

# Annual Report 2022



Crohn's  
& Colitis  
Australia



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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 Charity and Not for Profit Commission (ACNC).

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



For over three decades, Crohn's & Colitis Australia (CCA) has been empowering the more than 100,000 Australians living with Crohn's disease or ulcerative colitis – collectively known as inflammatory bowel disease (IBD) – to live fearlessly.



## Our Vision

At CCA we dream of a future that is free of Crohn's and colitis. We empower people to live fearlessly while we help search for a cure.

## Our Purpose

**We believe in being fearless.**

At CCA we're about **improving quality** of life by helping people understand, respond to and actively manage their care. We want people to be authentic and unapologetic about their Crohn's or colitis – whether that leaves them laughing or crying.

**On our journey to finding a cure**, our ambition is **to empower and support** our community – encouraging innovation, advancing quality of care and facilitating new knowledge informed by deeper research.

Fundamentally, we are an advocate and an educator, leading tough conversations about taboo topics.

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 ability to face things head on.

**Because in fearlessness, there is strength.**

## Our Ambition

We aim to be:

- an omnichannel provider of support services with extensive reach and engagement.
- an accessible, fearless and frank communicator and an advocate of information and education.
- using data and evidence as a core element in our work and measurement of impact.
- helping in the search for a cure and build research capacity.
- a trusted organisation, recognised and respected by others.
- innovative and financially sustainable.

Our ambition will be achieved through the delivery of our strategic priorities:

Digital transformation and delivery of omnichannel experiences across the lifespan	Outcomes and data driven: measure quality of experience and impact on the lives of our community	IBD research facilitation via capacity building, making meaningful progress and breakthroughs	Strong partnerships and relationships, with an engaging credible and respected brand	Healthy culture, evolving business model and sustainable organisation
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# From the Chair and CEO

2022 has been an amazing year with Crohn's & Colitis Australia taking on its bold new look, resonating fearlessness and beaming the new colours of purple and orange.

We have become stronger advocates and educators across our national organisation and increased our geographic influence this year with additions to our board skillset, growth in our volunteer base, more active and working advisory committees and a stable staffing structure because we believe in fearlessness, there is strength.

We are still dreaming of a future that is free of Crohn's and colitis and doing everything we can to support people across the lifespan to live fearlessly whilst we search for a cure.

Advocating for improved quality of care and educating through shared experience creates the changes necessary to improve health outcomes. Accessible high quality information and supportive environments and networks at the system and individual level will improve quality of life and help people manage their condition better.

Throughout 2022 we were excited and extremely proud to have:

- Launched our Young Adult Support Online program in September 2022
- Launched our new website with much more information and many more resources to help people living with Crohn's and colitis and those caring for friends and family
- Welcomed 460 new members who chose to join us in the IBD fearless community with nearly 35,000 people following us on social media platforms and a record 176 volunteers
- Educated over 279 health professionals about IBD on our GutSmart platform
- Provided support to 754 people via Crohn's and Colitis Helpline and NurseLine

- Invested in 5 Phd Scholars and 1 Post Doctoral Scholar undertaking IBD research
- Launched the top 10 IBD Research Priorities via webinar which has reached over 1700 viewers

These achievements are only possible when we have the support of an energized, national community of corporate and not-for-profit partners, charitable philanthropic organisations, health professional colleges and societies, volunteers, generous donors, active fundraisers, and generous people who leave CCA a gift in their Will. We extend our thanks to you all for this support.

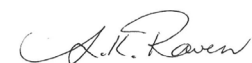
Just like every day is not a good day when you're living fearlessly with Crohn's and Colitis, CCA has its ups and downs as well and different challenges have presented throughout this year particularly due to the economic pressures within the community impacting on people's ability to give.

Together we are extremely proud to recognise everyone's contribution in facing these challenges boldly and in producing the outcomes and impact demonstrated in this report. We hope you see the value in your efforts and feel good about your own personal contribution to this important cause throughout 2022.

Your efforts are deeply appreciated.



**Bruce Rosengarten**  
Chair



**Leanne Raven**  
CEO



# Impact

## National Presence

**460**  new members

**2209**  total members



New website and brand

## Discovery

**\$150k**  committed to scholarships in 2022

**\$650k**  committed over all time

**4**  research articles published



Research Priorities project completed

## Advocacy

**4**  information forums

**1.4k**  Awareness month livestream views

**42**  World IBD Day light up sites

**3k**  magazines printed

## Empowerment

**608**  Helpline enquiries

**146**  NurseLine appointments

**17**  support groups

**2**  new educational GutSmart courses

**279**  health professionals enrolled in GutSmart

## Fearless Community

**176**  volunteers

**\$215k**  raised during Live Fearless Challenge


**\$90k**  donated to Tax Appeal

**\$45k**  donated to Festive Appeal


**\$325k**  received in Bequests

## Sustainability

**7.7%**  staff turnover

**44%**  success with grant applications

**74%**  funds expended on programs, services & membership

**17%**  funds expended on administration

**9%**  funds expended on fundraising

# National Presence

CCA is committed to being there for every Australian with Crohn's or colitis. No one should feel alone with these chronic conditions, which is why we have placed such high importance on becoming digitally capable and being a source of the best evidence-based information. By upgrading our services to be more accessible and user-friendly we aim to give more people the information and support they need to live fearlessly.

