



HeartKids

# GRANT-IN-AID AWARDS

Presentation 2016



# A MESSAGE FROM THE CHAIR

HeartKids Australia welcomes this opportunity to share the success of our National Research Program.

We meet this evening with a common goal: to support a childhood unaffected by childhood heart disease. **It is important to note that HeartKids Australia is the only research funding body in Australia that specifically provides funds to drive world-class research into the causes, treatment and management of childhood heart disease.**

Over time  
we have committed  
almost \$3 million to  
research programs

Our National Research Program not only provides support for our annual Grants-in-Aid research projects, but also interacts nationally as part of a five year National Health and Medical Research Council Partnership Grant for Better Health.

Currently, we are also facilitating a consortium of key clinician stakeholders who are working towards establishing an Australian and New Zealand Congenital Heart Disease Clinical Registry to inform better treatments.

The Grants-in-Aid Program supports research projects and capacity building in congenital and acquired heart disease. With the support of our sponsors and donors, we are delighted to be able to announce the successful research projects to be funded under our Grants-in-Aid Projects 2016. With your continued support, HeartKids Australia and the Research Advisory Committee hope to continue to support world-class research, to help children live their lives well.

**Dr Lisa A. Selbie, Ph.D.**  
Chair, Research Advisory Committee  
and HeartKids Australia Board



# HEARTKIDS AUSTRALIA GRANTS-IN-AID AWARDS

## PRESENTATION PROCEEDINGS

Welcome

**Mary Jung**  
Wilson HTM Foundation

Introduction

**Dr Lisa Selbie**  
Chair, Research Advisory Committee  
and HeartKids Australia Board

Guest Speaker

**Karen Eagleson**  
Cardiac Care Coordinator  
Lady Cilento Children's Hospital

Award Presentations  
and Vote of Thanks

**Dr Lisa Selbie**  
Chair, Research Advisory Committee  
and HeartKids Australia Board

**Jayne Blake**  
Chief Executive Officer  
HeartKids Australia

Official Photographs

Formal proceedings will conclude at 7pm  
Guests are welcome to stay and enjoy the hospitality  
of our hosts Wilson HTM Foundation



# WHAT IS HEARTKIDS?

HeartKids is a charity focused on improving the lives and futures of children with childhood heart disease (CHD) and their families. We do this by providing quality information and support services, advocacy and driving world class research.

Welcoming a new baby should be an extremely special time, but for the families of babies born with heart defects, the emotional and financial stress is profound. While the scope of CHD is broad, some children born with heart defects will undergo open heart surgery in the first three days of their life.

However, surgery is not a “cure”. Children with CHD will face unique challenges for their entire lives. This could include ongoing medical treatment, possibly repeated heart surgeries and in rare cases a heart transplant. Their physical and emotional development may be delayed which impacts on their capacity to live normal lives.

More than 32,000 Australian adults have lived with a heart defect since childhood.

CHD is for life, and Heartkids and their families seek support at every stage of the journey. HeartKids aims to raise the funds needed to provide this support, as well as help fund research into the causes, treatment and management of heart defects and broaden awareness of CHD in Australia.

## Did you know?

- Eight babies are born with a heart defect in Australia every day, that's one in a hundred and nearly 3,000 each year.
- Childhood heart disease is the biggest killer of Australian children under one CHD can go undiagnosed until adulthood
- There are more than 32,000 adult Australians who have lived with a heart defect since childhood CHD is not a single condition.
- It includes a wide range of heart defects that a child is born with or develops in childhood as a result of other illnesses.
- These conditions are not the result of lifestyle factors.

## HeartKids Australia Research Programs

HeartKids, with the support of its sponsors and donors, is proud to have committed almost \$3,000,000 of funding for research projects looking to unlock the mysteries of Childhood Heart Disease. HeartKids funds research through two programs: Grants-in-Aid and Project Grants.

