

Annual Report 2021



Crohn's
& Colitis
Australia



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For over three decades, Crohn's & Colitis Australia (CCA) has been empowering the more than 100,000 Australian men, women and children 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 Goals

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.

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.

We are a registered Health Promotion Charity and Deductible Gift Recipient.
ABN: 42 082 747 135

Strategy towards 2023

<p>2023 Ambition</p>	<ol style="list-style-type: none"> 1. An omnichannel provider of support services with extensive reach and engagement 2. Accessible, fearless and frank communicator and advocate of information and education 3. Data and evidence are core to our work and measurement of impact 4. Helping in the search for a cure, we build research capacity 5. We are a trusted organisation, recognised and respected by others, innovative and financially sustainable 		
<p>Our ambition will be achieved through the delivery of our strategic priorities:</p>	<p>Digital transformation and delivery of omnichannel experiences across the lifespan</p>	<ul style="list-style-type: none"> • Develop a digital strategy, road map for change, execute and fund • Physical and digital experiences are driven by consumer voice • Programs are accessible and have widespread availability and dissemination • Establish successful Customer Relationship Management (CRM) system 	<p>Outcomes:</p> <ul style="list-style-type: none"> • Digitally capable organisation • Measurable impact
	<p>Outcomes and data driven: measure quality of experience and impact on the lives of our community</p>	<ul style="list-style-type: none"> • Build reporting tools to measure quality of programs and activities • Advocate for high-quality integrated care which assists people to best manage their own health and improve quality of life 	<p>Outcomes:</p> <ul style="list-style-type: none"> • 100,000 engaged in support services • IBD Quality of Care Minimum Standards met by 20% of hospitals
	<p>IBD research facilitation via capacity building, making meaningful progress and breakthroughs</p>	<ul style="list-style-type: none"> • Develop engagement program for funding of research • Publish in priority locations • Grow our research scholarship program 	<p>Outcomes:</p> <ul style="list-style-type: none"> • \$200,000 annual spend • 5 funded multidisciplinary research initiatives • 1-2 meaningful improvements in care
	<p>Strong partnerships and relationships, with an engaging, credible and respected brand</p>	<ul style="list-style-type: none"> • Develop stakeholder map for relationship management • Increase engagement and seek more mature relationships with philanthropic sources and the business community • Continue seeking grants from government to deliver identified priorities in the National IBD Action Plan • Complete brand refresh and develop a strong, consistent brand 	<p>Outcomes:</p> <ul style="list-style-type: none"> • Trusted and respected national peak organisation • Ongoing federal govt. support for National IBD Action Plan
	<p>Healthy culture, evolving business model and sustainable organisation</p>	<ul style="list-style-type: none"> • Build current revenue streams and explore options for attracting new revenue • Develop risk governance practices to meet evolving needs • Explore building value from accessible data • Develop investment strategy for improved returns • Ensure workload for staff and volunteers is paced appropriately to avoid burnout 	<p>Outcomes:</p> <ul style="list-style-type: none"> • Financially sustainable organisation with a healthy culture

From the Chair and CEO

There is a sense of urgency gaining momentum as the prevalence of IBD increases in Australia with estimates predicting there will soon be 100,000-160,000 people living with Crohn's and colitis. We are committed to meeting this growing need and continuing to build awareness of Crohn's and colitis across the community.

During 2021 we were thrilled to see:

- a 44% increase in new members and an increase of 7% in renewing members compared with the previous year
- our social media followers increase by 10% across all platforms compared with the previous year, an increase of 2880 followers
- our successful Crohn's and Colitis Awareness Month campaign "You've Got Guts" reached more than 536,000 on Facebook and our live streamed IBD information forum reached more than 1,500 people
- for the first time we offered two IBD PhD scholarships bringing the total to six concurrent scholarships
- progress in implementing the National IBD Action Plan resulted in:
 - funding in the Medicare Benefits Schedule for faecal calprotectin testing
 - the launch of the Psychological Health and IBD course for psychologists on our e-learning platform, GutSmart
 - commencement of the Paediatric Audit focussing on care for children and their families.
- the number of participants in the Live Fearless Challenge was over 1,000 nationwide, with 7,777 people supporting the event. Participants travelled 6.5 laps of the Australian continent, raising an amazing \$410,000

- donors increased as people supported the Live Fearless Challenge and
- partner organisations including pro bono supporters, philanthropic partners, sponsors and project partners increased support of our programs and services for the IBD community

Why were we thrilled?

Because this means more people are reaching out to CCA to access trusted information and support services, these programs and support services are growing and more people and organisations are supporting our efforts, working with us in partnership as we help in the search for a cause or cure. As we approached 2022, we have been preparing to release new capabilities to support people including our new website, new training for General Practitioners and wrapping our organisation and its messaging in an engaging new brand.

At CCA we believe in being fearless because in fearlessness, there is strength.

As an advocate and an educator we are excited to see our impact at CCA strengthen recognising we are get closer to achieving our ambition. We know we cannot do this alone.

This year we are proud of our impact which shows that 73.5% of funds expended have been used to provide programs and services for the IBD community. This has increased by 26.5% compared with the previous year. Our administration costs have declined as well, sitting at 12.5% of funds expended, a decrease of 7.5% compared with the previous year.

We are also proud to have adopted a digital strategy providing a road map for change, moving us further towards becoming a digitally capable organisation. This will enable us to better connect and allow improved access and engagement for our community.

This remarkable result could not have been achieved without strong leadership and enthusiasm from our board members, committee members, volunteers, ambassadors, donors, fundraisers and the amazing team at CCA.

We are deeply grateful for the support from our corporate sponsors, philanthropic supporters, pro bono supporters, government funders and our program partners.

We hope you continue to embrace our work at CCA and find our bold new look a sign of our energy and commitment to making our dream come true: a future that is free of Crohn's and colitis.



Bruce Rosengarten
Chairman

Leanne Raven
CEO

Our Impact

9,322



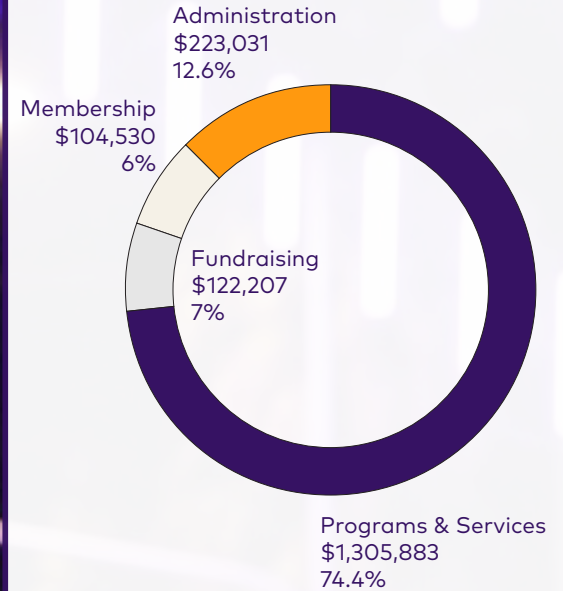
Donors

\$1.98m

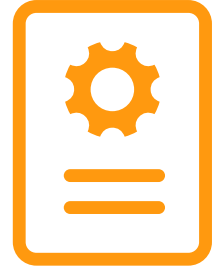


Raised

How funds were used



Programs and services



CCA provides a diverse range of support programs and services for the Crohn's and colitis community, so that everyone has the opportunity to increase their knowledge and find the best health care plan that works for them.

