



Crohn's
& Colitis
Australia

40 years of living fearlessly with IBD

Impact Report

2024



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Crohn's & Colitis Australia (CCA) is a not-for-profit company limited by guarantee, governed by a board of directors who represent the Crohn's and colitis community.

As a Public Benevolent Institution and deductible Gift Recipient covered by item 1 of the Income Tax Assessment Act 1997, CCA is registered with the Australian Charities and Not-for-profits Commission (ACNC).

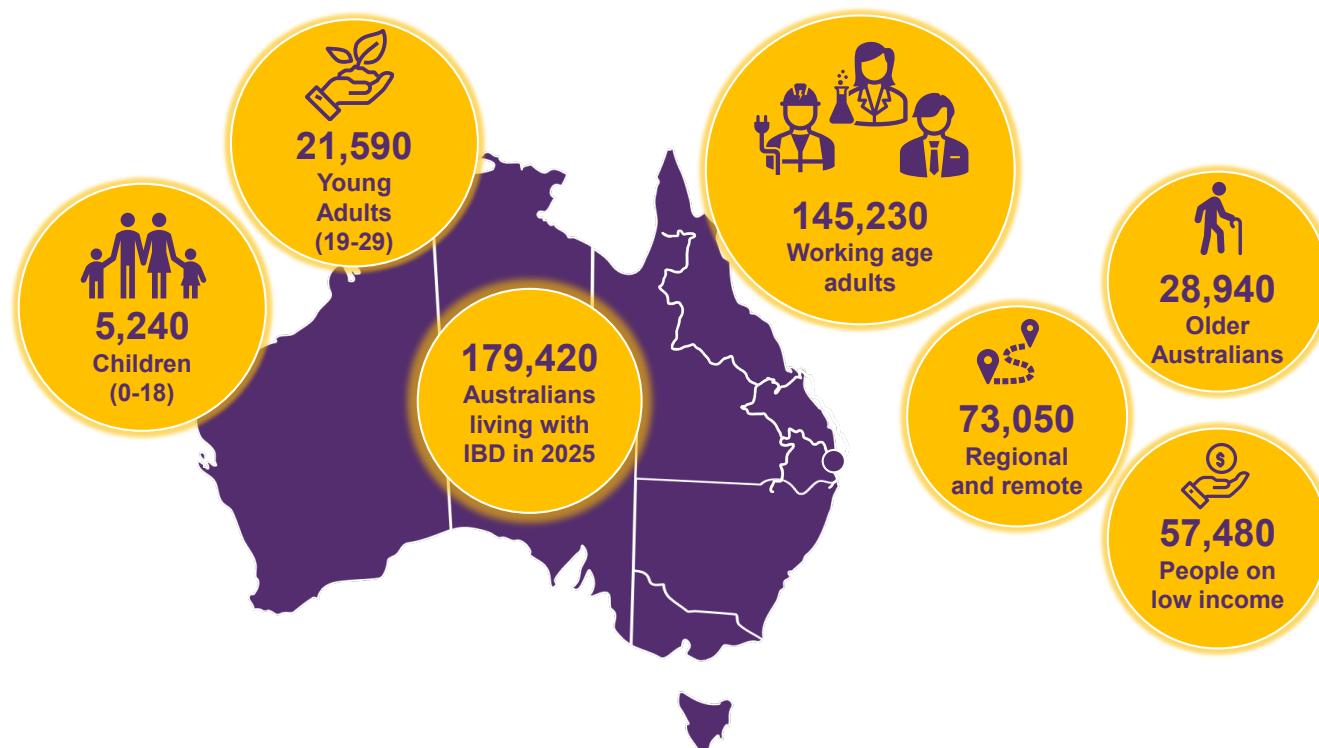


Australian Crohn's and Colitis Association trading as Crohn's & Colitis Australia
ABN: 42 082 747 135

State of the Nation in Inflammatory Bowel Disease in Australia

Australia has among the **highest incidence of inflammatory bowel disease (IBD)** of any nation globally, growing at the **fastest rate** among similar nations

IBD impacts young and working age Australians



About CCA

Our vision

Empower those with IBD to live fearlessly as we drive towards a cure and ultimately a future that is free of Crohn's and colitis.



Our purpose

We believe in being fearless, and at CCA we:

- Improve quality of life by helping people understand, respond to and actively manage their care.
- Empower and support our community – encouraging innovation, advancing quality of care, and facilitating new knowledge informed by deeper research.
- Advocate, educate and facilitate, leading tough conversations about taboo topics.

We want people to be authentic and unapologetic about their Crohn's or colitis – whether that leaves them laughing or crying. We know being fearless means there will still be bad days, bad months, or bad years – this is a long-term and life-altering condition – it's about giving people the courage, confidence, and the ability to face things head on.

Because in fearlessness, there is strength to drive us toward a cure.

Our 2026 ambition



A provider of valued services and products to support the IBD community across the lifespan.



A driver of research that progresses the search for a cure.



A fearless and frank communicator, advocating for system change, improved information, and education.



A trusted and influential organisation, respected by the community, philanthropy, health and medical industry and government.



A sustainably funded and financially stable with a diverse and wide community of support

From the Chair & CEO



2024 was a successful year for Crohn's & Colitis Australia (CCA) marred by a deep sadness with the passing of our founder Angela McAvoy AM on ANZAC Day. We were pleased to be able to join Angela's family in the celebration of her life and to pass on messages from people in the IBD community who had been touched by her compassion, support and advocacy in IBD. As one who lived fearlessly with IBD her legacy at CCA will never be forgotten and CCA will seek applications for a post-doctoral Fellowship in honour of Angela to commence next year.

Recognising that IBD affects all people across the lifespan we are keen to ensure that CCA supports everyone living fearlessly with Crohn's and colitis. However, over the last two years CCA, in partnership with key stakeholders and led by Associate Professor Edward Giles, has been undertaking an important piece of work that arose out of the IBD National Action Plan, the IBD Paediatric Quality of Care Hospital Audit and the IBD Paediatric Quality of Care Patient Experience Survey.

Consequently, in 2024 we had a particular focus on children, young people and their families and advocating for improvements in quality and equity of care that will improve their quality of life.

With Australia having among the highest incidence of IBD of any nation globally, 15% of Australians with IBD are children and young adults, a total of 26,830 living fearlessly with IBD.

