



Annual Report 2021



Supporting families and medical
professionals along their
CDH journey.

ABN 60 131 315 145

www.cdh.org.au

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President's report

I am pleased to present the 2021 Annual Report that provides a summary of CDH Australia's activities and financial results for the financial year 2020-2021.

The theme for the next three years is reaching the top of the mountain, and while we haven't quite reached the summit, we're much higher than where we started.

This has been a year of solid achievement despite many uphill climbs.

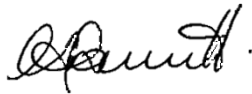
As a quick overview, our team welcomed several new volunteers at the beginning of the reporting year; we resolved our email issues; and we have launched our new website with updated information and resources.

And all of this in the middle of a pandemic!

Our vision, *for no family to face CDH alone*, has continued to inspire us to work in service of our community's needs.

We know the heart of success is a strong team with shared goals. We met early in 2021 to set our annual priorities and the individual drive and passion of each board member and volunteer is what propels us to reach these goals.

I have no doubt that next year will be just as exciting, and that we will work ever closer to the mountain top and seeing *no family face CDH alone*.



Courtney Vodopic
President

About us

CDH Australia is the only dedicated charity supporting families, friends and medical professionals affected by Congenital Diaphragmatic Hernia (CDH) in Australia.

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 40-50%. 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.



2020-2021 Org structure

Board members



2020-21 CDH Australia Board

CDH Australia is headed by a voluntary board who commit to serving a period of one year from the Annual General Meeting. We have been privileged to have a skilled and dedicated leadership team supporting our organisation in FY 2020-2021.

President: Courtney Vodopic

Courtney's eldest daughter was born with CDH, causing her to reach out to the CDH Australia community for support. A manager within the public service, Courtney later joined the board where she has led a review of our support services programs, refocussed our community events, and has headed up local fundraising activities.

Outside of the CDHA community Courtney, and her husband Denis like nothing better than getting out on weekends to explore as a family with their three children and dog, Pepper.

Vice President: Michelle Gibson

Michelle has never been directly impacted by CDH and became aware of CDH when her best friend's daughter was born with undiagnosed right-sided CDH. Michelle was inspired to join the Board of CDH Australia by Lucy's bravery, and stories of other CDHers and their families.

Michelle is a lawyer with over 12 years' experience within the public service. Michelle enjoys being active, cheering on her beloved Melbourne Demons and, most of all, spending time with her two beautiful children, Archie and Chloe.

Secretary: Lara Graham

Lara is a Melbourne-based mum who joined the CDH community while pregnant with her son Jackson. At the 20-week scan Jackson was diagnosed with right-sided CDH and unfortunately did not survive labour and birth. Lara has joined the board to give back to the CDH community that supported her so well during a very difficult time.

Lara is a registered nurse with a background in neurosurgical care. Most proudly she is mum to Jackson (dec.), Vincent (6), Marco (5) and Mila (1).

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.

Support services: Caitlin Ferguson

Caitlin is a mother to three children – daughter Leilani and twin boys Hurley and Jhye. At her twins' 12-week scan, Hurley was diagnosed with left-sided CDH. Caitlin hopes to give back and help families going through the same diagnosis; wanting to ensure that no family faces CDH alone.

Outside of CDH, Caitlin works as a kindergarten educator. She leads a busy life with her crazy family who enjoy being outdoors, and spending time with their family and friends.

IT: Derek Harris

Derek is dad to young CDH 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.

Marketing/IT: Emiko Hunt

Emiko joined the CDH Australia community when she and her partner learnt their baby had left-sided CDH. Their little boy Ari was born in July 2020, undergoing surgery at four days of age at The Royal Children's Hospital in Melbourne.

Hoping to give back to the CDH community that has helped her so very much, Emiko offers her knowledge and experience in marketing to the CDH Australia Board. Outside of work and being a mum, Emiko enjoys running her hectic rescue kelpie Jenga, loves spending time outdoors, travelling, reading, cooking, and being with family and friends.