Forums

There's a lot of complex information on Crohn's and colitis, which can often be confusing for people newly diagnosed. CCA's IBD information forums offer a chance for people to connect with experts in the field and those with lived experience.

As COVID-19 restrictions continue to limit in-person forum events, forums are held online. In 2021, we organised two online information forums, one during awareness month in May and the second one in October. You can watch them here: crohnsandcolitis.org.au/ibd-information-forums/

The forums covered a wide range of topics including pregnancy, COVID-19, IBD nurses, and how Crohn's and colitis can affect young people and older adults. Two courageous people also shared their experiences with Crohn's and colitis, to inspire and support the IBD community.

We are deeply appreciative of our 2021 forum speakers, and we thank everyone who attended the live events for their questions, comments and support.

A round of applause is deserved for our hosts and guest speakers:

- CCA Ambassador, Flic Manning
- CCA Ambassador, Jacinta Parsons
- Dr Emma Flanagan
- A/Prof John Ding
- Dr Chamara Basnayake
- Dr Lena Thin
- Clinic Nurse of IBD & Rheumatology, Daniel Lightowler
- Dr Ajay Sharma
- Tessa Maxwell

 **1,946**
forum views online

Thank you to event sponsors, Sandoz, Janssen and Eirene Lucas Foundation.



"Thank you all for tonight's forum. I was particularly interested in the COVID part but all parts were full of information. Very much appreciate you all giving your time" – Michael

"Thank you so much. Very much appreciated the fertility segment" – Gemma

"Many thanks for a wonderful presentation" – Rosalind

Volunteer support groups

Sharing experiences and building a support network is an important part of managing a chronic illness like Crohn's or colitis. Being able to relate to others can help people start difficult conversations and be the beginning of long-lasting friendships.

CCA volunteer support groups are a valuable platform for the IBD community. During 2021 we saw growing interest in online meetings, with several groups recording a high number of attendees. Our support group facilitators have shown their willingness to switch to an online platform where needed.

With more support groups moving online, more people from remote areas now have access to this resource.



21 active support groups

Some support groups continue to meet face-to-face but the number of people coming to the meetings has decreased.

22 support group facilitators

iConnect

Starting a conversation on Crohn's and colitis can be difficult. iConnect helps people connect, one-on-one, about any issues they have around managing their illness.

Four amazing new members joined the peer support service in 2021.

Young and energetic, with a range of IBD treatment experiences, they are happy to share and support people who use iConnect:

- Elif
- Mary
- Nathan
- Jasmine



145 iConnect questions answered

CCA Helplines

Crohn's & Colitis Helpline

The COVID-19-related queries continued to be received on our Crohn's and Colitis Helpline in 2021. Our Helpline was called upon to provide information on COVID-19 vaccination for people with IBD as well as guidance on living with Crohn's disease or ulcerative colitis, provided by our expert peer Helpline Coordinator, Anita Reilly. People living with Crohn's or colitis turn to this telephone helpline for support often when they are newly diagnosed, interested in new treatments or seeking suitable health professionals. They 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.



775 Helpline calls answered

Some need help sorting reliable information from questionable 'internet advice', while others just call for someone who listens and understands. Helpline is there for anyone who needs it: patient, carer, friend or colleague.

Crohn's & Colitis NurseLine

CCA's NurseLine is hosted by an IBD nurse that can provide specialised information and guidance for people living with Crohn's or colitis as well as provide information, education and guidance on a wide range of subjects. Bernadette Viney, who established the program within CCA retired after long career dedicated to supporting people with IBD and we have been fortunate to have Kerrie Goldsmith, an experienced IBD nurse, join the team at CCA.



144 NurseLine call bookings

Through the NurseLine telephone appointments, Kerrie helps people identify any issue that relates to their IBD, and help them build a personalised care plan based around those issues, and in some cases highlight and give access to services or resources.

This initiative is part of the Patient Pathways Pilot program developed by the Centre for Community-Driven Research.



86 NurseLine care plans

Youth and children's programs



As more children and young people are being diagnosed with Crohn's and colitis, CCA has sought to create engaging spaces where this group can share their experiences and ask questions to our mentors.

In 2021, CCA's youth programs were, again, unable to go ahead because of COVID-19 restrictions. But we have been hard at work to bring about a virtual youth program.

Young adult support

We have been working on a new online Young Adult Support program which was funded by a grant from the Consumer Health Forum of Australia (CHF).

The first steps involved creating a set of recommendations for this program with the help of more than 20 young adults who volunteered to co-design this new service, consisting of a brainstorm activity and focus groups.

Some topics of interest for young people raised through the brainstorm:

- Will I be able to travel abroad?
- How to cope when you have prolonged absences from your studies
- Non-vaccinated friends and family
- Recognising when stress is causing symptoms
- Support available at universities

CCA is excited to launch the new program in the second half of 2022.

YEP! Online

The new Youth Empowerment Program Online (YEP! Online) is an initiative that came about in direct response to the COVID-19 restrictions.

In 2021, we received an auDA Foundation grant which allowed us to develop this new program for 2022.

YEP! Online will help young Australians with Crohn's or colitis share experiences, start conversations and talk about tips on how to manage the disease during key stages of their lives.

The program aims to minimise stigma around the diseases and reduce isolation among young people by providing a safe space for them to make new friends while learning more about IBD.



Volunteers and supporters



Volunteers are an integral part of CCA's support services and without them, most of our programs would be unable to continue.

Thank you to our enthusiastic volunteers who helped us and the Crohn's and colitis community in 2021.

Ambassadors

CCA ambassadors have been a valuable addition to CCA campaigns and project. They have helped advocate for better understanding of Crohn's and colitis and shared their stories with the community.

Their positive energy continued to inspire those who are newly diagnosed and those that have been living with crohn's and colitis for decades. It is really important that people can see others with Crohn's or colitis leading happy and successful lives.

Our ambassadors' contribution to Crohn's & Colitis Awareness Month, the Live Fearless Challenge and other social media campaigns was invaluable.

Local Champions

CCA welcomed five new local champions to our pool of supporters:

- Morgan Williams
- Jessica Pritchard
- Hasan Erdogan
- Chris Galloway
- Stephanie Hannah

All our Local Champions are focused on spreading awareness of Crohn's and colitis by getting in touch with federal and state politicians, and connecting with people and businesses in their local areas.

Membership

Following a strong end to 2020, membership with CCA observed a further increase in 2021.