Insights gained from examining care pathways in hospitals and the experiences of children, young people and their families provided clear direction for improving quality of care and equity of care for young people with IBD. These insights told us that:

1. Youth living with IBD have a high disease burden
2. IBD can impose a profound psychological burden on young people

3. Families want care that extends beyond their primary specialist
4. Care is not fully meeting the needs of young people
5. There are areas where education and useful information can help

We were particularly proud to have achieved the following highlights at CCA:

- During Crohn's and Colitis Awareness Month in May the IBD Paediatric Quality of Care Hospital Audit Research Report was launched by The Hon Jenny Ware MP at an event in Parliament House hosted by the Parliamentary Friends of Autoimmune Diseases.
- Awareness about early diagnosis, multidisciplinary health professional team support, and affordable access to the best IBD treatments was raised via our #SavingKidsGuts campaign.
- An online information forum emceed by Luke Escombe, CCA Ambassador on the topic of IBD care for children and young people was streamed to over 1,400 people.
- Over one hundred children were supported at two Kid's Fun Days in Sydney and Melbourne and our first Camp Fearless held in 5 years (pre-covid).

We are both grateful to the children and youth who fearlessly shared their stories about living with IBD to raise awareness, the individual donors who have provided the necessary funds to run these programs via our fundraising appeals, the philanthropic organisations that have recognised how important it is to continue to support the children and youth and to the CCA volunteers and health professionals who make the events so successful. We will work to continue these valuable services for children and young people across the nation.

The board reviewed its strategy, setting its **ambition and strategic priorities** for the next three years and it made minor

changes to our constitution which were approved at the annual general meeting held in May.

We welcomed two new board members to CCA, Kate McQuestin and John Brennan who both have lived experience of IBD and farewelled three members, Professor Paul Pavli, Daniel Teller and Belinda Dimovski and we thank all board members for their contributions. We are fortunate to retain Prof. Pavli as a member of our Scientific, Medical and Quality of Care Advisory Committee.

We are working on a plan for our 40th year celebrations in 2025 and whilst we recognise the bold vision of an IBD cure we have achievements to celebrate given the advancements in IBD treatments and care over this time. We would also like to acknowledge the significant work undertaken by the CCA team led by Associate Professor Greg Moore on the State of the Nation in IBD in Australia Project. The report of this project is due to be launched in 2025, and the insights gained will identify the way forward for IBD in Australia.

We also would like to extend our gratitude to the staff at CCA most of whom are part-time as it never ceases to amaze us as to how much is achieved by such a small team of talented people committed to the organisation's vision and ambition.

To all CCA fearless volunteers, donors and pro-bono supporters we thank you too.

We believe in being fearless because in fearlessness, there is strength.

Bruce Rosengarten
FAICD
Chair

Leanne Raven
FAICD
CEO

Vale Angela McAvoy AM

Celebrating the founder of Crohn's & Colitis Australia – Angela McAvoy

In April 2024 we said farewell to Angela McAvoy AM. As someone who lived with Crohn's disease, Angela was a strong advocate for people living with Crohn's disease and ulcerative colitis. Her passion, resilience, and unwavering commitment to this community resulted in the formation of the *Australian Crohn's & Colitis Association (ACCA)* in 1985 - now Crohn's & Colitis Australia.

As the founder of ACCA, Angela worked tirelessly to raise awareness, support IBD research, and foster a sense of community among those living with IBD. Her profound impact on the CCA community can be found in the dozens of messages received in response to the announcement of her passing, reflecting on her advocacy work, relationship building and the support and education she offered to everyone living with Crohn's disease and colitis.

She was remembered at a funeral service on Wednesday 8th May attended by family, friends, and IBD researchers, CCA board members and staff and members of the IBD community.



LEFT: Angela (far left) with committee members at the inaugural meeting of ACCA.



RIGHT: Angela joined us at CCA's Silver Lining Lunch in Melbourne in 2019

Our 2024 highlights

No crap, just the good stuff!



543

CCA Helpline enquiries answered

171

CCA NurseLine assessments and support contacts



24%

increase in active users viewing CCA website



39,295

followers on social media platforms



6%

increase in followers in 2024



25

awareness month media outcomes



180

GutSmart course enrolments



2091

CCA members



200

volunteers throughout 2024

\$183k+

raised during 2024 Live Fearless Challenge



90+

sites lit up for World IBD Day



17

Support groups, both online and in person



3

youth events (Camp Fearless, Kids Fun Days)



3

information forums - face-to-face or online



2

reports produced

2

conference abstracts (posters)



10

research studies promoted

3

journal articles published

Strategic priority 1:

Develop valued, accessible, tailored and innovative offerings to enhance quality of life

Strategic initiatives focused on activating digital tools, automating our core business processes to improve experience and conducting our webinars and forums for the community. By assessing community demographics, services can be tailored to meet the unique needs of individuals across different life stages and points along the care pathway. This data-driven approach ensures that interventions are both relevant and effective, addressing disparities and improving access to care and quality of life.

To foster a more inclusive and collaborative approach, establishing connections—bringing together community members, general practitioners, and specialists—will be crucial in facilitating dialogue around IBD. This engagement will serve as platforms for education, engagement, and continuous feedback. Additionally, exploring the potential of artificial intelligence (AI) to support IBD helplines and information sharing could further enhance patient support and responsiveness, ensuring timely access to accurate resources and assistance when needed.

SUPPORTING KIDS WITH IBD ACROSS AUSTRALIA

In 2024 CCA held two Kid's Fun Days in Sydney and Melbourne and the national Camp Fearless, altogether over 100 children and young people participated in CCA's IBD engagement and support activities.

We were also successful in a grant application to the Wolper Jewish Hospital Foundation who will sponsor Camp Fearless for the next three years.

CCA would like to thank AbbVie, Bupa, the Pierce Armstrong Foundation and many individual donors and supporters and our wonderful volunteers for their help to put on these events.

Our YEP! Online teen platform had an encouraging increase in chat among users on Discord, much of it about Camp Fearless.

VITAL EDUCATION RESOURCES FOR HEALTH PROFESSIONALS

CCA's **GutSmart** delivers online training courses for health professionals on the topic of Crohn's disease and ulcerative colitis. The Crohn's and colitis community is spread out across the country, and no matter where they live, we want them to be supported by healthcare workers who understand their treatment needs. GutSmart currently offers three courses for health professionals: Nutrition and IBD for Dietitians, Psychological Health in IBD and IBD For GPs and Physicians. In 2024 CCA had 49 sales of the *Nutrition and IBD for Dietitians* course, 20 for *Psychological Health in IBD*, and 116 registrations for the *IBD for GPs and Physicians* course.

