## HoH Australia Contact Details

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| **ADDRESS:** | 39 Crystal Downs Drive<br>Blackmans Bay TAS 7052 |
| **HONE:** | 03 6229 8169 OR 04 1728 5445 |
| **HOMEPAGE:** | Info: www.hearts-of-hope.org<br>Stories: www.hearts-of-hope.com |
| **EMAIL:** | **contact.us@hearts-of-hope.org** |

More Information about HLHS is available on the internet. The Hearts of Hope website has links to reputable medical sites, support groups, hospitals, and also to stories written by parents of children born with complex congenital heart disease.

If you do not have internet access, please call one of our Family Support Contacts below, who will be happy to help you in any way they can.

## HoH Australia Family Support Contacts

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| **NSW:** | Allison Lawrence<br>Elese and Paul Titmuss | 02 4351 7242<br>02 4267 2925 |
| **QLD:** | Nev and Andrea Hyde | 07 5569 2669 |
| **SA:** | Tony and Natalie Jones | 08 8260 1539 |
| **TAS:** | Csaba and Anne Óvári<br>Kaye Nugent | 03 6229 8169<br>04 1041 0440 |
| **VIC:** | Leanne Amarant<br>Simone and Stewart Downs | 03 5358 2945<br>03 5940 4859 |
| **WA:** | Deb Rennie<br>Joanne Crisp | 08 9537 7568<br>08 9543 7696 |

## Bereavement Support

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| Heather Round : | 04 1227 9677 |
| Judith Lillis: | 04 1286 6932 |

## MEMBERSHIP

We would like to encourage everyone involved in caring for children with complex Congenital Heart Disease or supporting their families to become members of HoH. Membership is open to:

- Families with children that have been diagnosed with HLHS or other similar heart conditions,
- Parents who have lost children to CHDs,
- Health care workers, social workers or anyone who is interested in helping us achieve our aims.

For more information about joining HoH, please visit our website or contact the HoH Membership Secretary:

**Membership Secretary (Anne Óvári):** (03) 6266-3546

## MISSION STATEMENT

Hearts of Hope Australia was setup for the benefit of sufferers of HLHS and other complex congenital heart conditions. Our primary goals are to:

- Help relieve the suffering and distress of children born with these disorders by providing support, information and other assistance to their families,
- Raise awareness of congenital heart disease so that there is a broader community understanding of the challenges faced by sufferers of these disorders,
- Support the medical professionals that care for these children by disseminating information about our activities and providing feedback to hospitals, doctors and other health workers,
- Support research programs that lead to higher survival rates and a better quality of life for those that are born with heart disease,
- Help fund the purchase of medical equipment to improve the management of these disorders.
- To work co-operatively with other organisations that share our goals.

## HOH PROGRAMMES

To help achieve our aims we raise funds:

- to provide support and information to assist families living away from home for extended periods while their children are hospitalised,
- for the purchase of goods/services to increase the comfort of hospitalised children and their families,
- for events where the children and their families can enjoy social activities,
- to disseminate information about Congenital Heart Disease and our activities,
- to support Paediatric Cardiac Research Programs in Australia that lead to higher survival rates and a better quality of life for children born with heart conditions, and
- for the purchase of medical equipment to improve the management of these disorders.

**Hearts of Hope Australia is a health promotion charity and has been endorsement as a Deductible Gift Recipient by the Australian Taxation Office. As such, all donations over $2.00 are Tax Deductible.**

# *Hearts of Hope Australia*

Supporting Families Living with complex
Congenital Heart Disease

www.hearts-of-hope.org

Hearts of Hope Australia was originally setup in 2002 as the Australian HLHS Information Network. The organisation was started and continues to be managed by parents of children born with Hypoplastic Left Heart Syndrome.

We offer non-medical support to all families with a child born with a heart condition that cannot be cured through medical intervention. This includes, but is not limited to, single ventricle anomalies such as HLHS.

To provide better support services to these children and their families, the group was incorporated as a non-profit company in August 2004. HoH is a national organisation.