Members continued to enjoy special benefits such as fortnightly e-News which increased in readership throughout 2021, and many members took up the opportunity to access free toilet paper through our 2020 'Quilton One Million Rolls' initiative.

This became particularly popular through COVID-19 lockdowns in 2021 and when the pandemic began impacting supply chains.

Another result of the increase in new memberships was a record year of distribution of Can't Wait Cards, with 679 cards being printed.



44% increase in new members



7% increase in renewing members



78% Member e-News open rate



679 Can't Wait Cards printed



630 rolls of toilet paper sent

Inside Insight magazine

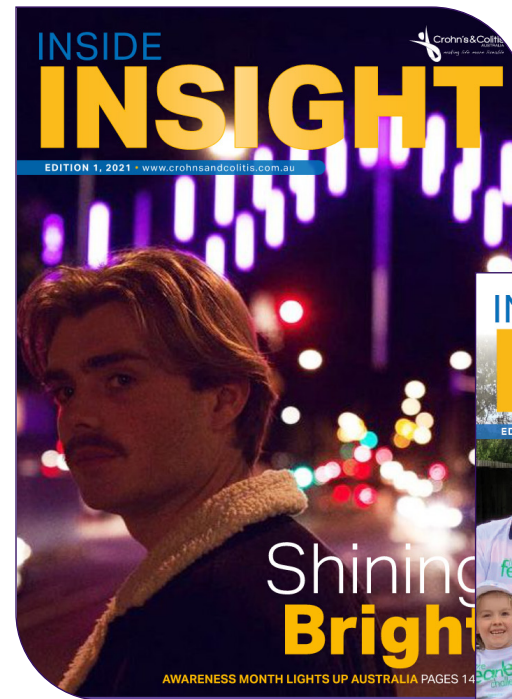
The Inside Insight magazine is a valuable resource for members, bringing the Crohn's and colitis community together with news and stories from around Australia. Articles included research updates, latest trends and developments in IBD, features on nutrition, and human interest stories.

This year one of the favourite articles was a poem submitted by Lauren French, on her experiences with Crohn's:

*A little over five years ago, and a distant memory to me,
I made a harrowing decision, that would eventually set me free.
Battling years of perianal Crohn's, I feared there would be no end,
But I took a leap of faith, and soon met my new best friend.
Thrilled with the freedom of my life back, my little stoma on my side,
I became thankful for the small things; a cup of coffee, a bike ride.
Six months on from surgery I vowed to trek the Great Wall with CCA,
The awareness raised was humbling, and I will never forget the day...
I reached a top part of the wall, and I looked down at my tummy and cried,
Because the reality was, without you, my friend, I may not be alive.
And so I ponder about the years of life, my little stoma has restored,
These years I cannot take for granted, I won't sit around feeling bored.
My stoma and I will explore the world, the mountains, the cities, the sea,
This is what I owe you, dear friend, for all you have given me.*

CCA produced two full-colour magazines in 2021 which were available in both print and digital formats. 3,100 copies were printed for CCA members, IBD clinics, nurses and gastroenterologists.

 **3,100** magazines printed



Research and education



Research plays an important role in improving the quality of care for people living with Crohn's or colitis. CCA is dedicated to supporting researchers through our scholarship program as well as collaborating with the science and healthcare community in national studies and projects that will make new discoveries and increase our understanding of these chronic diseases.

Quality of care

CEA-IBD (Consumer Education & Awareness-IBD) project

CCA is undertaking a four-year research project in collaboration with Swinburne University of Technology to improve the information and services that are provided to people with Crohn's and colitis.

In 2021, nine workshops were held with people with IBD, carers and health professionals. Results from the 2020 CCA National Health Literacy survey were discussed to generate ideas to improve health information and the supporting systems.

Extensive analysis was carried out and over 1,000 ideas were categorised into 70 health-literacy-informed actions. A co-design process involving people with IBD and clinicians was completed to assess the importance, implementation and feasibility of the 70 actions.

Four major project activities were prioritised from the data that will be implemented and evaluated within the CEA-IBD project over the next year to make it easier for people living with IBD and their carers to access, understand and use health information and services. The four activities are:

- CCA website redesign and up-to-date information published on a range of IBD topics
- To create culturally specific IBD resources
- To create rural/regional-specific information resources
- To create resources to provide to clinicians that link people with IBD to the CCA website



CCA is excited to progress this project into the next phase and produce high-quality, evidence-based information that is easily accessible to consumers. The materials and interventions are expected to be a range of online, interactive and print materials.

This project is supported by the Australian Government Department of Health.

To keep updated on the progress of this program and view publications from this project, please visit crohnsandcolitis.org.au/cea-ibd

Paediatric IBD Quality of Care project

The new Paediatric IBD Quality of Care project aims to look at the patient experience of young people with Crohn's or colitis and create recommendations for improving the quality of their care. This project is funded by the Australian Government Department of Health.



The first stage of the project involved creating a Project Advisory Committee and patient experience survey for parents and carers of a child diagnosed with IBD, and 16 and 17-year-olds living with IBD. CCA and the Project Advisory Committee obtained Human Research Ethics Approval for the 'IBD Paediatric Patient Experience Survey' in 2021.

Future steps include online interviews with families with a child under 18 years of age living with IBD, and an audit of Australian hospitals to examine their IBD-focused resources, organisation of care and quality of clinical care delivered to young people. The results will be compared to CCA's 2016 Australian IBD Audit to see what has changed and help guide future recommendations.

To keep updated on the progress of this project, please visit crohnsandcolitis.org.au/ibd-paediatric-quality-of-care

Research Priorities project

CCA is working on 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 2021, a survey was completed by almost 550 people with IBD, carers and healthcare professionals. The survey asked people to prioritise 56 unanswered research questions that were collected in a 2020 survey. The collected research questions were first evidence checked by the project Steering Group to ensure that they were not answered by current evidence. Keep an eye out through our social networks, as we will be sharing findings to the questions categorised as answered or partially answered by current research.

In 2022, the project will focus on discussion workshops, where people with IBD, carers and healthcare professionals will decide on the final top 10 list of unanswered research questions for IBD. This 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 research funding to IBD.

We are deeply grateful for the funding provided an anonymous philanthropic organisation and grants from Takeda and Janssen to support this project.

To keep updated on the progress of this program, please visit crohnsandcolitis.org.au/research-priorities

GP Aware project

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



In 2021, CCA worked to promote IBD education to GPs and other healthcare professionals through:

- Development of a centralised webpage to access project products and IBD resources available to GPs to better manage IBD
- The first of two webinars to promote and educate GPs about existing IBD guidelines
- Development of new two-page GESA summary IBD guidelines
- an eLearning platform developed to host education modules for GPs and physicians

The second awareness webinar, online education modules and workshops are scheduled to be released early 2022, they aim to improve knowledge and use of IBD guidelines and best practice by GPs and gastroenterologists. These modules will be available to GPs and physicians as part of their formal education requirements.

This project is supported by the Australian Government Department of Health.