Research: James Paull

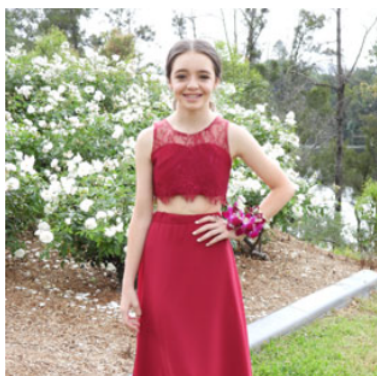
James is a CDH survivor. He was born in the UK with paediatric left-sided CDH and was successfully treated at 16 hours old by pioneering Australia pediatric surgeon Dr Helen Noblett. James has lived in Australia since 2017 and is a Management Consultant by day. James has been a CDHA Board member since October 2019, focusing on engaging with the medical community on research initiatives.

James has led an active lifestyle, largely unhindered by CDH after-effects. Over the years he has combined his love of exercise with his philanthropic nature and undertaken a number of challenges for various causes. Most recently, James has become a volunteer lifesaver at Bondi Beach in an aim to give something back to the Australian community.

Ambassadors

Our four 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 field and an inspiration to CDH families.

Ariana Melrose



Ambassador Ariana Melrose

Ariana was born in 2008 with Congenital Diaphragmatic Hernia. She lives in Western Sydney with her family and is the oldest of four girls. Ariana is a great role model to her three younger sisters, Emerald, Kensi and Havana.

Ariana loves to dance, it is her passion – and she is studying to become a professional dancer. When she is not dancing, you will find her with her head in a book. She has never let CDH get in the way of doing the things she loves or pursuing her dreams. If she ever has a setback, she finds a way to come back stronger than before.

About being born with CDH, Ariana said, “At first I became very sick when catching a cold or flu and would end up in hospital with respiratory issues. I also had a bowel obstruction caused by the scar tissue from my repair. Thankfully it corrected itself and I did not need another surgery. As I have gotten older, I have become stronger and more aware of my body. I don’t get as sick as often. I stay very active and try not to let CDH stop me from doing the things I love.

Sometimes I become short of breath, especially when I have back to back numbers to perform, but I have learnt when to stop and ‘recharge’ before getting back into it.”

Olivia Vivian



Ambassador Olivia Vivian

If life is a series of challenges, Olivia Vivian has lived more than her fair share. Born with Congenital Diaphragmatic Hernia, she was told she’d never compete in sports. At nine, in following her dreams to be a gymnast, she was told she was too tall. At 17, she was told to quit because she’d never make the Olympic team. And at 23, she was told she was far too old for the sport.

It’s all thanks to Olivia Vivian’s tenacious nature that saw her push through every obstacle to reach her sporting elite. With an impressive list of credentials to her name

including the World Championships and 2008 Beijing Olympics, more setbacks were to come: The death of her father and a broken back.

Making a full recovery to compete at the 2014 Commonwealth Games (and helping to win the silver medal for her team), Olivia Vivian eventually retired from gymnastics and ran away away to join the circus (Cirque du Soleil).

That was until she found Ninja Warrior, using it as a vehicle to change her life and unlock her full potential. When you change the way you look at things, the things you look at change... a maxim she happily lives by and promotes.

Her Ninja Warrior journey has seen her compete all over the world and to date, she is the only female in the Australian series to make the Grand Finals. Olivia is a true representation of a CDH warrior!

Brendon Santalab



Ambassador Brendon Santalab

In Brendon's own words, "it's a miracle that I ever became a professional footballer. It's a miracle I lived at all."

Born in 1982, most babies with CDH did not survive. "Life was a second-by-second proposition in the period immediately after I was born. I was flown from Wollongong Hospital in a helicopter to the Children's Hospital in Sydney.

It was a race against the clock. I was rushed in for emergency surgery to repair the hernia. I was cut in half, all the way around my stomach, leaving just the skin on my back connected. It's incredible that a human can survive that. The work of the doctors was incredible. Lifesaving."

