



Annual Report 2017



Supporting families and medical
professionals along their
CDH journey.

ABN 60 131 315 145

www.cdh.org.au

President's report

We are pleased to present this annual report that provides a summary of CDH Australia's activities and financial results for the financial year 2016-17.

The board refined and focused our strategic objectives to deliver our mission, and benefited from a diverse range of skills and knowledge offered by our six board members.

To continue to build infrastructure to address increased demand, we strengthened our digital capabilities with a community portal, which has webcasts and information sheets on a variety of topics.

We celebrated our fifteenth CDH Australia Annual Forum (CAAF), which was held in Adelaide for the first time. The CAAF was held at the South Australian Museum and families shared their thoughts in art therapy and small group sessions, and a beautiful memorial service.

Based on management accounts, CDH Australia's total operating revenue for the year ended 30 June 2017 was \$57,594, of which donations contributed \$33,905 and fundraising contributed \$14,830 to overall income. We registered a surplus of \$29,127 for the 2016/17 financial year. The official audited accounts will be presented in the coming weeks, and will be available on the website.

CDH Australia was fortunate to receive philanthropic grants this year that funded the CDH Australia Annual Forum. Our heartfelt thanks go to the Trustees for supporting CDH Australia.

We also gratefully acknowledge the hard work and dedication shown by families honouring their children with CDH with some significant amounts raised and donated to CDH Australia. Fundraising is critical, as our volunteer organisation could not operate without it.

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 and more opportunities to collaborate in order to step closer to realising our vision and mission.

Together we can do more. No family to face CDH alone.

Tara Gallo & Joshua Kirkwood

Co-Presidents

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 2,500-3000 births and remains lethal or associated with serious morbidity in a large number of cases – the devastating consequences of inadequate lung growth and development.

Strategic Priorities

The CDH Australia Board met in February for our annual strategy and planning 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 community, funding, advocacy and 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 CDH Sunflower Sunday awareness day fundraiser to be a major platform for awareness raising, especially throughout hospitals, and be a significant fundraising campaign
- Continue building a library of support resources including information sheets and 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.

Events

CDH Australia Annual Forum (CAAF) 2016

In October, the CDH Australia Annual Forum (CAAF) was held in Adelaide at the South Australian Museum. Many of our families enjoyed this opportunity to catch up with old friends, make new friends and share many laughs and tears. We heard from Dr Steve Keeley - Medical Director of the Department of Critical Care Medicine, Dr David Moore - Head of Gastroenterology and Ms Hala Abokamil - Clinical Psychologist.

We shared our thoughts during art therapy and small group sessions, and the dads enjoyed a social outing. At our family dinner, we were joined by many CDH families who couldn't make the forum. Luckily the restaurant could fit our 50 guests on one table.

Our memorial service concluded the CAAF and provided a moving and emotional ceremony to remember loved ones and babies lost to CDH.

Once again it was a great event for families to come together with peers and socially connected in a supportive environment. Our sincere appreciation goes to the Marian EH Flack Trust who provided a grant to facilitate the CAAF and to Lea Gardam and Tiffany Atze for organising the event.



CDH Champs

We appreciate and are sincerely thankful to those families who held fundraising events, raising significant donations for CDH Australia in honour of CDH children. Many of these families are ongoing supporters of CDH Australia. As a volunteer organisation, fundraising is critical, as our organisation could not operate without it

Heartfelt thanks to our 2017 CDH Champs:

- 'Candles for Clementine' by Kristin and Chris Bitmead
- 'What the Fact? Quiz Night' by Julianne Poland
- 'Fight Night for a Cause' by Jacinta Jones
- 'Solomon's Slam 2016' by Amanda and Glenn Tongue
- 'Noah's Hope' by Chantelle and Joshua Morrison
- 'Victoria Ladies Lunch' by Chantelle Morrison, Margaret Polacska, Allison Harper, Courtney Vodopic, Karen Vella and Danielle Kessner
- 'Townsville Ladies Lunch' by Mikayla Iythgo
- 'CDH Heroes: Trivia for Lucy' by Courtney and Denis Vodopic
- 'Footy Tipping Competition' by Danielle Kessner
- Entertainment Book fundraising by Elizabeth Montforte
- Peter Freeman Christmas lights