## Digital Transformation & Membership

2022 was a year of significant change for CCA in the digital space as we began to deliver on activities outlined in our Digital Strategy.

The new CCA website was launched in March. It champions our new brand and logo, offering new features such as the IBD service locator, connect with a peer and mapped support groups.

CCA took this opportunity to move to an org.au domain and all content from the previous CCA website, CCHub and iConnect were reviewed and consolidated onto a single website. New content was written, replacing gaps in knowledge and removing out-of-date content. Formal processes have been established to review content on a regular basis so that we can remain true to our goal to be a trusted and respected source of information on Crohn's and colitis. The new website provides a platform to deliver personalised content to our audiences in an easy-to-use way.

Upon the delivery of the new website, work began on the implementation of a CRM, which is an important next step for us as an organisation as it allows us to deliver personalised service and develop stronger relationships with our community. After an exhaustive evaluation a preferred solution was chosen and work began on migrating data from our existing CRM into the new one, ahead of an early 2023 launch. The new CRM is being designed to cater to more than just donor and membership needs, and we hope to bring more people on board to support our mission as well as access our services.









CCA's membership continues to retain a solid base with over 2,200 members fearlessly supporting CCA annually. Our *Inside Insight* magazine, published twice a year thanks to the support of Takeda Pharmaceuticals; and our *Can't Wait Card* sponsored by Pfizer, remain our most valued member benefits.

## CEA-IBD (Consumer Education & Awareness Project)

The Consumer & Awareness Education (CEA-IBD) Project played a major role in the launch of CCA's new website, reviewing and updating all content and filling in gaps in content based on feedback from the community. Together with Swinburne University of Technology, CCA developed resources on:



**Crohn's  
& Colitis**  
Consumer Education  
& Awareness

-  diagnosis and symptoms
-  living with IBD
-  IBD for kids, parents and young adults
-  supporting someone living with IBD
-  communicating about IBD
-  nutrition
-  medications
-  fatigue

Thank you to the 200+ people who gave their time to provide feedback on the new web content. We always love hearing from you and your feedback directly affects the direction of the CEA-IBD Project. Keep an eye out in 2023 for more surveys on this important project.

Learn more about the Australian Government Department of Health-funded CEA-IBD Project at: [crohnsandcolitis.org.au/cea-ibd/](https://crohnsandcolitis.org.au/cea-ibd/)



## Young Adult Support Online

CCA had a lot of fun working together with our young adult volunteers who were behind the development of the recommendations for our new online support program, which is dedicated to the needs of young adults living with Crohn's or colitis. After our volunteers narrowed down the themes and topics, we launched the Young Adult Support (YAS) service in September 2022.



YAS provided access to online support groups exclusively to people between the ages of 18 and 30 years. Specifically dedicated to their needs, this service is run by our young adult volunteers.

As part of the program, we ran special Zoom meetings dedicated to the topics suggested by the young adult panel and requested by the members of the service. The meetings were informal in nature and aimed at providing practical approaches to the presented topics:

*Strategies to cope with the mental health impacts of IBD*  
- Mark Micelli,  
Mental Health Social Worker



*IBD, employment and university*  
- Dominique Tim So,  
Senior Lawyer for James Cook University



As a recipient of an Incubator Grant from the Consumer Health Forum, we are proud to have launched this program in 2022.

## Social Media

CCA's social platforms play a huge role in building our national presence, and we continue to welcome more people to engage with us through them. Facebook and Instagram have the most active community, and we use them to share information and stories of fearless Australians living with Crohn's disease and ulcerative colitis and raise awareness of all our support offerings.



With many more young people receiving diagnoses of Crohn's or colitis, we have begun experimenting with a presence on TikTok to respond to the needs of teenagers and young adults.

Our community is most active during Crohn's and Colitis Awareness Month – many will choose this time to share their experiences. This lived experience is highly valued, especially on social media. We've introduced a submission page on the website where anyone can share their story. These stories are then shared on social media, where they receive a lot of support and positive comments from followers. For instance, Imogen McKinney, who was diagnosed with ulcerative colitis in May 2021, posted:

*"I truly believe that my experience has made me into a much stronger person and helped me to be able to understand others on a different level. My advice to anybody else that is suffering or looking for an answer, is that while it may seem like nobody is listening or validating your feelings, the most important person in this situation is and always will be yourself. If you can wake up and be confident in yourself and how you are feeling, that's all you need to take on the world!"*

One commenter replied:

*"When you said, 'the real Imogen had been missing', that was very powerful and painful to read. My young daughters have been through much the same as you Imogen. I admire your strength and honesty dear."*

# Empowerment

That moment when you're first diagnosed with a lifelong condition can be a punch in the guts (in more ways than one). It's so important to have a strong support network as well as someone to turn to on those understandably dark days. CCA aims to be another channel of support – a resource that's there when needed, so people can feel confident in their care. We advocate for better quality of care for people with IBD so they can have access to healthcare professionals trained and educated in the management of Crohn's and colitis and improved quality of life.

