## In fearlessness there is strength



## Impact Report 2023



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Crohn's & Colitis Australia (CCA) is a notfor-profit company limited by guarantee, governed by a board of directors who represent the Crohn's and colitis community.

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

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



### IBD care is inconsistent and inadequate, particularly in rural and regional areas.

IBD is a lifelong chronic

illness that needs to be

managed even after

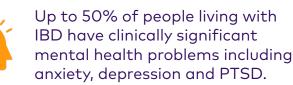
symptoms ease.



## $100K \rightarrow 300K \rightarrow$

By 2030, it is estimated nearly 300,000 Australians (1%) will have IBD.

30% of people with IBD also experience disease outside the gut including arthritis, eye, skin and liver diseases





The facts about IBD



Today, over 100,000

Australians have Crohn's

disease or ulcerative colitis.

C 2023 Impact Report

## From the Chair and CEO

As we write this Impact Report for 2023 we are preparing to mark our 40 year anniversary in 2025. Crohn's and Colitis Australia has been in existence since 1985 when it was founded by the late Angela McAvoy AM and other volunteers, to advocate, educate and support for those living fearlessly with IBD.

Since 1985 we have become purpose driven by fearlessly working to:

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

In 2023 we are proud to have:

- ✓ completed a national paediatric research project measuring the experiences of children and their families and the quality of care in children's hospitals.
- ✓ improved the quality of information on our website with 65% of users telling us they have taken action after visiting the website to help improve management of their condition
- ✓ launched IBD management plans to help people personalise their care and keep the information in one place
- ✓ funded a new PhD Scholarship awarded to Dr Richard Fernandes from the University of Queensland. He is aiming to evaluate the impact of surgical technique on disease recurrence, method of detecting recurrence and changes in immune signaling and the microbiome following resection.
- ✓ lead a major awareness campaign on access to best available treatments and care for people with IBD who are 60+ years with a significant impact -245,000+ reach on social media, 58 light up sites on World IBD Day and 21 media outlets relayed via radio, print and TV interviews.
- ✓ made a financial surplus whilst investing in our digital capability with a new CRM and virtual programs for teens and young people.

We are grateful for the help and support of everyone in the IBD community, whether as a person living with IBD, a family member or carer, friend, health professional or stakeholder or corporate partner we could not have achieved this without you. There are over 100,000 people living with IBD in Australia and CCA is committed to being there as a trusted partner and advocate.

Thank you to the CCA Board and committees who oversee the governance, accountability and organisational effectiveness and sustainability. They bring their professional and personal expertise, adding value to CCA's status and impact as the peak body for people living with IBD in Australia.

Together we are extremely proud to recognise everyone's contribution in stragetically addressing challenges 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 CCA. Your efforts are deeply appreciated.

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

Bruce Rosengarten FAICD Chair

( A TE Roven)

Leanne Raven FAICD CEO

## About CCA

## Crohn's & Colitis Australia

## **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 the ability to face things head on.

Because in fearlessness, there is strength.

## **Strategic priorities**

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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

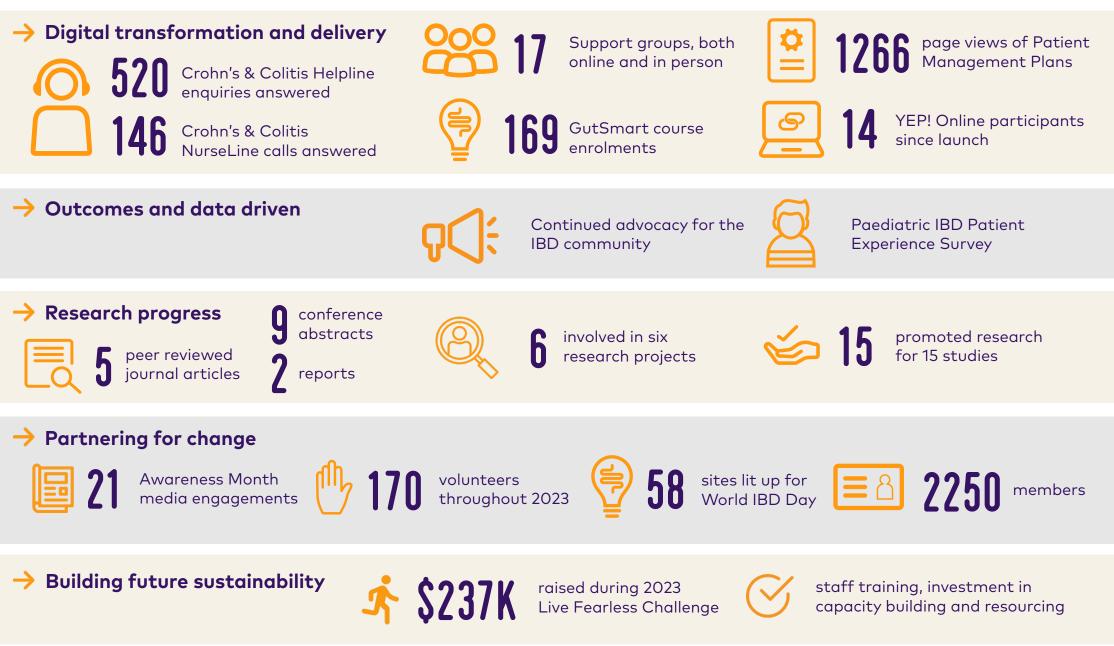


Strong partnerships and relationships, with an engaging credible and respected brand



Healthy culture, evolving business model and sustainable organisation

## 2023 highlights



## **Digital transformation and delivery**

### **Strategic priority 1:**

Digital transformation and delivery of omnichannel experiences across the lifespan

As CCA faces a rapidly growing number of people living with IBD in Australia we need to invest in our digital systems to ensure we can serve a growing client base and support them with omnichannel experiences across their lives.

In 2023 CCA's focus is on developing our capabilities as an omnichannel provider of support services with extensive reach and engagement.

## **CEA-IBD**

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

Crohn's & Colitis Australia (CCA) completed a major 4-year research project in collaboration with Swinburne University

of Technology Centre for Global Health and Equity to improve the information and services that are provided to people with Crohn's disease and ulcerative colitis.

The Consumer Education and Awareness (CEA) IBD project delivered thirteen major project activities to make it easier for people living with IBD and their carers to access, understand and use health information and services.

Part of this research involved developing the capacity of people with IBD to self-manage their health through improvements to and expansion of the range of practical and implementable information and support resources that CCA provides.

As part of the CEA-IBD project CCA launched a new website in March 2022 with health information about Crohn's disease and ulcerative colitis, including symptoms, diagnosis and treatment, and information about living with Crohn's and colitis, including exercise, nutrition, psychological health, fatigue, travel, fertility and pregnancy, and sexuality.

An IBD Service Locator was also launched to help people find an IBD service near them. Website analytics show that the most frequently accessed health information between

Crohn's disease

9 March 2022 and 30 August 2023 were topics that helped people to learn about Crohn's and colitis (including symptoms, diagnosis and treatment), as well as resources about nutrition and information about Crohn's and colitis for employers.