Brendon is a fighter – facing death at such a young age sparked a fire in him. "Growing up with the knowledge that I came so close to death shaped who I am as a person. I've gone on to celebrate goals and win trophies. I don't feel any lasting effects of that condition but it's something that has made me brave, determined and resilient."

Like all surviving CDH children, Brendon has a physical reminder of the battle he faced as a child. "I've still got a big scar on my stomach. Every time I see it I feel incredibly grateful for the life I have lived."

Brendon has had a successful career as a professional soccer player and is an A-League fan favourite. He has played internationally for multiple European and Asian clubs, and for A-League teams, Sydney FC, Western Sydney Wanderers, and Perth Glory.

Some of Brendon's achievements include being the first ever goal scorer for the Western Sydney Wanderers in the AFC Champions League and having the highest Goal-to-Minute ratio in the A-League competition – a goal scored every 70 minutes.

Michael Shelley



Ambassador Michael Shelley

Michael was born in Southport on the Gold Coast with CDH that needed immediate surgery. He started running aged 13 in high school, and later went on to complete a Bachelor of Business at Griffith University.

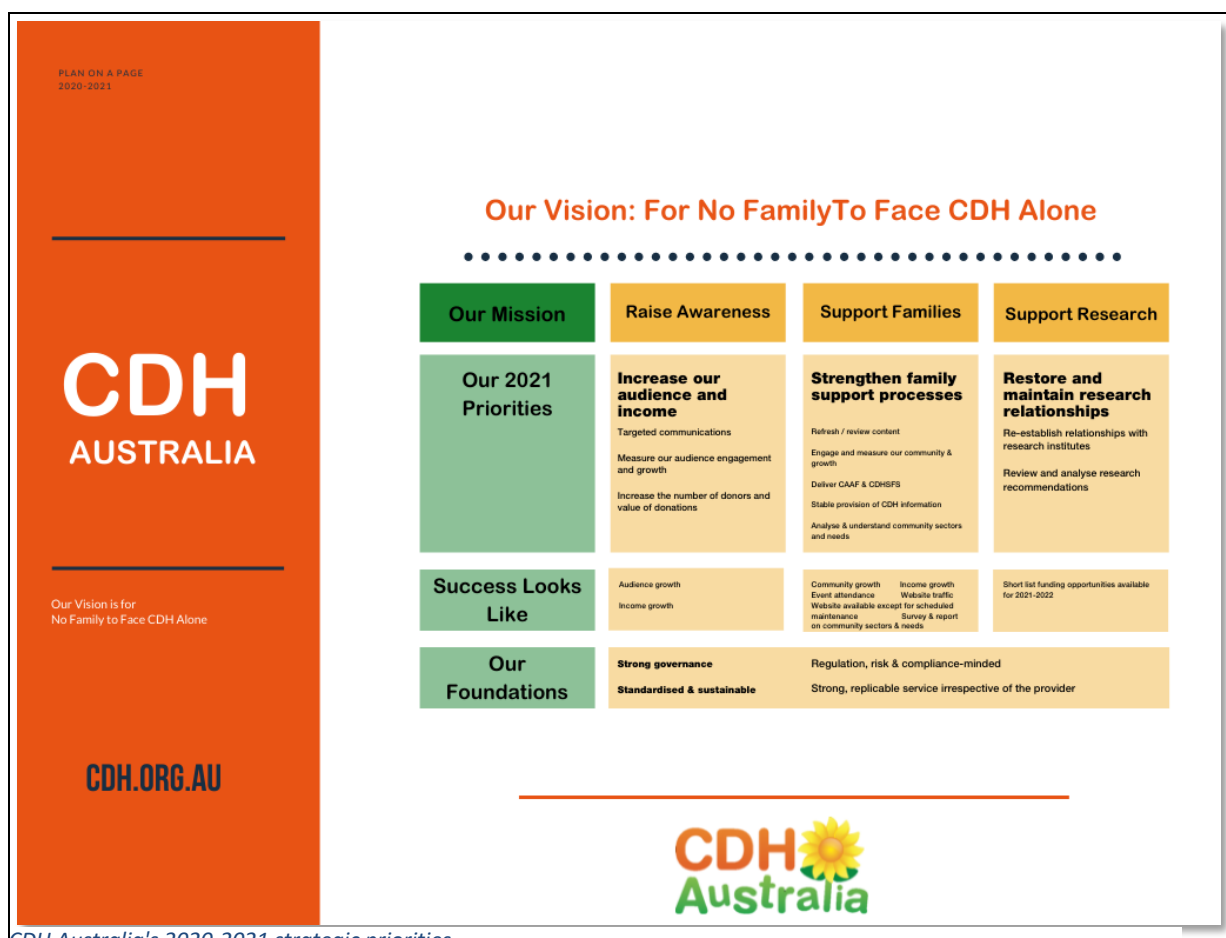
Michael is an Australian long-distance runner who competed in track events and road races. He has won gold medals in the marathon event at the 2014 Commonwealth Games at Glasgow, Scotland, as well as the 2018 Commonwealth Games on the Gold Coast, Australia.

