

# CDH Australia

## Annual Report 2020



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

We are pleased to present the 2020 Annual Report highlighting the activities and financials of CDH Australia for the 2019-2020 financial year.

The financial year started off well, particularly with the hugely successful 2019 CDH Sunflower Sunday event raising more than \$20 000 specifically to donate to furthering CDH research. Sunflower Sunday events were held across Australia, uniting CDH affected families across Australia. A massive thank you to our event volunteers who put in an incredible amount of effort and love into these events – we couldn't do it without you.

Three research opportunities were presented to the CDH community for the public to vote on which of the three projects would receive up to \$30,000 of funding. Based on the community votes, \$30,000 was donated to the Hudson Institute for Medical Research at Monash University for the purchase of a 'Concord Table'. You can read more about this concord table and the incredible impact it will have for expecting CDH parents in the Research and Collaboration section of this report.

This latter part of the financial year saw the emergence of the novel coronavirus Covid19 which unfortunately resulted in the indefinite postponement and subsequent cancellation of the 2020 CDH Australia Annual Forum (CAAF), which we hope will return to in a bigger and better format in Sydney in 2021.

CDH Australia faced further challenges through experiencing technical difficulties, both with the CDH Australia website being unavailable for majority of the financial year, and email issues resulted in lots of troubleshooting and investigating other communication options for our board.

Despite our technical difficulties, there has been a consistent increase in the number of families that continue to reach out to CDH Australia for support, and in care packages sent to expecting and bereaved families. Increases in numbers reaching out for support is a bittersweet milestone – while our hearts break for every family who receives a CDH diagnosis for their child, seeing an increase in numbers is one step closer to CDH Australia's ultimate goal: for no family to face CDH alone.

This year has been an incredibly tough year for our community facing the unknowns of the Covid19 pandemic and what impact that may have on our survivors, and many of our new families faced the NICU journey with difficult restrictions in place. But once again our families have continued to show that they are some of the most resilient people around.

We wish to extend our thank you to the entire community – thank you for supporting each other, thank you to our incredible volunteers who work behind the scenes and thank you for those who have continued to provide support to CDH Australia in a year we have mostly been 'behind the scenes'.

Together we can do more. For no family to face CDH alone.

Regards,

Sheree Kearns

**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 approximately 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 January for our annual strategy and planning workshop and devised a set of priorities and deliverables for 2020.



### 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 2020 priorities</b>	<b>Maintain our momentum:</b> <ul style="list-style-type: none"><li>• Create an integrated online presence</li><li>• Create presence in offline media</li><li>• Build relationships, and encourage referrals through 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>• Build on support resources and family assistance</li><li>• Build on attendance and success of CAAF</li><li>• Continue to enhance our volunteer-driven support model</li><li>• Engage specialist volunteers or freelancers for specific projects</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>• Build on relationship and funding to Monash for concord resuscitation table. Share information and regular communications with our CDHA community about this project</li></ul>
<b>What success looks like</b>	<b>Increase contact at diagnosis:</b> >60%, sustainably <b>More people:</b> on Facebook, at CAAF and CDH Sunflower Sunday <b>Strong Foundations</b>		
<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, review constitution <b>Information &amp; Technology:</b> develop communication strategy, develop data strategy and IT architecture		

# Events

## CDH Sunflower Sunday: November 2019



*Families gathered in Brisbane for CDH Sunflower Sunday*

### Background

CDH Sunflower Sunday is Australia's national awareness day for congenital diaphragmatic hernia; a day where our community typically 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.

2019's event is our seventh consecutive CDH Sunflower Sunday (CDHSFS). Since 2017 the Board has taken responsibility for the central arrangement of the administration, format and aims of the event. Prior to this we relied too heavily on local volunteers; the burden was too great to continue asking our volunteers to bear. This centralised model has resulted in greater efficiencies and freed up families to enjoy the events, rather than administer them.

2017 saw a heavy focus on fundraising at the events; this resulted in ~\$40,000 funds raised across the campaign, however feedback from the community was that they felt pressured to contribute financially. This is in contrast to the Board's broad intention for the event, being that CDHSFS is a day for the community to come together and remember their children and their struggles, celebrate their successes and honour the survivors. The Board also decided that it went against the spirit of the event to be relying so heavily on the community to contribute funds towards programs that were designed to support the same people who were funding them.

