

# CDH Australia

Supporting families and medical professionals along their CDH journey



CDH Australia

Annual Report 2013

**CDH Australia**

ABN 60 131 315 145

[www.cdh.org.au](http://www.cdh.org.au)

## President's Report

It is a pleasure to introduce the fifth Annual Report for CDH Australia. Again we have been successful in increasing awareness of CDH in the community, with promising developments Australia wide.

The friendships and involvement of our members and supporters encourage the Board to continue its efforts. One challenge we face is to obtain the licences to conduct fundraising in each of the states. This will make it easier for our valued fundraisers. A further challenge is to keep abreast of changes in government regulations and policies that affect our organisation. We are seeking opportunities to enlist pro bono and volunteer support in this area.

Our online support services continue to develop. This year marks the introduction of the CDH Awareness videos, now available on our Facebook pages and website, which continue to attract many visitors. Plans are in progress to add intranet facilities to improve the effectiveness of our communication. Our newsletter, now capably edited by Jess Willet-Hancey has become a valuable source of interest and information for members, supporters, and visitors to our website

Contact with CDH Australia is now available via a national 1800 number. This number, featured on our website, makes contact easier for those seeking assistance and has improved our administration.

CDH families have again been generous with donations and volunteering. Danielle and Julian Kessner's party in memory of their daughter Alyssa is one example which is featured later in this report. Members have also worked hard arranging fundraisers, raffles and events.

The Board appreciates the hard work of Maryanne Reid and Sharon Knott in organising the 2012 CAAF (CDH Annual Forum), which was held in Perth. The forum was a great success. Among the highlights was the announcement of a new research project into long-term development of CDH children.

The third annual Sunflower Sunday was held in March 2013. Once again this was a time to come together and enjoy the friendships and company of other CDH families across the country.

Our plan is to further increase interest in volunteering among the CDH family. On behalf of the CDH Australia Board of Directors I would like to take this opportunity to thank the volunteers who have given their time and support during the past 12 months. We would also like to thank our sponsors and our members who enable CDH Australia to remain sustainable.



Christine Waite

President

## Who We Are

CDH Australia is a national not-for-profit support group run solely by volunteers for families, friends and medical professionals affected by Congenital Diaphragmatic Hernia (CDH).

We are a registered Health Promotion Charity with Deductible Gift Recipient (DGR) status. Our organisation is run by a Board of Directors and we have membership spread throughout Australia.

### CDH Australia's Mission Statement

Our Mission as a volunteer organisation is to:

1. Provide support to families affected by CDH
2. Increase awareness about CDH to impacted families and the community
3. Support and help fund research into the causes and treatments of CDH

The services and information we offer include:

- telephone support
- a website packed with information, links, photos and stories
- information booklets
- a newsletter twice a year with group updates, latest CDH news and member profiles
- access to online forums, with one Facebook site open to the public and two set up for private use of our CDH family and chat rooms
- parent-to-parent matching – helping families who have experienced similar CDH situations get in contact with each other
- annual forum, held in October each year alternating between cities around Australia
- holding an awareness day, 'Sunflower Sunday', annually
- a newsletter distributed in June and December each year.

## Values and Aims

CDH Australia exists to support anyone who faces challenges with regard to Congenital Diaphragmatic Hernia (CDH).

CDH Australia is a non-judgmental organisation supporting a diverse range of families affected by CDH. This includes families expecting a baby diagnosed with CDH, families caring for a child with CDH, adults with CDH and grieving families who have lost a child to CDH.

The organisation is run by volunteers and their families and friends, many of whom have experienced all facets of CDH and so understand the issues families face in their journey. Although everyone's experiences are different, the common thread that ties —CDH— allows CDH Australia to support everyone with compassion and empathy.

CDH Australia strives to build upon our partnerships with medical professionals to work together to provide CDH education, and support research into the causes and better treatments for CDH. CDH Australia facilitates knowledge sharing between families and care providers through annual forums, videos, publications and online, and we believe collaboration is an important factor for advancing service levels in care.

## Summary of Achievements 2012–13

CDH Australia’s achievements can be attributed to the hard work of its volunteers and members who generously contribute their money and/or time and effort to enable our events and activities to take place.

### Results

#### Fundraising

Donations in memory/honour of children	\$3,538.00
Donations for Christmas in lieu of presents	\$800.00
Donation through workplace giving programs	\$473.81
Money raised for CAAF	\$854.80
Money raised via fundraisers	\$9,005.00
Sponsorships/grants	

#### Membership

Financial members	46
New members	17
Facebook followers	569

#### Administrative achievements

- Introducing an 1800 number and a generic registered office address
- Amending the constitution to include anyone who wishes to become a member to be approved
- Streamlined our records management system for improved transition of Directors
- Developed guidelines for volunteers when running events
- Developed guidelines for the use of social media.
- Successful transition to a new website host and service provider

### Online Support

Three private Facebook groups have been established to allow Australian CDH parents and adult survivors to openly share their CDH experiences with each other while providing and receiving support in a more secure social networking setting than what is available in our main open group.