In 2023, CCA launched the *Poo and A* podcast as part of the GP Aware resource, downloaded 1049 times in 2024.

CCA would like to thank Takeda, Johnson and Johnson and GSK for their support of GutSmart in 2024, along with the Australian Government Department of Health, who are also supporting an extension of the GP Aware project to improve health professional awareness and knowledge of IBD and increase the use of Crohn's and Colitis Management Plans.



DEEPENING PARTNERSHIPS FOR COMMUNITY BENEFIT

Australian Association of Psychologists: Crohn's & Colitis Australia recognises the importance of multidisciplinary care in supporting people living with Inflammatory Bowel Disease (IBD).

We have partnered with The Australian Association of Psychologists (AAPi) on educational resources for psychologists to help them support patients with IBD. We will be sharing videos about psychology in IBD from Associate Professor Simon Knowles on our social media platforms.

Coalition for Preventative Health Funding: Alongside almost 20 other leading consumer health organisations, CCA proudly joined the newly formed Coalition for Preventative Health Funding (CPHF). The CPHF is calling on the federal government to commit to greater investment in Australia's preventative health efforts.



"Investing in preventative care is so important. It can reduce flare-ups, prevent long-term health deterioration, and improve the quality of life for those affected,"

- Leanne Raven CCA CEO.

Missing School podcast: Wayne Massuger, Head of Quality Research and Support Programs at CCA, joined Sienna - a year nine student living with IBD, on the Missing School Live and Learn podcast. Together, they shared insights into the experience and challenges of living with IBD and the support available through CCA.

Australian Patient Advocacy Alliance (APAA): CCA joined the parliamentary summit held in February 2024. CCA's CEO was elected as the Chair of APAA and collectively advocates for improved government policy and support for Australians living with Chronic diseases.

Navigator project - Rare Voices Australia: CCA is working with RVA to evaluate consumer-led organisation-based telehealth services for the Australian Government.

Together with the Sydney Children's Hospitals Network, the Perth Children's Hospital, Mito Foundation and Tuberous Sclerosis Australia data is being collected and analysed to evaluate the impact and benefit to individuals, families, carers, the health system, and the overall cost-effectiveness and sustainability of various models. More information [here](#).



FILLING CARE GAPS WITH TELEPHONE SUPPORT

Our Crohn's and Colitis Helpline provides individual help, information and guidance on living with Crohn's disease or ulcerative colitis, provided by our expert peer Helpline Coordinator. People contact the Helpline for support when they are newly diagnosed, are interested in new treatments, travelling or seeking suitable health professionals.

CCA's NurseLine delivers telehealth nursing services for people with IBD. The service has addressed an unmet need in the IBD community for people who do not have access to an IBD nurse or have gaps in their IBD knowledge or access to services.

In 2024 the Helpline answered 543 helpline enquiries and NurseLine conducted 171 assessments and support contacts.

CCA would like to acknowledge support from Takeda and Sandoz for NurseLine and Dr Falk Pharma for Helpline.



CONSUMER EDUCATION & AWARENESS (CEA-IBD) PROJECT

CCA continues to improve access to reliable evidence based-health information through the CEA-IBD Project.

New content on intestinal ultrasound has been published and in 2025 we will have new multilingual content, including Nepalese and Korean, as well as new resources for older people with IBD.

These resources are funded by the Australian Government Department of Health.



Strategic priority 2:

Invest in advancing quality of life and care pathways through advocacy and research

To advance the understanding and treatment of Inflammatory Bowel Disease (IBD), a key strategic focus is to fund scholarships aligned with our research priorities, fostering the next generation of IBD researchers and clinicians. The launch of our Paediatric Audit marks an important step in evaluating care for younger patients, and we will actively advocate for the implementation of its recommendations. Additionally, the completion of our IBD State of the Nation Report, supported by horizon scanning partnerships, will provide critical insights to inform policy, planning, and future research directions.

Building on this foundation, we aim to develop targeted action plans guided by quality of care research, ensuring that improvements in clinical practice translate into better outcomes for patients. Advocacy for increased IBD research funding remains a core priority, essential for driving innovation and discovery. Equally important is the identification of quality of life (QOL) needs among people living with IBD, enabling the development of tailored responses that address the broader impact of the condition on daily living.

SHARING INFORMATION WITH THE COMMUNITY

Crohn's & Colitis Australia's IBD information forums provide much needed specialised information for people diagnosed with inflammatory bowel disease, their families and carers.

Awareness Month forum

In 2024 CCA held an information forum on 1 May to launch Crohn's and Colitis Awareness month, the topic was Children and Young Adults IBD Care. The event was hosted by CCA Ambassador Luke Escombe, with presentations from gastroenterologist Associate Professor Edward Giles, community member Aiyahna and dietitian Jasmine Wademan. The forum has had over 1,400 views online.

CCA would like to thank the Eirene Lucas Foundation and Bristol Myers Squibb for their support of the CCA Information Forums.



St Vincent's Hospital forum

A 'Surgical Aspects of IBD' Information Forum was held at St Vincent's Hospital in Sydney on 15th October 2024.

Speakers included Dr Simon Ghaly, Dr Hamish Urquhart, Dr. Gareth Owen, Kirsty Leray and Benjamin Blackburn. The recording of the event has received over 600 views to date.



FACILITATING IMPACTFUL RESEARCH

As the peak patient body for Crohn's disease and ulcerative colitis CCA facilitates impactful research by connecting researchers with patients and by participating in sector events and forums. CCA also received approval as an Medical Research Future Fund (MRFF)-Eligible Organisation in May 2024.