2018 saw us focus our fundraising campaign on running parallel to the event, with minor fundraising accepted on the day. The funds raised in this campaign were to contribute to Support Services – management, telephone support, care packs and financial assistance grants for needy families.



In 2019 we decided to ensure that no funds were accepted on the day (with options for online giving provided). This helped to focus the community and event hosts on the original aims of the day and took pressure off hosts and attendees who previously felt some pressure to donate or fundraise in order to attend what is - in essence - a support-focussed event.

## **2019 EVENT AIMS**

Our community has told us that the promise of research gives hope – irrespective of the family's personal outcome. We know that capital expenditure for Australian-based research is difficult to obtain, but that Australian research is particularly important to local families given the distinct differences between Australian healthcare protocols and those used overseas.

Fundraising in 2015 and 2016 allowed CDH Australia to contribute \$30,000 to a new CDH research project being run by Dr Ryan Hodges at The Ritchie Centre, affiliated with Monash Children's Hospital in Melbourne. They maintained contact with the organisation and reiterated the importance of that initial start-up injection of funds.

With this in mind the Board decided that funds raised in the 2019 campaign would be given to Australian CDH research. Five research projects were submitted for grant consideration, with voting completed by the community to determine the recipients of the eventual funding.

Dr Hodges' follow-on study was chosen as the recipient and received a further grant of \$30,000 to fund a Concorde table as part of their ongoing research.

## **2019 EVENT SUMMARY**

- Over 330 guests attended around Australia
- 7 sites hosted official CDH Australia-affiliated events
- \$20,424.26 raised to the event date
- Voters from our community decided that the recipient of the \$30,000 fundraising grant would be the Ritchie Centre's Concord Project

### **The fundraising breakdown is as follows:**

- \$398 from Entertainment Book sales
- \$5297.21 from the Lualua family, who fundraised in memory of their angel, Tasi
- \$5695.93 from the CDHSFS campaign on EverydayHero (33 donations, with an average gift of \$172.60)
- \$9033.12 by other fundraisers from our community on EverydayHero (108 donations, with average gift of \$83.84)
- ~ \$200 received through Facebook Giving and TryBooking event donations.

## CDH Sunflower Sunday images







## CDH Australia's 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.

### CDH AUSTRALIA AMBASSADOR

*Olivia Vivian*

Ninja Warrior legend,  
Commonwealth Games gold  
medallist, Olympian, Perth  
local, CDH survivor



### CDH AUSTRALIA AMBASSADOR

*Brendan Santalab*

Aussie & International soccer  
champ, My Game Guru co-  
founder, Commercial Football  
Sales Manager, Melbourne  
local, CDH survivor



### CDH AUSTRALIA AMBASSADOR

*Michael Shelley*

Inspirational marathoner, dual  
Commonwealth Games gold  
medallist, Olympian, Gold  
Coast local, CDH survivor



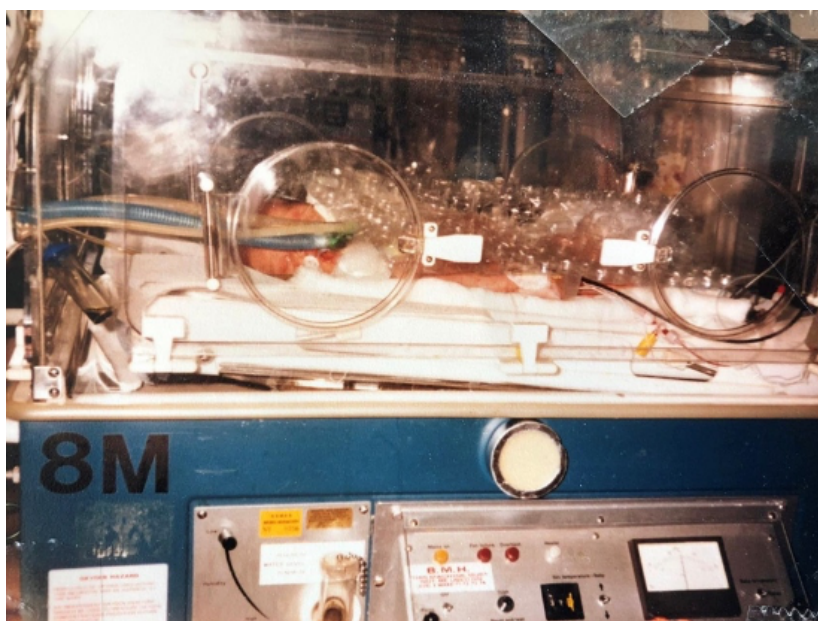


# Meeting CDHA Board Member James Paull

## James Paull shares his experience with CDH

I was born with undiagnosed CDH in the UK in 1987. Until I then joined the Board of CDHA in late 2019, I hadn't met a single person who had even heard of CDH, let alone been affected by it directly or even indirectly. As a CDH survivor, it is therefore such a pleasure to now be able to work with and for those affected by the condition via CDHA and all the great work it does.

