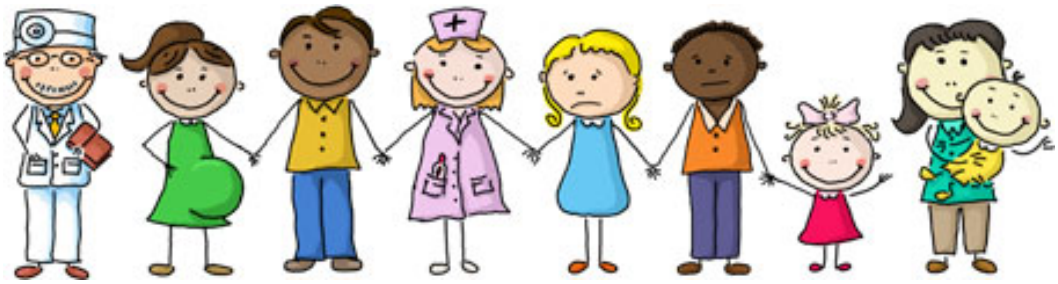
Annual Report

2014



Supporting families and medical professionals

along their CDH journey!

CDH Australia

ABN 60 131 315 145

www.cdh.org.au

President's Report

It is a pleasure to introduce the sixth Annual Report for CDH Australia.

This year we have been successful in undertaking a number of initiatives including the following

- Developing a new user friendly website to enable people to easily navigate around the site and find the support and assistance they require;
- Creating a new logo which is more in line with our Sunflower Sunday to ensure that when people see a sunflower they think about CDH Australia;
- Producing our first ever CDH Australia Calendar, which will help raise money for the organisation while increasing awareness throughout the community.

The three initiatives will be launched at the 2014 Qld CAAF, which has been very capably planned and organised by Linda West and Jessica Keavney.

CDH families have again been generous with donations and volunteering. The involvement and dedication of our members encourages the Board to continue with their efforts, which can be challenging as all Directors are volunteers and have other work and family commitments.

The Board is truly grateful to Danielle Kessner, Margaret Polascka, Karen Vella, Liz Proctor-Herbstreit and Sophie Franet for organising the 2013 CAAF (CDH Annual Forum), which was held in Melbourne. The forum was a great success being both informative and enjoyable for all who attended. Another amazing example of the enthusiasm and hard work undertaken by our CDH families is the "Chuckles for Cherubs" event that was organised by Liz and Neil Herbstreit. As well as raising $12,500.00 they increased awareness to all those who attended and through a full page spread in the Victoria Police Magazine.

The fourth annual Sunflower Sunday was held in March 2014. Once again this was a time to come together and enjoy the friendships and company of other CDH families across the country. Thanks to all those volunteers who ensure each of these events are a success. We hope they continue to grow with more and more people attending each year.

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 with information, support links, photos and stories;
- information booklets;
- a regular newsletter with group updates, latest CDH news and member profiles;
- access to online forums, with one Facebook site open to the public and four 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.
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Values and Aims

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

CDH Australia is an organisation devoted to 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 2013–2014

- New user friendly website – to make it easy for first time users to find the information they need.
- New logo – bringing the Sunflower of our Sunflower Sunday into all of media and merchandise to create a stonger link to Sunflowers and CDH. Our aim is to have Sunlowers synomonous with CDH Australia.
- Production of our first CDH Australia calendar. Through the generous donations of our supporters and families, we have been able to produce a high quality calendar which we hope will soon become a "must have" every year. This calendar will help raise much needed funds to help cover our annual administrative costs.
- We have finalised our fundraising permits across Australia which will enable us to raise funds with all valid legislative permits.
- Creating a series of five Awareness videos all available on You Tube and of course the website.
- Completing work instructions for all Director positions
- Completing fundraising guidelines for all potential fundraisers – people who want to hold a fundraiser will now have a guide on how to manage these events and donations.
- Applying and obtaining grants – two of which have been successful for assisting with the costs of running the 2014 CAAF and to develop the new website being included in the WA Genetic & Rare diseases register

Additionally we now have a permanent registered office which will save money on printing costs; moved all our files over to Google Drive to maintain our records accurately; started a new private Facebook page for extended family and friends and provided continued support to all our families when needed.

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.

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. The major event as mentioned previously was the"Chuckles for Cherubs" event which raised over $12,500.00.

Membership/Online Users

- Financial Members 46
- New members 15
- Facebook Followers 895 “likes”
- Facebook Posts Reached over 1000

CDH Research & Medical Support

There is some significant work happening in the field of research and medical support at a number of major hospitals across the country. Three current clinics are:

1. Royal Children’s Hospital (RCH) – Neurodevelopmental Follow-up Clinic

   The Department of Neonatal Medicine at RCH has introduced this dedicated clinic for children who had surgery for CDH in the newborn period. The Clinic is staffed by paediatricians, a neuropsychologist, an occupational therapist, a speech therapist and a physiotherapist. The clinic is not designed to provide long-term therapy, but rather to assess children at specified time points and identify areas of developmental concern so that referrals can be made to appropriate community based services.

