



## Annual Report 2019



Supporting families and medical  
professionals along their  
CDH journey.

ABN 60 131 315 145

[www.cdh.org.au](http://www.cdh.org.au)

## President's report

I'm pleased to present the 2019 Annual Report. This report provides a summary of CDH Australia's activities and financial results for the financial year 2018-2019. FY19 was again a very busy year for CDH Australia – we built on the success of CDH Sunflower Sunday, held our annual conference in Brisbane, received an influx of new families, and continued to adjust our model to better support families and raise awareness.

CDH Sunflower Sunday was held in five locations this year. The day is always a highlight, with time spent with old friends and meeting new families. This year we saw some great results from our fundraisers, with the team raising over \$20,000 in campaigns aligned to CDH Sunflower Sunday. A massive thank you to our event volunteers and fundraisers for making the national campaign a success.

We have seen a steady increase in the number of families we support and continue to refine our model to offer consistent and quality support. Thank you to all our support services volunteers who work so hard to support so many families.

We also celebrated our eighteenth CDH Australia Annual Forums (CAAF) in Brisbane in June 2019. Highlights from the event include a visit from CDH Australia ambassador Olivia Vivian, compelling presentations from medical professionals and a wonderful group of CDHA families. Thanks to everyone for making this year's event a lot of fun. We look forward to next year's event in Sydney.

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.

Your support is vital for CDH Australia to continue supporting families impacted by CDH and funding medical research that could improve outcomes for these children. Please consider donating, fundraising and volunteering today so we can continue this important work.

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

Regards,

A handwritten signature in black ink, reading 'Tara Gallo' in a cursive script.

Tara Gallo  
**President**

## 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 2019.

### Our Vision: For no family to face CDH alone

<b>Our mission</b>	<b>RAISE AWARENESS</b>	<b>SUPPORT FAMILIES</b>	<b>SUPPORT RESEARCH</b>
<b>Our 2019 priorities</b>	<b>Maintain our momentum:</b> <ul style="list-style-type: none"><li>▽ Create an integrated online presence</li><li>▽ Regularly communicate with our stakeholder groups</li><li>▽ Continue the success of CDHSFS</li></ul>	<b>Strengthen and broaden support:</b> <ul style="list-style-type: none"><li>▽ Expand support resources and family assistance</li><li>▽ Continue to enhance our volunteer-driven support model</li><li>▽ Engage specialist volunteers</li></ul>	<b>Closer relationships with medical professionals:</b> <ul style="list-style-type: none"><li>▽ Develop a plan to systematically engage our medical and research community</li><li>▽ Offer a grant to relevant local CDH researchers in honour of our 20 year anniversary</li></ul>
<b>What success looks like</b>	<b>More contact at diagnosis:</b> from ~25% of families to >60%, sustainably <b>More people:</b> online, at CAAF and CDH Sunflower Sunday <b>More funding:</b> develop a funding strategy that covers fundraising, grants and donations		
<b>How we work</b>	<b>Simple, Standardised, Sustainable</b>		
<b>Foundations</b>	<b>Volunteer Management:</b> scope roles/projects, recruit, train, engage and acknowledge our volunteers <b>Regulation, Risk &amp; Compliance:</b> document internal procedures and develop detailed handover notes <b>Information &amp; Technology:</b> develop data strategy and IT architecture based on IT Strategy On A Plate program		

## Events

### CDH Australia Annual Forum: June 2019



*CDH Australia Ambassador Olivia Vivian with CDHers at CAAF 2019*

The Australian CDH community met in Brisbane for the eighteenth CDH Australia Annual Forum, known as CAAF. Held across two days at the Mantra on Queen, we were pleased to see so many families come together to share their CDH children and experiences.