## Crohn's and Colitis Helpline

People living with IBD can use the Crohn's and Colitis Helpline for telephone support when they're newly diagnosed, interested in new treatments, seeking suitable health professionals or simply looking for an understanding ear to listen to their concerns. People call to find ways to get on with life: coping with work or school, planning to travel and finding insurance, or making strategies around illness-related financial issues.

Early in 2022, the Crohn's and Colitis Helpline received increased enquiries about COVID-19 vaccinations and returning to public spaces for people with IBD. Throughout the year, travelling with IBD enquiries have grown too.

Helpline is there for anyone who needs it: patient, carer, friend or colleague. Feel free to get in touch whenever the need arises.

In 2022, Dr Falk Pharma and Takeda Pharmaceuticals sponsored this service, which supported over 600 people with valuable guidance.



## Crohn's and Colitis NurseLine

CCA's NurseLine has continued to provide specialised information and guidance for people living with Crohn's disease or ulcerative colitis, helping people better manage their care and linking them to resources in the community.

To make it easier to book a time, we introduced an online booking capability. Anyone who needs help with their care can now conveniently pick a date and time from the calendar that suits their schedule.

While our three-year pilot project funding through the Centre for Community Driven Research concluded, CCA gained support from the McCusker Charitable Foundation and Janssen Pharmaceuticals Australia to continue this service through 2022 and enabled 146 people to have a consultation with an IBD nurse.

In 2023 we will continue to advocate for sustainable funding for this valuable service.



## GP Aware

A big part of ensuring quality of care in the IBD space is through training and education for healthcare professionals involved in treating Crohn's and colitis as well as other related health issues. This is why CCA's GP Aware project is incredibly important.

We have partnered with the Gastroenterological Society of Australia (GESA) and Australian General Practice Accreditation Limited (AGPAL) to help general practitioners and generalist gastroenterologists to participate in IBD management more effectively through awareness, education and Continuing Professional Development.

In 2022, CCA worked to promote IBD education to GPs and other healthcare professionals through:

- a webinar to promote and educate GPs about existing IBD guidelines
- development and promotion of an IBD online education platform to GPs and physicians with six education modules:
  - » The GP's role in early detection of Crohn's disease and ulcerative colitis
  - » Early intervention, therapies, referral and triage
  - » Management of IBD and preventative health
  - » Multidisciplinary team-based care
  - » Managing complex IBD issues – ages and stages
  - » Managing complex IBD issues – relapse and comorbidities
- hosting workshops on the six module topics
- resources available to healthcare professionals to help them improve their management of IBD

CCA also hosted a workshop and collected feedback from people living with IBD, carers and healthcare professionals to develop a Crohn's disease and ulcerative colitis Management Plan template.

It is common for someone with IBD to have multiple people involved in their care, such as GPs, nurses, specialists and allied healthcare professionals. The Management Plan will help keep everyone on the same page and keep track of any changes in treatment so that less time is lost on updating each person individually.

To keep updated on the progress of this Australian Government Department of Health-funded project, go to [crohnsandcolitis.org.au/gp-aware/](https://crohnsandcolitis.org.au/gp-aware/)



## GutSmart

GutSmart saw many new health professionals register throughout 2022 for the nutrition, psychology, and GP courses.

Progress is continuously being made on the treatment of IBD, and CCA is conscious of the need to continue to review and update the course. In 2022, the Nutrition and IBD for Dietitians course was reviewed and updated with the latest research and best practice. Thank you to our expert reviewers, Dr Emma Halmos, Dr Darcy Holt and Ms Liz Purcell, who gave their time and expertise to make sure the course is accurate and informative. The GutSmart platform was also upgraded during 2022.

Best of all, GutSmart now has a new course, introduced in May 2022, for general practitioners and physicians. It's called 'IBD for GPs and Physicians'. Together with Australian General Practice Accreditation Limited (AGPAL) and the Gastroenterological Society of Australia (GESA), IBD for GPs and Physicians is designed to provide general practitioners, general physicians, gastroenterologists and surgeons with IBD-specific foundational and advanced knowledge.

GutSmart has been supported by our founding innovation partner, The Erdi Foundation, and our other sponsors Ferring Pharmaceuticals and Dr Falk Pharma.



279  
courses studied  
in 2023

155

Nutrition and IBD  
for Dietitians

31

Psychological  
health in IBD

93

IBD for GPs  
and Physicians



## Paediatric IBD Quality of Care Project

CCA is excited to report on the progress of the Paediatric IBD Quality of Care project. This work provides invaluable insight into the quality of paediatric IBD care in Australia, looking into whether it meets national standards and providing improvement strategies that address the unique challenges facing young people living with IBD.