We have a group for bereaved parents, a group for surviving parents and adult survivors, and a general group where all Australian CDH parents and adult survivors can join and provide support to each other as well as expectant parents. These groups have been trialled with great success and we invite all interested Australian CDH parents and adult survivors to contact us at [information@cdh.org.au](mailto:information@cdh.org.au) if they would like to be added to the group.

## Online Shop

Our [online shop](http://cdh.org.au/products-page) <cdh.org.au/products-page> continues to stock a number of CDH Australia branded items. Purchasing these items is a great way to show support for CDH and also create awareness among your family and friends.

You can order merchandise, membership and support information through our online shop. It's easy to use and online payments are securely made through PayPal. Buying CDH Australia merchandise is a great way to raise awareness of CDH.

## CDH Research

A team of researchers in Western Australia is undertaking a study to look at whether children born with CDH have problems with their breathing, heart, growth or difficulties at school as they grow up.

This study will focus on the long-term outcomes of infants born with CDH in WA by looking at their lung function, chest and lung shape, heart function, bowel symptoms, educational achievements and quality of life.

A group of children with CDH and a group of children without the condition will be asked to undertake lung function tests, a CT scan of the chest, a heart ultrasound and questionnaires are completed.

The study's aim is to gain valuable information about the long-term outcomes in children born with CDH so that a follow-up program can be developed to help babies born with CDH in the future.

If you are interested in hearing more about this research study or would like to be involved please [contact them](mailto:CDH_Health@ichr.uwa.edu.au) at <CDH\_Health@ichr.uwa.edu.au>.

## Fundraising Events

Every year supporters and members hold events to raise funds for CDH Australia. Without these funds we would not be able to pay for insurance and audits, other administrative costs such as publishing our booklets and sending out membership packs, and the various miscellaneous costs associated with small not-for-profit organisations. This year has been no different, with some significant amounts raised and donated to CDH Australia. Some of the major events included the following:

- The event organised by Helena Ferguson, which raised almost \$800.
- Jaime Simmonds' head shave, which raised over \$1,100.
- Liz Proctor's workplace event, which resulted in \$650 being donated to CDH Australia. At the time of preparing this report Liz was organising a major event, 'Chuckles for Cherubs', and we wish her every success.
- In memory of their daughter Alyssa, Danielle and Julian Kessner held a 21st party at their home town of Morwell in Victoria. The Kessners were touched by the wonderful support from their family and friends, with around 80 guests attending the celebrations, as well as the fantastic support shown by 57 local businesses that donated over 70 goods or services for fundraising. This event raised over \$5,000 for CDH Australia. This will go towards funding this year's CAAF in Melbourne.

## HIGHLIGHTS OF 2012–13

### Videos

Early in 2013 Tara Kessner got very busy creating CDH awareness videos. This started with a video that was played at her sister's memorial 21st birthday event, and she has now completed five videos. The videos titles include *What is Congenital Diaphragmatic Hernia?*, *Q&A with CDHer Rayne*, *CDH Australia*, and a CAAF promotion.

Towards the end of the calendar year all five videos will be available to view on our Facebook pages and our website.

### CAAF – Perth October 2012

The 2012 CDH Annual Forum (CAAF) was held from Friday 19 October to Sunday 21 October in Perth.

Our first day at CAAF 2012 was spent at Princess Margaret Hospital, where families and members were given an opportunity to meet and share their stories, and hear from some of Perth's leading medical professionals.

We were fortunate to hear from several medical professionals who work at Princess Margaret Hospital. Among the medical professionals was Dr Andrew Martin, General Pediatrician, who encouraged us to ask questions and challenge the medical profession if we think there are things that should have been done that have not been done. Professor Graham Hall, Head of the Paediatric Respiratory Physiology Telethon Institute for Child Health Research, spoke about a congenital diaphragmatic hernia study that is a joint research project between the obstetric team at King Edward Memorial Hospital, the neonatal team at Princess Margaret Hospital (PMH), the respiratory team at PMH, the cardiology team at PMH, the surgical team at PMH and the Telethon Institute for Child Health Research. PMH Neonatal Intensive Care Unit Clinical Nurse Sarah Grimwood spoke about 'Transfer and transport of babies with CDH'.

Day 2 of the 2012 CAAF was enjoyed by all at the wonderful Perth Zoo.

A moving tribute to CDHers was followed by the group participating in a support workshop led by psychologist Natalie Deverneuil. This was followed by the AGM.

### Sunflower Sunday

A beautiful day was planned in March for our states to celebrate our annual awareness day, Sunflower Sunday (SS). The weather proved kind across the country as events were held in Victoria, Western Australia, South Queensland, South Australia and New South Wales.

At Paradise Point the kids swam at the beach, played in the sand and on the playground. Michael Shelly, 2012 Olympic Marathon Runner and CDH survivor, joined SS and chatted to parents about his achievements, struggles and his childhood. He answered lots of questions, joined us for our bubble ceremony and Sunflower Sunday cake, and was one of the last to leave! We had a wonderful day and are looking forward to next year.