Over 65% of users surveyed indicate that they made changes in their approach to living with IBD after visiting the website. These included changes to diet (29.6%), communicating with friends and family (22.4%), and sleep or rest (17.8%).





Crohn's disease

Crohn's disease

🛆 Menu 🚍





**New videos** - thanks to the support of Give2Asia and Amazon CCA developed three animated videos about living with IBD which were launched in 2023 on the new CCA website.

- Managing my Crohn's disease or ulcerative colitis WATCH
- My school friend has Crohn's disease or ulcerative colitis WATCH
- Working with someone who has Crohn's disease or ulcerative colitis WATCH

 $\ensuremath{\text{New Resources}}$  - new website information is now available on diet and IBD, including:

- anaemia in IBD,
- optimising bone health in IBD,
- Exclusive Enteral Nutrition (EEN) in Crohn's disease,
- managing a high stoma output, and
- frequently asked dietary questions in IBD.
- financial services resources: topics such as IBD and disability, Medicare support services, insurance, superannuation and much more.
- rural and remote resources to help understand what information and services may be available to those living in a rural or remote location in Australia. These resources cover topics including emergency assistance, Medicare services, psychological support and more.
- personal Management Plan templates with the help of people living with IBD, carers and healthcare professionals.

#### New languages

We now have IBD information available in Arabic, Farsi, Punjabi, Simplified Chinese and Vietnamese.

Topics include: About Crohn's disease and ulcerative colitis, symptoms, diagnosis and treatment.



"When I was diagnosed, I was directed to the Crohn's & Colitis Australia website as a resource. I found the personal stories section and I think I read every single one in full. The stories helped me to realise that while Crohn's is a testing disease, the challenges are not insurmountable and there are plenty of people with inflammatory bowel disease living fulfilling lives and doing amazing things." - Mark

#### LEARN MORE ABOUT CEA-IBD



GutSmart delivers online training courses for health professionals on the topic of Crohn's disease and ulcerative colitis.

The Crohn's and colitis community is spread out across the country, we want everyone living with IBD to be supported by healthcare workers who understand their treatment needs no matter where they live. GutSmart currently offers three IBD

courses for health professionals: Nutrition and IBD for Dietitians, Psychological Health In IBD and IBD For GPs and Physicians.

In 2023, CCA appointed Gemma Reeves, dietitian, as our first GutSmart Program Manager to lead the engagement and promotion of GutSmart.

In March 2023 Professor Antonina Mikocka-Walus, Professor Simon Knowles, CCA CEO Leanne Raven and CCA staff member and IBD patient Ian Stewart spoke at an Australian Association Psychologists Inc (AAPI) GutSmart webinar with over 200 psychologists in attendance.

VISIT GUTSMART





Working with

someone

who has

friend has

Crohn's or



## **GP** Aware project

GP Aware is delivered in partnership 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 2023 CCA delivered:

- 7 GP educational "Poo and A" podcasts completed and downloadable on all major platforms.
- Live online workshops with 130 GP participants
- Launched Patient management plans.

#### READ MORE ABOUT GP AWARE

### **IBD Patient Empowerment: Patient Management Plans**

Only 50% of patients surveyed in the IBD Audit 2016 and Patient Experience Survey reported having an agreed plan with their healthcare professional team about what to do if their symptoms worsen, or they experience treatment side effects.

In response to this need identified through the GP Aware Project, CCA developed individual care plans for IBD management in primary and specialist care settings. The tools can be used to help improve communication between people living with IBD and their healthcare professional team by storing important information in one document for shared accessibility. The electronic or printable document includes information about:

- your health,
- what to do if you have worsening symptoms,
- contact details for your healthcare professional team,
- medication plan,
- lifestyle behaviours, and
- regular health checks.

Since launching in late 2023 there have been 1266 page views of the Patient Management Plans.

## **IBD Information Forums**

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



CCA would like to thank the Eirene Lucas Foundation and Bristol Myers Squibb for their support of the 2023 CCA Information Forums.

The 2023 Online IBD Infomration Forum was held in Crohn's and Colitis Awareness Month and discussed IBD Management and research for older Australians, the theme of 2023 Awareness Month.

The forum was hosted by CCA Ambassador Jacinta Parsons and speakers were A/Prof Emily Wright, Gastroenterologist, St Vincent's Hospital Melbourne, Tamie Samyue, IBD Nurse Practitioner, St Vincent's Hospital Melbourne, Dr Sasha Fehily, Gastroenterologist and Research Fellow, St Vincent's Hospital Melbourne and Mr Tony Bolton, Awareness Month champion, provided a patient perspective.



The forum has received over 1,500 views and is available on YouTube.

Canberra Hospital also delivered a successful return to face to face CCA IBD Information Forums in the ACT.

## C 2023 Impact Report



Crohn's

& Colitis

## **YEP! Online**

#### A place to have fun – and to feel comfortable just being who you are.



CCA is excited to announce the launch of a new development in our Youth Empowerment Program (YEP!), YEP! Online. This new initiative, developed through a close collaboration with a panel of young people and funded by auDA Foundation, provides an ongoing peer support platform for all young people living with IBD across Australia, CCA's YEP! Online was launched in August 2023.

Designed for young people to help reduce the social isolation and stigma associated with IBD. CCA's YEP! Online community helps build a social support network, meet peers in a safe and supportive environment, chat with others about their IBD experiences and learn strategies to manage IBD.

YEP! Online is complemented by face to face engagement opportunities.



## YEP! Sydney High Noon Escape Hunt

There comes a time in every person's life when all we want to do is escape. For some Sydney teenagers, that time was Sunday 8 October 2023. Thanks to the support of the James N. Kirby Foundation CCA delivered the first face-to-face youth program since the COVID pandemic. Participants came together to solve a mystery in one of the exciting Escape Hunt game rooms, after a presentation from CCA ambassador Luke Escombe, mentor Carla and support from volunteer Megan..

Participant twelve-year-old Amelia was diagnosed with IBD at the age of 12 after a two-month-long absence from school. It took severe weight loss, significant abdominal pain and bloody diarrhoea before she was finally sent to see a paediatric gastroenterologist – a period her mum describes as both traumatic and challenging. Fast forward a few months, however, and Amelia was not just back on her feet, she was using them to have fun at the Sydney Escape Room, with 10 other kids in the same boat.

"I think the benefits of these events are enormous," said Amelia's mother. "Before then, Amelia hadn't met other young people with the same diagnosis. I think it was really helpful for her to see that living with IBD doesn't have to limit you. I want her to feel supported and connected and see that her diagnosis isn't her whole story. That there's no reason why it should prevent her from enjoying her life and doing whatever she wants to do."