He is the most consistent modern-day male marathoner in Australia with five sub-2:12 times from his 13 career marathons. He also has a remarkable championships record at Commonwealth and Olympic Games.

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

Michael is very generous with the CDH Australia community, often attending the CDH Sunflower Sunday event in Brisbane to help raise awareness and chat with families affected by CDH.

2020-21 strategic priorities



CDH Australia's 2020-2021 strategic priorities

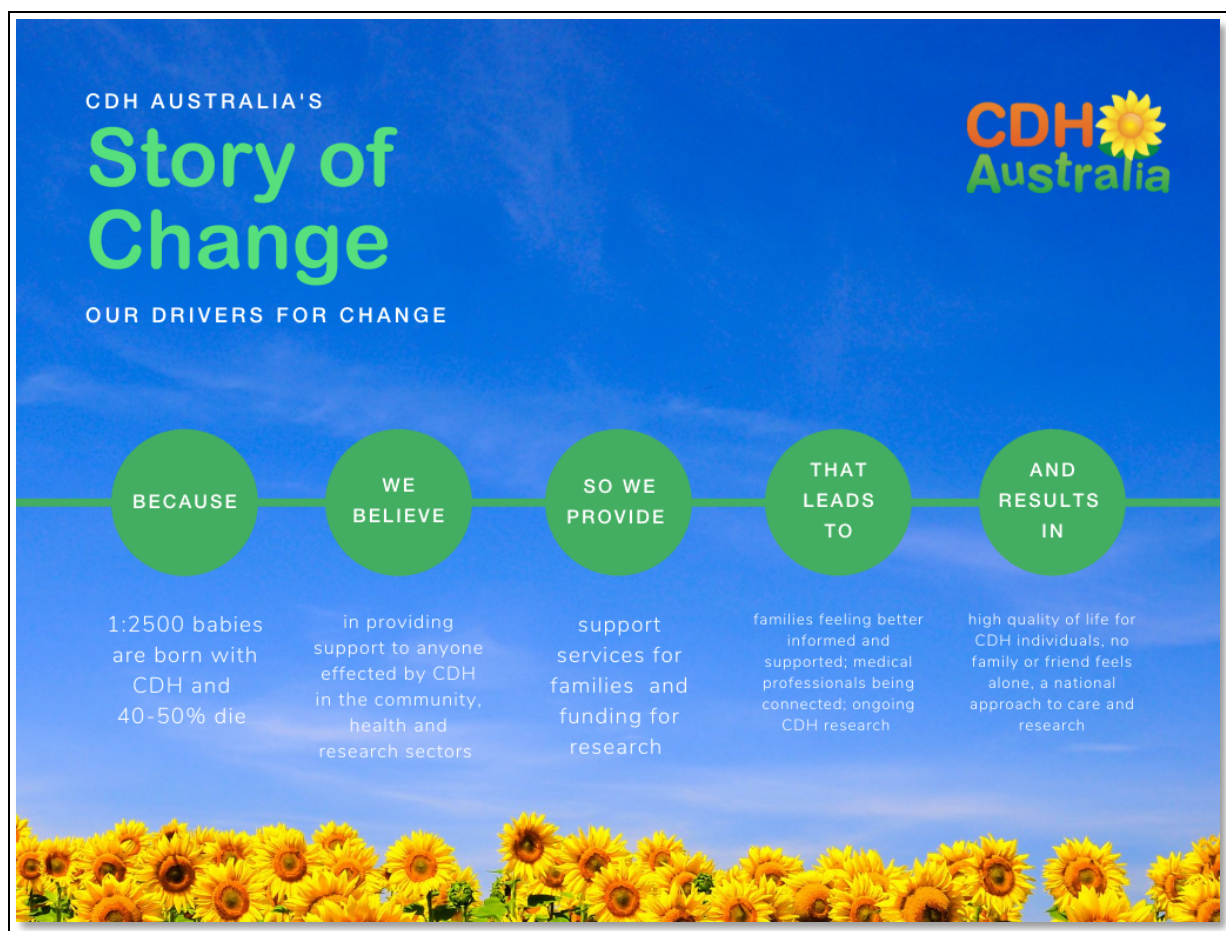
CDH Australia's vision is for no family to face CDH alone. Our mission is to improve the lives of those affected by CDH, advocate for affected families, raise awareness and support research.