These are some of the many research projects and publications we supported and shared with the IBD community:

- New publication in **Inflammatory Bowel Diseases** – *Feasibility, acceptability and Preliminary Efficacy of Acceptance Commitment Therapy for Adults Living with Inflammatory Bowel Disease and Distress*; Romano D, Chesterman S, Fuller-Tyszkiewicz M, Evans S, Dober M, Garry R, Gibson PR, Knowles S, McCombie A, O E, Olive L, Raven L, Van Niekerk L, Mikocka-Walus A. *Inflamm Bowel Dis.* 2024 Jun 3;30(6):911-921. doi: 10.1093/ibd/izad122. PMID: 37477361; PMCID: PMC11144983.
- Publication in **The American Journal of Gastroenterology** – *Acceptance and Commitment Therapy for Adults Living With Inflammatory Bowel Disease and Distress: A Randomized Controlled Trial*
- Publication accepted in the **Journal of Clinical Psychology in Medical settings** from Deakin Research Study led by Professor Antonina Mikocka-Walus and funded by Crohn's Colitis Foundation (USA) – Leanne Raven is an investigator; Wilkin, K., Evans, S., Van Niekerk, L. et al. *Moving Towards Acceptance and Values: A Qualitative Study of ACTforIBD Compared to IBD Psychoeducation.* *J Clin Psychol Med Settings* 31, 245–257 (2024).
- *The changing landscape of paediatric Inflammatory Bowel Disease medication in Australia 2015-2021, A population-based study* – poster presented at the European Crohn's and Colitis Organisation Conference (ECCO'24) in Stockholm in February.
- *Inflammatory Bowel Disease Paediatric Quality of Care Hospital Audit 2023 in Australia* – poster presented at Australian Gastroenterology Week in Adelaide in September

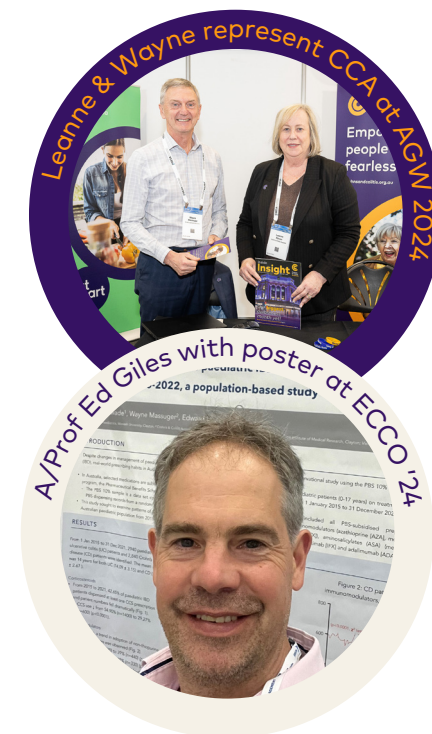
IBD State of the Nation Project

In 2024 CCA led a project to update estimates of the IBD incidence and prevalence in Australia, as well as quantify the financial and social burden of IBD. Understanding the prevalence of inflammatory bowel disease (IBD) and its burden on the Australian community is essential to the improvement in quality, equity and access to services for people living with these chronic inflammatory gut conditions.

The objectives of the project were to:

- Research IBD incidence and prevalence data to update national IBD estimates in Australia and its states and territories for 2024.
- Provide projections of prevalence of IBD in Australia and its states and territories for 10 years.
- Estimate the cost of IBD related healthcare and other financial costs.
- Describe the burden of disease of IBD in Australia including disability impact.
- Identify priority actions and conduct cost – benefit analysis.

The IBD State of the Nation Project was completed in 2024 and will be launched in 2025. CCA would like to thank our philanthropic donors and industry sponsors: Pfizer, Takeda, Bristol Myers Squibb, GSK and AbbVie for their support of the project, and Insight Economics for partnering with us for the report.



ADVOCATING FOR CARE

CCA works to raise awareness of IBD in the general community and with policy makers, politicians and healthcare professionals to make change happen. We are an active part of the IBD community and support community members to share their lived experiences and live fearlessly with IBD.

2024 Advocacy highlights

- Meeting with PBAC Vice Chair RE burden of biologics administration and paediatric access to medicines.
- CCA CEO Leanne Raven presented at the World IBD Day meeting in Mexico on paediatric projects
- Wayne Massuger and Leanne Raven attended meeting with Bionics Institute to assist in consumer engagement for their IBD research project
- Leanne attended Navigator Project- Expert Advisory Group meeting.
- Leanne attended Parliamentary launch for Preventative Health Funding in Canberra
- Lisa Neville and Leanne Raven attend Bristol Myer Squibb Parliament Summit at Parliament House in Canberra
- HTA Review Consultation - 2 submissions
- Meeting with PBAC Chair and Deputy Chair and GESA regarding biologics administration and streamlining of biologics to decrease administrative burden on health professionals
- Wayne Massuger attended St Vincents IBD Symposium with booth attendance
- Leanne presented at the ANZ IBD Research Consortium Meeting in Melbourne
- Submissions on Colonoscopy Clinical Care standards, Stoma Appliance Scheme, PBAC and MSAC.
- Quotes for media on Shingles Vax Ministerial announcement and new PBAC medications.
- Booth at Australian Gastro Week GESA conference in September with Paediatric project presentation by A/Prof Ed Giles.
- Wayne attended PharmAus in Parliament House, Canberra
- Leanne attended launch of Ostomy Association burden report in Parliament House, Canberra
- Leanne attended Women's Health Summit and Australian Patient Advocacy Alliance Summit at Parliament House in Canberra.
- Videos with Professor Jairath on IBD topics published: 366 impressions on Facebook, 1,898 impressions on Instagram, 1,745 impressions on LinkedIn
- Leanne attended GAFPA advocacy meeting in Singapore for immune mediated conditions with colleagues from Asia Pacific Region



FUNDING IMPACTFUL RESEARCH

The 2024 CCA IBD PhD Scholarship of \$96,000 over three years was awarded to Dr Richard Fernandes, University of Queensland. Dr Fernandes is a gastroenterologist who is undertaking the project 'Improving our understanding of post-operative Crohn's disease recurrence' Many patients with Crohn's disease require surgical resection of diseased bowel. However, surgery is not a cure, with high recurrence rates after surgery. This remains poorly understood; however, some factors associated with risk of recurrence include surgical technique, immune signalling, and the bacteria living in the gut (microbiome). This study aims to evaluate the impact of surgical technique on disease recurrence, methods for detecting recurrence, and changes in immune signalling and the microbiome following resection.

In 2024 CCA called for applications for the Crohn's & Colitis Australia Angela McAvoy AM Inflammatory Bowel Disease Fellowship which provides \$250,000 over 2 years for a post-doctoral researcher. It will be awarded in early 2025.

IBD Paediatric Quality of Care

On May 30, the Parliamentary Friends of Autoimmune Diseases partnered with CCA to launch the results of the Inflammatory Bowel Disease (IBD) Paediatric Quality of Care Hospital Audit 2023, supported by the Australian Government Department of Health and Aged Care.

The report was launched with Jenny Ware M.P., Dr. Gordon Reid M.P. and Dr. Sophie Scamps M.P. – Co-Chairs of the Parliamentary Friends of Autoimmune Diseases – together with Associate Professor Edward Giles, CCA CEO Leanne Raven FAICD and Awareness Month champions Aiyahna and Tyce.