## **Outcomes and Data driven**

## Strategic priority 2:

Outcomes and data driven: measure quality of experience and impact on the lives of our community

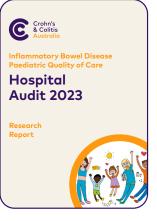
CCA works to build reporting tools to measure quality of programs and activities and advocate for high quality integrated care which assists people to best manage their own health and improve quality of life

## Measuring the childhood IBD experience

Up to 8-10% of IBD is diagnosed in childhood and adolescence, potentially affecting growth, puberty, education and psychosocial development. In Australia IBD quality of care has been shown to be variable for young people and fall short of the national standards. The Australian Government's IBD National Action Plan identifies as a priority the need for increased investment in research and focus on children with IBD. CCA with assistance from the Gastroenterological Society of Australia undertook a two-year project to:

- 1. Measure the patient experience of the quality of care for young people with IBD (IBD Paediatric Patient Experience Survey)
- 2. Audit the organisation, resources and delivery of hospital care to young people with IBD (Hospital Audit)

The IBD Paediatric Patient Experience survey was conducted through national online survey of parents/ carers and teenagers. Data is complemented by direct patient feedback from young people (under 18) collected through family interviews.



#### Crowins Australia Inflammatory Bowel Disease Peediatric Quality of Care Patient Experience Survey 2023 Research Report

The Patient Experience Survey was published in 2023. This report provides an invaluable illustration of realworld IBD care, from diagnosis to ongoing treatment, as directly reported by youth, parents, and carers. This research is essential in guiding changes at all levels of IBD care to ensure that services are consistent with bestpractice standards and equipped to provide the support most important to youth and those close to them. We are deeply thankful for the over 260 youth, parents, and carers that contributed to the questionnaire and those that shared their personal experiences in the 35 family interviews that followed.

The second part of the IBD Paediatric Quality of Care Project, the hospital audit complements the Patient Experience Survey by assessing whether the time youth spend in the hospital is met with age-appropriate clinical care that limits this challenge. This project comprehensively explores routine admissionto-admission care practices and the organisational resources, policies, and processes supporting optimal youth IBD management. This project will be published in 2024.

The research team want to thank all audit site team members from hospitals throughout Australia for their effort, enthusiasm, and shared vision to improve the unique and complex journey of youth IBD through high-quality hospital care.

READ MORE ABOUT THE IBD PAEDIATRIC QUALITY OF CARE PROJECT

## Advocating for high-quality integrated care

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

Some of our 2023 advocacy work included:

- Streamlining of biologic scripts to reduce administrative burden on clinicians and create more time for patient care
- Shingrix PBAC advocacy submission to make the new vaccine affordable for people with IBD
- Collaborating with GESA on an advocacy project on faecal calprotectin testing to be used for monitoring of inflammation with MSAC
- Providing recommendations from the Paediatric Audit regarding access to IBD medicines for children in Australia for the Federal Department of Health.
- Providing an update on the priority actions in the 2019 National IBD Action Plan
- Community feedback to PBAC on IBD medications appropriate for PBS listing
- Supporting the new 60-day prescribing rules for some common PBS medicines which came into effect in September 2023

Thank you to the members of our community who shared their stories with policymakers, politicians and media in support of change.



## CCA community members speak up in Canberra

CCA community members Sarah and Justan have had their say at a Consumer Health Forum (CHF) in Canberra.



Part of a series of consumer roundtables designed to get the patient perspective on Medicare, the November 9 forum discussed:

- a new voluntary patient registration model called 'MyMedicare' that would encourage patients to keep seeing the same GP and healthcare team
- community pharmacy and how it might improve accessibility and affordability for patients
- opportunities to improve telehealth.

"It was really interesting and I personally hadn't heard of My Medicare before," says CCA member Sarah Michel, who seized the chance to voice her thoughts about the various initiatives alongside CCA ambassador Justan Singh.

"It was a wonderful opportunity for me to use my experience as a patient in the healthcare system for the past 18 years to improve services for Australians into the future."

## **Research progress**

## Strategic priority 3:

IBD research facilitation via capacity building, making meaningful progress and breakthroughs

CCA facilitates high quality research into IBD treatments, support and eventual cures via capacity building, dissemination and promotion of research and engaging with the IBD sector.

## Awareness Month 2023: EFCCA survey

"Making sure we understand the experiences and the needs of older people living with IBD is an investment in the current generation of older people but also in all people who are diagnosed with Crohn's or Colitis or who will be diagnosed in the future. There is currently no cure for IBD and no preventative health promotion programs so we need to be able to provide the best possible healthcare to those who are diagnosed at every stage of their lives. This is the only way to give IBD patients the best possible quality of life." - CEO Leanne Raven



## **Facilitating impactful research**

As the peak patient body for Crohn's disease and ulcerative colitis CCA facilitates impactful research by connecting researchers with patients and by participating in sector events and forums.

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

- Coordinated consumer feedback on Gastroenterological Society of Australia's Transition (Paediatrics to Adult services) Guidelines.
- Swinburne University study of anxieties relating to faecal incontinence and use of public restrooms. LINK
- EFCCA Global survey into quality of care for people with IBD aged over 60. LINK
- Deakin University mindfulness based program for people living with IBD. LINK
- CaPPRe to better understand the experiences of people living with Crohn's disease and ulcerative colitis, with a view to improving the healthcare pathway. LINK
- University of Wollongong managing eating and your diet with IBD.
- Swinburne University IBD brain fog and fatigue. LINK
- Chronic Pain Australia into living with chronic pain or those who care for those living with chronic pain. LINK

## RESEARCH TRANSLATION: Welcoming Bowen to the Young Adult Support (YAS) team



"My experiences with my gastroenterologist, when I was diagnosed, inspired me to study medicine and my experiences as an IBD patient cultivated my interest in gastroenterology as a career. Living with IBD is a challenge and I hope to bring my experiences, from both perspectives as a doctor and as a patient, to Crohn's & Colitis Australia."

In 2023 Bowen reviewed current IBD research to identify information that may be of interest to young adults living with IBD and present it in the form of easy to digest posts.

### **READ MORE ABOUT YAS**

## © 2023 Impact Report

## Industry & health sector engagement

### Bristol Myers Squibb Patient and Parliament Summit

In October, CCA took part in the second annual Patient and Parliament Summit hosted by Bristol Myer Squibb at Parliament House.

Attended by CEO Leanne Raven and board member Dominique Tim So, the two-day Canberra forum was designed to help MPs understand some of the everyday struggles faced by Australian patients –especially those with a chronic disease.



## Forum: Progressing Policy: The Future of IBD Care in Australia co-hosted by CCA and AbbVie

Clinical experts and patient advocates came together in Melbourne on 3 November 2023 to discuss the future of IBD care. Organised by AbbVie and CCA, the forum explored ways to facilitate speedy diagnosis and specialist referrals, deliver integrated multidisciplinary care, support innovation, and improve access to novel treatments. CCA Board member Associate Professor Greg Moore and Leanne Raven both spoke at this AbbVie sponsored event. The forum was based on the whitepaper published by The Economist and commissioned by AbbVie.



As CCA's CEO put it in the accompanying whitepaper, "the vision for the Government's IBD National Action Plan was for all Australians living with inflammatory bowel disease to have access to high quality, integrated care. Whilst we have made advances in a number of areas, there is still significant work to be done."