The board gathered in early 2021 to dedicate time to developing the 2021 priorities for the organisation. Our 2021 priorities were to:

1. Increase our audience and income *(mission: raise awareness)*
2. Strengthen family support processes *(mission: support and advocate for families)*
3. Restore and maintain research relationships *(mission: support research)*

Progress and outcomes are expanded upon in the relevant report subsections, however it is relevant to say that pleasing advancement was made across all domains in FY 2020-2021. Congratulations to all of our volunteers and community members who have been involved in the various programs and projects undertaken this reporting year.

Story of change



Underpinning CDH Australia's strategic planning is our understanding of our theory of change. This methodology for planning, participation and evaluation is used to promote social change by defining long-term goals, then mapping backwards to identify necessary developments.

Following the development of this year's strategic priorities, the board was led through a "deep dive" of our audience's journey by Emiko Hunt. Emiko conducted research into the makeup and experiences of the CDH Australia community then took us through a process to understand the unique and complex needs of our community.

This depth of planning ensures that the resources we provide meet the needs of our community and that we are responding to the changing requirements of our families.

Research



Monash Children's Hospital's Dr Calum Roberts with the Concord Birth Trolley

Supporting research continues to be one of the main strategic pillars for the Board of CDH Australia, specifically improving outcomes for people diagnosed with CDH and to foster ongoing research.

As has been reported in previous Annual Reports, 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 then 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 CDH supporters at Sunflower Sunday 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. This was specifically to allow the Hudson Institute to purchase a Concord table in order to participate 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.

Throughout 2021, the CDHA Board has worked hard to re-connect (virtually!) with a number of institutions around the country who research or treat CDH. The aim was, and is on an ongoing basis, to understand the landscape of CDH research projects nationally and to see where CDHA might best focus its support for this research.

As a result, throughout 2021, CDHA has been in discussions with the Murdoch Children's Research Institute regarding potentially collaborating on a community research project. The project would seek to understand from those affected by CDH - parents/carers of CDH and former CDH patients - what their experience of the care system is/has been, and what it could/should look like to optimise outcomes for CDH babies.

To our knowledge this would be the first collaborative project involving parents and clinicians addressing the priorities of care and outcomes for babies with CDH.

Watch this space for further information!

James Paull

IT

In 2021, over the course of six months a new website project was mapped out, went to market, and was delivered live in July.

The new website features updated content and imagery, and has a focus on user experience, navigation, and resources to assist families on the CDH journey.

