

CDH Australia

Annual Report 2016



Supporting families and medical
professionals along their
CDH journey.

President's report

I am pleased to present this annual report that provides a summary of CDH Australia's activities and financial results for the financial year 2015-16.

A highlight for the year was CDH Australia's first significant donation to CDH research, which we hope will directly lead to improved outcomes for affected babies.

The board continued to refine and focus our strategic objectives to deliver our mission and benefited from the diverse range of skills and knowledge offered by ten board members, six of them new to the board.

The importance of organisational growth and increased access to support and resources for affected families was highlighted by an influx of expectant families seeking our services in the month of February. Around 1/3 of the number of new families we normally have contact with in a year, sought support from us within just over 1 month.

To begin building the infrastructure to address increase in demand, we continued developing our digital capabilities by building a community portal, launched later in 2016, and began recording webcasts on topics of interest and published facts sheets for our resource library.

Our awareness day, Sunflower Sunday, once again brought families together and featured awareness walks around the country to profile CDH Australia publicly.

The CDH Australia Annual Forum in Sydney introduced new initiatives: a move away from the hospital environment to a calming setting, a focus on self-care and our first memorial service.

The importance of strong community support for the sustainability of our organisation, financial as well as through benefits provided by partnerships, was highlighted by our financial results.

CDH Australia's total operating revenue for the year ended 30 June 2016 was \$47,980, of which fundraising and donations contributed \$42,644 to overall income.

Our \$30,000 donation made to Monash University for CDH research and some unsuccessful applications for project funding (that had previously been successful in 2015) saw CDH Australia registered a deficit of \$6,594 for the 2015/16 financial year.

We must continue to establish reliable income streams in order to be majority self-funded and sustainable into the future. We look forward to greater growth next year and more opportunities to collaborate in order to step closer to realising our vision and mission.

Together we can do more.



Margaret Polacska

President

About us

CDH Australia is a grassroots, national health promotion charity for families, friends and medical professionals affected by congenital diaphragmatic hernia (CDH).

Our **vision** is for no family to face CDH alone. Our **mission** is to improve the lives of those affected by CDH, support and advocate for families, raise awareness and support research. Our organisation is governed by a board of directors and support services are delivered by state contacts.

CDH is a rare lung disease that occurs in approximately 1 in 2,500-3,000 births and remains lethal or associated with serious morbidity in a large number of cases—the devastating consequences of inadequate lung growth and development.

“As the Medical Director and co-head of the Grace Centre for Newborn Care which cares for many babies who have surgical conditions I have worked with CDH Australia for nearly 15 years. During this time they have been extremely professional and supportive to people with CDH and their families as well as health professionals. During the last decade it would not be an exaggeration to say that the care for babies with CDH has been revolutionised as evidenced by the survival rate which has increased significantly from 50% to well over 85% comparable to that of the best centres worldwide.

Multidisciplinary follow up clinics are being established in many hospitals to ensure survivors have the best quality of life possible and to intervene when complications are identified. This is in no small part attributable to the rich collaborations between families and health professionals. I look forward to an ongoing association.”

Professor Nadia Badawi AM
Medical Director Grace Centre for Newborn Care
The Children’s Hospital at Westmead
Macquarie Group Foundation Chair of Cerebral Palsy
Cerebral Palsy Alliance

Strategic priorities

The CDH Australia Board met in February for our annual strategic workshop and came away with some bold aspirations:

- We want our organisation to be sustainable so we can support families in years to come.
- We need to increase our reach to people affected by CDH, their carers and healthcare professionals to get the best possible outcomes for families.
- We need to better support individuals born with a diaphragmatic hernia.
- We want to do all we can to support research to minimise the devastating impacts of congenital diaphragmatic hernia (CDH).

The outcomes we are striving to deliver include:

- strong, state-based network of volunteers in place and functioning collaboratively with increased male participation and formal training processes
- connect with and understand the needs of adolescent and adult CDHers
- assess opportunities to build relationships and leverage infrastructure of potential of community, funding, advocacy, research partners
- develop a fundraising strategy to diversify revenue streams and reach the target of being 80% self-funded to ensure long-term sustainability
- develop a marketing and communications plan to target communications and increase community and corporate supporters
- develop Sunflower Sunday awareness day fundraiser to be a major platform for awareness raising, especially throughout hospitals, and be a significant fundraising campaign
- continue building library of support resources: information sheets, webcasts with specialists, researchers and allied health professionals.

To get us to a position where we can deliver these goals is a big challenge for a micro-charity like CDH Australia. We need the technology, infrastructure, resources and funds of a much larger organisation and we are striving to build these in the coming years. Corporate and community support will be critical to achieve our goals.