A jam-packed first day saw families mingle and connect with friends, old and new. We also heard from a range of engaging and informative speakers. In particular, we wish to thank Nicole Millis, CEO of Rare Voices Australia; Dr Glenn Gardener of the Mater Mothers' Hospital; Mr Craig McBride of Children's Health Queensland Hospital and Health Service; and Aidan Kashyap of the Hudson Institute of Medical Research.

Day two saw us change pace, with some hands-on family-friendly activities in the morning, before CDH Australia Ambassador and CDH survivor Olivia Vivian joined us for the afternoon. We are incredibly grateful to Olivia for taking the time out of her busy schedule to spend time with us. Unsurprisingly, feedback from our delegates showed that our afternoon with Olivia was our most popular event at CAAF!



## CDH Sunflower Sunday: November 2018



*Families gathered in Perth for CDH Sunflower Sunday*

CDH Sunflower Sunday is Australia's national awareness day for congenital diaphragmatic hernia; a day where our community comes together to meet in person, build a stronger and more connected network, and raise awareness about congenital diaphragmatic hernia. It is a beautiful event that brings family and friends together with one goal: to ensure no family faces CDH alone.

Held every November, guests came together on Sunday November 11 to join in the CDH Awareness Walk at CDH Sunflower Sunday events across Australia, raising awareness and showing support for members of the CDH community.

The Walk finishes with a heartfelt reading to honour our CDH angels and their families. We close the reading with a beautiful ceremony where bubbles are blown into the sky as a group, to pay tribute to those facing their own CDH journey, and to remember loved ones lost.

We are seeing more families join us on CDH Sunflower Sunday every year, and were delighted to see 400 guests attending in 2018. Families came from far and wide to join together in celebration and remembrance in what is fast becoming the most important date in the Australian CDH calendar.

A special acknowledgement of appreciation to each of our CDH Sunflower Sunday 2018 volunteer event hosts:

- Townsville hosted by Mikayla Maurice 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 & Denis Vodopic, Elizabeth & Charlie Monforte
- Perth hosted by Rozanne Watts

A warm and heartfelt thank you to all of the volunteers who donated their time to help our event hosts make CDH Sunflower Sunday 2018 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 2019.



*CDHer Marley raising awareness in Townsville on CDH Sunflower Sunday*



## CDH Australia Ambassadors

Our three ambassadors have been working with CDH Australia 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.



### Brendon Santalab

Brendon Santalab is an Australian professional football player who plays as a striker for A-League club Dandenong City SC. Brendon has previously played for Perth Glory and Western Sydney as well as a number of other clubs in Australia and overseas. Outside of football, Brendon is the Co-Founder and Director of My Game Guru, a grassroots sports and game 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'. In this article, he quotes:

*"Growing up with the knowledge that I came so close to death shaped who I am as a person...it sparked a fire within me."*

### 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 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 continues to live 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. She has also competed in the 2005 and 2006 World Gymnastics Championships.

In 2017 Olivia was a competitor in the inaugural season of Australian Ninja Warrior. Olivia also competed in the second and third seasons of Australian Ninja Warrior in 2018 and 2019, and was the only woman to make it to the Grand Final in both seasons. Olivia said on the television show:

*"I hope these ninjas...can inspire others to give it a crack, give something new a go, because you just don't know what road it's going to take you down".*

Olivia also competed in the international Ninja Warrior finalists competition, being the only female in the Australian team which came second to the USA.

Olivia was also our first ambassador to attend a CDH annual forum this year.



CDHA board members (from left) Carine, Courtney and Tara with Olivia



## Research and collaboration

### Fetal Therapy Research study at the Ritchie Centre

Supporting research is one of the three pillars of CDH Australia. We began our efforts in 2015 when 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 and his PhD student, Aidan Kashyap. The main research goals for CDH Australia are to drive research into improving outcomes for people diagnosed with CDH and to foster ongoing research.

Ryan and his team began their research by 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. This research showed some promising results and is now being reviewed on a larger scale as part of international research.