The specific focus and aim of these programs has been to:

- Reduce mortality and/or morbidity from CHD
- Reduce the incidence of CHD
- Develop preventative measures to reduce CHD
- Improve early detection of CHD
- Understand the causes and disease processes of CHD
- Improve the treatments and management of CHD

Gain a better understanding of the consequences of CHD and its treatment including the neurological, cognitive or social impacts on children affected by CHD and how these issues may be addressed. The Grants-in-Aid Program was established by HeartKids Australia in 2011 with the support of our Founding Partner, Wilson HTM Foundation. The program supports Australian research into congenital and acquired childhood heart disease.

Grants-in-Aid differ from our Research Projects Grants which are intended to support large research grants over a two or three year timeframe similar to research project funding schemes operated by the NHMRC. Grants-in-Aid are intended to fund smaller projects (minimum \$20,000 and maximum of \$50,000 inclusive of GST) and have a shorter duration, with a maximum of twelve months.

The grant application process is also simpler; the application forms shorter, the decision process faster and hence the process should be less demanding on applicants. The Grants-in-Aid are intended to support and grow research capacity specifically directed to childhood heart disease (CHD).

## Funding Streams

There are three potential streams of funding:

1. Small Research Projects. Funds may be sought for a small research project, to contribute to a larger (already mainly funded) project, to provide a seed funding for a new idea, to fund a pilot study or to assist with a small clinical trial.
2. Building Research Infrastructure. Funds may be sought for purchase of capital equipment needed for research or for building of or access to specialised infrastructure, e.g. bio banks, clinical registers, databases etc.
3. Research Capacity Building. Funds may be sought to assist research capacity building by providing access to special expertise to bolster research or providing research leadership development.

It is a requirement that a substantial part of any research funded by HeartKids Australia, be conducted in Australia.





# A LEADER OF RESEARCH INTO THE TREATMENT, MANAGEMENT AND PREVENTION OF CHILDHOOD HEART DISEASE

HeartKids has developed a peer-reviewed,  
transparent and efficient process to identify  
and allocate research funding.

This ensures we obtain the best value from  
our funds and achieves the greatest impact for  
children affected by heart disease.

We are assisted in this process by the  
Research Advisory Committee.

## MEET THE RESEARCH ADVISORY COMMITTEE



**Dr Lisa A. Selbie, Ph.D. Chair**

Dr. Selbie received her Ph.D. in Biochemistry, Molecular Biology and Cell Biology at Northwestern University and began her career as both a scientist and project leader at the Garvan Institute of Medical Research in Sydney, Australia studying the cloning and expression of neuropeptide receptor genes. Dr Selbie moved to England in 1994 where she worked at Queens Medical School at the University of Nottingham as a Wellcome Trust Research Fellow for four years, studying cell-based models of receptor signal transduction. Dr. Selbie then moved to the US and for the past 11 years, has developed and delivered on-ground and online courses as a lecturer for Johns Hopkins University's Advanced Biotechnology Studies Program MS/MBA Program. After returning to Sydney in 2003, Dr Selbie has also been a consultant with an Australian management consultancy in the biotechnology and healthcare sectors, an instructor with Biotech Primer Inc., a global company providing biotechnology training for the non-scientist. Dr Selbie has served as a member of the NSW AusBiotech Committee and is both the Chair of HeartKids Australia and the Research Advisory Committee.



**Dr Anne Fletcher, BSc, MSc, PhD, FAICD, FAIMS**

Anne Fletcher is a non-executive director, currently serving on the Chinese Medicine Board of Australia and the Therapeutic Goods Administration (TGA) Advisory Committee for Biologicals. Anne was previously on the boards of the Australian Red Cross Blood Service, the Australian Bone Marrow Donor Registry, the CRC for Vaccine Technology and HeartKids Australia. In her early career Anne worked in diagnostic laboratories. After undertaking postgraduate study she pursued a career in medical research at the University of Sydney and the Australian Red Cross Blood Service. Anne managed the Australian research program of the newly formed national blood service. In 2002 Anne established a health consultancy which provided advice to the biotechnology, health and medical research sectors. Anne has been instrumental in establishing several research funding schemes, including a research fund for the Australian and New Zealand Society of Blood Transfusion. Anne served on the inaugural Consultative Council for the Victorian Cancer Agency, a Victorian government-funded initiative to provide translational research funding to Victorian cancer research and health services. Anne joined the HeartKids Australia board in August 2010 and established the Research Advisory Committee which she chaired until June 30 2014



**Dr Tom Gentles, Independent Advisor MBChB (Auckland), MD, FRACP**

Tom Gentles was awarded a senior fellowship from the Heart Foundation of New Zealand in 1994 whilst working as a fellow in cardiology at The Children's Hospital in Boston, and Harvard Medical School.