To keep updated on the progress of this program, please visit crohnsandcolitis.org.au/gp-aware

Scholarships

CCA was thrilled to be able to offer two \$75,000 CCA IBD PhD scholarships. The scholarships provide funding for three years to build IBD research capacity in Australia whilst we search for a cause or cure.

Scholarship for diet research

Jessica Fitzpatrick, a dietitian from Monash University and Alfred Health, was selected for her study *The role of a low emulsifier diet in treating Crohn's disease*.

Dietary emulsifiers are a category of food additives that are found readily available in the food supply. In animal models, emulsifiers cause inflammation in the gut, similar to that seen in Crohn's disease. The project aims to investigate if removing emulsifiers from the diet of people with Crohn's disease induces disease remission.

Scholarship for pregnancy research

Dr Ralley Prentice from Monash University, Monash Health, Hudson Institute of Medical Research and St Vincent's Hospital Melbourne, will undertake the *Pregnancy in Crohn's and Colitis: Observations, Level and Outcomes Extension* study.

Also known as the PICCOLO-A study, it is a multicentre study with observational and scientific aims. It is investigating how to accurately predict IBD activity in pregnancy and subsequently any changes to the foetal/neonatal immune system and brain development. The study will define how thiopurine metabolite, vedolizumab and ustekinumab levels vary through pregnancy, how much drug crosses the placenta, how quickly the baby clears the drug and, finally, how this may affect the immune system of both the mother and baby.

Research videos

CCA promotes research capacity in the field of IBD. Our Online Research Updates series provides members with the opportunity to hear new research findings directly from researchers. High quality interviews with specialists, researchers and academics are delivered firstly to CCA members through e-news and in our closed member's area on the CCA website. Following this, the interviews are released publicly within six months on our YouTube channel. This feature caters to the requests of members to be kept up to date with the latest research news.

CCA published a total of six research videos during 2021.

The first was a series of four videos featuring Dr Betty Wu, PhD Candidate at St George Private Hospital – Gastroenterology. Betty discussed the research she and the team at the Microbiome Research Centre in Sydney have been conducting into inflammatory bowel disease and what they have discovered thus far. In this video Betty shared what drove her passion and interest in contributing to research.



Catherine Emerson, PhD Candidate, School of Psychology, Deakin University discussed fatigue and IBD and what fatigue is like for people with IBD and the lack of understanding about the level of fatigue IBD patients can experience. Catherine provided helpful tips on managing and explaining fatigue to others.



We published a research video with Dr Antonina Mikocka-Walus, Associate Professor, School of Psychology, Deakin University speaking on the topic of research into psychology and IBD including the latest therapies and the important role that psychologists play in working with IBD patients.



Thank you to our partner Bristol Myers Squibb for supporting these important research updates.

GutSmart

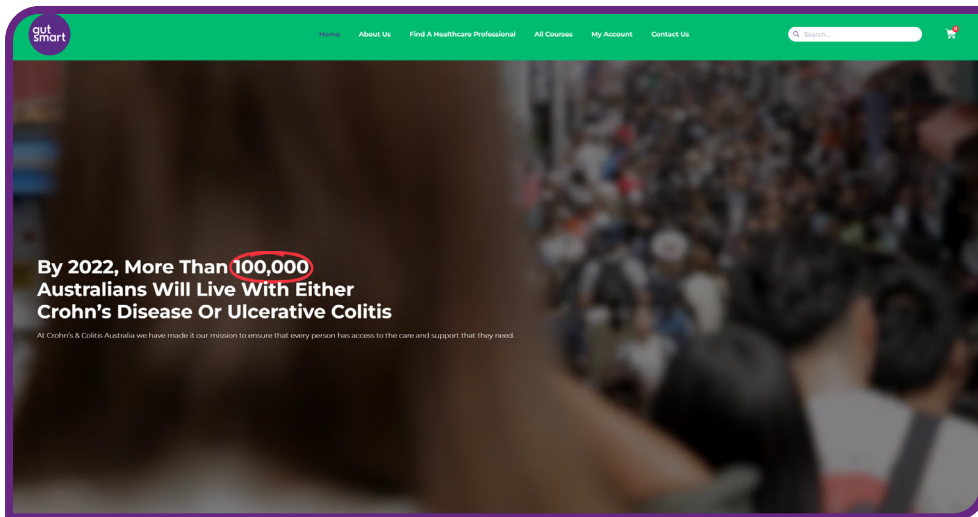
CCA continues to increase the understanding of Crohn's and colitis in the healthcare system through the education platform, GutSmart. We hope that by increasing the number of health professionals knowledgeable in Crohn's and colitis, Australians diagnosed with the diseases can find better, expert care.

 **69** new Gutsmart users

Only one in three people with IBD have a dietitian in their treatment team, and only one in 10 a psychologist. That is why our first course was targeted at dietitians and the new second course is for psychologists.

Psychological Health & IBD was released 23 November 2021 and will cover topics from the gut-brain connection to the psychosocial impacts of IBD at different points in the patient journey. As more health professionals complete the course, the GutSmart directory will grow and make finding a dietitian or psychologist who is an expert in IBD much easier.

We are deeply grateful for the funding provided by The Erdi Foundation, the founding innovation partner for GutSmart and the grants provided by Ferring and Dr Falk Pharma in support of this project.