“As the Director of Neonatal Medicine at The Royal Children’s Hospital in Melbourne I can strongly endorse the endeavours of CDH Australia. This group of committed families have provided immeasurable networking support to new parents who face this rare condition in their newborn babies. They are well placed to direct families to appropriate resources as required, and their annual forums provide educational updates to affected families through provision of up to date research results. Beyond this, CDH Australia engage health professionals as an active consumer group, and stimulate research into areas of concern for affected families. In all of these facets, they are doing fantastic work.”

Dr Rod Hunt FRACP, MRCP (UK), MMed, PhD
Director of the Department of Neonatal Medicine

Events

CDH Australia Annual Forum (CAAF) 2015

The CDH Australia Annual Forum (CAAF) was held in Sydney on 16-17 October in the tranquil setting of Centennial Parklands. A slight change of focus to previous CAAFs, the forum centred on self-care and peer support, with plans to deliver more of the medical and allied health talks via webcasts. The peaceful, natural environment set the scene for the nurturing yet emotionally raw gathering that ended with our first memorial service.

Prof Adam Jaffe and Dr Sandra Chuang from Sydney Children's Hospital contributed to the forum. Adam presented on the Australian approach to rare lung diseases, the initiatives that currently exist, how far Australia is from having a National Rare Disease Plan and how families can advocate to government. Sandra participated in our self-care session on the topic of Beyond the First Years covering issues that CDHers face in their development.

Once again it was a great event for families to come together with peers and be socially connected in a supportive environment.



Sunflower Sunday

Sunflower Sunday, CDH Australia's annual awareness day for congenital diaphragmatic hernia (CDH), was held on 20 March. Many families enjoyed a great social day out and raised awareness of CDH by raising banners, doing an awareness walk and handing out balloons and sunflower seeds.

It is a day to reflect on the struggles and triumphs that families face dealing with the condition, and a day to celebrate the friendships that have blossomed through the support provided through the CDH Australia community, as well as raise awareness amongst the general public.

Events were held in Townsville, Brisbane, Newcastle, Western Sydney, Geelong, Adelaide and Perth.



Deepest gratitude for our CDH Champs

Our heartfelt thanks to all our CDH Champs who make it possible for us to support families affected by CDH this year.

Noah's Hope



Chantelle and Joshua Morrison worked tirelessly in organising and hosting a very successful inaugural Noah's Hope Gala Night with 110 guests in July 2015. The event successfully raised close to \$15,000, half of which contributed to our research donation, and a huge amount of awareness in the media through Channel Nine and the Bendigo Advertiser reaching hundreds of thousands of people.

Jacinta Allan MP was event ambassador and special guest speakers included Dr David Tingay and Dr Joe Cramer from the Royal Children's Hospital.

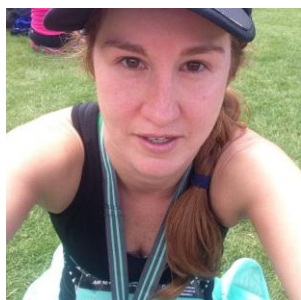
Solomon's Slam

Solomon's parents, Amanda and Glenn Tongue, worked hard to raise awareness of CDH and funds through Solomon's Slam three-on-three basketball tournament and family day in October. The event was featured in the Mandurah Mail and was a true show of community spirit with support from the Mandurah Filipino Sports Club, where Glenn plays basketball, and the Lions Club running a sausage sizzle. The day included a raffle, door prizes, various basketball competitions with winners taking out prizes, and successfully raised \$3,435 for CDHA.

And thank you Manda Tongue for inspiring the creative collaboration between georgie boy, piccolo studio, squirrel & fink, creative bowerbird and kwasi & co who donated beautiful products in support of CDH Australia as part of the Collaborate for a Cause charity auction.



Emily runs for Sean



Emily Winwood ran the exhausting Queenstown International Marathon in New Zealand in memory of her nephew, Sean, son of Josh and Tara, to raise an outstanding \$2,748 for CDH Australia. Emily listened to the favourite songs of her family and friends and used them as motivation thinking of her loved ones as she ran.

Emily said "When my brother Josh's songs came tears filled my eyes as I remembered why I was doing it. I'd always wanted to run a marathon but the motivation really came after Sean's passing as I found a good cause to run for. I'm really proud of the money we raised and I know it will go towards helping families just like mine which makes it so much more rewarding."

Keira's Cookies

Gorgeous Keira proved that you are never too young to make a difference and raised funds in honour of her cousin, CDHer Matilda. Keira busily baked and sold her favourite cookies to support CDH Australia and to celebrate Matilda's special 1st birthday and to thank all the amazing people who helped Matilda and her family. An outstanding effort by Keira.



Expectant Booklet Sponsors



Thanks to CDH Champs who enabled us to print our next edition of the Expectant booklet by fundraising for CDHA.