We are thrilled by the response to our Patient Experience Survey, in which over 260 young people, plus their parents and carers, provided detailed reports of their paediatric IBD care environment, including their access to important inpatient and outpatient support services, psychological needs and care, and treatment satisfaction. These issues were further illustrated in 35 interviews, in which young people living with IBD and their family members voiced personal accounts of their journeys through the IBD care process.

The project's second component is to assess the quality of paediatric IBD care from the clinical perspective through an audit of hospital care. The audit data that is currently being received presents a crucial point of comparison with CCA's 2016 IBD Audit, allowing us to explore changes in the quality and resourcing of paediatric IBD care over this period, as well as opportunities for improvement.

Outcomes for this Australian Government Department of Health-funded project will emerge in 2023.

## Information forums and webinars

Four information forums were held during 2022:

1. IBD Research Priorities Launch, Crohn's and Colitis Awareness Month (May)  
Professor Paul Pavli AM, Blake Tierney, Dr Ralley Prentice, Dr Aysha Al-Ani
2. Introduction to IBD, hosted by Western Sydney Local Health District, Blacktown NSW (Sep)  
Dr Viraj Kariyawasam, Dr Brandon Baraty, Brook Maguire, Christine Buttigieg
3. IBD Care and Wellbeing, hosted by The Queen Elizabeth Hospital, Adelaide SA (Nov)  
A/Prof Rob Bryant, Taryn Lores, Dr Alice Day, Dr Alex Barnes, Sangwoo Han, Zita Crawford
4. IBD Paediatric Forum, hosted by Monash Health, Melbourne VIC (Dec)  
Caitlin Watson, Dr Pat Khoo, Dr Lani Prideaux, Rachel Botros

Thanks to our sponsors, Celltrion Healthcare, Sandoz and Bristol Myers Squibb for their support of our information forums program.



# Advocacy

CCA aims to magnify the voice of the Crohn's and colitis community through our initiatives to raise awareness of the diseases within the general community, as well as among politicians and healthcare professionals to make change happen. We also highly value our community sharing their own lived experiences, and we're committed to helping their stories reach people who need to hear that it's possible to live fearlessly with IBD.

## What we advocated for in 2022!

- More IBD medications to be included on the Pharmaceutical Benefits Scheme
- Reduced medicine costs for people with IBD
- Removal of administrative burdens that are associated with some restricted IBD medicines, which reduces time clinicians can spend on patient care
- National Medicines Policy Review
- Changes to Health Technology Assessment
- Action to support people who are immunocompromised and at-risk due to the ongoing COVID-19 pandemic
- Complex disease navigation and telehealth nursing
- IBD and inflammatory condition nursing models

## Crohn's and Colitis Awareness Month

During our 2022 Crohn's and Colitis Awareness Month, the spotlight on #IBDHasNoAge resonated deeply within the community. We had many people sharing their fearless journeys of living with IBD.

The Crohn's and colitis community were very engaged with these stories – especially Joe, who shared his struggles with receiving a Crohn's disease diagnosis when he was a child. CCA ambassador and Victorian politician, Minister Lisa Neville, also received a lot of attention, while NBL basketballer Antonius Cleveland's Instagram reel had over 1.3K views.

*"My name is Joe, and I am 13 years old. I was diagnosed with Crohn's disease when I was 8 but I have had symptoms my whole life with daily stomach cramps, toilet urgency, fevers, psoriasis, mouth sores. I also didn't grow well and was/still very underweight."*



*I was misdiagnosed by many doctors and specialists. Misdiagnoses included abdominal migraines, constipation (even though I wasn't constipated) and irritable bowel syndrome. Once I got my diagnosis my Crohn's disease was classed as aggressive.*

*Since grade 5, Mum has home schooled me. I missed a lot of school due to doctor's appointments and hospital stays and it was very difficult trying to catch up on missed schoolwork. Home schooling is less stressful. It also helps that my friends are very understanding even though they have limited knowledge about Crohn's disease.*

*To anyone who has Crohn's or colitis, don't let it stop you from doing anything. Rest when you need to."*

**– Joe Griffiths**



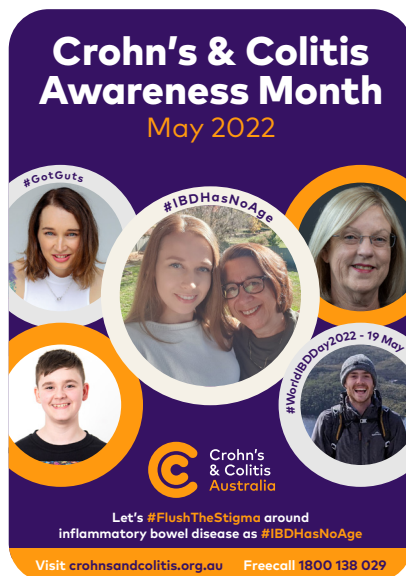
Our 2022 Awareness Month poster, which showcased Australians living with IBD across the lifespan.

Thanks to our Awareness Month sponsors:

Platinum partner Pfizer

Gold partners Janssen Australia & New Zealand  
Dr Falk Pharma

Silver partners Takeda  
Celltrion Healthcare





## World IBD Day

The Shine a Light World IBD Day campaign was a huge success on social media. One of our most popular posts of the month was the one on the morning of World IBD Day, reaching 23,500+ people and generating 207 shares.