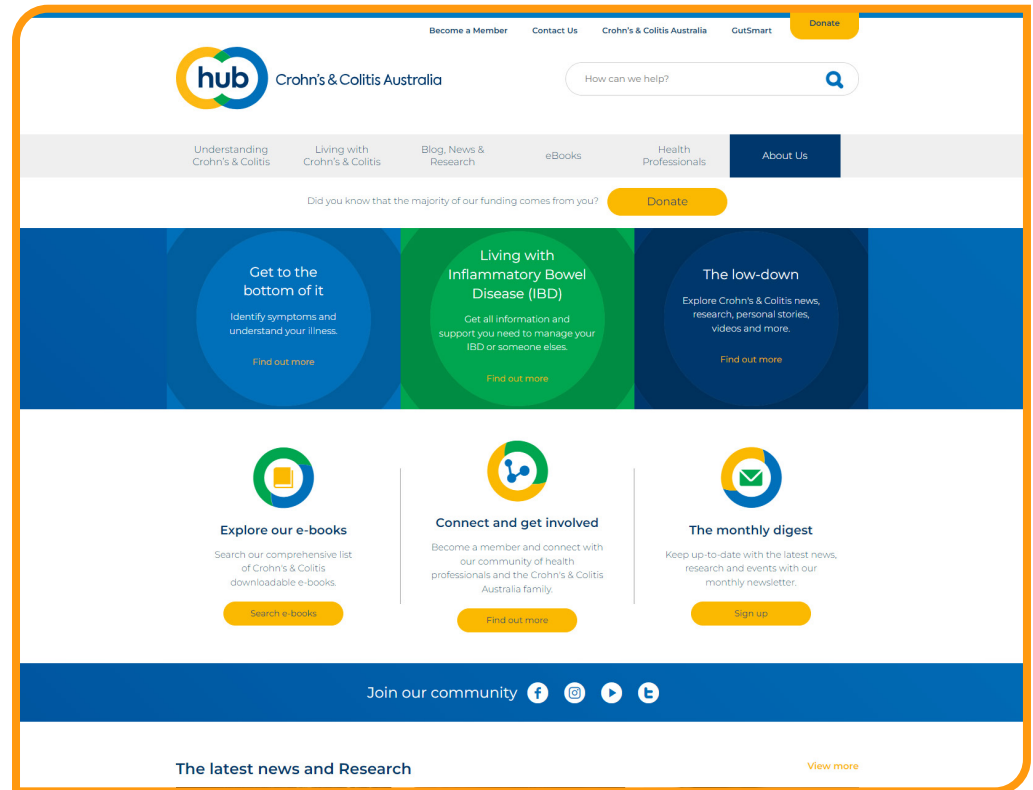
CCHub

The Crohn's & Colitis Hub (CCHub) was a website managed by CCA that aimed to provide information on living with IBD and the latest research on treatment and gut health. The freely available articles covered topics such as nutrition, psychological wellbeing, medication and also included personal experiences from people living with Crohn's or colitis. On the CCHub were also free eBooks on pregnancy, living with IBD and how to care for your psychological health.



23,668
new users on CCHub

Thank you to the CCHub sponsors Pfizer and Sandoz.



Events and community fundraising



Fundraising is vital to CCA and is the primary way in which our organisation generates funds to provide research scholarships and support services across Australia. Fundraising events held by individuals within the community are especially valued by CCA and are also important for raising awareness and initiating conversations about Crohn's and colitis.

Community fundraising

Families and communities came together in 2021 to support their loved ones and raise funds and awareness of Crohn's and colitis. People diagnosed with IBD impressed everyone with their courage, sharing their stories and overcoming physical and emotional challenges in support of the IBD community.

We saw people celebrate their birthdays with us, run marathons, and have get-togethers at work and at home. Samantha Abarca raised an amazing \$3,000 across five City2Surfs while wearing her CCA t-shirt to raise awareness.

We continue to be inspired by the resilience and energy of the Crohn's and colitis community, and everything that fundraisers achieve. We can't wait to hear what our fundraisers have planned next and look forward to their future achievements.

"I saw an ad for the Sydney City2Surf on television in hospital, in four months' time. I had never done the City2Surf but always thought it would be a fun event. I made it my goal, in my hospital bed, to do the City2Surf that year" –
Samantha Abarca raised a total of \$3,000 across five City2Surf marathons.

"With my 50th birthday, CCA became my chosen charity – IBD now lives with us daily, and as a family we have to help my son manage it, and at the same time keep moving forward. It's my hope that the fundraising can also hopefully get some support to others through CCA's resources. I know I have used the PDFs for the school teachers and employers and it has been invaluable" –
Richard Luke celebrated his 50th birthday with CCA in support of his son, Will, raising \$800.

"With the support of our local community, we offered purple decorated cupcakes, chocolate chip cookies, gluten-free cookies and even some fudge. We were amazed at the offers from friends and family to provide goodies for our stall, and also the equipment needed for the setup." –
Rachael and her family raised \$1,488 during a bake sale in support of their family member, Sophie, recently diagnosed with Crohn's disease.

Tax Appeal

The funds raised by the tax appeal support the creation of CCA research scholarships, so it was decided that this year's tax appeal would focus on communicating the importance of research.

Prof Paul Pavli AM was the writer of the letter this year that was sent out to members and donors in 2021. The 2021 tax appeal was significant this year as the other two appeals at the beginning and end of the year have been removed in favour of only making one big ask of donors each year instead of many.



\$130,000

raised through the Tax Appeal

Crohn's and Colitis Awareness Month

The chosen theme for the 2021 Crohn's and Colitis Awareness Month was 'You've got guts'. We acknowledged that living with and speaking about Crohn's and colitis takes courage. That even the small, everyday achievements were worth being proud of and shared with the community.

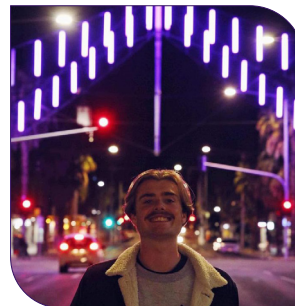
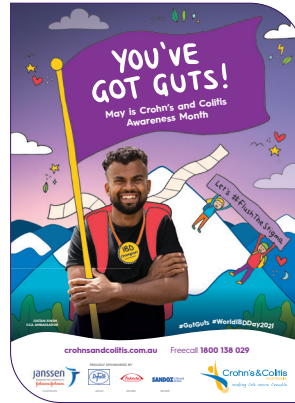
As COVID-19 restrictions continued to limit live events, we focussed on connecting with people through social media and other digital initiatives. For the first time in many years we had a male as the face of our campaign, CCA Ambassador, Justan Singh. Along with MJ Pureza's bright illustrations, we created a positive and friendly atmosphere to encourage people to start their own conversations on IBD. Our other CCA Ambassadors also provided video footage for social media, sharing their own 'got guts' message.

Our Awareness Month online information forum was well-received by the community. Hosted on 25 May, by Flic Manning with panellists Dr Emma Flanagan, DA/Prof John Ding and Dr Chamara Basnayake, it was live streamed via both Facebook and the CCA website.

There were over 1,500 views and 2,000 people reached from this activity. The feedback from the online community was overwhelmingly positive, with much interest and questions asked about IBD, plus pregnancy in particular.

We would like to thank all those who got involved in Crohn's and Colitis Awareness Month 2021, for your support, fundraising and enthusiasm. Without you, this special month wouldn't be possible, so we hope you continue to support the IBD community into the future.

Thank you to our Awareness Month sponsors Janssen, Dr Falk, Takeda and Sandoz for supporting another successful and vitally important Crohn's and Colitis Awareness Month in May 2021.