Through this research, Ryan's team identified other unexpected positive results and the effects of delayed umbilical cord clamping. We had the pleasure of having Aiden, among others, speak at the CAAF this year – where he talked about their further research into physiologically based cord clamping. The team are working with international collaborators to develop a clinical trial specifically aimed at infants with CDH. More details on this and the most recent news from the team at the Ritchie Centre can be found here:

<https://hudson.org.au/latest-news/giving-little-lungs-a-fighting-chance/>

This year we have been working towards another one-off research grant fund like we provided back in 2015 and also to develop a steady and consistent research funnel to promote ongoing research into CDH. For a one-off research grant, we are reviewing research proposals from the Ritchie Centre and several universities across Australia with a focus on CDH. Ongoing research funding will help sustain progress on CDH outcomes, grow new understanding, and encourage new researchers coming into the field.

### 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

## Observership program

This year the CDH Australia board had Annabel Downing join us through the Observership Program. The Observership Program provides training and practical experience in not-for-profit board leadership and ongoing networking opportunities to create a passionate and motivated community of future leaders.

Annabel works as a consultant in the social sector at Social Ventures Australia where she advises not for profits, corporates and government on creating greater impact. Annabel participated in the Observership Program to get a better understanding of how not for profits are run and to understand the role of the board. As part of her time on the Board of CDHA Annabel has led work in developing our story of change and Theory of Change to help articulate the impact CDHA is striving to achieve. Through identifying the priority outcomes of our programs, Annabel has also been working on developing a measurement and evaluation framework so that CDHA can measure the outcomes of its programs for families. This will help CDHA optimise its services in the future to ensure we are achieving impact for our end beneficiaries. Annabel has been a valued member of the team through 2019 and her work will underpin much of CDH Australia's work for years to come.

This year CDH Australia has focused on defining its story of change. During our strategy workshop we undertook an exercise to develop our draft narrative of change and a more detailed Theory of Change. Both these frameworks are helpful in articulating the impact our organisation is striving to achieve as well as identifying the outcomes we want to see as a result of our support services and activities. This work will also support us in being able to measure progress against our priority outcomes for individuals diagnosed with CDH as well as their families and friends, the medical community our organisation and the wider community. Ultimately, this will mean we can improve our services to better achieve those outcomes and have greater impact.

Both of these frameworks are live frameworks that we will continue to update as our organisation grows and changes.