   Inquiries should be made to Dr Rod Hunt, Director Neonatal Medicine, RCH (rod.hunt@rch.org.au).

2. The Children’s Hospital at Westmead – CDH/Infant Lung Multidisciplinary Clinic

   This is an initiative of the doctors meeting a perceived need, and children from all over Australia are welcome. Unfortunately there is no funding from the hospital as yet for staff e.g. physiotherapists or dieticians. Transport costs would need to be met by the family or assistance from state funding agencies sought.

   Data exists from overseas centre that for CDH and some other chronic respiratory conditions suggests that patients are best helped by multi-disciplinary teams in large centres with the most individual and collective experience. The doctors involved have extensive experience in managing children with chronic respiratory and cardiac conditions.

   For more details and access to this clinic contact the Secretary to Associate Professor Dominic Fitzgerald, Debra, on 02 0845 3397

3. Sydney Children's Hospital Randwick

   Sandra Chuang is a respiratory sleep specialist who has a special interest in children with congenital diaphragmatic hernia, and has set up a CDH clinic for families who live in the area. The CDH clinic is aimed to be a multidisciplinary clinic with involvement from general paediatrician, paediatric gastroenterologist, cardiologist, surgeons, nurse, dietician, and physiotherapist as required.

   Future research involving the long term outcomes of CDH babies is planned. They will keep us informed about this future research .

We now have a medical liaison officer (Danielle Kessner) who is liaising with the medical profession and will keep us informed of all medical updates and news.

Online Support

Four private Facebook groups have now 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, a group for extended family and friends 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 a great success and we invite all interested Australian CDH parents and adult survivors to contact us at information@cdh.org.au if they would like to be added to the group.

Highlights of 2013–2014

CAAF – Melbourne (Oct 2013)

This 2013 CAAF was held in Melbourne, at the Royal Children's Hospital in Parkville and at Taralye in Blackburn. Both of these venues were fantastic for our needs and were donated by their organisations for use by CDH Australia.

Day One's medical and support forum was held in the Ella Latham Auditorium at the new Royal Children's Hospital (RCH). The hospital is an amazing place with plenty of interesting features such as the Meer Kat exhibition and the giant aquarium. Speakers included a representative from Heartfelt, who accepted a camera kit donated by CDH Australia that has been given to Townsville Hospital. Dr Rod Hunt and Dr Ralf Heine then spoke on their latest research and current developments, followed by Lauren Mathews, executive officer from Early Childhood Intervention Australia. In the afternoon a Q&A session was held with a panel of medical practitioners.

On Day two the morning was spent remembering all our CDHer's with some very moving tributes made. A discussion facilitated by Dr Penny Brabin was well received.

Annual General Meeting

The Annual General Meeting was held on 19th October 2013 – minutes are available on the request.

Sunflower Sunday

Our 4th Annual Sunflower Sunday Awareness Day was held on March 23rd. We had events all around Australia, including Warrnambool and Townsville in addition to the major capital cities.

A number of new volunteers were responsible for organising very successful events, with lots of positive feedback from attendees.

The tributes to our CDHer's were heart-warming, and the cup cake decorations just keep getting better and better.

Thanks to everyone involved in organising these days.

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. With a background in Business Management, she is retired but works part-time as an authorised civil celebrant 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. With an extensive career in strategic management Kay is now a part-time 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 mum to CDHer 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 commitment 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 Australia exists. Without these people, who give their time and compassion, we would be unable to provide the necessary support to our CDH "Family".

Family Support Contacts

Bereaved Families	Surviving & Expectant Families
Rebecca Mills	Judy Scherrenberg
Kirrily Hanlon	Jessica Keavney
Robyn Mills	Karen Vella
Linda West	Sharon Knott
Helen Harrison	Sabine & Lindsay Kingston
Danielle Kessner	Mel Nichol
Lisa Bonser	

Administative Positions

Funding Offcer	Margaret Polacska
Projects Officer	Danielle Kessner
Merchandise Officer	Danielle Kessner
Information Officer	Linda West
Events Co-Ordinator	Kerrie Elliot

Join Us or Contact Us

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Email: information@cdh.org.au

Phone: 1800 149 562

www.cdh.org.au

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Financial Report for the year Ended 30 June 2014

Income Statement

Revenue	
Membership	900.00
Donations	5,075.00
Fundraising	16,781.40
Sponsorship/grants	2,750.00
Merchandising	2,141,15
interest	881.03
Total revenue	**$28,528.58**
Expenditure	
Auditors Remuneration	1,100.00
CAAF expenses	8,034.76
Website & IT expenses	888.16
Merchandise	844.91
Printed material	366.30
Postage	233.65
Insurance	3,349.63
PayPal fees	109.72
Telephone (1800/mobile)	972.02
Donations	1,106.88
Bank fees	7.00
Other	1,668.00
Total Expenditure	**$18,681.03**
Net surplus for the year	**$9,847.55**

Note: CDH Australia's Audited Financial Statements are available to view online at 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.