Being undiagnosed, what happened next must have been all very scary and unexpected for my family. In addition, back then it wasn't a well-known or understood condition.



Infant James being treated in hospital

Following birth, a midwife noticed within the first hour that I was slowly going blue from lack of oxygen. After a scan and some rushed-in consultants, CDH was diagnosed. I understand that I was the first known case of the condition at the hospital. I was rushed from Yeovil to Bristol (only about a 1hr drive) in an ambulance with parents and three older siblings in tow and operated on at around 16 hours. My chances were quoted at well below 50%, but all went well.

A cosy incubator was home for the next little while, and thankfully after no further complications I was home in just two weeks. This puts me on the very lucky end of the spectrum in terms of treatment and after-effects. Whilst in my incubator, my mum noticed that all the other babies in the ward had lovely soft toys looking protectively over them through the glass. My mum went and bought 'Olof' the koala from the hospital gift shop. At the time he was bigger than me, and though I am now a touch bigger than he is, I still cherish him today (see pic below). He sleeps with me every night – a constant reminder of how lucky I am. Other than an annual check-up until 4 years old, that was about it in terms of support. No support groups. No social media. No internet. Off you go and good luck is how my parents had to work through their experience. It's therefore great that families now can have access to much more information before, during and after and why I see so much value in the work that CDHA and its members do.

In the intervening years, not much has been spoken of it in my family. Either through a lack of wanting to drag up the past, or more likely purely due to a lack of information or understanding, we have never explored the experience as a family. Through my work with CDHA I now know much more than before, for which I'm grateful.

My childhood was normal, and a sporty disposition meant that I managed to cultivate a decent enough set of lungs to allow me to play lots of sport and not be held back other than being a bit wheezy at times. I now see straight through my scar and don't even notice it in the mirror, despite it having grown with me to now be a decent 20cm long across my tummy. Since then I've taken a love of being active to levels that my parents must have never thought possible at the time; participating in ultra-marathons, cross-



James today

continent cycles, triathlons and fitness challenges. My latest interest is as a volunteer surf-lifesaver on famous Bondi Beach.

Although this story may not sadly be the case for many babies and families affected by the condition, it is my experience nonetheless. I guess it shows that anything is possible following the condition and hopefully provides a smidge of inspiration and hope for those reading this whilst currently in the thick of it.

The advances in knowledge, understanding and treatment of the condition gives me so much comfort as compared to 30 years ago and the work of CDHA and its network of members should never be underestimated – I'm very proud to be involved.

## Research and collaboration

### Hope for the future

Supporting research is one of the main priorities for the board of CDH Australia, specifically improving outcomes for people diagnosed with CDH and to foster ongoing research.

Our first significant financial contribution occurred 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 foetal therapies for CDH by Dr Ryan Hodges and his then-PhD student, Aidan Kashyap.

2019 saw the board consult the CDHA community with regards to where the next research grant should be bestowed - a case of letting those most likely to benefit to have a say in the outcome. We shared submissions from verified Australian CDH research partners which outlined the proposals and programs seeking funding and encouraged voters to vote for the proposal they felt was most deserving of the fundraising money for that particular round of giving. A project proposed by the Hudson institute received the most votes.

As a result, in early 2020 we granted a further \$30,00 to the Hudson Institute.



Former President Tara Gallo with Monash Children's Hospital's Mr Ram Nataraja and The Hudson Institute's Dr Aidan Kashyap

This most recent financial support will specifically allow the Hudson Institute to purchase a Concord table in order to participate locally in a global multi-year CDH medical trial led out of the Netherlands.

A Concord table allows full standard care to be given to newborns whilst the umbilical cord remains intact; this delay in cord clamping has been shown to be beneficial where lung aeration is compromised, as in CDH cases.