We had light up sites confirmed in every state this year, with 42 landmarks across Australia (compared to the previous year's 21), illuminating purple to raise awareness of IBD. We loved seeing how the community shared their photos as they travelled around their local areas to catch a sight of the purple infrastructure.



## CCA Heroes

Every year, we are blown away by the generosity and enthusiasm of our volunteers, ambassadors and community champions. Our programs and support services would not be possible without these very special people. They have helped us by raising awareness, running support groups, sharing their experiences with IBD, speaking at events, mentoring youth and much more. We cannot thank them enough!

### Our Ambassadors



Brittani Nicholl



Jacinta Parsons



Teigan Nash



Luke Escombe



Justan Singh



Lisa Neville



Flic Manning

### Our Community Champions:

Melissa Lord  
Melita Griffin  
Tracey Murrin  
Sarah Starkey  
Kiara Schonberger  
Alyssa Shapland  
Dylan Swan  
Alexandra Sechi  
Harrison Bence  
Christopher Galloway  
Stephanie Hannah  
Jack Jones  
Sarah Michel  
Alana Plummer  
Jessica Pritchard  
Ryan Smith  
Morgan Williams

### Thanks Jan!

We are especially thankful towards our long-term volunteer and IBD nurse, Jan Platten, who has now retired after 17 years of supporting CCA.

Her dedicated service towards the Crohn's and colitis community is an inspiration to us all. Thank you Jan!



*"The nurse is the linchpin of the IBD service and Jan was an exemplar. She was 'the first port of call' for our patients and with her wealth of experience and knowledge was able to deal with all manner of problems in a quietly confident and competent fashion."*



*I will never forget her farewell from nursing in Canberra. It was held at a CCA forum, and the auditorium was full and there were many, many heartfelt testimonials.*

*It was a moving tribute to Jan's commitment and dedication, and a night that I'm sure she will always remember. She is greatly admired by all!"*

**– Professor Paul Pavli AM**



# Discovery

Our dream is that one day CCA won't need to exist, because a cure for Crohn's and colitis has been found. Until then, we believe that there needs to be continuous improvements in management and treatment of Crohn's and colitis and CCA's role is focused on capacity-building, making meaningful progress and breakthroughs. Research into the diseases is vital for answers to be found to improve care, which is why CCA places such importance on supporting the tireless efforts of researchers with their work in the field.

## Sending the Research Message

Australia is an active IBD research hub, and CCA helps to get the message out to people with IBD, other researchers and health service planners.

CCA supports awareness of current clinical trials and research studies through promotion of ethical research that is consistent with our vision. In 2022, 12 research projects were promoted that will further the knowledge base informing the clinical management of IBD.

We also do research ourselves in collaboration with clinicians and universities. Last year we published the following articles in peer reviewed journals:

- *High symptom burden and impact on health-related quality of life in patients with Crohn's perianal fistulas: results from a global burden of illness study.*
- *Higher work impairment and increased healthcare resource utilisation in patients with Crohn's perianal fistula: results from a global burden of illness study.*
- *Can an online expressive writing program support people with inflammatory bowel disease? A feasibility randomised controlled trial.*
- *Research priorities inflammatory bowel disease: applying an internationally adopted method to identify the top 10 research priorities of people living with inflammatory bowel disease, their carers and healthcare professionals in Australia.*

Our CEO, Leanne Raven, presented at the Gastroenterological Nurses Conference held in Sydney in August, while CCA also had a booth at the 2023 GESA Conference in September, where a poster on the IBD Research Priorities Project was presented.



## CCA IBD PhD Scholarship

The CCA IBD PhD Scholarship, which provides \$75,000 over three years, was offered in 2022 as a result of donations made by our generous community during the 2022 Tax Appeal.

We are thrilled to announce that Sarah Melton, a dietitian studying through Monash University and working at Alfred Health, has been awarded the scholarship for her research: *The role of exclusive enteral nutrition on intestinal physiology and microbiology.*



This project aims to identify the mechanisms of action of exclusive enteral nutrition (EEN), a liquid diet used to treat and reduce inflammation in Crohn's disease. This will be done through examining its effects in healthy participants, using highly sensitive markers of intestinal injury in patients with Crohn's, and examining its effects in siblings of those with Crohn's.

Our PhD and post-doctoral scholars now total six, due to the generosity of our community, a charitable philanthropic organisation which wishes to remain anonymous, the Yencken Family, and the Fenton Family.

## CCCure

CCA works closely with Crohn's Colitis Cure (CCCure) and our CEO attended a meeting held in Sydney. The meeting discussed IBD clinicians' health record system called CCCare, research and treatment pathways.



## Research Priorities Project

CCA completed an 18-month project in collaboration with the James Lind Alliance to identify the top 10 research priorities of people with IBD, carers and healthcare professionals.

In 2022, people with IBD, carers and healthcare professionals participated in two workshops to decide on the final top 10 list of unanswered research questions for IBD (see right for top 10 list).

