



Annual Report 2015



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 2014-15. It was a year to 'test the waters' as CDH Australia undertook a number of new initiatives to continuously improve and grow.

As President, I was fortunate enough to undertake an Australian Institute of Company Directors scholarship on the Role of the Not for Profit Chair made possible by generous support from the Perpetual Foundation and JS Love Trust. The course provided a great opportunity to build skills in leadership and governance, network with large not for profit organisations, and gain insight into many of the challenges not for profits face.

In late May, our support volunteers attended a course customised to our needs at the Australian Centre of Grief and Bereavement in Melbourne. The aim of the training was to provide our support volunteers with the knowledge and tools to care for themselves whilst providing appropriate support for other families. This was made possible through the generous support of the Collier Charitable Foundation.

We looked into how digital technology could streamline our administration and chose ASI iMIS200 as the platform to develop our community and automate membership and e-commerce administration. We look forward to launching our new community portal, with member groups, event management and fundraising capabilities, on our website in late 2015. This technology was made possible by the generous support of Opec Systems and the Murphy family.

We formed collaborations with the Lung Foundation and Monash Health to advocate for families and invest in research. Further details of these partnerships are provided on page 8.

Our awareness day, Sunflower Sunday, took a slightly different format in 2015 with the first awareness walks undertaken as part of the day's activities to profile CDH Australia publicly.

The CDH Australia Annual Forum in Brisbane was an informative and successful event with an array of speakers from Mater Health Services and group support sessions. Further details of these events can be found on pages 9 and 10.

Financial results

CDH Australia's total operating revenue for the year ended 30 June 2015 was \$70,625, a 145% increase from 2014. Philanthropic grants contributed \$38,176 and fundraising and donations contributed \$29,682 to overall income. CDH Australia registered a surplus of \$10,878 for the 2014/15 financial year.

CDH Australia was fortunate to receive philanthropic grants this year that helped fund our new website and branding, the CDH Australia Annual Forum and training our volunteers. 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.

In an inspiring and kind-hearted mission, the family and friends of Kristin and Chris Bitmead rallied to create something special to keep the memory of their daughter Clementine alive and spread awareness of the condition. They began making and selling beautiful "Candles for Clementine" with all profits donated to CDH Australia.

Jeff Maurice once again organised the Shoes off for Marley event this year, in honour of his daughter Marley, to fundraise much-needed funds for CDH Australia and the Townsville Hospital. It is the third time the annual event has been held.

Taleah and Joel Blayney, raised funds for CDH Australia and awareness of CDH by holding a tombola in their son Kurt's honour in Maryborough, Queensland, which held special significance as it was held on our awareness day - Sunflower Sunday.

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.

Fact and figures for the year:

- Financial members 44
- Facebook followers 1258 (140% increase)
- Highest Facebook post reach 7,660 (organic)
- 18,500 CDHA website users (313% increase)
- Media coverage:
 - 1,367,000 viewers in 5 metro cities watched SEVEN News report on Monash Health's CDH pilot study
 - 400,000 viewers in Australia and 1 million viewers in the UK regularly tune into to watch Neighbours
 - TODAY Weekend program, which covered the story on Noah's Hope Gala fundraiser for CDH Australia, had around 200,000 viewers
 - numerous articles in local papers around the country.

Many of the opportunities that CDH Australia enjoyed this year were created by parents of children with CDH raising awareness: the fundraising, wide media coverage, Neighbours CDH storyline and our partnership with Monash Medical, all came about because a CDH parent took the initiative to make a difference. Our community relies on much-needed support, both financial and networking and partnerships, to exist.

We look forward to greater growth next year and seeking more opportunities to collaborate in order to step closer to realising our vision and mission.

A handwritten signature in black ink, reading "M. Polacska". The signature is fluid and cursive, with the first letter 'M' being particularly large and stylized.

Margaret Polacska

President

About us

CDH Australia is a national health promotion charity for families, friends and medical professionals affected by congenital diaphragmatic hernia (CDH). Our organisation is run by a Board of Directors and we have membership spread throughout Australia.

Our vision

For no family to face congenital diaphragmatic hernia (CDH) alone.

Our mission

To improve the lives of those affected by congenital diaphragmatic hernia (CDH), support and advocate for families, raise awareness and support research.

Our strategic priorities

- Increase profile and revenue
- Increase support and partnerships
- Increase awareness of CDH.

What does CDH Australia mean to you?



Our family has been linked to CDH Australia for almost two years now. When I first contacted them I wasn't sure what to expect. I soon learned that CDHA would become an invaluable support for whatever lay ahead with our unborn son. I discovered a group of people who are more like family than just a "group", a family whom without I don't think I could of got through the pregnancy, or the birth, or anything since then. We were lucky ones; our son survived. But the heartache we have

experienced through everything, is something many will never comprehend. Heartache, made that little easier to get through thanks to our CDHA family.