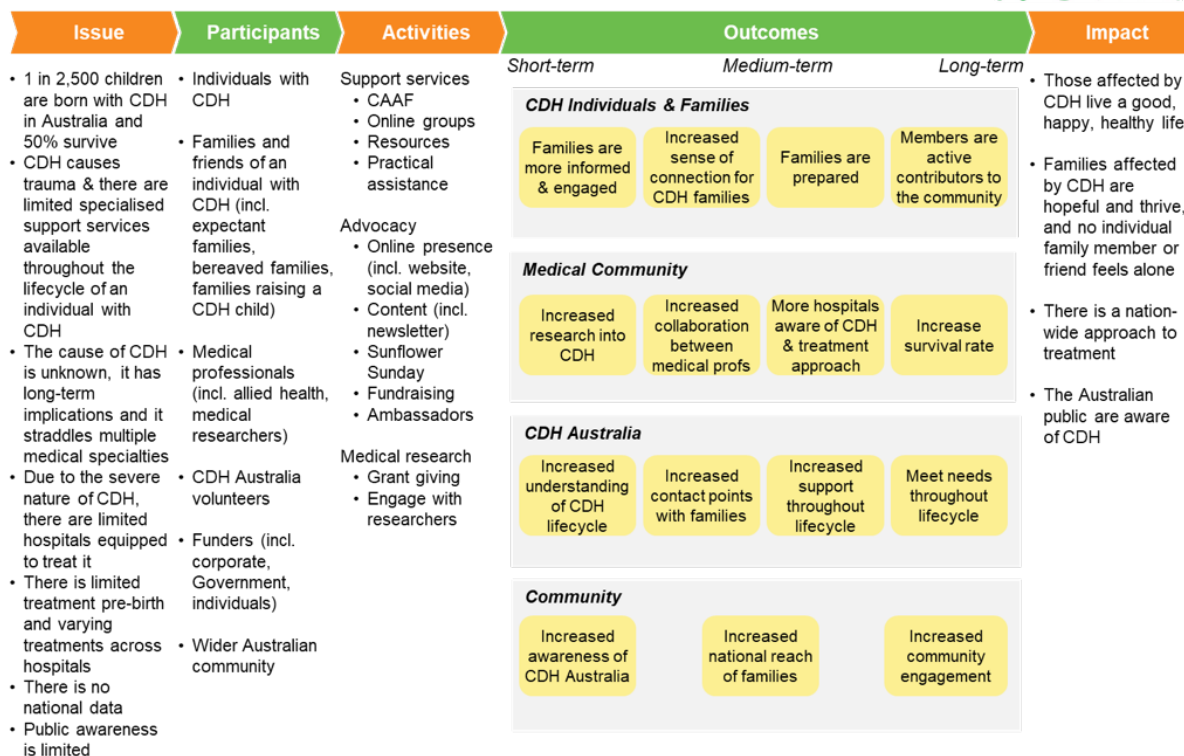


*CDHA board members (from left) Stuart, Tara, Derek and Courtney with Annabel*

## CDH Australia's Story of Change



## CDH Theory of Change





## Board of Directors

CDH Australia welcomed new and returning members to the board for 2019. Retaining their positions for this year was President Tara Gallo; Treasurer, Ray Cohen; and Courtney Vodopic transitioned from secretary to general board member. Derek Harris and Stuart Wall both joined as general board members. Carine Ziegler joined as secretary part way through the year.

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

**Secretary – Carine Ziegler:** Carine is a Social Worker who has worked for almost 10 years in a variety of community and government settings and roles including counselling, group programs, mental health and management. Carine first came into contact with CDHA whilst pregnant with her CDHer, Sofia. Carine lives in Townsville.

**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. Ray continued his commitment to CDH all the way from London, where he moved in 2018.

**General Board Member - 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 CDHer Lucy, Courtney lives in Melbourne.

**General Board Member – Derek Harris:** Derek is dad to young CDHer Riley, and joined the board to offer his professional expertise and skills to help CDHA continue to break technological barriers in their quest to offer support to every Australian CDH family.

**General Board Member – Stuart Wall:** Stuart works at a medical device company, where he has held a number of roles from managing post market surveillance, to his current role as a design engineer for custom cranial implants. Prior to this he was emerging as a tech analyst and web developer. Stuart has a Bachelors of Biomedical Engineering, as well a Bachelor of Science. Stuart became involved with CDHA to bring his background in science and the medical industry to help build the research support pillar of the organisation.

*Sincere thanks to all our Board Members for their effort and commitment in 2019 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  
Kylie Stace  
Emily Prunty  
Sharon Knott  
Kristal-mae Littlejohns  
Carine Ziegler  
Cheryl-anne McBay  
Jo Ross

### Grants & Administration:

Kezia Brett

### Events & Fundraising:

Carmel Chesterfield  
Rozanne Watts  
Kylie Stace  
Mikayla Maurice  
Carine Ziegler  
Tara Gallo  
Courtney Vodopic  
Denis Vodopic  
Donna Triantafyllou  
Elizabeth Monforte  
Charlie Monforte  
Shanae Cross  
Ebonie Trotter

### Projects & Production:

Danielle Kessner  
Tara Kessner

## Financial report for year ended 30 June 2019

**Financial report not yet available.**

**Full financial report is expected to be completed by auditors and available on CDH website within 2 weeks.**

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

**Join us or contact us**

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