

CDH Australia

Annual Report 2018



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 2017-2018. FY18 was a very busy year for CDH Australia – we moved CDH Sunflower Sunday to November, organised two CAAFs in Perth and Melbourne, received an influx of new families, and adjusted our operating model to meet increased demand.

CDH Sunflower Sunday was held in six locations in Australia and New Zealand. The day is always a highlight, with time spent with old friends and meeting new families. The corresponding social media Facebook campaign resulted in a number of new families contacting CDH Australia for support – we had around 40 families contact us in November, December and January alone!

Given the increase in contact and demand for our services, we revisited our operating model to offer consistent and quality support. Thank you to all our support services volunteers who have worked with us during this change, and for the wonderful support you continue to offer to our families.

We also celebrated our sixteenth and seventeenth CDH Australia Annual Forums (CAAF), which were held in Perth in late 2017 and Melbourne in May 2018. Both events had small group sessions, art therapy, and a beautiful memorial service. As always, it was lovely to see our families in person, and we look forward to our event in Brisbane in 2019.

Based on management accounts, CDH Australia's total operating revenue for the year ended 30 June 2018 was \$116,288, of which donations contributed \$54,218 and fundraising contributed \$50,522. We registered a surplus of \$31,910 for FY18.

CDH Australia was fortunate to receive philanthropic grants this year that funded our new support model. Our heartfelt thanks go to the Trustees and corporations for their support.

We also gratefully acknowledge the hard work and dedication shown by families honouring their children with CDH with significant amounts raised and donated to CDH Australia. Fundraising is critical, as our volunteer-led organisation could not operate without it, and we must continue to establish reliable income streams to be majority self-funded and sustainable into the future.

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

Regards,



Tara Gallo and Joshua Kirkwood
Co-Presidents

About us

CDH Australia is the only dedicated national charity supporting families, friends and medical professionals affected by congenital diaphragmatic hernia (CDH).

CDH is a rare lung disease and affects 1 in 2,500 births. This week, two families will receive a CDH diagnosis for their child, either during pregnancy or at birth. CDH remains lethal, with a fatality rate of 50%. Many survivors face ongoing health conditions.

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 nationally.

Strategic priorities

The CDH Australia board met in February for our annual strategy and planning workshop and devised a set of priorities and deliverables for 2018.



Our Vision: For no family to face CDH alone

Our mission	RAISE AWARENESS	SUPPORT FAMILIES	SUPPORT RESEARCH
Our 2018 priorities	Build on our momentum: <ul style="list-style-type: none"> Leverage social media (share how we can help, tell personal stories, provide factual, reliable information and raise funds) Make our website more accessible Accelerate CDH Sunflower Sunday and CAAF to continually improve our key CDHA events 	Strengthen and broaden support: <ul style="list-style-type: none"> Enhance our volunteer-driven model to support families across Australia Recruit Support Service volunteers and Administrative support Implement practical assistance for families (food, travel, babysitting) Determine how we can help beyond diagnosis 	Closer relationships with medical professionals: <ul style="list-style-type: none"> Visit key medical professionals / institutions once a quarter Create bespoke communications to our medical community (<i>twice a year</i>)
What success looks like	<p style="text-align: center;">More contact at diagnosis: from ~25% of families to >60%, sustainably</p> <p style="text-align: center;">More people: on Facebook, at CAAF and CDH Sunflower Sunday</p> <p style="text-align: center;">More fundraising, donations & grants: from \$55,000 in FY17 to \$110,000 in FY18</p>		
Foundations	<p>Volunteer Management: scope roles/projects, recruit, train, engage and acknowledge our volunteers</p> <p>Regulation, Risk & Compliance: document internal procedures and develop detailed handover notes</p> <p>Information Management: identify best fundraising platform and CRM to suit our needs</p>		

Events

CDH Australia Annual Forum: October 2017

Perth hosted our 2017 Annual Forum (“CAAF”), with attendees meeting at the picturesque Sorrento Beach Resort.

Around 20 families came from all over Australia to connect, share experiences and hear from noted names in the medical field. We were grateful to spend time learning from neonatologist Dr Jason Tan and surgeon Mr Parshotam Gera. Dr Tan was able to share some preliminary learnings from long-term research being conducted in Perth, and Mr Gera spoke about his experiences repairing congenital diaphragmatic hernia with and without patches.

Additionally, The Grief Centre’s Kath Budzinska took our bereaved families through a session called “Grief and Loss,” whilst counsellor Sally Langsford talked with families raising CDH children about the “Circle of Security” parenting model.