FMD Financial for donating \$1,200 in honour of Anna, **Mothercraft Childcare Centre – Toowoomba** for donating \$1,030 in memory of Arabella and **Chub Bubz** in New Zealand for donating \$1,000 in memory of Josiah.

These donations have helped us produce this essential resource for newly diagnosed families.

(Pictured: CDHA President Margaret Polacska receiving FMD Financial's donation from adult CDHer Anna Fogarty).

Supporters 2015-16

CDH Australia supports 100-200 parents and their extended family each year. Our organisation receives no government funding; we rely on donations and the passion, gratitude and commitment of our volunteers who run our board, fundraise, organise events and manage projects.

We give many thanks to the businesses and individuals who generously donated and/or provided voluntary services enabling CDH Australia to exist.

Sponsors

Maryanne Lanigan
Tara Gallo
Courtney Vodopic
Carine Ziegler
Carmel Chesterfield
Amanda and Glenn Tongue
Anchorarage Drive Physiotherapy
Danielle Kessner
Lisa and Blair Bonser
Sheree Raffin
Shirley Romanyk
Jess Keavney

Corporate Donors

FMD Financial
Mr Fothergills
Macquarie Group Foundation (Macquarie Gift Matching Program)
Good2Give

Community Support

Emily Dawson
Emmanuelle Delannoy
Keira Flowers
Helen and Craig Goldberg
Peter Freeman and Mary McLaughlin
Elizabeth Montforte
Chantelle and Joshua Morrison
Amanda and Glenn Tongue
Emily Winwood
Mothercraft Childcare Centre – Toowoomba
Chub Bubz New Zealand
Little Quacker Duck Charity Auction
Collaborate for a Cause

Pro Bono Support

As One Digital Design
Corrs Chambers Westgarth
HLB Mann Judd
Rodney Greenfield Photography

We also truly appreciate the donations that were directed to CDH Australia by families in lieu of gifts or in memory of their loved one, as well as the contributions of individual donors who supported these events and/or made general donations to CDH Australia.

Research and collaboration

Pilot study

With an overall survival rate of 50-60% for babies diagnosed with congenital diaphragmatic hernia (CDH), research into therapies to increase survival rates is crucial. Earlier this year, the CDH Australia Board formally established a research fund to direct donations nominated for CDH research. And in September, we were excited to grant our first donation to Monash University for the amount of \$30,000. These funds contributed to funding a pilot study into CDH fetal therapies by Dr Ryan Hodges. Our donation was made possible by parents of CDHers who generously donated in honour and in memory of their child.

Dr Ryan Hodges, leads high risk obstetrics (Perinatal Services) at Monash Health, and had returned to Melbourne after training overseas in fetal therapy in Belgium and in Canada. During his time abroad, Ryan trained in fetoscopic tracheal occlusion for CDH with Professor Jan Deprest, who has visited Melbourne in July.

Ryan spoke with CDH Australia about the world first pilot study Monash Health is conducting in partnership with The Ritchie Centre, Hudson Institute of Medical Research and Monash University Department of Obstetrics and Gynaecology.

What is the research project you are working on?

With my research partners Professor Stuart Hooper (one of the world's leading lung physiologists) and Professor Jan Deprest from Belgium, we have developed a sheep model of CDH where we are now testing new therapies to treat the lungs in utero before the baby is born. Specifically, we are using a small camera to access the lungs of the fetus with CDH, and then we are delivering stem cell therapy to the lungs and giving medication to the mother in order to promote fetal lung development before birth. We are also developing new ventilation strategies for these lambs at birth in order to reduce lung injury that can occur from oxygen therapy at birth.

What are the stages of the project?

This is a pilot study designed to generate the initial data that is required for a major grant application. To be competitive for major funding, we must be able to show very promising results that would then deserve funding by the Australian Government NHMRC. Major funding would allow us to then develop a large research program that is specifically designed to move to human clinical studies very quickly.



What do you hope the research will achieve? How will it help babies with CDH in the future?

We are confident that the pilot data will show improvement in the quality of lung tissue and increased survival for babies with severe CDH. Now that we can safely access the baby's lungs while still early in pregnancy using a miniature camera, it opens brand new opportunities for us to deliver new therapies directly to the lungs to promote normal growth and development. We hope that when born, these babies will have larger and healthier lungs ready to begin air breathing and more likely for corrective surgery to then be successful. This is a world first, combining the latest technology in fetal surgery with the latest advances in placental stem cell therapy. We are striving to save all babies diagnosed with CDH in pregnancy.

Vasopressin

A/Prof Arvind Sehgal and the team at Monash Children's Hospital used the experimental drug Vasopressin, a hormone vital for fluid balance, on CDH baby Charli in the hope it could lower the critical pressure in her lungs while simultaneously increasing her plummeting blood pressure.