### Australian Gastroenterology Week Conference

Over 1,500 clinical experts, researchers, allied health practitioners, nurses, clinicians and educators got together in Brisbane in September to discuss all things gastroenterological.

Organised by the Gastroenterological Society of Australia (GESA), the five-day conference was a chance to showcase CCA's latest research into Crohn's and colitis and the different ways that we treat them. The CCA team presented two posters and three CCA staff and volunteers presented research updates:

- Wayne Massuger, who provided a "paediatric audit" of IBD in Australia and a birds-eye view of the patient experience
- Stephan Moller, who discussed how the risk of psychological distress in paediatric IBD patients is closely associated with the type of information they receive from their treating team
- Gauravi Gawade, who explored recent changes in prescription patterns for paediatric ulcerative colitis.
- Gauravi Gawade who described changes in Anti-TNF prescribing patterns in paediatric Crohn's disease
- Hailey Fisher presented a poster on "Developing IBD consumer health literacy using the Ophelia process"

### **Biosimilar and Chronic Disease Summit**

As complex chronic disease conditions involving multiple morbidities increase, the summit discussed novel ways of funding this unmet need in the health system.

We proposed changes to policy for government. CCA's CEO discussed areas to focus on to benefit patients in need, in relation to inflammatory bowel disease - including research, system change and new areas of unmet need.



(L-R) Deidre MacKechnie (CEO, APAA), Dr Gordon Reid MP, Leanne Raven, Clint Holland (CEO, Sandoz), Marnie Peterson (Generic & Biosimilar Medicines Australia)



## Building Research sector capacity

CCA is committed to encouraging further research into Crohn's disease and ulcerative colitis through our research scholarship program.

The 2023 CCA PhD scholarship was awarded to Dr Richard Fernandes, University of Queensland.

Dr Fernandes is a gastroenterologist who is undertaking the project 'Improving our understanding of post-operative Crohn's disease recurrence'

Many patients with Crohn's disease require surgical resection of diseased bowel. However, surgery is not a cure, with high recurrence rates after surgery. This remains poorly understood; however, some factors associated with risk of recurrence include surgical technique, immune signalling, and the bacteria living in the gut (microbiome). This study aims to evaluate the impact of surgical technique on disease recurrence, methods for detecting recurrence, and changes in immune signalling and the microbiome following resection.

## Publishing and promoting research

In 2023 CCA was involved in the publication of five research papers.

There have been publications on:

- Health literacy LINK
- Crohn's disease perianal fistulas LINK
- Gastroenterological Nursing College of Australia (GENCA) LINK

Further manuscripts are being prepared about the Paediatric IBD Quality of Care project and Consumer Education and Awareness project in for 2024.

Two Papers were accepted for publication in Inflammatory Bowel Disease and World Journal Gastrointestinal Surgery:

- https://pubmed.ncbi.nlm.nih.gov/37477361/
- https://pubmed.ncbi.nlm.nih.gov/38111766/

## IBD Prevalence and Economic Impact Study

In 2023 CCA received sufficient funding from generous donors to progress the IBD Prevalence and Economic Impact Study, to be called the IBD State of the Nation report.

The IBD State of the Nation report will include prevalence and economic impact of IBD and assess priority areas of unmet need to address the burden and improve health outcomes.

The development of the study is informed by an Economist Impact global report, sponsored by AbbVie, Inflammatory Bowel Disease - Addressing the "hidden" disease with innovative, multidisciplinary, and patientcentric care. The report provided an independent analysis of the arowing



global burden and unmet needs of IBD and drew attention to the direct and indirect costs. CCA was a contributor to the Economist Impact report.

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Improving access and informati inflammatory bowel disease: co (Optimising Health Literacy and	-design using the Ophelia
Melanie Hawkins <sup>1</sup> , Wayne Massuger <sup>2</sup> , Hailey Fisher <sup>2</sup> , Christin. Leanne Raven <sup>2</sup> , Richard H Osborne <sup>1</sup>	a Cheng <sup>1</sup> , Sanne Elbrink <sup>1</sup> , Ranjit G Nadarajah <sup>1</sup> ,
Popul. Med. 2023;5(Supplement):A1516	
DOI: https://doi.org/10.18332/popmed/164592 Article (PDF)	
ABSTRACT	
Background and objective: The quality of care and information for people living with inflar sub-optimal, and does not meet the prevailing Australian IBD SI (Optimising Health Literacy and Access) process, aims to co-des resources with and for people with IBD and their carers.	tandards. Crohn's and Colitis Australia (CCA), using the Ophelia
Methods: Vignettes were developed from interviews (n=17) and cluster a Using the vignettes in participatory co-design (online workthch professionals (n=38), the Ophelia process facilitated the gen wrices. These ideas were collated and coded into specific activ	ops and an online activity) with consumers (n=38) and health eration of ideas to improve access to IBD information and





## **Partnering for change**

### Strategic priority 4:

Strong partnerships and relationships, with an engaging credible and respected brand

CCA is committed to building strong partnerships and being a trusted and respected peak body and advocate for the IBD community in Australia through promotion, awareness, sector leadership and relationships.

## Crohn's and Colitis Awareness Month 2023: IBD and the Older Australian

Each May we celebrate Crohn's & Colitis Awareness Month, taking the opportunity to share your stories and raise awareness nation-wide of living with inflammatory bowel disease (IBD).

This year, CCA focused on increasing awareness of the disparities in care for people aged 60+. Australian research found that people aged 60+ are not necessarily receiving access to the best treatment options. More specifically, older Australians are:

- Less likely to experience steroid-free clinical remission
- Prescribed Biologics at a lower frequency
- Less likely to have specialist IBD nursing contact and/or a multidisciplinary IBD Team

Furthermore, this group are underrepresented in IBD clinical trials, resulting in minimal data surrounding the characteristics and outcomes of the disease in advanced age and issues such as comorbidities, polypharmacy and cognitive decline.

CCA recognises the importance of increasing awareness of the disparities in care and taking steps to ensure that older Australians living with IBD can access the best treatment options to improve health outcomes and overall quality of life.



## World IBD Day

On Friday 19 May we celebrated World IBD Day, the global day of recognition of people living with IBD. Landmarks and venues around the world light up purple, and CCA secured support from over 50 sites around Australia!

This included some state icons such as Flinders St Station Melbourne, Luna Park Sydney and the Big Banana in Coffs Harbour, plus many more in towns and cities across the country. Thank you to everyone who sent us their photos of the purple buildings in their area and their special purple events.

We also loved hearing stories of local councils and buildings joining in, in response to requests from members of the IBD community.

## **Social Media**

Social Media played a vital role in raising awareness, with CCA welcoming more than 2,500 new followers to our Facebook and Instagram communities. It was wonderful to see so many messages of support and positivity for those who fearlessly shared their stories.

And we worked late into the night to share images of Shine A Light venues as they happened. There was also a lot of support from the media, particularly around World IBD Day, which helped spread our message to a national audience.