The Hudson institute hopes that participation in the global trial will accelerate the progress of local research and give vital experience to Australian clinicians on the logistics involved in providing support for infants with CDH at birth

CDH Australia is delighted to continue its close relationship with the Hudson Institute, and particularly wishes to thank Aidan Kashyap and colleagues for their ongoing engagement and commitment to CDH research.

We would like to thank all of the institutions who we work with and we hope to support as many of them as possible in the coming years.

## Our 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 keep pushing for better outcomes for CDH families. .

Our heartfelt thanks to the below people, whose time and dedication to our organisation have ensured that no family faces CDH alone.

### Support Services:

Carmel Chesterfield  
Emily Prunty  
Sharon Knott  
Kristal-mae Littlejohns  
Carine Ziegler  
Cheryl-anne McBay

### Social Media:

Carmel Chesterfield

### Projects & Production:

Danielle Kessner  
Tara Kessner

### Grants & Administration:

Carine Ziegler  
Courtney Vodopic





## Fundraising Activities

Although we - like other non-profits and businesses around the world - have suffered from Covid-19 related lack of funding in 2020, we have been buoyed by the incredible effort our community have put in to include CDH Australia in their donations and fundraising activities this year.

The board is very grateful – this year more than most - to all of our community members for their incredible efforts throughout the year.

Below are just some of the many fundraisers that have been held to raise money for CDH Australia.

### The Littlest Beekeeper



**Super CDHer Sofia has been raising money for CDH Australia by selling honey from her very own hive! Already this year her family has donated \$321. Thank you for your effort, Sofia!**







### **Masks for Mates @ CDHA**

Super CDHer Lucy and her mum, Courtney, sewed over 300 face masks for anyone who wished to make a donation to CDH Australia. This resulted in a fantastic \$1500! Thank you for your hard work, Lucy!

## Amanda's Big Shave



Thank you to Amanda, mum of super CDHer Solomon, who raised \$1200 for CDHA by shaving her head.

Amanda had thought to get her long hair turned into dreadlocks, but on a whim she decided to shave her head if she could raise \$1000. It took just two weeks to hit her goal, so in late August Amanda's long locks were shaved!

We think she looks amazing - just as amazing as the total her family have raised for CDHA over the years. Since Solomon was born in 2014, the Tongues have raised \$7500 for CDHA. To put that in context, it's enough money to provide Care Packs to every newborn CDH baby in Australia for a whole year!

Our heartfelt thanks to Manda and her family for again supporting our incredible families.

## Board of Directors

CDH Australia welcomed new and returning members to the board for 2020. Retaining their positions for this year were Secretary Carine Ziegler and general board member Derek Harris. Courtney Vodopic transitioned from general board member to Vice President. Sheree Kearns joined as President, Cindy Cheung as Treasurer, with both James Paull and Samantha Cairns joining as general board members.

**President – Sheree Kearns:** Sheree brings 8+ years of project management experience to the CDH Australia board through her role as an Environmental Engineer in an emergency management setting. Sheree found CDH Australia while pregnant with her CDHer Calla, and was inspired by the support she received to join the board. Sheree is from Warrnambool, Victoria.

**Vice President - Courtney Vodopic:** Courtney brings over ten years' experience with the public service in a both community-facing and managerial roles. A board member since 2015, Courtney is mum to CDHer Lucy, Matilda and Thomas. Courtney is based in Melbourne.

**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 – Cindy Cheung:** Cindy is an accountant with experience across a range of roles in both private and public sectors. She joined CDHA in 2019 hoping to contribute in the CDH Community. Cindy is mum to CDHer Donna and 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 – James Paull:** James is a Management Consultant in Sydney, having moved from London in early 2018. James is a CDH survivor and keen fitness enthusiast. In his spare time, James is a volunteer lifesaver on famous Bondi Beach and enjoys participating in triathlons.

**General Board Member – Samantha Cairns:** Sam is mother to CDHer Jaxon, and found CDHA shortly after her 18 week morphology scan. Sam is passionate about children and is an Early Childhood Teacher and Director. Sam joined the board to help advocate for children born with CDH.

*Sincere thanks to all our Board Members for their effort and commitment in 2020 to ensure that CDH Australia can continue to deliver upon its mission and strive towards achieving the vision of no family facing CDH alone.*

# Financial report for year ended 30 June 2020

The audited financial report is not yet available.

Our full financial report is expected to be completed by auditors and available on CDH Australia's 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/](http://www.cdh.org.au/)

## Join us, contact us, or receive support

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