Did you know?

Up to 25 per cent of IBD is diagnosed in childhood and adolescence, potentially affecting growth, puberty, education and psychosocial development.

Source: IBD Paediatric
Quality of Care
Patient Experience Survey
2023 Research Report

#savingkidsguts

The process of diagnosis is harder than it should be

The lead-up to diagnosis for a young person is often described as "long", "frustrating", and an emotionally draining "fight" with healthcare providers for action.

Increased mental health risk

Young people with IBD have more than a 50% risk of developing mood or anxiety disorder. Despite this, none of hospitals audited had an on-site psychologist as part of their IBD treatment team.

Lack of access to medication

IBD medications listed on the Pharmaceutical Benefits Scheme are limited for youth, compared with adults.

Lack of access to healthcare professionals

Most youth living with IBD don't have access to a multidisciplinary team: only 23% of Crohn's Disease inpatients were seen by a IBD nurse, compared with 33% in 2014.

CCA is calling for more funding and IBD research investment towards #savingkidsguts, and avoiding unnecessary surgeries through earlier diagnosis and access to broader treatment options.



IBD Awareness Month
Information Forum

Speakers



Luke Escombe
Event Host
and CCA
Ambassador



Aiyahna
Browning
Lived
experience



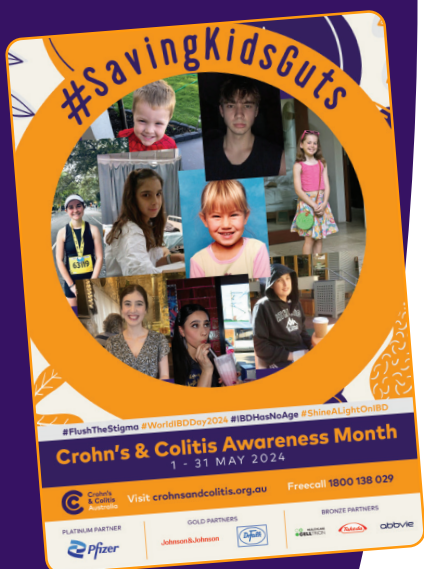
Dr Edward Giles
Consultant
paediatric
gastroenterologist



Jasmin
Wademan
Dietitian,
Perth
Children's
hospital



**Strategic
priority 3:**
Strengthen
leadership
and
advocacy
to influence
better
outcomes
for our
community



A vital component of our strategy is the advancement of our ambassador program, which plays a key role in raising awareness and representing the voice of the IBD community. We will explore expanded advocacy opportunities to ensure that the needs and priorities of those affected by IBD are heard across a wider range of platforms and decision-making arenas. By developing structured advocacy and education programs, we aim to engage and inform key stakeholders, including policymakers, healthcare providers, and the general public.

To strengthen our impact, we are committed to actively expanding partnerships across multiple sectors. This includes collaboration with corporate partners, the health industry, patient organisations, health professionals, research institutions, and government bodies. Through these partnerships, we can amplify our message, enhance our reach, and drive collective action toward improved care, research, and support for people living with IBD.

CROHN'S AND COLITIS AWARENESS MONTH 2024 #savingkidsguts

This year's Awareness Month centered on young people living with IBD in support of the CCA Paediatric report launch, and it was filled with activity and engagement!

In May 2024 Crohn's and Colitis Australia (CCA) launched two major research reports: The Inflammatory Bowel Disease Paediatric Quality of Care Hospital Audit 2023 and Inflammatory Bowel Disease Paediatric Quality of Care Patient Experience Survey 2023 which were led by CCA and made possible through the support of the Australian Government Department of Health.

The research findings have supported CCA's advocacy for early diagnosis, multidisciplinary support and medication access which will provide the support needed to help young people diagnosed with IBD live with their condition and avoid surgical treatments. We want kids and young people with IBD to have the best quality of life they can and to prevent surgery and loss of their bowels.

Associate Professor Ed Giles, Head of IBD Paediatric Quality of Care Project Advisory Committee who led the audit, spoke about the impacts he sees on the young people he treats:

"In my practice, three of my paediatric patients were given access to off label medication, which ultimately, was the only reason they kept their colon. Giving young people access to the same medications that adults have, would prevent so many kids from going on to live a life full of medical complications,"

CCA would like to acknowledge the 15 individuals and their families who fearlessly shared their challenges, frustrations and hopes for the future – Aiyahna Browning, Charlotte Hyne, Cooper Thompson, Elena Tsiounis, Indiana Dalton, Issy Neilson, Jordan Lambropoulos, Joshua Christie, Liam Bucco, Madeleine Jandura, Magnolia Riemersma, Ruby Hope, Sienna Warren, Tyce Khalil and William Quick.

Through their honesty and fearlessness, these Champions inspired others in the community to share their experiences during the campaign and helped start important conversations about living with IBD at any age.



We kicked off with a successful Information Forum, and have been sharing stories from our fearless Awareness Month Champions across our social media channels.

We had an excellent Kids Fun Day at the Sydney Wildlife Zoo, and launched the results of the Paediatric Quality of Care Hospital Audit 2023 at Parliament House on May 30.

On World IBD Day, over 90 venues and landmarks across Australia were illuminated in purple in support with everyone living with IBD, and the photos from the CCA community were fantastic!

CCA would like to thank sponsors Pfizer, Johnson&Johnson, Dr Falk Pharma, Celltrion, Takeda and AbbVie and our many donors and community supporters for making 2024 Awareness Month a success.

WORLD IBD DAY LIGHT-UP SITES

Adelaide Railway Station, SA

The Bell Tower, Perth WA

Civic Park, Darwin, NT

Story Bridge, Brisbane QLD

Morpeth Bridge, NSW

Flinders St Station, Melbourne VIC

Torrens River Footbridge, Adelaide SA

Surfers Paradise, QLD



EFCCA ROUNDTABLE: UNITING FOR ACCESS

In May, CCA CEO Leanne Raven joined a roundtable discussion organised by EFCCA - the European Federation of Crohn's and Ulcerative Colitis Associations - titled 'Uniting for access to IBD care.'

As part of this discussion, leaders and stakeholders from Australia, Brazil, Canada and the US addressed barriers to quality IBD care, and advocated for increased awareness, support and resources.

"We all have common understandings of the impact of these complex chronic conditions and, even though we speak with different languages, we have similar unmet needs and priorities and a wonderful opportunity to learn from each other,"
- Leanne Raven, CCA CEO.