Fundraising events were bigger and better than ever before. There was a strong focus on health and wellbeing with pilates and yoga classes, funs runs and even a 496km bike ride! There were also trivia nights, luncheons and morning teas.

A very special Thank you to our Awareness Month Ambassadors Tony Bolton and Jan Clark who fearlessly shared their experiences living with IBD.

Thanks also to everyone in the community who shared their story, visited a Shine A Light site, renewed their CCA membership, and purchased an Awareness Month ribbon.

Finally, thank you to our Crohn's and Colitis Awareness Month sponsors, Pfizer, Janssen and Johnson & Johnson, Dr Falk Pharma, Takeda and Celltrion Healthcare, plus IBD forum sponsor Bristol Myers Squibb. Your support is invaluable.



## Crohn's and Colitis Awareness Month 2023 fearless champions

**Tony Bolton**, currently in his sixties, has gone through a journey with IBD that's been anything but straightforward. Like many older people who have now been diagnosed with IBD, the knowledge, resources, and medicine necessary for making a clear diagnosis simply weren't accessible for the majority of Tony's life.

Up until the age of 30, Tony suffered from regular diarrhoea, stomach pains and weight loss. While disruptive to his life, he said the symptoms up until that point had been manageable. Now, Tony looks back at photos of himself in his teens and twenties and it's obvious to him there were times when he was experiencing a Crohn's attack.

When he was 50, Tony started to experience serious attacks around three times a year and had to be rushed to hospital on a few occasions.

At this stage he was finally given a Crohn's diagnosis that was classed as 'moderate'. He says, "There's only one way to describe an attack and that's

agony. The only thing you want is morphine and a dark room."



Around a year later, Tony had to have 150mm of his bowel removed. After this, he was able to manage his symptoms with fulltime medication.

He says that maintaining a positive frame of mind has been key to helping him manage the disease, "My state of mind is positive, always has been. Negativity and Crohn's don't go well together. It's attached to the nervous system, so if something goes wrong, it brings on a flare up. Being relaxed, stress-free and drama-free is so vital for anyone with Crohn's. We need to live a content life. We

can't afford to have unnecessary drama."

**Jan Clark's** story will likely resonate with a lot of other people around her age. She's now 78 and like so many older Australians, Jan lived with IBD for decades before receiving a diagnosis.

As a baby, she suffered with problems with her digestive system and intolerances to various foods. During her childhood and teenage years, she was thin and frequently had bouts of diarrhoea. At that time, one of the remedies offered to Jan was castor oil - a particularly shocking suggestion given that castor oil is known to cause diarrhoea. She says, "the outcome from attempting to treat my symptoms with castor oil was so horrific and torturous that I wished I was dead." Thankfully Jan's parents decided to cease the castor oil treatment but as she moved into her 20s, she suffered from almost constant diarrhoea.

Throughout her 30s, 40s and 50s, Jan continued to experience pain, bloating, diarrhoea, malabsorption and weight loss, along with joint and muscle aches and pains, fatigue and skin problems. Throughout this time, doctors simply prescribed herbal medications, "better nutrition" and, at one stage, she was treated for the more commonly diagnosed IBS.

In 2001 following a colonoscopy, Jan received her first diagnosis of possible Crohn's disease. Jan's life continued to centre around her bowel problems and, as time passed, her condition worsened. Out of desperation, she began her own research, which is when she found the CCA website and contacted the CCA IBD nurse.

> Following yet another colonoscopy and endoscopy with multiple biopsies, there was finally a definitive diagnosis of Crohns, along with the IBS and diverticulitis. A faecal calprotectin test at this time showed the inflammatory marker at 463 – the normal range being up to 50.

For older people who are living with IBD or going through the diagnostic process, Jan has two pieces of advice. The first is that you should never accept worsening symptoms as part of the aging process. If you find that your condition is becoming worse, get a range of opinions and find a specialised medical professional who can dedicate time to assisting you.

The second piece of advice Jan has is to remain positive. She says, "A positive attitude is key. Make the most of when times are going well and learn to accept it when things aren't going well. Pace yourself and don't become too stressed trying to accomplish more than is feasible."



## **Membership**

CCA is continuously looking for ways to improve the membership experience, so we conducted a survey to ask members how they thought CCA was doing.

Thanks to all for who took part in this year's member and past-member surveys.

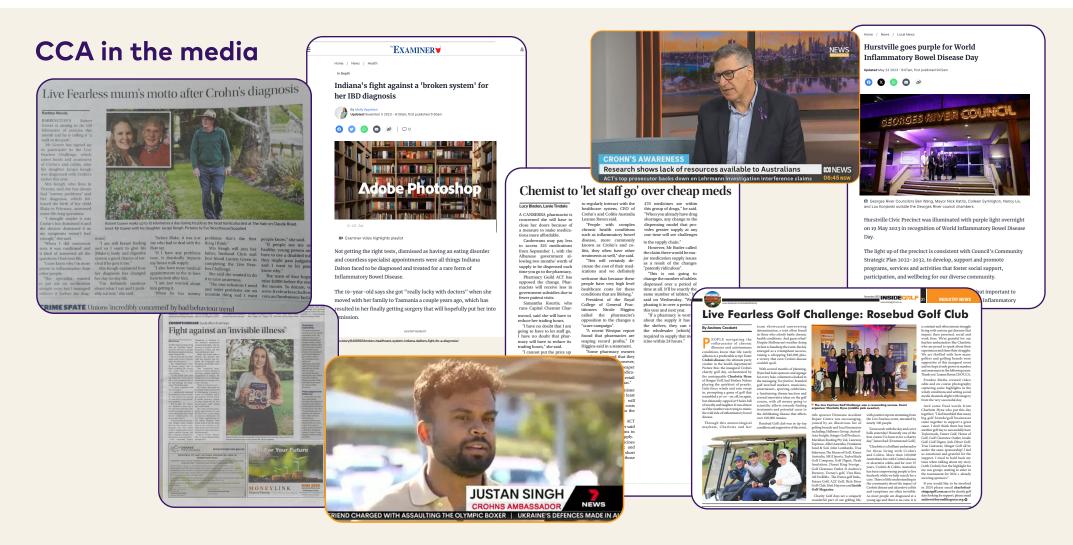
We had a fantastic response and received a wealth of information on all aspects of our programs which we will use to deliver improvements and outcomes to benefit all the IBD community.

## Volunteers

Volunteers provide invaluable support for CCA and enable our small staff team to support people living with IBD across Australia. In December we recognised eight of our CCA volunteers who have given 5 and 10 years of service with certificates and logo pins.

In 2023, we had 170 volunteers help CCA in the office, running support groups, at events, in their professional capacity, and in many other ways to enable CCA to thrive.

### **THANK YOU!**







## **Building future sustainability**

## Strategic priority 5:

Healthy culture, evolving business model and sustainable organisation

We are a trusted organisation, recognised and respected by others, innovative and financially sustainable.