Other states celebrated SS by having picnics and spending time with other families and their children.

## IN THE PIPELINE

### Awareness videos

A major achievement since the end of the financial year 2012–13 is the completion of a series of five Awareness videos.

### Annual CDH Australia Calendar

We plan to produce a CDH calendar, which will be on sale before the end of the calendar year. This will include special dates such as Sunflower Sunday and the CAAF and other helpful information.

### Others

Other plans include:

- gaining our fundraising licence in all states
- completing work instructions for all Director positions
- completing fundraising guidelines for all potential fundraisers
- applying and obtaining grants
- Investigating and researching pro bono opportunities

## Board of Directors

Our Board is comprised of a diverse group of people who commit many hours to CDH Australia on a voluntary basis. While the work may sometimes be difficult, it is always rewarding.

The Board meets each month using Skype and has a workshop annually to identify our goals for the following year.

### CDH Australia's Directors

The purpose of the Board of Directors is to advise, govern, oversee policy and direction, and assist with the leadership and general promotion of CDH Australia so as to support the organisation's mission and needs. All Board positions are filled by volunteers.



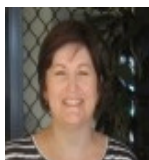
President – Christine Waite. Christine is a family friend of a CDH family. She is retired and lives in Ocean Grove, Victoria.



Vice President – Kay Holwell. Kay has no links with any of our CDH families and volunteers her time as a community service. Kay is an instructor in a local gym where she lives with her family in Drysdale, Victoria.



Treasurer – Kath Murphy. Kath is a long-term member of CDH Australia and is mum to CDH Angel, Jessica. Kath has an accounting background but keeps very busy in her work as an authorised marriage celebrant. Kath lives with her family in Tintenbar (Northern Coast) NSW.



Secretary – Linda West. Linda is another long term CDH member, first as a Volunteer Grieving Contact for South East Queensland. Linda is mum to CDH Angel Emma. Linda lives with her family in Brisbane, Qld



Family Liaison Officer – Sharon Knott. Sharon is another long-term CDH Australia member and is mother to CDH Liam. Sharon helps in the family business and lives in Perth, WA.

Each Director's appointment is for one year only. All current Directors are able to nominate for a position on the Board at the AGM.

Sincere thanks go to all our current Directors for the effort and commitments each and every one of them gave to ensure that CDH Australia continues to grow and develop.



## Volunteers

Our volunteers are the only reason that CDH exists. Without these people, who give their time and compassion, we would be unable to provide the necessary support to our CDH Family.

<b>Family Support Contacts</b>		
<b>State</b>	<b>Bereaved families</b>	<b>Surviving and expectant families</b>
ACT	Rebecca Mills	
NSW	Kirrily Hanlon	
Nth Qld	Robyn Mills	Judy Scherrenberg
Sth Qld	Linda West	Jessica Keavney
SA	Helen Harrison	
Vic	Danielle Kessner	Karen Vella
WA	Lisa Bonser	Sharon Knott
Tas		Sabine and Lindsay Kingston
Outback Aust		Mel Nicol

<b>Administrative Positions</b>	
Newsletter Editor	Jessica Willet Hancey
Funding Officer	Margaret Polacska
Projects Officer	Danielle Kessner
Information Officer	Linda West

## JOIN US OR CONTACT US

Telephone support is available on 1800 149 562 (free call from landlines)

Suite 2, 40 Central Walk

Joondalup, WA 6027

T: 1800 149 562

E: [information@cdh.org.au](mailto:information@cdh.org.au)

W: [www.cdh.org.au](http://www.cdh.org.au)

Please see below for current details including roles and contact details of:

### Volunteers

[To find out more information about volunteering](http://cdh.org.au/volunteers) <cdh.org.au/volunteers>.

### Board of Directors

[To contact Board members](http://cdh.org.au/board-of-director) <cdh.org.au/board-of-director>.

## Financial Report for Year Ending 30 June 2013

### Income Statement

<b>Revenue</b>	
Membership	930.00
Donations	4,811.81
Fundraising	9,859.80
Sponsorship/grants	1,873.92
Merchandising	1,206.25
Other	631.99
<b>Total revenue</b>	<b>\$19,313.77</b>
<b>Expenditure</b>	
Fundraising costs	169.52
CAAF 2012 expenses	7,903.91
Website & IT expenses	188.10
Merchandise	0.00
Printed material	332.54
Postage	929.40
Insurance	3,213.16
PayPal fees	137.51
Bank fees	7.75
Other	6,279.01
<b>Total expenditure</b>	<b>\$19,160.90</b>
<b>Net surplus for the year</b>	<b>\$152.87</b>

Note: CDH Australia's Audited Financial Statements are available to view online on at [www.cdh.org.au/annual-reports](http://www.cdh.org.au/annual-reports)

#### Financial health

Integral to CDH Australia's ability to provide services is fundraising, donations and voluntary work, which pay for and manage our events, publications, support and research initiatives and our website. As with any organisation run by volunteers, the help of many is always welcome.