He took up a position as senior Heart Foundation Fellow at Green Lane Hospital for three years. This tenure included research into heart muscle function.

Following this he was appointed a Consultant Paediatric Cardiologist at Green Lane Hospital and is currently Director of the Paediatric and Congenital

Cardiac Service at Starship Children's Hospital in Auckland New Zealand.

Dr Gentles has maintained an active research role and continues to publish in a number of peer reviewed journals and is involved in multi-centre studies in New Zealand and Australian centres.

He is an invited speaker at national and international meetings and is a New Zealand representative of the Australian and New Zealand Paediatric Cardiac Association.

He is a fellow of the Cardiac Society of Australia and New Zealand and is the Chair of the Paediatric and Congenital Council of the Cardiac Society.



**Dr Jemma Lawson, Ph.D.**

Dr Lawson achieved her Ph.D. in Molecular Biology and Cell Biology at Flinders University of South Australia, in collaboration with the Co-operative Research Centre for Tissue Growth and Repair. Dr. Lawson subsequently began her career in the biotechnology industry at GroPep Ltd, undertaking roles in research: investigating signal transduction pathways in mammalian cell culture, project management: as the team lead for commercial production of growth factors and receptors for scientific research, and scientific evaluation: seeking and assessing in-licensing opportunities for early phase clinical development.

In 2006 Dr Lawson embarked on her current career path in Clinical Research, initially working for a small Australian Clinical Research Organisation (CRO), operating in a dual role as a Clinical Research Associate and a Clinical Project Manager. She currently works for a large Global CRO as the Clinical Team Leader, responsible for clinical operations across South Australia and Western Australia. In addition to resource management and personnel management, Dr Lawson continues to keep up to date with Australian clinical research Regulatory and Ethical requirements by continuing to work also as a Senior Clinical Research Associate on a selection of clinical trials across a broad range of therapeutic areas.



**Dr Siiri Iismaa, PhD.**

Dr Iismaa graduated from the Australian National University with BSc (Hons I) and the University Medal, and then a PhD in Genetics and Molecular Biology. Dr Iismaa began her career at the University of California, Irvine as a US Biotechnology Program Fellow, where she coupled her molecular biology skills with protein engineering and protein structure-function studies.

Dr Iismaa returned to Australia to the Heart Research Institute in 1990 as an NHMRC Australian Postdoctoral Fellow to work on heart disease, studying

proteins of immunological importance and regulation of gene expression. In 1994 Dr Iismaa embarked on her current career at the Victor Chang Cardiac Research Institute, where she uses various transgenic mouse models to study proteins involved in receptor signal transduction. Her work is currently focussed on heart muscle cell division and differentiation, and on heart regeneration following cardiac stress or injury. Dr Iismaa is a highly regarded and internationally recognised senior scientist, who publishes in leading scientific journals and is an invited speaker at national and international meetings. In 2015, Dr Iismaa undertook a two-week lecture tour of Japan as a Japan Society for the Promotion of Science Fellow.

#### **Dr Graham Nunn**

We are also privileged to have Dr Graham Nunn as a member of the committee.



# RECIPIENTS OF THE 2016 GRANTS-IN-AID PROGRAMS



**Comprehensive genetic analysis in neonates with CHD and associations with neurodevelopmental outcomes**

**Principle Investigator:** Dr Gillian Blue

**Institution:** Heart Centre for Children, Sydney Children's Hospitals Network (Randwick and Westmead)

**Additional Investigators:** Professor David Winlaw, Professor Nadia Badawi, Dr Karen Walker

Dr Gillian Blue is a translational researcher with skills and experience in clinical, laboratory as well as psychosocial research. Her primary interest is in the genetics of congenital heart disease, more specifically in the application of next generation sequencing technology towards understanding disease causation in the clinical setting, from a laboratory as well as psychosocial perspective. Her research also focuses on improving ways to communicate genetic information on the causes of congenital heart disease back to patients and their families. After having recently completed her PhD on the 'Genetics of congenital heart disease: new genes, mechanisms and attitudes' she plans on continuing her interest in translational research in the field. Gillian also manages the Kids Heart Research DNA Bank in Sydney, a resource dedicated to genetic research into congenital heart disease.