## Fundraising

Fundraising is vital to CCA and is the primary way in which our organisation generates funds to provide research, scholarships, education, programs and support services for the IBD community across Australia. CCA's fundraising activities are also important in raising awareness and initiating conversations about Crohn's disease and ulcerative colitis.

## **2023 Live Fearless Challenge**

The CCA Live Fearless Challenge is held annually across Australia to raise awareness and funds for CCA. Starting on the 1st of September and running through the entire month, the challenge is to complete 150km of physical activity. Participants can choose how to get active whether it is walking, running, swimming, yoga, scooting, skating, or doing a gym workout and fundraise from their networks.

We would like to thank everyone who contributed to the Live Fearless Challenge 2023. That includes the 538 fearless participants who travelled almost 60,000km, and the nearly 2,500 friends, family and colleagues who got behind them and helped raise a whopping \$237,877.

Funds raised through LFC will ensure CCA can continue to provide free programs, research scholarships, education, advocacy and support initiatives for people living with Crohn's and colitis.

We hope that everyone enjoyed the Live Fearless Challenge this year and will take their new exercise habits with them beyond September.

We greatly appreciate the ongoing support of our event partners – AbbVie and Amazon Give2Asia.



#### Live Fearless Challenge Walk – Brisbane

On Sunday 3 September, we held the inaugural Live Fearless Challenge Walk to launch the 2023 Live Fearless Challenge. The walk was held in Brisbane to coincide with the Gastroenterological Society of Australia's national conference.

Thank you to the 70 people who joined us bright and early at the BRISBANE sign for a gentle ~4km walk along the scenic Brisbane River.

A special Thank You for volunteers Becky, Bowen and Ella who helped on the day.

"Awesome challenge. Let's educate friends and family about this debilitating disease. This disease may be invisible to the outside world but to us living with it are strong, tough individuals who deserve support, education and understanding. Let's get talking." - Denise Burrell

"My first year participating in the Live Fearless Challenge was a joy. I loved raising awareness, blowing away my fundraising target by nearly five times my original goal, and getting more active, helping to create healthier habits moving forward. I will absolutely be back bigger and better in 2024 – next time hopefully as part of a team!"

- Simon Conibear

## **Appeals**

Thank you to the many donors who supported CCA's tax appeal and end of year appeal. The tax appeal raised over \$118,000 for research scholarships and the end of year appeal raised over \$43,000 for CCA's children and youth programs for 2024.



## **Community fundraising**

Thank you to all our fundraisers in 2023! Over 139 of you ran, walked, baked, campaigned, cycled and lots of other activities to raise funds for CCA in 2023. Here are a few of the highlights.



## Liam Bucco

EventDaily 5km RunAmount Raised\$1,780"I love running and staying active, which is why I took on the<br/>challenge of running 5 kilometres every day to raise money for<br/>Crohn's disease awareness. I am grateful for all my support<br/>networks and like-minded individuals who have guided me<br/>through the tough times, and the bum jokes from my brothers<br/>which never fail to bring a smile to my face."

## Steve Wood

Event Run Melbourne (2nd year in a row) Amount Raised \$2,000

"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. My family made the trip with me from Tasmania to Melbourne. They have all been so supportive, as has everyone."

## Harry Manoharan

Event Amount Raised

Sydney Marathon ed \$2,533.85

"After 6 years together now, I am a proud husband and champion of my wife Caitlin's progress since her diagnosis with ulcerative colitis in 2020. We have been supporters of CCA since 2021, due to their amazing support in helping us learn and navigate things during the early stages of hospital admissions, whilst getting to grips with the painful symptoms and required lifestyle changes especially during more intense flare-up periods."



## Sara Ferola

Event Yoga and relaxation Amount Raised \$5,000

"The day started with a yoaa class which aot us all nicely stretched out. This then was followed by a very relaxing sound bath. After we were all relaxed we enjoyed some lunch and had time to all mingle and chat before we were introduced to Natasha a very beautiful and well spoken speaker from Crohns & Colitis Australia. We then had the pleasure to hear from a very inspirational girl named Jordan. There was not a dry eye in the room and it was safe to say we definitely had a light shine on just how hard this illness could be."



## Ashlee McDonald

Event

Health & Wellness with Pilates and Yoaa Amount Raised \$2,000

"I suffered years of debilitating symptoms with no answers until 2020 where I was finally diagnosed with Ulcerative Colitis. I decided to share my story publicly and the love, kindness and understanding I received was completely overwhelming. I never could have imagined how opening up about my battles with UC would help build such an amazing community of support around me. Something that helped me through my darkest days and gave me hope for the future.

So my goal moving forward is simple, to keep spreading awareness of Crohn's and Colitis so that maybe I can help even just one person feel a little less alone on their own journey."



## **Rachael Whittle**

HBF Run for a Reason Event Amount Raised \$1.214 "If you were to have a look at my google search history the most found search would have to be 'toilets near me'. This is definitely not how I pictured spending my 20s. However, through all this I have continued to work and try and see the best of life."



## **Tahnee Lapham and Jake Williamson**

Event

HBF Run for a Reason formed the team: "Strollin' for the Colon".

Amount Raised \$2,156

"I'd let myself suffer for so long thinking it couldn't get worse, I was so ill-informed about my disease that I'd let myself get sicker and sicker because I didn't know any better, so I made it my mission to spread awareness about IBD. While sitting in the hospital bed I looked on CCA's website and saw that I could participate in the HBF Run for a Reason to raise awareness and funds for CCA so that's what I decided to do. I was sore in places I've never thought could hurt but if it means just one person learnt what IBD is, it was worth it!



## Madeleine Jandura

Event

Cycling for the cause 496km riding in May Amount Raised \$5,280

"This is an emotional, embarrassing, and invisible disease that most people wouldn't know I had or the aftereffects that I still deal with, unless I have told them. When I could, exercise really helped my physical and mental health as well as recovery throughout this journey. It is now something I hold so important in my life and feel very passionately about."



## Irene Giouroukis

Trivia night with Spartans Gym Kilsyth Event Amount Raised \$1.400

"As a young female, I know how challenging it can be to speak up about these silent illnesses. That's why I wanted to share my story and organise the trivia night - to show people that they're not alone and that these illnesses are very real and don't discriminate."

"Sharing my story on the night was a powerful experience, and I'm proud to have helped spread awareness and raise funds for such an important cause so close to my heart."





## Lauren Reynolds

Event Walking 125km in May Amount Raised \$5,780

"20 years with Crohn's - the crappiest anniversary! I've been treating it as a celebration because I am lucky enough to currently be in good health, and I wanted to use that good fortune to raise some money and awareness along the way!. For a long time I refused to tell anyone about my Crohn's Disease unless absolutely necessary, it was too embarrassing to talk about bowels and bums and the pain I was in. But once I opened up a little, time and time again I found people to be understanding and always curious to know more. So now I try and tell people more! I will continue to celebrate every healthy day (fingers crossed they stay that way)."



## Cassandra Anslow, Wendy McKern and Helen Moon

Event Awareness Month information stand Awareness Month morning tea at Cassandra's workplace and helped raise awareness in the local community with an information table at the local shopping centre.

