:** Development in 8/9 Year Old Children After Major Cardiac And Non-Cardiac Surgery

**Principle Investigator:** Associate Professor Karen Walker

**Institution:** Grace Centre For Newborn Intensive Care Westmead Children's Hospital, Sydney

**Project Description:** The Development After Infant Surgery (DAISy) study is a world-first prospective longitudinal cohort study evaluating the developmental outcomes of infants, who underwent cardiac and non-cardiac surgery compared to healthy newborns. It showed that infants who underwent surgery as a baby, at one and three years of age, had increased delay, with infants having cardiac surgery at the highest developmental risk. These children may continue to be at risk at school age. The third phase of the study (DAISy8) is currently underway to evaluate the educational and developmental skills of the children in the original cohort at eight/nine years of age.

**7) PROJECT:** Precision medicine in CHD: genetic variants guiding post-operative clinical management

**Principle Investigator:** Professor David Winlaw

**Institution:** The University of Sydney

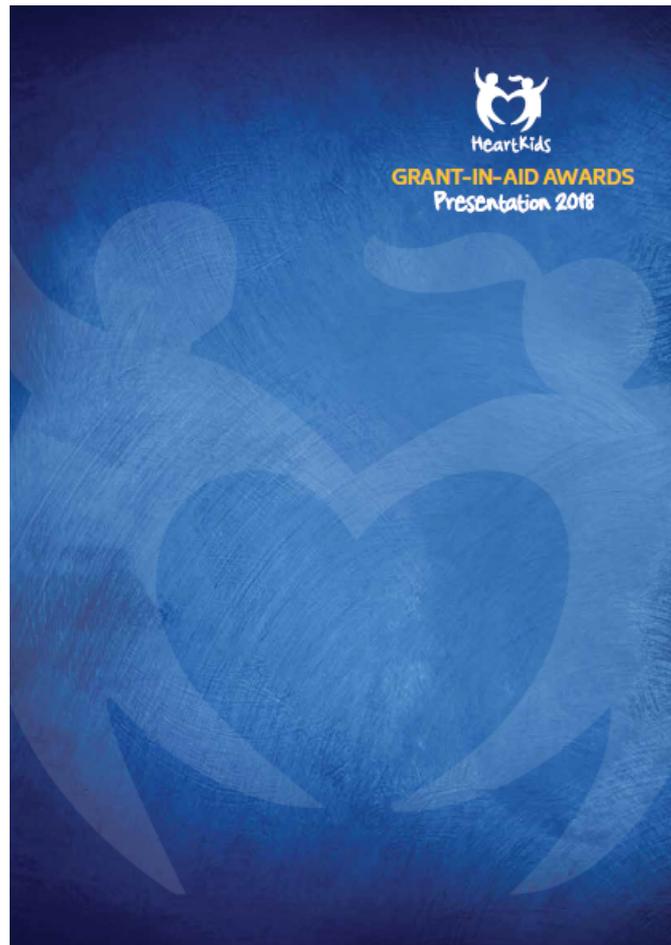
**Project Description:** Neonatal cardiac surgery for transposition of the great arteries (TGA) is a success story, with most babies now surviving well into adulthood with a 'normal' circulation. Outstanding concerns are early post-operative cardiac dysfunction and other serious complications requiring prolonged intensive care in up to a third of patients. The aim is to use patient genotype to target therapy and achieve better outcomes. The project will identify individual variation in genes associated with the development of low cardiac output, and length of intensive care stay, that will form the basis of a personalised approach to post-operative care.



HeartKids Family Coping Program is just one example of how our Grants-in-Aid seed funding for research is helping families heal the trauma of congenital heart disease.

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