## Project Description

Up to 20% of infants who undergo major cardiac surgery develop a neuro-developmental disability (NDD) including developmental delay, motor and cognitive impairment and later school-based issues. Patient-specific gene changes play an important role, and there are many known genetic syndromes in which both cardiac and neurological problems occur. Using next generation sequencing technology this study will identify genes and pathways that may lead to the development of congenital heart disease (CHD) and NDD. Use of gene panels will allow earlier identification of at-risk infants and earlier referral to intervention programs to maximize their full potential.



### **Neurocognitive outcomes in children and adults with a Fontan circulation**

**Principle Investigator:** Dr Rachael Cordina

**Institution:** Royal Prince Alfred Hospital and University of Sydney

**Additional Investigators:** Associate Professor Yves d'Udekem, Professor David Winlaw, Dr Karin du Plessis, Professor David Celermajer, Professor Nick Glozier, Dr Julian Ayer, Dr Tom Gentles

Dr Rachael Cordina is a clinical academic cardiologist with a special interest in Adult Congenital Heart Disease. She is appointed as Staff Specialist at Royal Prince Alfred Hospital. Dr Cordina graduated from the University of New South Wales with Honours in 2002 and was awarded FRACP in 2009 after undertaking her general medical and cardiology training at Royal Prince Alfred Hospital. She received a NHMRC Postgraduate Research Scholarship and was awarded her PhD in 2013. Her thesis, studying important pathophysiology in adults with congenital heart disease, was awarded the Peter Bancroft Prize for outstanding thesis from the University of Sydney. Her PhD research won her the Young Investigator Award from the Cardiovascular Disease in the Young Council at the American Heart Association Scientific Sessions in 2012. Dr Cordina spent 2 years undertaking post-doctoral training in London, United Kingdom as Clinical Fellow in Adult Congenital Heart Disease and Maternal Cardiology at the Heart Hospital, University College and Adult Congenital Heart Disease Echocardiography Fellow at the Royal Brompton Hospital. She has also completed her Accreditation in Congenital Heart Disease Echocardiography through the European Association of Cardiovascular Imaging. Currently, Dr Cordina works in the Adult Congenital Heart Disease Service and Pulmonary Hypertension Service at Royal Prince Alfred Hospital in addition to her role in the General Cardiology team. She has clinical and research interests in adult congenital heart disease, pulmonary hypertension, echocardiography, exercise physiology, maternal cardiology and vascular function. Dr Cordina is also appointed as Clinical Senior Lecturer at Sydney University and currently teaches cardiovascular physiology in addition to her role as Unit of Study Co-ordinator for Cardiovascular Metabolic Disease Management for Masters students.

### **Project Description**

This project aims to investigate neurocognitive function in people with a Fontan circulation aged 13 years and over. Many children born with complex congenital heart disease (CHD) that results in a single cardiac pumping chamber are palliated with a Fontan operation. A small amount of literature suggests these people have reduced cognitive function and intelligence however this area is poorly characterised, especially in older children and adults. Aside from important implications for social functioning and life achievement, these problems also affect quality of life. A deeper understanding of contributors to altered brain function may help us to develop ways to optimise management strategies including timing and type of surgery. Furthermore, characterisation of the problem will also enable us to institute appropriate educational and psychological intervention for affected individuals if important abnormalities are identified.