## Alliances

CCA partnered with Rare Voices Australia to deliver the Federal Department of Health Coordination Rare and Complex Disease Telehealth Nurse Program service. CCA is one of three organisations selected to work with Rare Voices Australia to deliver a nurse line for people living with rare diseases.

### LEARN MORE ABOUT RVA

Also in 2023, CCA CEO Leanne Raven was elected to the Board of the Australian Patient Advocacy Alliance (APAA).

LEARN MORE ABOUT THE APAA

## **Data and Risk**

In 2022 CCA took the step of investing in our cyber security and digital capabilities by purchasing Zoho CRM. Zoho is a customer relationship management platform delivering advanced security features, data protection, broad coverage, analytics, and intuitive AI. The Zoho capabilities provide CCA an opportunity to invest in staff capabilities and build capacity to deliver more programs and services to an expanding IBD community.

In 2023 the CCA digital team managed the implementation of Zoho across the organisation including importing contacts, cleaning data, developing roles and specific functionality for teams, developing modules for NurseLine and volunteer management, project management, website integration, and investing in staff capabilities.

#### **Financial report**

This report is for the 12 months ended December 2023. The financial surplus of \$36,507 has decreased by \$182,391 compared with the previous year.

Operating revenue dropped by 11.6% compared to 2022. This was primarily due to the conclusion of our Government projects supporting Consumer Education of IBD, GPs, and the Pediatric sector, alongside a decline in bequest income.

Despite this, 2023 marked another successful year for our Live Fearless Challenge, with a 14% income growth compared to 2022.

Our costs remained steady, rising by just 0.8% compared to 2022. We achieved savings in administrative areas, which were reinvested into bolstering our fundraising efforts and programs.

A total of \$77,842 was generated from term deposit investment and returns from our managed low-risk investment, resulting in a \$56,658 increase compared to 2022.

Given the above, our cash position has remained strong in 2023 and we have maintained a healthy liquidity ratio of 2.05.

With a stronger balance sheet, we can report an increase in net equity to \$1,767,650 for this year, compared with \$1,731,143 in 2022.

During the year the organisation has continued its focus on organisational sustainability. Risk managment has continued to be a key theme with cyber security a regular focus at our finance audit risk committee meetings.

Our staffing structure has remained small and steady with some slight restructuring of roles to ensure delivery of KPI's, while our staff turnover was higher than the previous year as we completed three of our government-funded projects.

A full copy of CCA's audited financial report for 2023 can be downloaded from our website at **crohnsandcolitis.org.au/annual-report** 

#### Sustainability Key Performance Indicators

Category	Notes	Target	2023	2022	2021	2020	2019
Liquidity Ratio	Current Assets/Current Liabilities	2:1	2.05	1.74	2.03	2.40	1.99
Profitability	Net Income/Equity	10-14%	2%	12%	15%	349%	19%
Debt to Assets	Total Liabilities/Total Assets	<1	0.36	0.43	0.47	0.41	0.49
Staff turnover	Industry benchmark 11.4%	10%	19.8%	7.7%	-	-	-
Grant application success		40%	65%	44%	-	-	-

### Governance **Board of Directors**



**Bruce Rosengarten FAICD** Chair



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



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



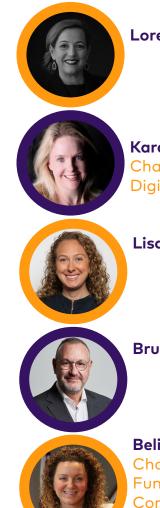
Paul Pavli AM, FRACP



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



**Daniel Teller OAM** 



## Loretta Bayliss GAICD

## Kara Ward Chair **Digital Transformation Advisory Group**

Lisa Belcher

**Bruce Goodwin GAICD** 



Belinda Dimovski Chair Fundraising and Communications Advisory Commitee

Lisa Neville

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

### **Board Advisory Committees**

### Project Advisory Committees

#### Governance, Nominations and Remuneration Committee

**Dominique Tim So (Chair)** Bruce Rosengarten James Oliver Bruce Goodwin

### Finance, Audit and Risk Committee

James Oliver (Chair) Bruce Rosengarten John Brennan Loretta Bayliss Dominique Tim So

#### Scientific, Medical and Quality of Care Advisory Committee

#### A/Prof Gregory Moore (Chair)

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

#### Fundraising and Communications Committee

- **Belinda Dimovski (Chair)** Bruce Rosengarten Kara Ward
- Lisa Belcher Lachlan Pike Daniel Teller

#### Digital Transformation Advisory Group Kara Ward (Chair)

Bruce Rosengarten Lisa Belcher Loretta Bayliss

### CEA-IBD Project Advisory Committee

A/Prof Gregory Moore (Chair) A/Prof John Ding A/Prof Simon Knowles Alex Sechi Julie Weldon Hugh Whittaker Leanne Raven Wayne Massuger Hailey Fisher

IBD Paediatric Quality of Care **Project Advisory Committee** Dr Edward Giles (Chair) Dr Chris Burgess Dr Shoma Dutt Dr Nitin Gupta Dr George Alex Dr Paul Hammond Dr Ajay Sharma Dr Scott Nightingale Professor Paul Pavli Deirdre Burgess Merran Spargo Helen Jurgens Prof Antoning Mikocka-Walus A/Prof Ram Nataraja Elliot Harris Wayne Massuaer

Leanne Raven Stephan Möller

#### GP Aware Project Advisory Committee

Prof Jane Andrews (Chair) Dr Eva Zhang Dr Yoon-Kyo An Fiona Bailey Stacy Kambouris A/Prof Jane Smith A/Prof Simon Knowles Cynthia Tait Bronwyn Lebrasse Christine Buttigieg Leanne Raven Wayne Massuger Hailey Fisher

C 2023 Impact Report

## **Our fearless donors**

Crohn's & Colitis Australia are grateful for the generous support of so many individuals, organisations and businesses. We would like to acknowledge and thank everyone listed below for making a positive difference and contributing to our impact at CCA during 2023.