CDH Australia Annual Forum: May 2018

2018 saw a shift in the traditional CAAF scheduling with a move to May. We were delighted to offer a second CAAF within a seven month period, and our community was equally supportive, with approximately 30 families being represented.

Considering the breadth of community represented at this event, we were able to offer an extended program. For the first time we ran a group for extended family and friends alongside sessions for grieving families, and the families of surviving children.

A session titled “Insights from the Medical Profession” was particularly well-received. PhD candidate Aidan Kashyap updated the group on the research commenced with a donation made by CDH Australia in 2015. Monash Children’s Hospital surgeon Mr Ram Nataraja, and Royal Children’s Hospital neonatologists Dr Anastacia Pellicano and Dr David Tingay, also presented on a range of topics and specialties, which gave rise to a number of interesting discussions.

Our group also participated in an interactive ‘Self Care’ session with clinical psychologists Amanda Dando and Felicity Garland. In addition to some great ideas, participants also took away some practical tools.

CDH Sunflower Sunday: November 2017

In November 2017, CDH Sunflower Sunday events were held in 6 locations across Australia and New Zealand.

Guests were invited to create an online fundraising page and encourage donations in their own communities for the first time in 2017. As a community, we were delighted to have raised over \$40,000 at these events and with the associated fundraising campaigns. We were also pleased to see many workplaces support us with “matched giving.”

In addition to community fundraising, our CDH Sunflower Sunday event hosts and volunteers worked hard to organise fundraising activities at each location to raise funds for CDH Australia.

A special acknowledgement of appreciation to each of our CDH Sunflower Sunday 2017 volunteer event hosts:

- Townsville hosted by Mikayla Lythgo and Carine Ziegler
- Brisbane hosted by Kylie Stace and Carmel Chesterfield
- Sydney hosted by Donna Triantafyllou, Tara Gallo and Josh Kirkwood
- Melbourne hosted by Courtney Vodopic, Elizabeth Proctor and Chantelle Morrison
- Perth hosted by Rozanne Watts
- New Zealand hosted by Susan Groube

A warm and heartfelt thank you to all of the volunteers who donated their time to help our event hosts make CDH Sunflower Sunday 2017 a very special day for our families. We are also grateful for the contributions of board members, local businesses, schools, workplaces, fundraisers and donors. Thank you on behalf of every CDH family who has benefited from CDH Australia’s services in 2018.



CDH champs

We appreciate and are sincerely thankful to the many families who fundraised and encouraged vital donations in honour of CDH children.

Heartfelt thanks to our 2017-2018 CDH Champs:

- Noah's Hope by Chantelle and Joshua Morrison
- Alyssa and Noah Memorial Walk by Danielle Kessner and Margaret Polacska
- 10kms for Sean by Tara Gallo
- Fight CDH with Xander by Kali McAuliffe
- Kaddy Conquering Everest by Kaddy Fogarty
- Amelia's Hope by Tony Burgess
- Anna's fundraiser for CDH by Anna Fogarty
- Calendars for CDH by Courtney and Dennis Vodopic
- Collaborate for a Cause by OllyG Handmade, Rees Kids, Rogus Industries & ZacMak Designs
- Entertainment Book fundraising by Elizabeth Monforte
- Footy Tipping Competition by Danielle Kessner
- Lani's fundraising for CDH by Alannah Sullivan
- Ruby's Crew - Dress Up Day for CDH by Kate Shaw
- Solomon's Slam by Amanda and Glenn Tongue

Noah's Hope

Chantelle and Joshua Morrison held the third annual 'Noah's Hope' fundraiser on 9 August 2017 with a "Casino Royale" theme. Held in Bendigo Victoria, the event was the second casino style fundraising event which Chantelle and Joshua have hosted for CDH Australia. Additions included a silent auction, raffle, balloon pop and other fun activities to help raise funds to support CDHA. The event increased the attendee's awareness of CDH and raised over \$5000 to support families affected by CDH.



Alyssa and Noah Memorial Walk

On Saturday 11 November, Margaret and Lorre Polacska along with Danielle and Julian Kessner trekked 35km along the Warburton Trail. Each kilometre represented a year since their respective children, Noah and Alyssa, were lost to congenital diaphragmatic hernia. Friends and family were asked to donate \$35 (one dollar for each kilometre) as part of CDH Sunflower Sunday 2017. Together the team raised over \$2400 to support families affected by CDH.