### **Nanovaccines against Rheumatic Heart Disease**

**Principle Investigator:** Dr Rachel Stephenson

**Institution:** The University of Queensland

**Additional Investigators:** Dr Waleed Hussein, Professor Istvan Toth, Professor Michael Good

Dr Rachel Stephenson is an early career researcher experienced in Peptide-based Drug Discovery and Development. In 2007 she was granted the competitive Vice Chancellor's Doctoral Scholarship from Massey University, New Zealand to pursue full-time PhD studies. Rachel was awarded a PhD degree in organic and analytical Chemistry in November 2010. Following this, Rachel completed a Postdoctoral Research Fellowship in the field of Virology at Kansas State University, Department of Diagnostic Medicine and Pathobiology, USA. During this position she undertook research on the detection and surveillance of exotic zoonotic diseases affecting the swine industry. Towards the end of 2012, she started her current role as a Post-doctoral Research Fellow at The University of Queensland, Australia investigating the properties of nanoparticles for the use in targeted vaccine delivery for diseases including Group A Streptococcus and the tropical parasite, *Schistosoma japonicum*. Dr Stephenson has experience in the teaching and tutoring of graduate and undergraduate students in the areas of Chemistry, Biochemistry and Molecular Biology, and is actively involved with community and university organisations, including being the Chair for the School of Chemistry and Molecular Biosciences Early Career Researchers committee, Communication manager for the Australian Controlled Release Society, and a leader for the Brisbane Bush Walkers club.

### **Project Description**

Untreated or recurring infection with Group A Streptococcus (GAS) causes 500,000 deaths worldwide each year. Similarities between GAS surface proteins and human heart proteins result in an autoimmune response, leading to acute rheumatic fever (ARF) and rheumatic heart disease (RHD). Children from Australian Aboriginal and Torres Strait Islander communities suffer the highest reported incidence of ARF and RHD in the world. We aim to prevent these deaths by making a vaccine from small, specific parts of GAS proteins so the body makes safe antibodies that prevent GAS infection without the risk of ARF or RHD.





### Families coping with child heart disease

**Principle Investigator:** Professor Alun C Jackson

**Institution:** Heart Research Centre

**Additional Investigators:** Associate Professor Erica Frydenberg, Dr Barbara Murphy, Dr Rosemary Higgins

Professor Alun Jackson PhD, has been Director of the Australian Centre for Heart Health (formerly the Heart Research Centre) for two and a half years, and holds Honorary Professorships with the Office of the Pro Vice Chancellor Health, Deakin University; the Melbourne Graduate School of Education, University of Melbourne; and the Centre on Behavioural Health at the University of Hong Kong. A behavioural scientist, with an interest in mechanisms of behavioural change and coping, he worked in the behavioural addiction field as Director of the Problem Gambling Research and Treatment Centre at the University of Melbourne, where he has also been an Associate Dean (Research), and an Associate Dean (Resources) as well as holding the Chair of Social Work at the University of Melbourne for a decade and being Head of School of Social Work from 1997-2002. Among other appointments, he has also been Director of the HIV/AIDS Socio-behavioural Research Unit at the University of Melbourne, a program of the National Centre for HIV/AIDS Social Research; a Fellow of the Murdoch Children's Research Institute and an Adjunct Professor of Public Health at Latrobe University. Professor Jackson is currently an Executive Committee Member of the Australian Cardiovascular Health & Rehabilitation Association and because of his interest in the relationship between sleep disorders, depression and cardiovascular disease, he is a member of the Sleep Research Society (US); and the International Collaboration on Sleep Apnea Cardiovascular Trialists. He has conducted extensive research on service system effectiveness, discharge planning and individual and familial coping in relation to areas of health such as paediatric brain tumours and paediatric heart disease; and in adults, acquired brain injury, end stage renal failure; HIV/AIDS; depression / distress and cardiac disease; and motivations for and impacts of elective cosmetic surgery.

### Project Description

Childhood heart disease (CHD) can place families, particularly parents, under strain as they adjust to their child's condition and strive to cope with the impact of these changed circumstances. This follow-up project will trial a novel manualised parenting intervention, the Heartchild Family Coping Program based on the successful Parents can do Coping program, and heavily adapted for use with CHD families. The intervention uses the findings from two systematic reviews on CHD familial impacts and parenting programs for special needs children together with intensive interviews with parents, conducted in the first phase of this project, funded by HeartKids Australia.