A report describing all of the unanswered research questions and highlighting the top 10 was launched online by Prof Paul Pavli and Blake Tierney, a committee member living with IBD, in a forum celebrating IBD research in May.

The results from this project will help to encourage researchers and research funders to focus on the most urgent and relevant needs of people living with IBD, with a view to attracting more funding for IBD research.

This project was supported by a charitable foundation who wish to remain anonymous, Takeda Pharmaceuticals, and Janssen Australia.

To view the Project Report and Summary Infographic, visit [crohnsandcolitis.org.au/research-priorities/](https://crohnsandcolitis.org.au/research-priorities/)

## Live Streamed IBD Information Forum

This year, CCA's live streamed IBD Information Forum during Awareness Month in May unveiled the top 10 research priorities for IBD in Australia as discovered through our Research Priorities Project.

Hosted by CCA CEO Leanne Raven, it outlined the two-year research project that involved clinicians, healthcare professionals, and people living with IBD and their carers to discover the top IBD research areas that matter most to the IBD community.

Speakers included Professor Paul Pavli AM, Blake Tierney, Dr Ralley Prentice and Dr Aysha Al-Ani, with over 1,400 views of the streamed event and hundreds more on CCA's YouTube channel, with online feedback from the community overwhelmingly positive.



1. What are the risk factors for developing IBD (e.g. environmental factors, stress, insecticides, vaccines, antibiotics, glandular fever, removed appendix, susceptibility genes)?
2. How can microbiome (bacteria and other organisms) be modified to prevent IBD?
3. How can IBD be prevented (including those with a family history of IBD or genetic risk, and lifestyle factors, such as food and exercise)?
4. How can quality of life be improved for people with IBD (e.g. reduced visits to the toilet, coping with illness and psychological support)?
5. How can an individual's response to specific IBD medications be predicted?
6. How can food cause or prevent IBD symptoms and/or improve IBD disease severity?
7. What are the potential short- and long-term health effects from taking different IBD medications?
8. What is the most effective treatment for maintaining remission in IBD?
9. What is the link between IBD and mental health and are people with IBD adequately screened for mental health conditions?
10. What is the cause of IBD flares and how can they be recognised and avoided?



CCA are working towards promoting the top 10 list to stakeholders to act through research directions, funding and awareness. We need your help to share these top 10 research priorities.

# Fearless Community

CCA is dedicated to being trustworthy and staying true to our values of prioritising the care of our fearless community and our commitment to lifelong learning. We place high importance on our relationships with everyone who is involved with the IBD community. We believe that by bringing everyone to work together for a common cause, we can make a difference in the lives of people with Crohn's or colitis.

## New Brand

2022 was a big year for Crohn's & Colitis Australia. We introduced our new brand which we had been working on for two years and developed our new website, which we are enormously proud of. One of the most important aspects of the brand change was highlighting the concept of 'living fearless' with Crohn's or colitis. There is a lot of emotional turmoil involved with having a chronic disease like inflammatory bowel disease, and one of the most important roles of our organisation is to empower people to live their lives confidently.



In line with this thinking, our new logo and brand assets are bold, contemporary and strong. They have been designed to connect better with our various audiences and community members, and they also better represent who we are as an organisation.

Incorporating purple – the international awareness colour of IBD – into our new logo was also important, as it connects CCA to the Crohn's and colitis community worldwide and helps boost awareness of the diseases.

Enormous thanks to our pro-bono rebrand partner Houston. Their expert team have been extraordinary and such a pleasure to work with.

## Grants

We continue to pursue grants from organisations to fund our important projects and support services. In 2022 we submitted nine proposals, and were successful with four, a 44% success rate:

- auDA Foundation – Youth Empowerment Program! Online: \$40,000
- Australian Government – Volunteer Grant 2022: \$5,000

## Our Partnerships

There are a lot of other amazing organisations in Australia achieving great things, and we are thrilled when we have a chance to work together with them. In 2022, we had several great partnerships:

- Dietitian Connection during their Gut Health Month campaign in February, promoting healthy eating and the fantastic work of dietitians.
- Greening Australia, who dedicated tree plantings in proportion to the number of people involved in the Live Fearless Challenge 2022.
- Hospitals who co-presented our information forums: Western Sydney Local Health District, The Queen Elizabeth Hospital Adelaide, and Monash Health, Melbourne.
- Government-funded project partners: Gastroenterological Society of Australia, Australian General Practice Accreditation Limited, Swinburne University Centre for Global Health
- Childrens hospitals across the country involved in the Paediatric Audit Project
- Crohn's Colitis Cure - we participated in their Sydney meeting in September (*pictured right*)

By partnering with others, we hope to bring more attention to IBD and form long-lasting relationships with organisations that have similar values to our own to strengthen our cause.



Live Fearless Challenge

The Live Fearless Challenge (LFC) marked its fifth consecutive year in September 2022. The challenge called on participants to complete 150km of exercise during the month, with a theme of 'back to nature'.