The CDH rollercoaster brings with it an enormous magnitude of feelings, emotions and the unknown. But everyone you speak to in the forums, that you personally meet, that you become close to, understands it all. They understand why you randomly start crying, why every trip to the hospital even now, still causes anxiety, why you worry every time the smallest thing seems to be wrong with your child. Everything is normalised, you are not judged. It isn't just your CDHer that is welcomed with open arms but your whole family. CDHA is there for those who grieve after the most unthinkable loss happens, for those who celebrate their child leaving the hospital in their arms.

When I think about what CDHA means to me/my family, there is a multitude of responses. They are our saving grace through the storm. They are an organisation so dedicated to those who link in that you can never thank them enough for all that they do. CDHA are our family. They are who I want to share our son's highlights and his challenges with. They are who I turn to when I feel lost, scared, and unsure. CDHA are just simply amazing, and without them, all of us families facing the CDH rollercoaster would potentially be alone. **Chantelle, mum of CDHer Noah**

"CDHA are just simply amazing, and without them, all of us families facing the CDH rollercoaster would potentially be alone. "

"I have been given hope, strength and courage in the midst of darkness and despair. They are my stars on the darkest nights, the calm amongst the storm and the rainbow through the rain. "

Through text, phone, facebook and email we are never alone and we are able to reach out whenever we need, no matter where we are. The support, guidance, words of comfort and understanding ease the burden we carry every day and help us keep on moving forward. It is somewhere safe where we can freely express our feelings and emotions without criticism or judgement.

Family is a group experience of love and support and that is what CDH Australia is to me.....family. We are a group of people from all different walks of life but we have all been brought together by one single medical condition. The CDH journey is made easier with the support of this family. It is said that the family that grieves together, heals together. **Carmel, mum of angel CDHer Arabella**

CDH Australia has meant that I haven't had to face this journey alone. I have been given hope, strength and courage in the midst of darkness and despair. They are my stars on the darkest nights, the calm amongst the storm and the rainbow through the rain.

Through text,



Supporters 2014-15

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

Baker Foundation
Collier Foundation
Marian EH Flack Trust
Perpetual Foundation and JS Love Trust.

Sponsors

Smith Wilson
Grace Newborn Centre - CHW
Dan Harvey
West Family
Rodney Greenfield Photography
Kleid family
Wilmar Sugar
KFSU
Romanyk Family
Kenway Family
Shaw Family
Rooftight
Murphy Family
Pauline Hammett
Opec Systems
Teramo Catering

Corporate Donors

Bunnings
Macquarie Group Foundation (Macquarie Gift Matching Program)

Community Support

Tara Gallo and Joshua Kirkwood
Kristin and Chris Bitmead
Eleanor Bullen
Mikayla Lythgo and Jeff Maurice
Taleah and Joel Blayney
Franet Family
Fergusson Family
Lea Gardham and Ian James
Carmel Chesterfield and Daniel Keen
Elizabeth Montforte
Peter Freeman and Mary McLaughlin
Shaun Wyss - HQ Cruise Club of Victoria

Pro Bono Support

As One Digital Design
Corrs Chambers Westgarth

Research and collaboration

CDH pilot study at Monash

Dr Ryan Hodges, leads high risk obstetrics (Perinatal Services) at Monash Health. Ryan trained in fetoscopic tracheal occlusion for CDH with Professor Jan Deprest, who visited Melbourne in July and is conducting experiments with Ryan. Monash Health is conducting a world first pilot study in partnership with The Ritchie Centre, Hudson Institute of Medical Research and Monash University Department of Obstetrics and Gynaecology. They have developed a sheep model of CDH and are testing new therapies to treat the lungs in utero before the baby is born. Specifically, they are using a small camera to access the lungs of the fetus with CDH, and then delivering stem cell therapy to the lungs and giving medication to the mother in order to promote fetal lung development before birth. They 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 and are confident that the pilot data will show improvement in the quality of lung tissue and increased survival for babies with severe CDH.

CDH Australia proudly supports this research project, and is excited by the potentially life saving outcomes that it may lead to.

Young Lungs Program

The Young Lungs Community Consultation was held on 28 February and was an opportunity for CDH Australia to provide feedback and recommendations to the Lung Foundation Australia, together with other community groups, to consider when planning out the Young Lungs Program strategy.

The Young Lungs program, the first Lung Foundation Australia's paediatric specific program, will work with health professionals, families and disease-specific organisations for improved outcomes for all paediatric rare lung diseases, such as, congenital diaphragmatic hernia.

This program will be led by Professor Adam Jaffe, a paediatric Respiratory Specialist and Chair of the Young Lungs Clinical Advisory Group. Adam will present at our CDH Australia Annual Forum in Sydney in October.

Outcomes for families from the program will include information guidebook, online forums, community nurse to champion in each state, support, advocacy and promotion.