Our new website has fantastic integration with our email and other functions – we would love to hear about your experience with our new website.

To align with the new website, a new ‘What is CDH?’ video was created with Dr Leah Hickey (Director of Neonatal Medicine, Melbourne’s Royal Children’s Hospital) and Dr David Tingay (Neonatologist, Melbourne’s Royal Children’s Hospital).

Dr Tingay also reviewed and had input across the medical content on the new website.

CDH Australia will be working closely with these doctors ongoing to provide up to date CDH medical insight for our community.

Another success was the resolution of ongoing email system issues. CDH Australia moved across to Google Mail in June.

FY2020-2021 has also seen us develop an underpinning marketing strategy. Informed by the customer understanding we have been working towards through the reporting year, this strategy will allow us to communicate with stakeholders more efficiently – including our CDH families – in the years to come.

Emiko Hunt

Marketing

Our primary marketing tool this reporting year has been social media and the e-newsletter.

The instability of our previous website meant that our social media feeds became our primary news channels, not simply a conduit to more content online. This also impacted our ability to share website links on our social media pages.

Our audience has shown moderate growth on Facebook and Instagram. Our e-newsletter subscribers have increased due to our fundraisers and donors choosing to sign up and receive updates from us. Our engagement levels have remained steady.

CDH awareness continues to build on social media but has slowed in recent years. With the new website up and running, we have more content to share, and more time to focus on social media growth and engagement. Social media growth will also come more naturally as families will find us via the new website and join our Facebook support groups.

Susan Fisher

Finance and governance

A complete review of the various reporting and governance requirements of the business was undertaken in FY2020-2021. Despite the many challenges in navigating state and federal requirements, we are proud to maintain our fully compliant state with all local authorities.

As the only CDH charity to support local hospitals, families and research initiatives, CDH Australia is proud to have earned the Australian Charities and Not-for-profits Commission's "tick of approval", a digital signature only afforded to charities who comply with rigorous reporting requirements.

We also maintain our deductible gift recipient (DGR) status with the Australian Tax Office (ATO), meaning that donations greater than \$2 may be tax deductible.

Please note that FY 2020-2021's full audited financials will shortly be made available on our website.

Michelle Gibson and Cindy Cheung

Support services

This reporting year we have seen a steady number of families diagnosed with CDH reaching out to CDH Australia. Despite the pandemic again impacting our ability to deliver face-to-face support, we have maintained connection with our community through emails and our families interacting in the private online support groups.

Although it is bittersweet having new families join us, we are always so relieved they have found CDHA. We are proud to have such a kind and welcoming community who, without fail, wrap around our new families to support them on their journey.

Our families have provided feedback on our new website, telling us how informative and easy-to-use it is. We are pleased to have been able to take our community's ideas on board to ensure that the renewed and expanded online resources meet the needs of our families.

Online support groups

Main Support Groups FY2020-2021

Facebook continues to be the preferred platform for our online support groups. A number of our users have located our groups from a simple search, which then allows them to access the key support resource offering before waiting for a word-of-mouth referral from a hospital, midwife or social worker. 95% of our families make initial contact with us from Facebook. We anticipate that this number will be split next year with the availability of the new website and reliable emails.

Care packages

CDH Australia support expecting and bereaved families, as well as families raising a CDH child. No matter the stage of their journey, we love to welcome them with a beautiful care package. This reporting year has seen a fantastic response to our care package offerings. We offer all families free access to a newly-diagnosed pack; a bereaved family pack; and seasonal packs (depending upon donations.)

This year's seasonal offerings were beautiful hand-knitted beanies by volunteer Robyn Findlay. Robyn's beanies were sent to newborn babies and siblings all over Australia this year, and have been very gratefully received, with one recipient noting that "it is so heartening to know that there are people out there thinking of us."

Support services is also working through a relaunch of our financial assistance package, which allows us to provide a support to families for the purchase of essential goods such as groceries. We hope that this will be popularly received as the rest of our care packs have been.