Although the challenge itself remained the same, LFC has diversified each year, encouraging participants to select their own activity options with their own personal activity and fundraising goals. Participants were encouraged to create teams of friends, family or workplace colleagues as motivational stimulus to achieve their personal goals.

This year saw more than 600 individuals travel 63,400km and raise \$215,000 in funds. A total of \$1,328,902 has now been realised over the lifetime of the Live Fearless Challenge.

Thank you to the 15 Live Fearless Challenge Ambassadors around the country who shared their stories and provided hints and tips for reaching their goals.

Thank you to our corporate sponsors – Pfizer and Abbvie – for their ongoing commitment to LFC.

Thank you as well to Greening Australia, who partnered with CCA in 2022 by committing to plant one donated tree for every LFC participant. Finally, a huge thank you to Lachlan Pike who donated these native plants.

*"Completing the Live Fearless Challenge was really good for my soul. It gave me something to focus on and I feel like it helped my daughter and our family by raising funds and developing awareness."*





## Community Fundraising

Once again, our amazing community has shown their dedication to supporting CCA with innovative ways to raise funds. We had lots of fun runs, morning teas and special event celebrations. 2022 also saw new events such as a motorcycle muster, mountain bike challenge and even the sale of silly socks.

Nine individuals were particularly successful in raising more than \$1,000 each through their fundraising activities. The Orange Bunnings BBQ (above right) was a fantastic group effort raising more than \$2,000. CCA was also fortunate to receive a \$19,000 donation as the nominated beneficiary of the annual Eastern Hills Charity Car Show (right).

Community fundraising continues to play a vital role in supporting CCA fund its education and support programs while working towards the dream goal of finding a cure for Crohn's and colitis.



*"I don't consider myself to be a runner, perhaps a 'social jogger' – mostly 5km or less. Run Melbourne had 5 and 10 km events, but if I was to ask people to donate to the cause I believed I should make it a challenge for myself. So, I thought why not a half marathon!"*



*Both my children live with Crohn's. As a parent, you always want to help your children. Unfortunately, I feel a bit helpless in their fight with Crohn's, so the run was a way in which I could feel that I was at least doing something."*

**- Steve Wood (pictured right), raised \$1,600 participating in Run Melbourne**

## Appeals

### 1. Tax Appeal (End of Financial Year Appeal)

The EOFY Appeal is CCA's main annual appeal and in 2022 we highlighted the completion of the Research Priorities Project. We are truly humbled by our donors, who continue to support this appeal every year, as well as our wonderful first-time donors.

*"Offering up my opinion on behalf of people like myself was so rewarding and I felt like I could be really making a difference for the world of Crohn's and colitis. The Research Priorities Project is so important because it allows people like me to have a real voice in terms of what we want answers on in regards to Crohn's and colitis."*

**- Marnie O'Brien, Steering Committee member living with IBD**

### 2. Festive Appeal (End of Year Festive Appeal)

The fundraising appeal at the end of the year focussed on raising funds to kickstart our youth programs and resources in 2023. Many of our in-person events were put on hold during the peak of the COVID-19 pandemic, but we plan to restart our face-to-face support events with safety as a priority for those who are immunosuppressed. We will also continue to build on our online programs to increase accessibility to everyone around Australia.

It was thanks to the generous Crohn's and colitis community and our fearless volunteers, Hannah, Caitlin, Mary, Megan and Patrick, that the appeal was an incredible success.

*"I have been a volunteer with the Young Adult Support program since 2021, as I believe that no one deserves to go through a journey with this horrendous condition alone."*

**- Caitlin Manoharan (pictured right)**



**\$106k**

Funds raised

**433**

Number of donations

**\$209**

Average donation

**\$58k**

Funds raised

**257**

Number of donations

**\$182**

Average donation

# Sustainability

## Financial

This report is for the 12 months that ended in December 2022. The financial surplus of \$218,898 has decreased by \$9,585 compared to the previous year, however this came in \$127,000 ahead of budget.

Despite this, operating revenue increased by 2% compared to 2021. This was largely driven by donations and bequests, which helped to offset an overall decline in CCA's community fundraising and membership revenue during the year.

Revenue from the government has been stable in 2022 as we continued to support key projects in consumer education, awareness, GP education and the paediatric sector.

While our direct costs have remained stable, our administrative expenses increased by 32% compared to 2021, driven largely by the investment in technology. This investment is an ongoing initiative that aims to ensure our digital footprint is aligned across our programs, the workforce and the direct support we provide to the IBD community.

CCA renewed its current building lease during the year, resulting in an increase to the right-of-use expense for 2022.

Given the above, our cash position remained strong in 2022. As a result, the organisation invested \$500,000 in a managed low-risk investment which is now a non-current asset and this has contributed to the decline in our liquidity ratio compared to 2021.

With a stronger balance sheet, we can report an increase in net equity to \$1,731,143 for 2022, compared with \$1,512,245 in 2021.

During the year CCA continued its focus on organisational sustainability. Risk management was a key theme, with cyber security a regular focus at our Finance Audit & Risk Committee meetings. A review was conducted on organisational compliance and the board established its risk appetite with key risk indicators specific as financial sustainability, cyber/ICT, key person dependency, and reputation.