10kms for Sean

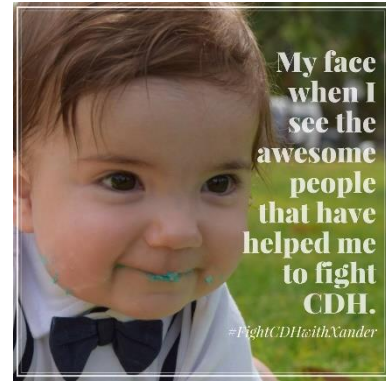
On Saturday 4 November, Tara Gallo took part in a 10km running event in memory of her second son, Sean. When Sean was born in 2015 his prognosis was good; he was given an 85-90% chance of survival. Sadly, Sean passed away at 8 days old. Tara asked friends, colleagues and family to donate to her online fundraising campaign and her employer, Macquarie, generously matched the total. As a result, Tara, raised over \$28,000 for CDH Australia. During her run, Tara had the names of other CDH angels on her arms to honour the families of children lost to CDH.



Fight CDH with Xander



Xander's mum, Kali McAulife, decided to raise funds for CDH Sunflower Sunday in honour of her son Xander. Xander was about to have his first birthday, and had been diagnosed with right-sided CDH at birth. Kali was one of our first "online" fundraising campaign success stories. Kali generated donations through emails and social media posts about Xander, his journey with CDH and how CDH Australia had supported her family. Kali's family also helped with her fundraising efforts by hosting events such as a drinks fundraiser at school. Kali and her family raised over \$2800 to support families affected by CDH.



Kaddy Conquering Everest



Kaddy's sister, Anna, was born with CDH 32 years ago. "Anna had multiple surgeries and ongoing health issues growing up. It would have been beneficial for us to have the support that CDH Australia now provides to families," Kaddy says. Kaddy trekked to Mount Everest Base Camp in October 2017 to raise over \$1400 to help support families on their own CDH journey.

CDH Australia Ambassadors

Three ambassadors joined the CDH Australia family to help raise awareness for congenital diaphragmatic hernia. Each ambassador is a CDH survivor, a leader in their chosen sport and an inspiration to CDH survivors. To help promote CDH Sunflower Sunday, each created a one-minute video to tell their story, raise awareness and encourage event registrations.

Brendan Santalab



Brendon Santalab is an Australian professional football player who plays as a striker for A-League club Perth Glory. Outside of football, Brendon is the Co-Founder and Director of My Game Guru, the world's first Grassroots sports tracking app for planning and locating sports games.

In 2017, Brendon wrote an article for the Player's Voice detailing his CDH journey called "It's a miracle I lived at all".

Michael Shelley

Michael Shelley is an Australian long-distance runner who competes in track events and road races. He has won gold medals in the marathon event at the 2014 Commonwealth Games at Glasgow, Scotland, and the 2018 Commonwealth Games at Gold Coast, Australia.

Michael has also represented Australia at the IAAF World Cross Country Championships and the IAAF World Half Marathon Championships. On the road, he won the Gold Coast Half Marathon and City2Surf race in Sydney.



Michael lives on the Gold Coast and regularly attends CDH Sunflower Sunday in Brisbane.

Olivia Vivian



Olivia Vivian is an Australian artistic gymnast who competed in the 2008 Summer Olympics. After the Olympics, Olivia competed for Oregon State University in NCAA gymnastics for four years.

Olivia also competed in the 2005 and 2006 World Gymnastics Championships. In 2017 she was a competitor in the inaugural season of Australian Ninja Warrior. In 2018, she competed in the second season of Australian Ninja Warrior and was the only woman to make it to the Grand Final.

Research and collaboration

Fetal Therapy Research study at the Ritchie Centre

CDH Australia formally established a CDH research fund in 2015. In September of that year, CDH Australia donated \$30,000 to The Ritchie Centre (Monash University and Hudson Institute of Medical Research) to support a pilot study into fetal therapies for CDH by Dr Ryan Hodges. At the time, Dr Ryan Hodges led the high-risk obstetrics program at Monash Health, and he is now the Director of Women's and Newborn services. He originally studied medicine at Monash University before receiving specialist training in fetal surgery and medicine in Belgium and Canada.

Ryan and his PhD student, Aidan Kashyap, are investigating innovative therapies to improve the way that babies with CDH transition to newborn life. "FETO" is a fetal surgical therapy already offered at some specialist centres around the world, but now Ryan's team are also investigating a medication called sildenafil. When given to a mother during pregnancy, results from preclinical studies suggest that it can improve the way the babies' lungs develop and allow them to breathe a little easier after birth. They are also looking at the effects of delayed umbilical cord clamping - allowing the baby to more gradually transition to newborn life while still supported by mum's placenta. Early results are promising and Ryan and Aidan plan to publish their results by the end of 2018.