Caitlin Ferguson

Fundraising and donations

As a micro-charity we rely upon the kindness of our generous fundraisers and donations to continue providing services and support to the Australian CDH community.

We are grateful to our loyal supporters who continue to raise awareness and funds for CDH Australia.

In 2021 we conducted a review on fundraising and donation websites to find the best fit for our small organisation. We needed to make sure we had the right mix of reliability, automation, and low fees.

We now use the Grassrootz website for the majority of our online fundraising, fun runs, event registrations, and membership sales.

We also use Facebook and the Paypal Giving Fund for select fundraisers and direct donations because of their zero-fee policy.

Our major fundraising campaigns are CDH Sunflower Sunday and the End of Financial Year Appeal. We'd like to thank the 33 fundraisers who supported CDH Australia by encouraging donations in FY2021.

Susan Fisher

Our community partners

Thank you to our major donors

Tara Gallo, Macquarie Bank matched-giving program

Thank you to our fundraisers

Martina Jones – *In Memory of Freddie*

Green Leaves Early Learning Centre – *Teddy Bear's Picnic*

Courtney Vodopic – *Masks for Mates*

Thank you to our “run-raisers”

Emiko Hunt, Jeremy Koadlow, Bridie McKenna-Parry, Matt Koadlow, Bec Ampt –
Run Melbourne's *Team Tiger*

James Paull – Blackmore's Virtual Sydney Running Festival

Lydia Brewer – Gold Coast Marathon's *In Memory of Freddie*

Melissa Scaife – Gold Coast Marathon's *Running for CDH*

Thank you to our CDH Sunflower Sunday fundraisers

Melissa Scaife, Brayden Love, Caitlin Ferguson, Carmel Chesterfield, Cristina Avati,
Ebony Mattschoss, Leah Hobbs, Peta Whiley, Tamika Armstrong, Tiffany Buckow,
Travis Weerts, Carine Ziegler, Tasha McCarthy, Teegan Lawrance

Thank you to our Facebook fundraisers

Allison's birthday fundraiser for CDH Australia	Amanda's fundraiser for CDH Australia
Cherilee's birthday fundraiser for CDH Australia	Ebony's birthday fundraiser for CDH Australia
Karlie's birthday fundraiser for CDH Australia	Kerrie's fundraiser for CDH Australia
Leah's birthday fundraiser for CDH Australia	Lianna's birthday fundraiser for CDH Australia
Mikayla's birthday fundraiser for CDH Australia	Penny's Birthday Fundraiser for CDH Australia
Rachel's Birthday Fundraiser for CDH Australia	Tanika's birthday fundraiser for CDH Australia

CDH Sunflower Sunday

Traditionally, CDH Sunflower Sunday is hosted as in-person events at major locations across Australia on the second Sunday of November. In 2020, due to Covid-19, we made the decision to host an online virtual awareness day event so that we could ensure that our event would go ahead and our families could take part safely.

We sent free event packs to the 70 families who registered to take part from home. Our community came together across Australia to watch our virtual video event which had over 2600 views

13 amazing fundraisers encouraged over 220 donations so that we could beat our target of \$20,000

Christmas video

Each December we ask the CDH community to send in photos of their family celebrating the festive season. In 2020 over 50 families shared their beautiful holiday snaps with us for our annual video which was viewed 1300 times.

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.

Our thanks to everyone who has donated to us, supported our campaigns, interacted with our social media posts, read our newsletters and contributed to our community.

Extra thanks to the following people, without whom our organisation would not run as smoothly:

Social media

Carmel Chesterfield
Rebecca Monforte

Beanies for care packages

Robyn Findlay

Support services

Cheryl-anne McBay
Kristal-mae Littlejohns
Carine Ziegler

Entertainment book sales

Elizabeth Monforte

Join us or contact us

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Financial report for year ended 30 June 2021

The audited financial report not yet available, and is expected to be completed by auditors and available on our website within 4 weeks.

Note: CDH Australia's historical audited financial statements are available to view online at www.cdh.org.au/annual-reports