LIVING FEARLESSLY FOR IBD

Live Fearless Challenge (LFC) was first established in 2018 as a virtual walk. With evidence demonstrating there is a significant health benefit in gentle exercise for people living with Crohn's and colitis, LFC encouraged participants to walk 150kms for the month of September. Over time, the physical challenge has evolved to include any activity – even mindfulness and meditation – to ensure there is no barrier to participation for those experiencing low physical health. The goal is to ensure LFC is inclusive for anyone wishing to participate.

In 2024 the Live Fearless Challenge raised \$183,460 for CCA and attracted almost 500 participants.

Following the success of the inaugural LFC walk in Brisbane in 2023, CCA again organised the LFC Walk to take place in conjunction with GESA AGW on Sunday 15 September in Adelaide. There were more than 100 people in attendance at the event, including State Minister for Health SA, Hon Chris Picton MP, three LFC Champions, President of Gastroenterological Society of Australia, Professor Alex Boussioutas plus members of the Adelaide IBD community and AGW attendees. It was a fantastic opportunity to bring the community together and demonstrates the success of the return of face-to-face events for LFC.

"Before the Live Fearless Challenge 2024, I didn't want to tell anyone about my recent Crohn's diagnosis. Doing the challenge changed that. Suddenly, I had something positive to talk about and was able to share my diagnosis in a way that helped raise awareness and funds for other people too. It totally changed the way I felt and helped reduce the stigma."

LIVE FEARLESS CHALLENGE 2024: BY THE NUMBERS



OUR FEARLESS FUNDRAISERS

Awareness Month

Brett Moody ran in the Brisbane Marathon, raising \$1,808:

"I was diagnosed with Colitis in 2021 at the age of 40 in the midst of a punishing COVID lockdown in Melbourne, it runs in the family so it wasn't a total surprise – more like a "pass the baton" moment with less cheering and more bathroom breaks. My sister is also affected, and my late mother suffered a debilitating form of Colitis starting from the age of 16. The opportunity to raise vital funds and awareness for CCA inspired me to partake in the Brisbane Marathon this year. Despite a slightly haphazard training schedule during the weeks (fitting it into my busy work schedule) I was relieved to hobble over the line at a time of 3:54. The aching and cramping was quick to set in as I wobbled out of the finisher's recovery area but nothing so bad that it stopped my traditional post event steak and couple of glasses of red that night!"



Kelli Densten raised awareness in the workplace, raising \$138

This isn't the first time Kelli has helped CCA raise awareness of IBD in her workplace – Northeast Health Wangaratta. Kelli is committed to educating her colleagues about her disease. This year, Kelli set up a space with posters and information to share, sold Awareness Month ribbons, and gave out homemade purple frosted cupcakes to the hospital staff.

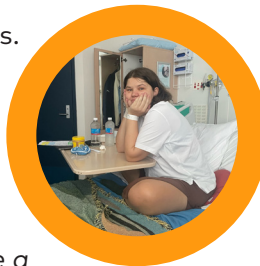


Chloe MacKenzie ran an Instagram fundraiser, raising \$1,215

Chloe was in hospital at 30 weeks due to her ulcerative colitis. Chloe set up a fundraiser on Instagram to share her story.

"I'm super excited to meet him (her baby) but keeping my disease under control, and keeping him in for as long as possible, has been the hardest thing I've ever done. He'll be coming early so this disease not only makes my life really challenging sometimes, but it'll also make the start of his life a tricky one too.

Autoimmune disease flares in pregnancy are rare but it happened to me. Understanding how it happened and stopping it from ever happening to anyone else will require a broader understanding of this IBD. That requires research money so doctors can help change the lives of people with this tricky disease."



Live Fearless Challenge

Thomas Zahariou topped our leaderboard in 2024, raising \$16,439

Thomas Zahariou is an award-winning Music Producer, Film Scorer and Podcaster. Thomas is also co-host of "The Footy with Broden Kelly", and used his platform to share his personal experience – particularly the impact of ignoring symptoms and avoiding medical intervention. Thomas' fearlessness is sharing his story so publicly saw him top of the leaderboard for LFC 2024.



"I've managed to do so many things I've wanted to do. I've now mostly been in a state of remission for 13 years, but they've recently discovered inflammation in my bowel, where the surgery scars are...Now my prerogative is to live for as long as possible because of my beautiful baby boy."

Paul Orton raised \$2,254

"My name is Paul. I'm 38 and my wife and I have two beautiful children. In 2019 I was diagnosed with Ulcerative Colitis. I'd never heard of it and I had no idea what it could do. I considered myself fit and healthy and had never experienced any health issues.



As a part of my recovery and rehabilitation after a year of surgeries and lengthy hospital stays, my family and I are getting active to raise awareness and much needed funds for Australians living with Crohn's disease and ulcerative colitis. As a family, we rode the highs and lows together throughout my fight with severe Ulcerative Colitis, so we've decided to achieve this target together also. "

Josh Bee raised \$4,379

"For the last 15 years I've been living with Crohn's, and to be honest it's thrown up some challenges and been a real pain in the arse. I've been blown away by the support of so many amazing (and often times stretched) doctors, nurses and organisations doing their best to take care of and make progress for people living with IBD.

After a wee bit of surgery recently, we serendipitously discovered the Live Fearless challenge starts on 1 September. So to give a little something back, Jordan and I are getting active to raise awareness and much needed funds for Australians living with Crohn's disease and ulcerative colitis."



Community Fundraising

Coogee United Football Club ran the 'Coogee Unites for a Cause' fundraiser, raising \$4,675

"This event started in order to raise money and awareness to honour one of our own, in what has become one of our favourite days of the off-season. This is a mixed 6 a side charity fundraiser. It is for all abilities, genders and ages.

This year CUFC is raising funds and awareness for another incredible cause near to our hearts - Crohn's & Colitis Australia. Help us make sure everyone who is affected by Crohn's and colitis feels supported and knows that they are never alone."



Kara Hadgraft ran the Sandy Point Marathon, raising \$3,202

"After experiencing bouts of unexplained illness off and on since I was a teenager, I was diagnosed with Crohn's disease two years ago. I've spent the last two years navigating the ups and downs of experimenting with different treatments and the symptoms of what can be a shitty disease (haha - literally). It has been a challenge to learn to advocate for myself in my own medical care and mentally grapple with the reality of having an incurable chronic disease."