Noah's Hope

Chantelle and Joshua Morrison held the second annual 'Noah's Hope' fundraiser on November 5th 2016. Held once again at The All Season's Bendigo, the event saw Chantelle and Joshua step away from a traditional sit down formal evening and move towards a Casino Royale night. Additions included a silent auction, raffle, balloon pop and a few other fun activities to help raise crucial funds to support CDHA. The event increased the

attendee's awareness of CDH and raised over \$5,000 for CDHA. Overall, the night was a great success, despite Noah being hospitalised just a few weeks out from the event, and the continued community support was overwhelming. Chantelle and Joshua plan to continue their work through Noah's Hope and hope for it to continue as an annual event.



Victoria Ladies Lunch



Victoria held a Ladies Lunch fundraiser on Saturday 11th February 2017 and raised over \$1,000 for CDH Australia. The event provided a great opportunity to relax while enjoying an indulgent lunch, learn about CDH and fundraise for CDH Australia. Our speakers included CDHA Founder, Danielle Kessner; CDHA past President, Margaret Polacska; Chantelle Morrison, mum of CDH survivor Noah; and Dr. David Tingay from the Royal Children's Hospital. Thank you to Chantelle Morrison, Margaret Polacska, Allison Harper, Courtney

Vodopic, Karen Vella and Danielle Kessner for organising such a wonderful event.

CDH Heroes: Trivia for Lucy

Courtney and Denis, parents of CDHer Lucy, organised 'CDH Heroes: Trivia for Lucy' to raise awareness of CDH and fundraise on behalf of CDH Australia. They were thrilled to have the support of the extended community, with over 100 people attending the trivia night and \$6,500 being raised for CDH Australia. Many local businesses supported the event, including the Highton Bowls Club and Shell Club, who provided the venue and catering respectively. Adult CDHer, and A-League soccer star Brendon Santalab made a guest appearance via video, and local media got involved, spreading the CDH Awareness message to 65,000 people. Over 50 businesses donated their time or services to the event, which included a silent auction, fantastic giant "CDH" letters, "CDH Heroes" cupcakes and "CDH Awareness" selfie frames. Aside from bragging rights, the winning team took away signature "CDH Heroes" wine glasses and top-shelf Shiraz from local vineyard, Moshulu Wines. It was a huge success, and great fun!



Supporters 2016-17

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.

Philanthropic Trusts and Foundations

Marian EH Flack Trust

Corporate Donors

Bendigo Bank

Car Craft

Golden City Concrete Pumping

Just Auto

Lenfri Pty Ltd

Macquarie Group Foundation (Macquarie Gift Matching Program)

NAB (Good2Give Gift Matching Program)

Shine

Strategem

Strzelecki Holdings

Community Support

Jacinta Allen MP

Blair and Lisa Bonser

Daniel and Catherine Colonnelli

Jennifer Craig

Danielle and Julian Kessner

Tara Gallo and Joshua Kirkwood

Margaret Polacska

Julianne Poland

Wayne Poland

Makybe Rise Primary School

Rochdale State School

Pro Bono Support

As One Digital Design

HLB Mann Judd

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

CDH Australia formally established a research fund to direct donations nominated for CDH research in 2015. In September of that year, CDH Australia donated \$30,000 to Monash University to support a pilot study into CDH fetal therapies by Dr Ryan Hodges. Dr Ryan Hodges leads high risk obstetrics (Perinatal Services) at Monash Health, and trained in fetal therapy in Belgium and Canada.

Ryan and his PhD student, Aidan Kashyap, are researching the effects of sildenafil administered to the mother during pregnancy to improve fetal lung function. Early results are promising and Ryan and Aidan plan to publish their results in 2018.

CDH Australia continues to work closely with the Ritchie Centre at Monash Health, and are planning to visit in the 2017-2018 financial year to meet the broader team to better understand the vital work they do and deepen our relationship.