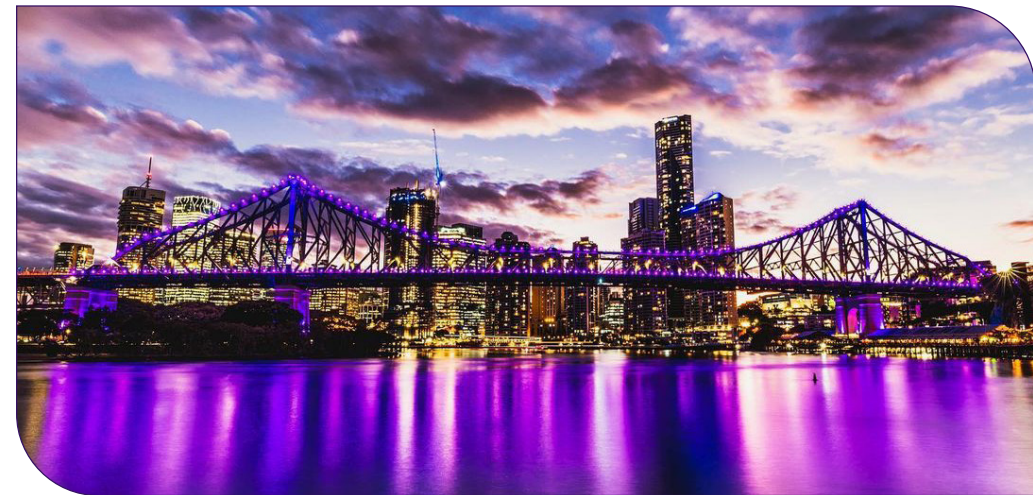
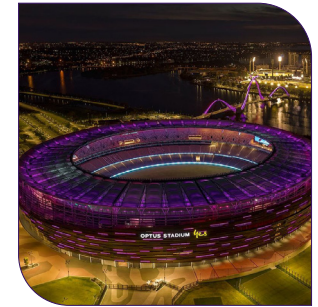


World IBD Day

We had a record number of light-up sites booked in 2021, with 28 sites across Australia lighting up purple on World IBD Day and every state represented.

World IBD Day was the peak of our online campaign with our Facebook page reach at 82.9K on this one day and 10.6K on Instagram. We had a huge response from Facebook followers posting photos of light-up sites and Instagram followers sharing their stories. This was an exciting time for everyone, and posts were shared late into the night as the Crohn's and colitis community rallied around Australia turning purple.

 **28** sites lit up in purple nationwide



Live Fearless Challenge

The annual Live Fearless Challenge, held in September, was a lot of fun for everyone involved. Over the last four years \$1,122,000 has been raised and 2021 has been the most successful year to date, raising over \$410,000 in support of CCA and the Crohn's and colitis community.

We were especially pleased to note an increase in teams participating and more participants coming from Western Australia and Tasmania. One of the main goals of the Live Fearless Challenge is to bring the community together from all around Australia.

Some changes were made this year to make the challenge accessible to more people, including the removal of restrictions on the type of physical activity. Promoting manageable exercise for people with IBD is another important aspect of the Live Fearless Challenge. We also realised that a lot of people were participating for friends or family, so we added a tribute feature to the Live Fearless Challenge website.

Thank you to the 12 Live Fearless Challenge Ambassadors who helped motivate and inspire during the challenge, and to our three sponsors Abbvie, Sandoz and Celltrion Healthcare.



\$410,000

raised in the 2021 challenge

"In 2020 I watched on via social media as a friend of mine completed the Live Fearless Challenge. I could do little else but watch on as I was one month post-surgery and couldn't walk a kilometre (heck, at that stage I couldn't do much beyond lying on my side - a total proctocolectomy has that kind of impact on the body!).

Sitting there, feeling a little sore and sorry for myself, I would daydream that next year, I might be able to have a crack at the challenge in some way, shape or form.

It took me a long time to get my core to a point where I could run without pain... as in, it took me 12 months before I managed my first run. So, imagine how amazing I felt when I commenced the Live Fearless Challenge 13 months post-surgery and 20 years after being diagnosed with Crohn's disease.

Running those first 5km was a genuine feeling of bliss. Sure, my legs were tired and I was puffing hard – but by golly the grin on my face could light up the grid. And then, my first social media post went up, sharing my story... wowee. The reactions of support made me realise that I have had a whole team of people riding through this Game of Crohn's with me... following my every heartache and triumph.

And then, the donations started rolling in. Well, that truly brought a tear to my eye. To have family and friends financially contribute to something that means so much to me is an act of generosity and kindness that I found overwhelming – in the best kind of way.

So all in all, I deem the 2021 Live Fearless Challenge a raging success; 150km covered (98km of running), over \$4,000 raised and a flood of support and kindness from those around me. How lucky I am to feel this happy? How lucky am I to have a trusty ileostomy and outstanding medical team to make me healthy? Life is good when you live fearless." - Jodi Evans



Our new brand

A big change has swept through CCA with the help of Houston branding agency. Over the course of 2021 CCA has been brainstorming and reviewing new brand guidelines for our organisation to refresh and reinvigorate our old brand.

Some of the main considerations of the new brand guidelines were:

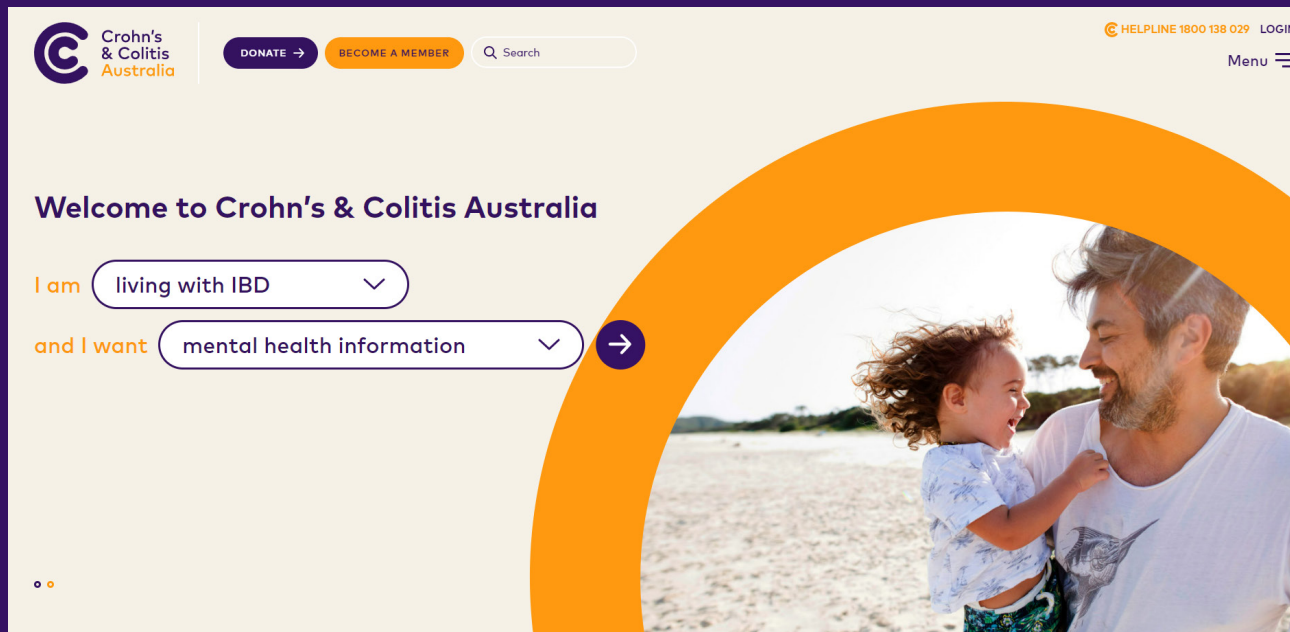
- Tone of voice
- Colour schemes
- Logo

The new brand was especially significant as it was being developed alongside a new CCA website.