Tony Concannon took part in the 'Hyrox Challenge; and raised \$2,010

"I did the HYROX challenge on my own on Saturday 14 December and completed it in 1 hr 44 min. I had trained for 6 months to do it but the cumulative fatigue was still exhausting.

It's not clear what triggers the condition and the person affected by it has to manage "flare-ups" which can be difficult and embarrassing. My family has been directly affected by Colitis for the past 14 years."



Beer & Beef Club Adelaide nominated CCA as their 2024 charity, raising \$3,300

CCA was thrilled to be chosen as the nominated charity of the Beer and Beef Club Adelaide, thanks to a nomination from long-time CCA champion Jordan Lambropoulos' grandfather, who is a member of the club.

In 2024, the Club generously raised more \$3,000 for CCA through their monthly social lunches and raffles.



AWARD RECOGNITION FOR CCA

In 2024 CCA was a finalist in two major awards:

2024 Health Industry Hub Awards, in two categories

- Advancing Health Policy (with Bristol Myers Squibb)
- Non-Government Organisation (NGO) of the Year

Research Australia Health and Medical Research Awards, in one category

- Advocacy Award, for our paediatric campaign *#SavingKidsGuts*.

Strategic priority 4: Increase awareness and engagement, driving knowledge, support and commitment to our purpose

To deepen our understanding of the IBD community, we will undertake a dedicated data acquisition program that captures meaningful insights into patient experiences, needs, and outcomes. This evidence base will inform a refreshed engagement strategy designed specifically for key stakeholder groups, ensuring our communication is both relevant and effective. By developing tailored two-way engagement programs, we aim to foster stronger, more meaningful connections that reflect the diverse voices within the IBD community.

In parallel, we will expand our network of brand champions to help raise awareness, share lived experiences, and extend our reach across different audiences. To drive continuous improvement and innovation, we will implement a “test and learn” experimentation framework. This approach will support the development of impact-driven solutions, allowing us to trial new initiatives, evaluate their effectiveness, and adapt in real time to better serve our community.

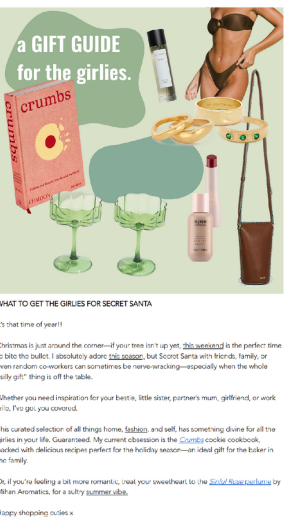
A SAMPLE OF OUR MEDIA COVERAGE IN 2024:



9Honey August 20 at 2:02 PM - *** She'd been showing signs of an incurable disease for almost a year, but this was the first time doctors really paid attention.



A GIRLY GIFT GUIDE



MEMBERSHIP

2024 membership remained steady at over 2000 members supporting Crohn's and Colitis Australia over the course of the year.

New membership increased by 5%, with 496 new members welcomed to the IBD community during 2024.

CCA has invested in programs to further support our members including education resources on our GutSmart site to be launched in 2025.

CCA has continued to optimise the member experience based on the 2023 member and past member survey and continues to provide the Can't Wait Card to members.



In 2024 CCA also launched a general newsletter 'Digestibles' to all CCA subscribers to keep them informed and engaged in CCA's work and the latest news.

VOLUNTEERS

Volunteers provide invaluable support for CCA and enable our small staff team to support people living with IBD across Australia.

In 2024, 200 volunteers helped at CCA in the office, facilitating support groups, at events, in their professional capacity, and in many other ways to enable CCA to thrive – an increase of 20 from 2023.

THANK YOU FOR YOUR VALUABLE CONTRIBUTIONS!

- 5 years**
- Anita McLean
 - Andrea Pelizzari
 - Alyssa Shapland
 - Becci Fazldeen
 - Chloe Davis
 - Emily Lawson
 - Grace Qualtieri
 - Jeff Mitchell
 - Randal Engel
 - Rose Mitchell
 - Scott Crowley
 - Wendy McKern

- 10 years**
- Cassandra Anslow
 - Geoff O'Hare
 - Susan Milgate



Strategic
priority 5:
Promote
a healthy
culture and
sustainable
organisation

To ensure long-term sustainability and growth, we will further develop our engagement plans targeting key funders, including government bodies, corporate partners, and philanthropic supporters. Strengthening these relationships will be essential to securing the resources needed to support our mission. Alongside this, we will develop a dedicated bequest strategy, offering supporters meaningful opportunities to contribute to our work through legacy giving.

Internally, we are committed to maintaining a strong and adaptive organisation. This includes reviewing our investment and capital position to ensure financial stability, completing necessary policy updates, and refining the CCA risk framework. To deliver on our strategic goals, we will focus on retaining and building the capacity and capability of our team. Additionally, we will keep our business model under regular review to remain responsive to emerging challenges and opportunities in the health and not-for-profit sectors.

FINANCIAL REPORT

This report is for the 12 months ended December 2024. The financial surplus of \$483,640 has increased by \$447,133 compared with the previous year.

Operating revenue increased by 27.4% compared to 2023, primarily driven by one-off Bequest income received, which significantly boosted donation income.

This was partially offset by a decline in grant revenue, as some of our government-funded projects were completed (eg paediatric audit and experience study and others were extended with less funding. In 2024, attention shifted to the development of the IBD State of the Nation Report, set to launch in February 2025.

Our costs remained steady compared to 2023. We achieved savings in administrative areas, which were reinvested into bolstering communications and programs.

A total of \$125,509 was generated from term deposit investment and returns from our managed low-risk investment, resulting in a \$47,668 increase compared to 2023.

As a result, our cash position continued to strengthen in 2024, increasing the liquidity ratio to 2.32.

With a stronger balance sheet, we can report an increase in net equity to \$2,251,290 for this year, compared with \$1,767,650 in 2023.

During the year the organisation has continued its focus on organisational sustainability. No workplace incidents were reported in 2024. Risk management has continued to be a key theme with cyber security a regular focus at our finance audit risk committee meetings.

CYBER SECURITY

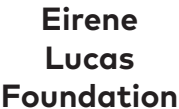
CCA takes your personal information and cyber security very seriously. That's why we introduced a new Cyber Security Framework during 2024. We have increased our monitoring, testing, tightened processes and secured applications to best practice. In the unlikely event of a security breach we have also introduced processes and procedures to limit the impact to users and CCA infrastructure.