In May, two members of the CDHA board, Tara Gallo and Courtney Vodopic, visited the Monash Health Translational Precinct (MHTP) to gain a better understanding of the bench-to-bedside research being undertaken at The Ritchie Centre and Monash Children's Hospital (MCH). The thoughtful care and scope of research was impressive, and we look forward to seeing the formal results later this year.

Mr. Ram Nataraja and Aidan Kashyap also joined us at the Melbourne CAAF to give presentations on the current management of CDH babies at MCH, and some of the exciting new research on the horizon.

Lung Foundation Australia

Lung Foundation Australia is a national charity dedicated to supporting anyone with lung disease. In 2015 they launched 'Young Lungs', a paediatric program created specifically to help families and carers of children with a rare lung disease. CDH Australia provided feedback and recommendations to assist with the program's establishment.

One of their current initiatives is to produce a practical booklet with tips for managing lung diseases (such as congenital diaphragmatic hernia) in young people. CDH Australia, as well as other major lung-related charities, will partner with them to produce the booklet.

Follow-up clinics

There are CDH follow-up clinics around Australia, and CDH Australia is working to strengthen our relationships with these clinics. They are:

- Royal Children's Hospital (RCH) – Neurodevelopmental Follow-up clinic
- The Children's Hospital at Westmead – CDH / Infant Lung Multidisciplinary Clinic
- Sydney Children's Hospital Randwick

Further information on the follow-up clinics is on the CDH Australia website at <http://cdh.org.au/hospital-medical-institutes/>.

Board of Directors

CDH Australia welcomed new and returning members to the board for 2018. Retaining their positions were Secretary, Courtney Vodopic; and Co-Presidents Tara Gallo and Joshua Kirkwood. They were joined by a newly elected Vice-President, Lona Sarson and Treasurer, Ray Cohen.

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 – Lona Sarson: Lona's career has spanned a number of senior human resources roles within the not-for-profit profit health and sporting sectors. Lona is currently employed as the Head of People and Culture Operations within the insurance industry and lives in Brisbane.

Secretary – Courtney Vodopic: Courtney has worked in the public service for 10 years in a range of roles – from counselling to executive management in both community and custodial settings, and corporate head office. Mum of CDH Lucy, Courtney lives in Melbourne.

Treasurer – Ray Cohen: Ray is a chartered accountant and has experience working across a broad range of accounting functions within commercial and public practice environments. During 2018 Ray made the move to London, where he continues his commitment to CDH.

Sincere thanks to all our Board Members for their effort and commitment in 2018 to ensure that CDH Australia can continue to deliver upon its mission and strive towards achieving the vision of no family facing CDH alone.

Volunteers

As a volunteer-led organisation, our people truly are the backbone of our organisation. Our volunteers serve on our board, deliver programs and offer specialised services. It is the inspirational compassion and generosity of our volunteers which provides us with the momentum necessary to ensure that no family faces CDH alone.

Support Services:

Carmel Chesterfield
Emily Prunty
Kylie Stace
Cheryl-anne McBay
Sharon Knott
Jo Ross
Carine Ziegler
Courtney Vodopic
Kali McAulife

Grants & Administration:

Kezia Brett
Susan Fisher

Events & Fundraising:

Chantelle Morrison
Krystal Downing
Anna Fogarty
Carmel Chesterfield
Rozanne Watts
Elizabeth Hancey
Mikayla Maurice
Susan Groube
Courtney Vodopic
Tara Gallo
Susan Fisher
Carine Ziegler
Donna Triantafyllou
Rebecca Gargan
Elizabeth Monforte
Charlie Monforte
Tari Bonser
Jenna Bonser
Kylie Stace

Projects & Production:

Danielle Kessner
Tara Kessner

Join us or contact us

Postal Address: PO Box 5034, North Geelong VIC 3215

Email: information@cdh.org.au

Phone: 1800 149 562

www.cdh.org.au

ABN: 60 131 315 145

Financial report for year ended 30 June 2018

Income Statement

Revenue	2018	2017
	\$	\$
Donations	54,218	33,755
Fundraising	50,522	14,231
Memberships	1,091	735
Grants	10,000	6,091
Interest Received	457	440
Other Revenue	-	1,587
Total Revenue	116,288	56,839
Expenditure		
Auditors Remuneration	1,539	-
CAAF & AGM	15,813	8,315
Consultancy Fees	40,235	-
Fundraising Costs	9,288	3,741
Insurance	2,682	2,683
MYOB Fees	315	280
Paypal Fees	857	467
Postage	303	129
Strategy Day	2,318	2,682
Sunflower Sunday	5,965	-
Telephone	937	961
Website & IT	2,811	2,891
Depreciation	547	-
Other Expenses	769	940
Total Expenditure	84,379	23,090
Net surplus for the year	31,910	33,749

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