The new brand was launched together with the new website in early 2022.



Crohn's
& Colitis
Australia



Digital transformation



Digital Strategy

In June 2021 the CCA Digital Strategy was delivered and later endorsed by the CCA board. The Digital Strategy outlines a large body of work that will digitally transform the organisation to support and implement CCA's Strategic Plan. The strategy includes a framework and roadmap of activities to lead CCA into 2025 and beyond.

Key foundational projects within the strategy include a new website for CCA that is aligned with user needs, and a new customer relationship management tool that will allow CCA to provide tailored information for our various stakeholders.

Cyber security

Following on from the work on CCA's Risk Management Strategy, a number of activities were completed to improve the cyber security of the organisation. These included introducing password management tools and a cyber security workshop for staff conducted by Deloitte Digital as part of their giving day.

Organisational culture

The way we work at CCA is based on FACTS - this has again been tested during 2021 as we have faced the challenge of living our values within the workplace.

F	Fast	Responsive to new ideas and insights - we design experiences with better outcomes and we are quick to act in ways that empower people
A	Agile	Our agility helps us to drive meaningful positive change and ensure social and fiscal responsibility
C	Connected	We strive to deepen the connection to the Crohn's and colitis community, understand its meaning and improve experience based on evidence
T	Transparent	Proud of what we do, we aim to showcase our achievements, disclose our failures and learn from our experiences
S	Smart	We innovate by trialling new initiatives, gathering evidence, adding value and sharing our learnings

Financial report



This report is for the 12 months ending December 2021. The financial surplus of \$288, 483 has decreased by \$220,151 compared with the previous year. This has been purely driven by COVID-19 stimulus provided by the Commonwealth Government which supported the organisation through 2020.

We are pleased to report that despite this, our revenue has grown by 6 per cent vs. 2020 and 38 per cent since 2019. This has been largely driven by securing funding from the Commonwealth Department of Health to support key projects in Consumer Education of Awareness in IBD, GPs and the paediatric sector.

Whilst our direct costs have increased in line with our funding, we have continued to preserve our cash flow and reduced our administrative expense

by 10 per cent vs. 2019 to ensure protections of our programs, workforce and the direct support we provide the Crohn's and colitis community.

As a result, our cash position has also improved this year and demonstrates a healthy balance sheet and the strong liquidity position of CCA as we move into 2022.

With a stronger balance sheet, we can report an increase in net equity to \$1,512,245 for this year, compared with \$1,283,762 in 2020.

A full copy of the audited Financial Report for 2021 can be downloaded from the CCA website.

Category	Calculation	Target	2021	2020	2019	2018	2017
Liquidity Ratio	Current Assets/Current Liabilities	2:1	2.03	2.40	1.99	2.58	4.30
Profitability	Net Income/Equity	10-14%	15%	349%	19%	13%	45%
Debt to Assets	Total Liabilities/Total Assets	<1	0.47	0.41	0.49	0.3	0.2

Board of directors



Bruce Rosengarten FAICD, Chairman

Bruce Rosengarten has spent over 35 years in executive roles across eminent organisations, and has been living with ulcerative colitis for more than 40 years. Until mid-2017, Bruce was Executive General Manager, Commercial at Caltex responsible for all sales, marketing, innovation and convenience stores. Bruce has held senior roles at Weight Watchers (President Asia Pacific and emerging markets) at Shell (Global Vice President Retail, Marketing) where he led Fuels, Convenience stores, Loyalty, Cards, Marketing and the Shell brand globally.



Bruce has extensive governance experience across a diverse range of organisations including ASX listed, private companies, joint ventures, industry associations and not for profit.

Bruce is the author of *Passionate Leadership*, runs his own consultancy and is a member of several advisory Boards: Binyan 3D Studios (Chairman), Link Financial Services (Chairman) and MadMex.

James Oliver, Treasurer

James Oliver is a partner with Deloitte Touche Tohmatsu, specialising in governance, regulation, audit and risk management services to the financial services sector. He has worked in Deloitte's London, Sydney and Melbourne offices and is well connected within the business community.

James has a BSc Economics from the University of Nottingham and is a Fellow of the Institute of Chartered Accountants in England and Wales as well as a registered company auditor. He is a member of several industry working groups on matters related to regulation, internal controls and governance.



He has seen first-hand the impact IBD can have on people, and the difference CCA is making. His goal as a board member is to contribute to making what is an already well-run organisation even better, through strong risk management, compliance and oversight of financial processes.

Paul Pavli AM, FRACP

Professor Paul Pavli AM trained in Gastroenterology at Concord and Royal North Shore Hospitals in Sydney and has had an ongoing interest in the basic science and clinical aspects of the inflammatory bowel diseases (IBD) since he finished his specialist training. Paul completed a Ph.D. in gastrointestinal immunology at the Australian National University (ANU) and has pursued an active research program studying the causes of IBD. Working with researchers from the ANU, he helped establish the Australian Familial IBD Register in the early 1990s, and more recently, has been studying the role of bacteria in triggering IBD.



In parallel, he has helped develop a clinical service in IBD at Canberra Hospital where patients have access to all facets of treatment including clinical trials of novel therapies and nursing, surgical, nutritional and psychological support for patients and their families. Paul has maintained an active role as a teacher and mentor for undergraduate medical students, hospital resident staff, and advanced trainees in Gastroenterology who wish to specialise in the management of IBD.

Gregory Moore, FRACP

Associate Professor Greg Moore is an IBD specialist gastroenterologist. He founded the Inflammatory Bowel Diseases Unit at Monash Medical Centre in 2006 and oversees a specialised IBD clinic. Greg coordinates a busy clinical trials unit, undertakes ongoing research and combines private practice and undergraduate and post-graduate teaching.



He is a senior lecturer in the Department of Medicine Monash University and supervises research students. Greg is also a member of Australian Inflammatory Bowel Disease Association, the peak medical IBD group, and is a sought after speaker at both scientific and public forums.

Daniel Teller OAM

Daniel Teller OAM started his working career as a Non-Ferrous Metals commodity trader and then transitioned into the family business (Teller Group Pty Ltd).

Daniel became a Director of both the Group's businesses (Teller Automotive Group & Harlea Properties) and is today focused on the family's long term property investments.

Daniel has for many years been working with both State & Federal Governments in supplying Affordable Housing and in 2016 was Awarded an OAM for "...services to aged persons in community..."

Loretta Bayliss GAICD

Loretta Bayliss offers an accomplished history of building successful organisations and teams through strong governance, values-based, sustainable relationships and a deep understanding of client requirements, having grown Prescience Group (Australia) from a single Australian entity to three operating entities across Australia and ASEAN, headquartered in Brisbane, Australia.

Loretta has been an active and involved supporter of and fundraising volunteer for Brisbane based Act for Kids since 2008, and is also a strong supporter of the Cure Brain Cancer Foundation.