A full copy of CCA's audited financial report for 2022 can be downloaded from our website at [crohnsandcolitis.org.au/annual-report](https://crohnsandcolitis.org.au/annual-report)

## Healthy culture

Hybrid working arrangements continued, with a minimum requirement of 50% work in-the-office. Employees were encouraged to work from home if symptomatic and to take personal leave if unwell. Masks were voluntary and COVID-19 vaccinations encouraged.

WiFi capability was extended within the office and a refresh of the environment completed in line with the implementation of the new brand.

All employees participated in an education session on new Child Safety Principles.

Staff turnover was well below target sitting at 7.7% within an industry benchmark of 11.4%.

## Sustainability Key Performance Indicators

Category	Notes	Target	2022	2021	2020	2019	2018	2017
Liquidity Ratio	Current Assets/Current Liabilities	2:1	1.74	2.03	2.40	1.99	2.58	4.30
Profitability	Net Income/Equity	10-14%	12%	15%	349%	19%	13%	45%
Debt to Assets	Total Liabilities/Total Assets	<1	0.43	0.47	0.41	0.49	0.3	0.2
Staff turnover	Industry benchmark 11.4%	10%	7.7%	-	-	-	-	-
Grant application success	See page 14	40%	44%	-	-	-	-	-



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**Bruce Goodwin GAICD**



**Belinda Dimovski**

For more information on our board, please visit  
[crohnsandcolitis.org.au/our-board](https://crohnsandcolitis.org.au/our-board)

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### IBD Research Priorities Steering Group

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#### Katherine Cowan (Co-chair)

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Dr Ed Giles  
Dr Emma Halmos  
Prof Antonina Mikocka-Walus  
Claire Reilly  
Blake Tierney  
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# Thank you

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 2022.



## Community Fundraising

**\$19,000**  
East Hills Car Show

**\$5,000+**  
C Moon, L Pike

**\$2,000 - \$4,999**  
C Anslow, Abbvie Pty Ltd, Nutrien Ag Solutions, Yarranabbe Foundation

**\$1,000 - \$1,999**  
C Massingham, C Chalker, T Johnson, Magain Real Estate

## \$200 - \$999

M Vriens, G Warner, Hey Sweetie, H Boulter, Scots All Saints College, D Nedanoski, C Anslow, H Lo, Entertainment Publications Of Australia Pty Ltd, P Sword, J Ferola, A Nuccitelli, D Witte, J Young, S Murray, P Laycock, P Howell, R Brownlee, K Herrschaft, J Oliver, S O'Brien, T Tzioutziouklaris, A Schwartz, A Walter, J Poloni, P Armstrong, A Brown, L Murrin, A Sarathy, B Purkiss, E Dean, L Bayliss, C McNaughton, B Percy, K Moran, C McCabe, J Hedley, E Schmidt, P Timpani, M Cuttler, G & Gaynor White, A Abraham, A Abraham, N & N Noble Patterson, S Kearns, S Hallo, E Armstrong, H Pearce, S De Winter, R Teese, K Pannell, J Barber, N Yu, M Newman, A And Janet Russell, D Cipolla, L Sarzin, M Joseph, P Gamon, C Anson, C Jukes, D Cordato,

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## Research Donations

**\$75,000**  
Anonymous philanthropic organisation

**\$20,000**  
The Fenton Family

**\$10,000**  
The Redman Family

**\$1,000 - \$1,999**  
A See, N Barrow, P Hellsing, C Thorne, J Watson,

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## General Donations

### \$78,000

The McCusker Charitable Foundation

### \$10,000

Blackford Family Gift - Jonathon Blackford

### \$5,000 - \$9,999

S Trevor, P & H Butts, D Birner, J O'Kane

### \$2,000 - \$4,999

J Mandel, The Jackson Foundation, S Hillebrand-Roellgen, Cabam Pty Ltd T/as Matheson Family Trust, P Paul Szumowski, Bruce & Ros Rosengarten Family Fund, G Board, S Agar, T Sandison, C Azzopardi, R Turner

### \$1,000 - \$1,999

S Walker, D McDermid, A Kingsford-Smith, K Rogers, P Ahern, C & H Martin, K Dyer, B Dimon, C Busby, M Chew, C Mangubat, J Avramides, B Whitlock, K Gallus, P Williamson, V Hoogstad, M Kousins, N Barrow, M Walker, D Shanahan, M Kousins, Lions Club Of Morayfield & Dist Inc., M Winter, P Maguire, A Newman, K Rich, J Van Der Hoek, M Higgs

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## Bequests

The Estate of the late Elizabeth Anne Phipps  
The Estate of the late Margaret Anne Watkins

## In Memoriam

C Brain, I van der Hoek, K Mocicki, L Cross, M Higgs, P Sen, R O'Kane, R Uttley, V Morrison

## In Celebration

A Briner, B White, E Damen, H Turner, J Masson, R White, S Inberg

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.

# Our partners



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