



THE NATIONAL CHILDHOOD HEART DISEASE ROUNDTABLE COMMUNIQUE

The Roundtable

The inaugural National Childhood Heart Disease Roundtable held on Tuesday 5th September 2017 at Parliament House Canberra, discussed the implementation of the 2011 *'Congenital Heart Disease in Australia – Current Practices and Future Needs'* White Paper and considered the currency of the Report's twenty recommendations and looking forward proposed priority focus areas and actions.

The Roundtable comprised representatives of the Paediatric and Congenital Council of Cardiac Society of Australia and New Zealand; hospital and health organisations, paediatric and adult Cardiologists and Surgeons; researchers; and non government health organisations; along with parents of heart kids and heart angels; young people and adults living with congenital heart disease. In total forty representatives from every Australian State and Territory participated.

Participants brought their collective expertise, experience and a deep appreciation of life with congenital heart disease and the impact of such to the discussion. Diverse perspectives were united in a common desire to ensure the best care for all Australians living with or impacted by CHD.

The Roundtable acknowledged that whilst some advances have been made, the most significant being HeartKids' funding of the National Congenital Heart Disease Research Registry and the National Childhood Heart Disease Survey, it also concluded that a National Action Plan for Congenital Heart Disease is urgently required for policy and systemic reform.

The Roundtable was conducted in two parts – a section devoted to participants interrogating the White Paper and identifying priorities for action and later a panel of doctors and patients presenting evidence and the lived experience from several perspectives to Members and Senators.

Future Priorities and Next Steps

The Roundtable welcomed the announcement by the Minister for Health The Hon. Greg Hunt who together with heart kid parent The Hon. Steve Ciobo, Minister for Trade and Tourism committed to fund a National CHD Action Plan the purpose of which is to coordinate all levels of government and progress identified priorities.

The Roundtable after careful deliberation concluded the following priorities to be strategic imperatives. There was strong consensus amongst the participants that these priorities should be implemented within the next three years to ensure all Australians regardless of age or background have access to the best available support and treatment.

The identified priorities as agreed by health professionals and patient representatives alike include:

Develop a National CHD Action Plan including the ongoing engagement of Federal and State / Territory Health Departments

The Action Plan should include:

- A National Model of Care incorporating agreed standards of care, clinical guidelines; workforce and service plan; how to capture those lost through transition from paediatric to adult centres; the scalability of proof-of-concept models of care (e.g. psychological/holistic support at Westmead, neurodevelopmental monitoring at Lady Cilento, transition services at Royal Children's Hospital); assessment standards for who needs what care and support; continuing patient education; supported by funding.
- A federally sponsored Advisory Group feeding to an Australian Health Minister's Advisory Council (AHMAC) approved Action Plan. The advisory group would comprise Federal and State / Territory Health Department representatives; PCC of CSANZ, and HeartKids.

Build awareness of CHD as a condition requiring whole of life care for adults & children

- Build awareness among stakeholders, health systems and the general public (through mechanisms of AHMAC committee; National CHD Survey; HeartKids-facilitated information, education and advocacy working with CHANZ and PCC/CSANZ)
- Address the challenges of the 'language' of CHD, needing to highlight it as a chronic condition for some of the population.

Build capacity and access to service provision

- Enhance holistic services for children, adolescents and adults with CHD, including screening practices, referrals practices, reduced surgical cancellations, neuro-developmental assessments, psychological support, allied health support, and family support.
- Improve equity of access for all patients (improved regional, remote and Indigenous access, NDIS, Carer's Allowance, consistent application of the Patient Assisted Travel Scheme)
- Build a skilled workforce across the spectrum of treatment, care and support

- Increase capacity required in adult CHD service provision (in addition to what is already provided for other adult cardiac care)
- Measure the effectiveness of service provision and how it increases value for the patient (based on physical, mental and social improvements)

Targeted CHD research funding

- Ring-fence funds from the Medical Research Future Fund (MRFF) to fund targeted CHD research initiatives in particular transitional research projects
- Targeted research could be distinct from current NH&MRC funding of CHD research, and includes targeted research for mechanisms of CHD, genomics, health economics, neurodevelopment
- Government support for CHAANZ National CHD Registry to match the \$3.75M philanthropic gift from The Kinghorn Foundation.