Follow-up clinics

There are CDH follow-up clinics around Australia. These 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>.

Events

CDH Australia Annual Forum (CAAF) 2014

The CAAF 2014 was held in Brisbane. Day one was held at the Mater Medical Centre and began with President, Chris Waite, launching CDH Australia's new logo and website, and our inaugural calendar.

This was followed by guest speakers:

Dr Glenn Gardener, Director of Maternal Fetal Medicine (MFM), Mater Mothers' Hospital, who spoke about CDH Prenatal Therapy – The TOTAL Trial.

Cherelle Evans, Senior Social Worker, Mater Health Services, who spoke about how social work is a standard multi-disciplinary referral in case management of CDH at MFM. The social work Case Manager – midwifery - is the coordinator of multiple professionals, a central point of contact.

Dr Adrian Mattke, a Paediatric Intensivist from the Mater Children's Hospital. Dr Mattke is part of the ECMO (Extracorporeal Membrane Oxygenation) group, which developed the current approach for CDH patients requiring ECMO. He spoke about the ventilation options and how they decide on ECMO.

Professor Roy Kimble, Paediatric Surgeon and Director of Burns and Trauma in the Combined Department of Paediatric Surgery, Brisbane. Prof Kimble also spoke about the variation in scope of research projects and trials leading to differing results and statistics, and about the outcomes in regards to patch and stitch repairs.

Day two was held at Sports Super Centre in Runaway Bay and opened with a ceremony to honour CDH children. This was followed by a share circle where participants shared their individual stories, and group sessions facilitated by social workers to cover specific topics.

Many thanks for the professional organisation of the successful forum go to event organisers Jessica Keavney and Linda West, also to Tara Kessner for once again producing a beautiful and moving slideshow presentation for the ceremony.



Sunflower Sunday

Sunflower Sunday, held on 29 March, started its growth to a more public awareness event this year by including an awareness walk profiling our cause and brand in public areas across the country. Many families enjoyed a great social day out and raised awareness of CDH by raising banners, handing out balloons and sunflower seeds.

We also began our Sowing Seeds for CDH awareness campaign by distributing 250 packets of sunflower seeds generously donated by Bunnings. The campaign aims to grow supporters through the fun of growing sunflowers and harvesting seeds to pass on to more people to repeat the cycle, with each grower asked to watch our Sowing Seeds for CDH video.

Next year we hope to be in a position where we can include hospitals, businesses and schools and kindergartens connected to CDH families in our Sunflower Sunday celebrations by holding awareness raising morning teas with gold coin donations.



Sunflowers are unique in their ability to provide energy in the form of nourishment and vibrancy; attributes that mirror the sun and the energy provided by its heat and light. We hope one day the sunflower will be widely recognised in Australia as representing CDH, just as the daffodil is for cancer.

Board of Directors

CDH Australia welcomed new and returning members to the board for 2015. Retaining their positions were Secretary, Linda West; and Family Liaison Coordinator, Sharon Knott; who were joined by a newly elected President, Margaret Polacska; and Vice President, Damon Knott – the first male to join the board. After some searching, the board was thrilled to appoint another male to the board, John Hurley, in the role of Treasurer.



President – Margaret Polacska: Margaret 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.



Vice President – Damon Knott: Damon has run his own advertising/web agency for 10 years and is married to Sharon Knott and dad to CDHer Liam.



Treasurer – John Hurley: John joined CDHA in 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.

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



Family Liaison Officer – 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 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	Sharon Knott
Linda West	Sabine & Lindsay Kingston
Helen Harrison	Mel Nichol
Lisa Bonser	

Administrative positions

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

Join us or contact us

Registered Office: C/-As One, Suite F, Level 1, 52 Davidson Terrace, Joondalup, WA 6027

Postal Address: PO Box 1366, Joondalup DC, WA 6919

Email: information@cdh.org.au

Phone: 1800 149 562

www.cdh.org.au

ABN: 60 131 315 145

Financial report for the year ended 30 June 2015

Income Statement

Revenue	2015	2014
Membership	1,290	900
Donations	27,121	5,075
Fundraising	2,561	16,781
Sponsorship/grants	38,176	2,750
Postage for merchandising	7	231
Sales	254	1,911
Interest received	1,216	881
Total revenue	70,625	\$28,529
Expenditure		
Auditors Remuneration	1,100	1,100
CAAF expenses	9,796	8,035
Website & IT expenses	19,000	888
Merchandise	118	844
Printed material	0	367
Postage	528	234
Insurance	3,089	3,349
PayPal fees	227	109
Telephone (1800/mobile)	974	972
Donations	0	1,107
Bank fees	27	7
CDH Workshop	22,649	57
Other	193	1,610
Total Expenditure	59,747	\$18,681
Net surplus for the year	10,878	\$9,848

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