SUSTAINABILITY KEY PERFORMANCE INDICATORS

Category	Notes	Target	2024	2023	2022
Liquidity Ratio	Current Assets/Current Liabilities	2:1	2.32	2.05	1.74
Profitability	Net Income/Equity	10-14%	21%	2%	12%
Debt to Assets	Total Liabilities/Total Assets	<1	0.34	0.36	0.43
Staff turnover	Industry benchmark 11.4%	10%	12.5%	19.8%	7.7%
Grant application success		40%	46%	65%	44%

A copy of CCA's audited financial reports can be found on our website at crohnsandcolitis.org.au/annual-report

Our fearless partners



GOVERNANCE

Board of Directors



Bruce Rosengarten FAICD
— Chair



James Oliver
— Treasurer
Chair
Finance, Audit & Risk Advisory Committee



Dominique Tim So GAICD
— Company Secretary
Chair
Governance, Nominations & Remuneration
Advisory Committee



Gregory Moore, FRACP
— Chair
Scientific, Medical and Quality of Care
Advisory Committee



Loretta Bayliss GAICD



Kara Ward



Lisa Belcher



Bruce Goodwin GAICD



Lisa Neville
— Chair
Stakeholder and Engagement
Advisory Committee



Kate McQuestin
— Appointed 12 August 2024



John Brennan
— Appointed 12 August 2024

Retired directors, 2024:

Daniel Teller (retired 26 May 2024)

Paul Pavli AM (retired 26 May 2024)

Belinda Dimovski (retired 26 May 2024)

For more information on our board, please visit crohnsandcolitis.org.au/our-board

GOVERNANCE

Board Advisory Committees

Governance, Nominations and Remuneration Committee

Dominique Tim So (Chair)

Bruce Rosengarten
James Oliver
Bruce Goodwin

Finance, Audit and Risk Committee

James Oliver (Chair)

Bruce Rosengarten
John Brennan
Loretta Bayliss
Dominique Tim So

Scientific, Medical and Quality of Care Advisory Committee →

A/Prof Gregory Moore (Chair)

Dr Fergus Gardiner
Prof Paul Pavli
A/Prof Edward Giles
Leanne Raven
Prof Jane Andrews
Dr Emma Halmos
A/Prof Simon Knowles
Bruce Goodwin
Ruth Malcolm
Dr Hugh Giddings

Stakeholder and Engagement Advisory Committee
Committee formed August 2024

Lisa Neville (Chair)

Kate McQuestin
Bruce Rosengarten
Bruce Goodwin
Blake Tierney

Fundraising and Communications Committee
Committee disbanded May 2024

Belinda Dimovski (Chair)

Bruce Rosengarten
Kara Ward
Lisa Belcher
Lachlan Pike

Digital Working Group
Advisory Committee reformed as a working group to focus on AI Strategy. Members included Kara Ward, Loretta Bayliss, Leanne Raven and Ian Stewart

Project Advisory Committees

IBD Paediatric Quality of Care Project Advisory Committee

A/Prof Edward Giles (Chair)

Dr Chris Burgess
Dr Shoma Dutt
Dr Nitin Gupta
Dr George Alex
Dr Paul Hammond
Dr Ajay Sharma
Dr Scott Nightingale
Professor Paul Pavli
Deirdre Burgess
Merran Spargo
Helen Jurgens
Prof Antonina Mikocka-Walus
A/Prof Ram Nataraja
Elliot Harris
Wayne Massuger
Leanne Raven
Stephan Möller

IBD State of the Nation Project Advisory Committee

A/Prof Gregory Moore (Chair)

Julie Weldon
Kelly Lambert
A/Prof Edward Giles
A/Prof Rob Bryant
A/Prof Simon Knowles
Prof Antonina Mikocka-Walus
Dr Emma Halmos
Ruth Malcolm
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Blake Tierney
Rose Mitchell
Leanne Raven
Wayne Massuger

Our fearless donors

Crohn's & Colitis Australia are grateful for the generous support of so many individuals, organisations and businesses. We would like to acknowledge and thank everyone listed below for making a positive difference and contributing to our impact at CCA during 2024.



Community Fundraising

\$10,000+

Paypal Giving Fund

\$10,000

The Yarranabbe Foundation

\$2,000 - \$9,999

S Starkey, C Trevillyan, C Orton, Adelaide Beer and Beef, Play for Purpose

\$1,000 - \$1,999

J Avramides, H Higgins, C McNally, A Cuda, D Paredes, A Brackley, The Estate of Les Klemke, S Dostal

\$200 - \$999

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General and Research Donations

\$50,000
Anonymous Foundation

\$20,000+
P & H Butts, Redman Family

\$15,000
The Pierce Armstrong Foundation

\$5,000 - \$9,999
Stan Perron Charitable Foundation, The Eirene Lucas Foundation, The Grand Court of NSW, Order of the Amaranth Inc., S Hillebrand-Roellgen, R Tatarka, B Ruming, T Fenton, S Trevor, D Shanahan, Dick & Pip Smith Foundation, Cabam Pty Ltd T/as Matheson Family Trust, Max and Lorraine Kousins Charitable Fund, D Birner

\$1,000 - \$4,999
L. Raven, R. Singleton, J. Mandel, L. Szumowski, N. Barrow, C. Busby, E. Yencken, C. Condon, The Bruce & Ros Rosengarten Family Fund, Australian Philanthropic Services Foundation, H. Gunther, K. McDonald, T. Sandison, D. McDermid, C. Azzopardi, R. Ramsden, A. Newman, C. Berryman, K. Rogers, K. Rich, V. Hoogstad, P. Crupi, Stauff Corporation Pty Ltd, Agar Cleaning Systems Pty Ltd, C. & H. Martin, B. Whitlock, C. Floreani, C. Mangubat, D. MacCue, G. Board, Hea Meng Chew, J. Neill, Lions Club Of Morayfield & Dist Inc., M. Walker, N. Heyes, N. Went, R. Brierley, Vantage Hotel Community Fund Group

Bequests

\$ 727,509.30 The Estate of Catherine Kan

\$ 97,786.63 The Estate of Graeme Light

\$ 84,944.72 The Estate of Dianne Marie Greenwood

\$200 - \$999
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In Memoriam

G Morgan, J Harvey, L Yelland, R Petrarca, T Costa

In Celebration

C Mynard, F Manning, J Farnham, S Maher

CCA also received a number of donations from donors who wish to remain anonymous.
We wish to express our gratitude to these donors for their generosity.



- ✓ **Get involved**
- ✓ **Find out more**
- ✓ **Donate today**
- ✓ **Join our community**



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