While the drug had been used in 13 cases in the US, there was no record of it having been tried in Australia for a baby in Charli's condition, though neonatologist Arvind had used Vasopressin in 2014 for a baby who had inhaled a mixture of meconium and amniotic fluid during birth and required oxygen support: it was life-saving.

Five days after Charli was given Vasopressin her condition had stabilised and she got through a 2½-hour operation to put her organs in their correct position and has recovered from surgery to go home.

Of the 13 similar US cases, six were also able to stay off ECMO and Charli's case is now being written up for research into Vasopressin, with A/Prof Sehgal recommending the drug be used as treatment for newborns with diaphragmatic hernias before they are placed on ECMO.

A/Prof Sehgal recorded a webcast for CDH Australia to further explain how Vasopressin works for babies with CDH and this recording can be found on our website.

Board of Directors

CDH Australia welcomed new and returning members to the board for 2016. Retaining their positions were President, Margaret Polacska; Secretary, Linda West; Treasurer, John Hurley; and Family Liaison Coordinator, Sharon Knott; who were joined by six new board members: Joshua Kirkwood, Bridget Beattie, Carmel Chesterfield, Chantelle Morrison, Courtney Vodopic and Carine Ziegler.

President – Margaret Polacska: Margaret is a long-term member has a background in project and contract management, bid management, tender/grant writing and fundraising in the commercial and not for profit sectors. Margaret is mum to CDH Angel, Noah and she lives in Melbourne.

Secretary – Linda West: Linda is a long-term 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 and works part-time as a Legal Assistant for a large corporate law firm.

Treasurer – John Hurley: John has extensive experience in banking and business management. He has also volunteered for The Compassionate Friends for many years, at board level as well as facilitating men's support groups. John lives in Melbourne.

Family Liaison Coordinator – Sharon Knott: Sharon is a long-term member and the heart and soul of the organisation in her role as Family Liaison Coordinator. Mum to CDHer Liam, Sharon helps manage the family's digital design business and lives in Perth.

Board Members:

Josh Kirkwood – Josh is Dad to angel CDHer Sean. Josh joined NAB in October 2014 as Executive Manager, Finance and Strategy and lives in Sydney. Josh has assisted the board with his expertise in governance and provided a valuable male perspective.

Bridget Beattie – Bridget is the Group Executive Vice President for Asia Pacific Middle East for Right Management, the global leader in talent and career management workforce solutions within Manpower Group. Bridget facilitated CDH Australia's strategy workshop and lives in Melbourne.

Carmel Chesterfield – Carmel is mum to angel CDHer Arabella and joined the board as a way to give back to the organisation that supported her family through the diagnosis, birth and the passing of Arabella. Carmel works in retail management.

Chantelle Morrison – Mum to CDHer Noah, Chantelle has a background in social work as a Home-based Care Case Manager and is currently studying for a Diploma in Event Management. Chantelle's background gives her a great level of empathy and compassion.

Courtney Vodopic – With a work background in the Department of Justice, Courtney has worked primarily in counselling and management roles over the past 8 years. Mum of CDHer Lucy, Courtney enjoys being able to blend her work experience with her passion for supporting CDH families.

Carine Ziegler – Mum of CDHer Sophia, Carine's background in social work has been with a number of community and government organisations with individuals, families and children, and has included counselling and program delivery.

Sincere thanks go to all our Board Members for the effort and commitment each of them gave in 2016 to ensure that CDH Australia continues to grow and develop. In particular we thank outgoing Board Members for their hard work and dedication.

We accomplished some great achievements this year that we can be proud of and we look forward to continuing that success to build on our strong foundations to deliver our mission.

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	Kylie Stace
Linda West	Sharon Knott
Helen Harrison	Sabine & Lindsay Kingston
Lisa Bonser	Mel Nichol
	Alexandra Lane

Administrative positions

Funding and Fundraising Officer	Margaret Polacska
Information Officer	Linda West
Projects Officer	Danielle Kessner
Production Coordinator	Tara Kessner

Contact us

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Financial report for the year ended 30 June 2016

Income Statement

Revenue	2016	2015
	\$	\$
Membership	615	1,290
Donations	42,644	27,121
Grants	-	38,176
Interest received	717	1,216
Other expenses	4,004	2,822
Total revenue	47,980	70,625
Expenditure		
Bank charges	12	27
CAAF expenses	9,983	9,769
Website & IT expenses	1,233	19,900
Printed materials	62	-
Other expenses	1,223	193
Fundraising costs	251	2,073
Donations	30,000	-
Paypal fees	227	227
Insurance	3,238	3,089
Merchandise	1,905	118
Postage	241	528
Telephone	1,126	974
CDH Workshop	4,214	22,649
Auditor's remuneration	1,100	1,100
Total Expenditure	54,815	59,747
Net surplus for the year	(6,594)	10,787

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