Research into Long-term Cardio-Respiratory outcomes

Research is also being completed by Dr Jason Tan and his associates in Western Australian to assess the long term cardiorespiratory and psychosocial outcomes in CDH survivors. Children born with a congenital diaphragmatic hernia are at risk of breathing, growth and development issues as they are growing up. This team have recently completed a study in Perth (Western Australia) in collaboration with Princess Margaret Hospital and Telethon Kids institute.

The study has helped build understanding of long-term issues, assess the changes that may occur in the lungs as these children grow up, and guide future research to improve outcomes. In this study they found that children and adolescents born with a CDH were at risk of reduced lung function, issues with growth and reflux and some mild social and developmental issues. The children in the study were examined and subjected to a number of tests (lung function, cardiac echo, chest CT) to understand long term effects of CDH and guide follow-up programs for children born with CDH. The research will help evaluate other ways to improve health in children born with a CDH. Jason and his associated hope they can collaborate nationally to further improve outcomes of children born with CDH.

Board of Directors

CDH Australia welcomed new and returning members to the board for 2017. Retaining their positions were Treasurer, John Hurley; and Family Liaison Manager, Sharon Knott. Joshua Kirkwood and Courtney Vodopic returned to the board and have taken up new roles – Co-President and Secretary, respectively. Our former board members were joined by two new board members: Tara Gallo, Co-President; and Anna Fogarty, Vice President.

Co-President – Joshua Kirkwood: Josh has a background in economics, investment banking, finance and strategy. Josh currently works at Suncorp, as the Head of Group Strategy and Performance Management. Josh is dad to CDH Angel, Sean, and lives in Sydney.

Co-President – Tara Gallo: Tara brings 15+ years of business consulting and strategy experience to the CDH Australia board. Tara is currently an Associate Director at Macquarie Bank, in the Business Improvement and Strategy Division. Tara is mum to CDH Angel, Sean, and lives in Sydney.

Vice President – Anna Fogarty: Anna is the first CDH survivor to join the board, and has been involved with CDH Australia since 2001. Anna works in the Financial Planning Industry and resides in Melbourne.

Secretary – 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.

Treasurer – John Hurley: John joined CDH Australia in 2014 and has extensive experience in banking and business management. He has also served on the board of The Compassionate Friends for many years and facilitates men's support groups. John lives in Melbourne.

Family Liaison Manager – Sharon Knott: Sharon is a long-term CDH Australia member and is mum to CDHer Liam. Sharon helps in the family business and lives in Perth.

Sincere thanks to all our Board Members for their effort and commitment in 2017 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 things this year that we can all 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	Kylie Stace
Tara Gallo & Joshua Kirkwood	Rebecca Roberts
Helen Goldbert	Alexandra Lane
Linda West	Sabine & Lindsay Kingston
Lisa Bonser	Courtney Vodopic
Mel Nichol	Sharon Knott

Administrative positions

Information Officer	Courtney Vodopic
Projects Officer	Danielle Kessner
Production Coordinator	Tara Kessner
Fundraising & Events Coordinators	Chantelle Morrison Carmel Chesterfield
Office Administrator & Project Manager	Susan Fisher

Join us or contact us

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Financial report for the year ended 30 June 2017

Income Statement

Revenue	2017	2016
	\$	\$
Membership	735	615
Donations	33,905	42,644
Grants	6,091	-
Fundraising	14,836	-
Interest received	440	717
Other revenue	1,587	4,004
Total revenue	57,594	47,980
Expenditure		
Bank charges	-	12
CAAF expenses	8,715	9,983
Website & IT expenses	2,891	1,233
Printed materials	1,092	62
Database fees	1,100	-
Other expenses	1,184	1,223
Fundraising costs	3,740	251
Donations	-	30,000
PayPal fees	415	227
Insurance	2,683	3,238
Merchandise	-	1,905
Postage	129	241
Telephone	962	1,126
CDH Workshop	2,682	4,214
Consultants	2,475	-
Auditor's remuneration	-	1,100
Total Expenditure	28,068	54,815
Net surplus for the year	29,127	(6,594)

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