**Hearts of Hope Australia Limited**
ABN 70 110 635 517

HLHS is the fifth most common Congenital Heart Disease that occurs approximately once in every 5000 live births. It is a severe condition and without treatment it is fatal. Before the 1980's nothing could be done for these babies. Fortunately, through the dedicated efforts of health professionals, there are hundreds of these children worldwide bringing joy to the lives they touch. In Australia 40-50 babies are born with this condition every year. When diagnosed, parents are usually presented with two options:

- Compassionate care / termination of pregnancy, or.
- Palliative surgery involving a series of open-heart procedures

In general, a very negative outlook is given to most parents and many opt for the former choice. There have been cases where families have sought treatment in the United States as they were not made aware of the work being done at the Royal Children's Hospital in Melbourne. We also know of parents that have lost children and are devastated when they find out that something could have been done to try and save their babies.

None of this is meant as a criticism of our health care professionals. It is understandable, in these days of rapid development, that it does take time for knowledge to filter down to where it is needed. Also, it is not our intention to encourage parents to go one way or the other. Each case of HLHS is as unique as the child it affects, and only those directly involved have the right to choose what is best for their circumstances. However, it is vital that facts are available to families to allow them to make informed decisions for their children.

**Hearts of Hope Australia aims to disseminate accurate information to parents, health workers and the general public throughout Australia.**

Being confronted by any Congenital Heart Disease is extremely stressful. Parents, that more than likely, have never heard of HLHS are bombarded with information and have to settle on what is best for their child. This, together with feelings that may include anger, guilt, disbelief and the prospect of having to face the high risk surgeries can be overwhelming.

Some babies do not survive HLHS while others may have ongoing medical problems. We believe parents should not have to face these issues on their own.

**We aim to support families through our network of volunteers. There are parents in most States that are eager to help others who find themselves in the same situation. We also provide contact details for other support groups such as SANDS Heart Kids, & Compassionate Friends.**

Parents that choose to have surgery for their children usually have to commit to a 4-5 month stay at the Royal Children's Hospital. Many families have to relocate from interstate for this period to help care for their babies. Finding accommodation and everyday activities such as shopping, transport and care for siblings adds to an already very stressful situation.

**Hearts of Hope Australia aims to provide up to date information on services and government programs that are available to help families through this difficult time**.

As a support group, Hearts of Hope Australia welcomes comments and suggestions from anyone involved in the care of these special children. The more people that participate in this process,, the more effective we can be in helping others deal with the challenges faced by those that are living with complex heart diseases.

Hearts of Hope Australia does not set out to provide medical advice but staying up to date with what is happening in the medical world is important to families that have children with complex congenital heart disease.

We believe that discussing our personal experiences in regards to our children's medical treatment and other health concerns can help us ask the 'right' questions of the medical professionals that care of our children.

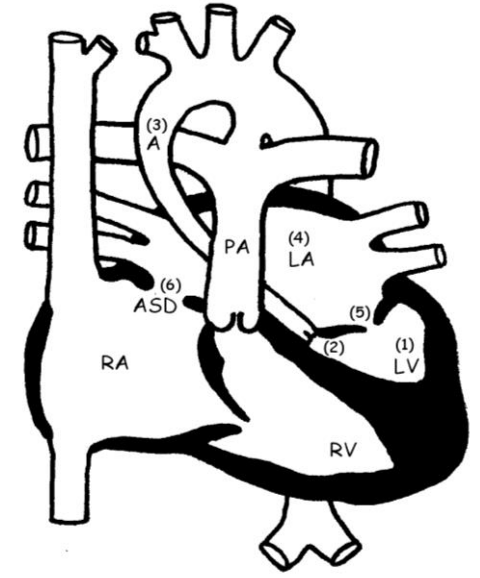
**The information above has been endorsed by Heartkids (Vic).**

HEART KIDS VICTORIA

Hypoplastic Left Heart Syndrome (HLHS) is a Congenital Heart Disease where the left side of the heart has failed to develop properly. In the Hypoplastic Left Heart, there are varying degrees of malformation but usually

- The left ventricle (1) is very small or non-existent
- the aortic valve (2) may be narrowed or closed;
- the aorta (3) itself may also be very small;
- the left atrium (4) is sometimes small;
- the mitral valve (5) between the left atrium and left ventricle can also be narrowed or closed; and
- There may also be a 'hole' or ASD between the left and right atria (6)

These defects put extra work on the right side of the heart, so chambers and blood vessels on this side may be enlarged or stretched larger than normal.



**ASD**: Atrial Septum Defect
**RA**: Right Atrium
**LA**: Left Atrium
**RV**: Right Ventricle
**LV**: Left Ventricle
**PA**: Pulmonary Artery
**A**: Aorta