### Parents' role in buffering the emotional and neurobiological correlates of CHD treatment.

**Principle Investigator:** Associate Professor Nadine Kasparian

**Institution:** The University of New South Wales

**Additional Investigators:** Dr Bridget Callaghan, Associate Professor Gary Sholler, Associate Professor David Winlaw

Associate Professor Nadine Kasparian is a senior research fellow in Medicine at the University of New South Wales (UNSW). She is also Head of Psychology at the Heart Centre for Children, The Sydney Children's Hospitals Network (Westmead and Randwick). In 2010, under the auspices of the Sydney Children's Hospitals Network and UNSW, Nadine established the Asia-Pacific's first integrated psychology research program and clinical service dedicated to childhood heart disease. Her 'Hearts and Minds' team leads national and international research collaborations focussed on: discovering the factors that contribute to psychological risk and resilience in medical settings, understanding patients' experiences of new and emerging medical technologies, and developing clinical services to improve child and family health and well-being. Her program is also committed to nurturing resilient, compassionate and high functioning teams in medicine and psychology. Nadine's work has been acknowledged by numerous awards, including the International Psycho-Oncology Society Hiroomi Kawano New Investigator Award for outstanding contributions to research.

### Project Description

Babies with complex congenital heart disease (CHD) often experience a range of uncommon and painful events, including surgery, invasive medical procedures, and limited interaction with their parents while in hospital. These experiences can have profound consequences for the developing child, with early life experiences shaping brain development, the body's immune system, and responses to stress. This study will – for the first time in the world - examine how children with CHD respond emotionally and neurobiologically when presented with images of medical stimuli. We will also investigate whether parents serve as a 'buffer' to reduce their children's emotional and neurobiological responses.



### Optimising Heart Function in Survivors of Surgery for Congenital Heart Disease

**Principle Investigator:** Jonathan Mynard

**Institution:** Murdoch Childrens Research Institute

**Additional Investigators:** Associate Professor Michael Cheung, Associate Professor Joe Smolich, Dr Lucas Eastaugh, Ms Erin Date

Jonathan Mynard is a research fellow in the Heart Research group, Murdoch Childrens Research Institute and an honorary fellow with the Department of Paediatrics, University of Melbourne. With a background in bioengineering, his research focuses on developing and applying state-of-the-art analytical and imaging techniques to better understand and treat cardiovascular problems in infants and children. Specific areas of interests include aortic abnormalities, coronary haemodynamics, pulmonary hypertension, cardiovascular dynamics during the birth transition in vulnerable infants and assessment of cardiovascular risk in patients with congenital heart disease. Jonathan holds undergraduate degrees in Medical Biophysics and Electronic Engineering (Swinburne University), a Master's degree in Computer Modelling (Swansea University, Wales) and a PhD in cardiovascular dynamics in the perinatal period and complex congenital heart disease (University of Melbourne). He received a CJ Martin Early Career Fellowship from the National Health and Medical Research Council, which funded two years at the Biomedical Simulation Laboratory at the University of Toronto (Canada), where he developed expertise in medical imaging and computational fluid dynamics. Dr Mynard has served as an expert reviewer for 4 international granting bodies and 30 scientific journals, and is on the editorial board of the journal Heart, Lung and Circulation.

#### Project Description

Children with repaired congenital heart disease (CHD) may have hearts with a reduced pumping ability. To maximise the pumping action of the heart it would be useful to know what pressure it has to pump against. A method to measure this - central pressure, which is different to the pressure measured in the arm, would allow optimisation of medical treatment. To establish a new non-invasive method of measuring central pressure, we will simultaneously measure arm blood pressure with a cuff and central pressure with highly sensitive pressure sensors in 46 children undergoing routine catheterisation procedures.

# GRANTS-IN-AID PROGRAM

IS PROUDLY SUPPORTED BY



## GRANTS-IN-AID FOUNDING PARTNER



HeartKids Australia  
Suite 301, Level 2, 39 Hume St  
Crows Nest NSW 2065  
p. 02 9460 7450  
f. 02 9439 8132  
e.office@heartkids.org.au  
heartkids.com.au





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[heartkids.org.au](http://heartkids.org.au)