Kara Ward

Kara Ward is a digital experience strategist and marketer. She has over 25 years experience designing and leading transformation programs for start-ups, joint ventures, non-profits, government agencies, and global corporations.

As one of the early pioneers of digital, Kara launched significant brands in the Australian market including Microsoft, Telstra, and Nine Digital. She has brought new products and services to market, and established profitable revenue streams for multinationals such as Macquarie Bank, Westpac, Merrill Lynch, and Insurance Australia Group. Kara has worked for the top two globally ranked leaders in digital, Accenture Interactive and Wunderman, and instructed the business leaders of tomorrow at General Assembly. She runs a digital strategy and management consulting business. Kara has family and friends living with Crohn's disease.



Lisa Belcher

Lisa Belcher is a seasoned leader with 20 years experience in sales and marketing. She has lived and worked in both the Australia and the US while serving markets across the Asia Pacific region. Her work has spanned family businesses to multi-national corporations. Lisa has a Master of Business Administration from Columbia Business School in New York City.

Lisa currently works as a Vice President of American Express and leads the small and medium merchant team for Australia and New Zealand. She is responsible for the vision, strategy, and engagement of this important and growing customer base.

Lisa has lived with Crohn's disease since 2017 and proudly uses an ostomy.

Bruce Goodwin GAICD

Bruce Goodwin has more than 35 years of experience in the Global Biopharmaceutical industry having previously been employed by the Janssen Pharmaceutical Companies of Johnson & Johnson. His tenure with Janssen included more than a decade in General Management roles including Managing Director Janssen Australia & New Zealand, as well as President & Representative Director Janssen Japan. He has overseen significant commercial success, and he has deep experience in organizational strategy as well as building and engaging talent.

Bruce is a respected Industry Leader and is currently a Selected Director and Board Member of Medicines Australia Limited. Whilst in Japan he served as the Vice Chair of the Japan Based Executive Committee of the Pharmaceutical Research and Manufacturers of America (PhRMA).

Through his multiple non-executive Director roles, Bruce seeks to contribute to the development of innovation in healthcare and equality of access to treatments. He was appointed Director and Board member of the Australian Genomic Cancer Medicine Centre Limited (Omico) in 2018, Rare Cancers Australia Limited in 2020, and most recently Delica Therapeutics Pty Limited in 2021.

Former directors who stepped down from the Crohn's & Colitis Australia board in 2021 include:

David Reckenberg, Julie Weldon, Dr Sally Stockbridge



Board and Project Advisory Committees

Governance, Nominations and Remuneration Committee

Bruce Rosengarten
(Chair and Acting Company Secretary)

James Oliver
Bruce Goodwin
Julie Weldon

Finance, Audit and Risk Committee

James Oliver (Chair)

Bruce Rosengarten
John Brennan
Loretta Bayliss

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Julie Weldon (Chair)

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Bruce Rosengarten
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Lachlan Pike
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Cassandra Anslow
Leanne Raven
Wayne Massuger
Hailey Fisher

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 those listed below for making a positive difference to those living with inflammatory bowel disease during the 2021 calendar year.

Community Fundraising

\$5,000+ Order of the Eastern Star - Tamar Chapter No. 178, L Pike	S O'Brien, J Staples, A Virgona, F Almoail, D Orchard, K Smith, P Pollard, N Thomson, S Cundall, P & S Fonteyn, P & V Pandya, A Russell, L Exton, O Putilin, G Peer, M Winford, A Bond, O Davies, J Dukino, K Andrews, T Arkell, H Bell, R Blake, D Bradley, G Dodman, W Duncan, R Lawson, M Lofaro, S Mark, C Neal, J Honan, M McCann, D Dreverman, J Evans, H Heffron, M Johnstone, M Kerr, A Park, M Thompson, L Fahad, P Deighton, J McCosker, J Pene, S Barber, J Belcher, P Bliss, R Dumonic, B East, D Fittler, L Gandler, S Gross, D Harris, P Herrschaft, A Hickey, K Lynch, L Mantell, A Maroush, E Mayes, R Muthukrishna, R Pandya, D & F Prizmic, C Russell, S Street, J Taylor-Bartels, D Walker, J Gould, A Broughton, L Jones, J Kambelos, L Kempler, N Lowman, Professionals Prospect, N Smith, J & E Vella, T McKenzie, M Perna, K Srikanthan, A Zehnirith, A Finck, R Tal, C Stevens, J & E Foster, M Anslow, K Barracu, P & D Basford, A Bayros, A Bernstein, S Bramwell, T Carey, S Carr, E Clingan, T Coles, I Connolly, C Cooper, G Dannoun, L Dillon, M Drew, A & R DSouza, J Duncan, T Falinski, Valiozis Family, F Frappa, P Gleeson, B Goodwin, E Gordon, S & J Graham, H Gray, A Griffiths, N Habib, J Height, G Hershan, G Holden, S Ivany, G James, R Jarrett-Dalton, N Jens, L Kelleher, E Kennedy, L Kerr, HT Khong, T Klingler, D Lane, J & E Lane, N Levien, T Lincoln, J Lombardo, E Lowy, M MacDonald, F Macrae,	A Macrae, K Mantzarapis, E Marjoribanks, W McCartney, C McDonald, K McGready, Mclnerney Family, P Milne, K Moran, D Mullins, A Nemz, J Nicotra, M O'Brien, J Palma, C Papalia, L Phelps, A Prusa, T Reinders, P Robertson, K Rockman, E Romanas, A Russell, J Samaras, P Screpis, S Spiers, R Starkins, G Stevenson, G Strong, M Syron, C Thomas, P Trainor, J Trivedi, S Wahhab, H Ward, S Whitcombe, W Wilkes, T Wise, G Yeoman-Dale, Z Nipperess, L & D Ando Arends Posse, Y Ares, L Bennett, K Boeree, R Cairns, P Galea, K George, T Gillham, S Gillon, M Grgat, K Haddin, J Hadgkiss, J & H Hage, M Hansford, L Harris, K James, W Kelly, A Krekacs, R Matterson, A Richardson, N Russell, D Russell, J & P Studd, S Tamizi, K Thomas, H Titterton, C Tsiounis, H Tuckey, R Williams, A Xusen, C Young, Fr P Anastasiadis, S Benjamin, A Besse, A Brewer, P Chandrashanker Urmila, S Davis, M Edwards, H Eslick, F Gomez, H Head, D Ingram, A Jackomos, B & G Jones, N & F Lonersouza, M Clarke, T Mullen, P Ossington, C Pollard, S Robson, E St Clair-Pearce, S Trivedi, E McDonald, P Biddle, E Kirkpatrick, F Macrae, J Sunderland, D Toohey, Ahern Sisters, C Andrews, B Aubin, L Bastin, V Beauchamp, M Beauchamp, L Bevis, D Clark, M Davey-Nichas, J Koeck, Rustom M, P McArdle, S Mullner, S Ortenburg-Light, V Peplow, A Reynolds, J & C Roberts, B Sager, B Smith, R Whipps
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L Irving	T Hughes

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