

## HeartKids: regional and remote support for children with childhood heart disease and their carers

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Lee Morgan is an independent Director and founding Board member of *HeartKids Australia*. Lee has specialised in the areas of regional and remote support as well as research into congenital heart disease. Lee Morgan has recently taken up the position of Manager, Remote Operations South for the *Power and Water Corporation* in the Northern Territory, responsible for the provision of water and power to 35 remote Aboriginal communities in the Northern Territory. Prior to this role, Lee was for five years responsible for coordinating essential services (water, road and electricity networks) infrastructure for all of the Aboriginal communities with the Department for the Premier and Cabinet in South Australia, and was involved with the development of emergency services, waste management and community planning, taking into consideration sacred land within Aboriginal communities. Lee is married with three adult children, Jason (29), Eryn (27) and Glynn (22) all of whom have completed their university degrees in psychology, in Chinese medicine (double-degree), and film-making respectively.

Neil McWhannell was appointed as the founding CEO of HeartKids Australia in July 2007. Since his appointment he has been awarded the Equity Trustee CEO of the Year Award for first year achievers and Runner Up in the Australian Fund Raiser of the Year Awards. Neil has developed a real passion for HeartKids and sees the role as a great opportunity to make a real difference in an area with such large needs. Neil initially came from an educational background where he was principal at some of the leading independent schools in Australasia. Prior to his appointment at HeartKids, Neil was CEO of the YMCA of Sydney where he served for four years. Neil has many interests and is a positive contributor to his community. He serves as a Justice of the Peace and has been State Chairman and National Board Member for the Duke of Edinburgh Award scheme. Neil also referees Rugby Union and is a keen handyman and gardener. Neil is married and has 2 children, Andrew 27 and Emma 26.

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HeartKids is Australia's only charity solely focused on all aspect of Childhood Heart Disease. This is heart disease that the children are born with as opposed to coronary heart disease we develop as a result of lifestyle. HeartKids does however also assist with some acquired heart disease in children. In the main this is a result of rheumatic heart disease which you will hear is rampant in our indigenous communities.

There are some most alarming statistics related to children's heart disease that most people are not aware of.

Heart Disease is the most common birth abnormality affecting one in every 100. That is 6 children every day and more than 2000 every year.

Heart Disease is the greatest killer of children under the age of five, taking more lives than all other childhood diseases combined—twice that of childhood cancers.

Appreciating these figures, one can imagine the significant impact this has on our hospitals and medical services. If you were to visit the Intensive Care Unit of any of the major Children's Hospitals in Australia you would see that almost ½ the beds are filled with heart kids.

HeartKids was established some 30 years ago with its beginnings as state based parent support groups. It was grown significantly through these years to the point where it recently established a National office.

HeartKids is unique as it is the only organisation in Australia solely focused on all aspects of children's heart disease. There are 400 charities for cancer, yet only one solely focused on Childhood Heart Disease. People often ask what about the Heart Foundation. Their primary focus is on coronary heart disease—people like you and me who have smoked, eaten too much or abused their body in some other way! HeartKids deals with congenital heart disease that the children are born with. This has nothing to do with diet of lifestyle—it is just a cruel hand of fate.

Our vision is to have life unaffected by CHD. Our mission is to be able to assist in reducing the incidence of childhood heart disease, improve the mortality rates currently being experienced and to expand our very

special support services that are provided to HeartKids and their families as they go through these incredibly traumatic times.

HeartKids work is primarily focused on supporting these children and families. We employ family support coordinators in each of the main children's hospitals to support parents through this incredibly traumatic journey.

You know the worst thing that could happen to you in your life is not losing your job or home, but losing your child. This is something HeartKids parents face on a regular basis and one of the main driving factors in why HeartKids started its work.

HeartKids is also funding a number of research projects in the hope we can reduce the incidence and improve the management of children undergoing these life saving operations.

We also aim to provide additional resources for the doctors and hospital services.

Finally, we are hoping to develop outreach services for rural and remote areas. There are currently a disproportionate number of Aboriginal children with acquired heart disease usually resulting from rheumatic fever which is rampant in their communities.

It is bad enough living in a capital city and having a child with a heart condition—let alone if you live in rural and remote Australia.

As HeartKids grows and gains capacity it is our goal to provide support services in all areas of our country. However rather than create new or duplicate services we aim to partner with existing regional service providers and work together to ensure these children and families are supported. We also hope to develop a training and accreditation of our Regional Family Support Staff to ensure they are fully equipped to deal with the many complex and challenging issues they face. We are also in the process of developing of a comprehensive data base in order to effectively track and manage those affected by CHD—as they need ongoing specialist care throughout their lives.

Our key goals are:

- make available our Family Support Coordinators to attend CHD Clinics in regional areas
- provide funding to assist with Rheumatic heart Disease
- expand our relationships / partnerships with existing regional services such as Angel Flight, RFDS, Ronald McDonald, retrieval teams, Indigenous health programs
- develop our HKA Directory of available regional services & support
- extend travel assistance support for separated family members
- improve our focus on assistance for regional and remote people in the major cardiac hospitals—through our Family Support Coordinators in our hospitals in Perth, Adelaide, Melbourne, Sydney and Brisbane
- provide support for accommodation, food, clothing, communication services
- capacity build our regional HeartKids groups—using local expertise for additional support and local networks.

This year HeartKids is also introducing a new indigenous Heart Beads program in the hope that the gift of a new and attractive bead each month will encourage young aboriginal children suffering from Rheumatic Heart Disease to attend the monthly clinics. This program is to be trialled by Prof Jonathan Carapetis as part of his work undertaken from the Menzies School of Health.

HeartKids recently completed a White Paper into the clinical and community needs of CHD. This provides us with evidence based recommendations which we recently presented to Government to encourage them to better support all aspects of CHD.

Contained in the report were a number of key recommendations relating to our indigenous communities and the provision of health services to rural and remote Australia. These include:

- review feasibility of establishing a supported network for congenital heart disease to set standards, monitor, plan and support paediatric and adult services throughout Australia
- develop an agreed plan for services and associated physical and human resources to deliver services
- develop targeted health care initiatives for Aboriginal and Torres Strait islander people (including action plan for those with rheumatic heart disease)
- ensure the provision of more equitable coverage of travel and accommodation costs for families required to travel to C&ACHD centres
- develop an effective strategy to create awareness of the needs of children with congenital heart disease and their families
- work with those in remote areas including organisations that work with Aboriginal and Torres Trait Island Communities to advise on how best to provide family support
- work with specialist centres and hospitals to develop a communication plan for prevention, treatment and management of CHD throughout life stages, including bereavement support.

Should readers require more information on HeartKids and its services please contact our National Office of 02 9875 4090 or email [neil@heartkids.org.au](mailto:neil@heartkids.org.au)