Advocate for the federal government to commit to end Rheumatic Heart Disease

- Partnering with RHD Australia to include Rheumatic Heart Disease as a priority in the proposed Action Plan to address the overrepresentation of Indigenous communities and to incorporate measures to close the gap.

About Congenital Heart Disease

Congenital heart disease incorporates a group of abnormalities of the heart and is a general name for any type of malformation of the heart, heart valves or major blood vessels, which are present at birth. Defects can range from simple to complex and can occur alone or in groups, depending on how the heart has developed.

Congenital heart disease is the most common congenital disorder in newborns. The birth rate prevalence of congenital heart disease is understood to be approximately 8 – 10 cases per 1,000 live births. In Australia, there are approximately 300,000 registered births per year resulting 2,400 – 3,000 babies born each year with a form of congenital heart disease. Cumulatively, taking into consideration newborns through to adults living with congenital heart disease, this now could conceivably represent well over 65,000 Australians.

Although there is no indication that the incidence of congenital heart disease is increasing, as Australian birth rates increase and enhanced medical care and technology continue to improve survival rates following medical interventions, and as such the prevalence is predicted to increase. In particular, there are an increasing number of adults with congenital heart disease who are not well serviced by the existing health care system

Gaining a better understanding of the entire spectrum of congenital heart disease, the number of people living with congenital heart disease, and the total burden of disease across the disease continuum is imperative to patients and those responsible for treating them, including health policy makers, ultimately delivering not just better but sustainable care.

Acknowledgements

In the lead up to the Roundtable HeartKids held ten Focus Groups with people living with or impacted by CHD. These focus groups identified core consumer issues, concerns and possible solutions. HeartKids appreciates the support of the 227 people impacted by CHD participated.

HeartKids would like to thank the following partners and participants of the inaugural Roundtable.

Dr	Bo Remenyi - Royal Darwin Hospital – Northern Territory
Dr	Darshan Kothari – Princess Margaret Hospital – West Australia
Prof.	David Celermajer – Royal Prince Alfred Hospital – New South Wales
Prof.	David Winlaw – Westmead Children’s Hospital – New South Wales
A/Prof	Gary Sholler - Westmead Children’s Hospital – New South Wales
Dr	Gavin Wheaton – Women’s and Children’s Hospital – South Australia
Dr	Julia Charlton – Royal Children’s Hospital - Victoria
Dr	Lisa Selbie – HeartKids Research Advisory Committee
Dr	Rachael Cordina – Royal Prince Alfred Hospital – New South Wales
Dr	Robert Justo – Lady Cilento Children’s Hospital - Queensland
Prof.	Yves D’Udekem – Royal Children’s Hospital - Victoria
Dr	Anne Fletcher – CHD Researcher
Ms	Barb Ferres – Pharmaceutical Company Observer - Queensland
Ms	Bev Barber – heart child parent – South Australia
Ms	Claire Boardman – Rheumatic Heart Disease Australia – Northern Territory
Ms	Evelyn Culnane – Royal Children’s Hospital - Victoria
Ms	Jan McClelland AM – Chairperson HeartKids
Mr	Jonathan Toze – Parent of a CHD Child – Australian Capital Territory
Dr	Kevin C Thompson – Department of Health – Australia Capital Territory
A/Prof.	Nadine Kasparian – Westmead Children’s Hospital – New South Wales
Mr	Anthony Mahady – Adult with CHD - Victoria
Ms	Claire Hollingworth – Young Person with CHD – Australia Capital Territory
Ms	Courtney Green – Young person with CHD – West Australia
Ms	Jaden Dixon – Young person with CHD - Queensland
Ms	Rebecca Peters – Young adult with CHD - Victoria
Mr	Rohan Geddes – Adult with CHD – New South Wales
Major	Allison Gillam – Parent of CHD Child – Australian Capital Territory
Mr	Ben Taylor – Parent of CHD Child - Queensland
Ms	Cecilia Donovan – HeartKids State Manager – West Australia
Ms	Celine Thurlow – Heart Angel Parent – New South Wales
Mr	Craig Nicholls – Heart Angel Parent – West Australia

Mr	Matt Turner – Parent of CHD Child – South Australia
Mr	Patrick McConville – Adult with CHD - Tasmania
Ms	Rachel Maree – Parent of a CHD Child - Victoria
Mrs	Sarah Nicholls –Heart Angel Parent – West Australia