#### **Community Fundraising**

\$26,000+ Charlotte Hyne

\$17,000+ Paypal Giving Fund

\$10,000 The Yarranabbe Foundation

\$5,000 - \$9,999 Toccolan Club Limited, Kevin Egan, Lachlan Pike, Play for Purpose

#### \$1,000 - \$4,999

The Spoonie Society, Spartans Gym, Neil / Craig Collins, Jan Wheeler, Neometals Ltd, Abbvie Pty Ltd

#### \$200 - \$999

Better Future Fund, Beechworth Primary School, K Colin-Thome, E Auguste, M Kirkpatrick, B Lapham, R Lapham, P Moss, H Hallam, M March, K Lapham, J Viney, C Manoharan, T Tench, P Gillon, S Chu, M Produce, D Teulan, Z Chen, R Komesaroff, J Johnson, J Duncan, M Germano, G Smith, M Schutters, A Elmasri, J Clarke, H Arvanitis, Franky R, B Greig, E Pullum, L Niccol, V Nguyen, A Mathias, T Saldias, K & T McDonald, M Jones, K Mokdad, A Family, J Howell, D Saliba, Y Perez, E Whitelock, J Starr, A Solomon, S Roth, J Taylor, M Christie, D Jaensch-Brown, P Honey, C Gatt, M Chu, P Rotili, V Velardo, D Piercy, M Dwyer, T Bishop, N Datson, M Daddy, W Declase, THELB Pty Ltd, M Donnison, K Byrne, J Brown, R & J Kaesler, D Lustig, M Le Maitre, N Farmilo, E Hughes, B Seidel, B Goodwin, B Reizer, S James, R Hill, D Laws, N Russell, R Fletcher, P Herrschaft, J Welbourne, S Starkey, D Ranger, M Oneill, T Roth, M Ortenburg, S Hughes, B Thomas, S Ivany, S Barber, K Moran, R Kavnat, I Shanks, P Hammer, T Tzioutziouklaris, L Rodrigues, C Young, S Barton, H Mitchell, L Harris, A Schwartz, S Saunders, J & A Gould, T Pick, F Macrae, P Ingram, S Gillon, J Thomas, L Reynolds, J Stewart, E Yencken, C Symons, J Giardina, A Di Stefano, G Dick, M Richie, R Trewartha, A MacDonald, B Luke, Haven Pilates

#### **General and Research Donations**

\$65,000

Anonymous Philanthropic Foundation

\$12,300 The James N Kirby Foundation

\$10,000 Redman Family, P & H Butts

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

CMV Group, H Waterham, Erdi Foundation, The Lord Family Trust, S Trevor, T Fenton, D Birner, L Raven, Eirene Lucas Foundation

#### \$1,000 - \$4,999

J Mandel, S Hillebrand-Roellgen, L Szumowski, The Bruce and Ros Rosengarten and Family Fund, Hammond Family Foundation, T Sandison, C Berryman, Independent Order of Oddfellows Centenary Rebekah Lodge I.O.O.F, D McDermid, P Crupi, K Rogers, C & H Martin, C Busby, C Condon, R Ramsden, H Francis, C Levinthal, D Shanahan, G Bell, St George Illawarra Dragons RLFC, N Barrow, B Whitlock, C Floreani, C Mangubat, H M Chew, J Avramides, Lions Club Of Jervis Bay, M Ensabella, M Kousins, M Walker, N Went, N Barrow, P Williamson, P Knight, V Hoogstad, R Brierley, A See, G Board, M Kousins, R Singleton, G Board, C Azzopardi

#### \$200 - \$999

D Reckenberg, S Inberg, D Uttley, F Sessions, K Attfield, Stauff Corporation Pty Ltd, V Anich, D Anderson, H Boulter, J Chan, B Thomas, C Bready, M Whitten, P Trichilo, P Mullins, D Jeliba, J Fenton, Carnegie Lions Club, H Koustas, I Mackenzie, L Axford, M Mcphillips, S Thompson, St Luke's Anglican Church, A Newman, A Helgensen, B Azzopardi, C Nicolaou, D Werner, D Fehlberg, Double Scotch Pastoral Co. I Turner, J Becher, K Rich, Lions Australia District 201v5, M Ebb, N Spitzer, N Abbott, N Sonenberg, R Hibbard, P Bide, J Heath, J Partridge, P Honey, A Bortollon, J Connery, J Strauch, K Osborne, L Potok, S Fox, C Australia Pty Ltd - Vic State Office, T Kim, M Barry, D Denham, E Saba, J Kooloos, L Gatfield, B Coppin, M Ossedryver, N N Patterson, Australian Patient Advocacy Alliance, K Muckert, M Melville, S Field, P Shannon, B Coppin, A McWhirter, D Esposito, I Jensen, K Gallus, N Poteri-Collie, P Farnan, R Vague, D Chhabra, B Cohen, K Shanks, L Kowaltschny, A Patane, R Johnston, A Young, B Hayllar, G Bell, G Bosworth, G Down, K Lu, L Lickiss, M Catchpoole, P Humphreys, P Snell, P Roumanos, R Legoe, S Gillon, S Sackson, S Dunne, H Bainger, N Pyne, P Shannon, T Nuij, S Atkinson, Cabam Pty Ltd T/as Matheson Family Trust, B Schilling, M Zerafa, M Branford, S Windle, T Pick, A Newman, A Kanachowski, J Voigt, M Corbett, S Henderson, A Pike, A Potter, A Brothers, C Hage, D Greenwood, D Sacco, D & Norma Simonds, E Tinawi, F Macrae, J Andrews, J Fahad, M Ismay, M Kent, M Stratis, M Moorhouse, P Wilson, R Schwartz, S Klineberg, A Joyce, A Prasanth Bhamidipati, C Floreani, C Salanitri, L Hoult, M Ismay, M Jeffries, M Colangelo, M Hayes, M Dean, M Culvenor, S Klineberg, S Uhlenbruch, B Braham, H Newman, J Ulman, L Spira, A Mills, D Angelopoulos

#### Bequests

\$144,218.49 Estate of Elizabeth Ann Hardie

\$50,000 Estate of Jill Robyn Sewell

#### In Memoriam

A Maharaj, D Moores, G Angelopoulos, G Shanks, M Wade, M Winter, N Kowaltschny, P Dean, P Grocke, P Maguire, R Corish, R Ruming, R Uttley, T Bowles, T Browne

#### In Celebration

A Rooke, A & I Carroll, C Parker, G Greathead, J Rocks, L Goodwin, L Pratt, M Hanson, R Goldberg, S Inberg, W Quick

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.

## Charlotte Hyne: living fearlessly

On Friday 8 September, CCA supporter and advocate Charlotte Hyne and almost 100 golf enthusiasts, fearlessly braved wild and windy weather at the Rosebud Golf course for the firstever Live Fearless Golf Challenge.

Charlotte struggled with "tummy issues" since her early teenage years, until she was properly diagnosed with Crohn's disease and later diagnosed with ulcerative colitis. Initially, Charlotte pushed through the daily pain which was hidden by her infectious smile. Fast forward several years, Charlotte's disease became quite uncontrollable. In 2022 Charlotte underwent six surgeries plus laparoscopic keyhole surgery, and now on relies on regular infliximab infusions to help manage her IBD.

Charlotte says: "For those who may not understand, it can be so challenging to explain the daily struggles of living with an invisible illness. How do you explain to someone that you are living with a condition that has no cure and cannot always visible from the outside? It's exhausting... It's essential to remember that just because someone 'looks' happy and healthy on the outside, doesn't necessarily mean they are on the inside. These illnesses can have a significant impact on a person's daily life. I want to thank my support system for their love and encouragement. Living with my disease has been a journey, almost like living on a permanent rollercoaster, but I'm determined to believe it's onwards and upwards from here!"

Early in 2023, Charlotte shared part of her journey on a LinkedIn post and never imagined the response she received. It became apparent to Charlotte that she was in a position to help raise awareness for a cause so close to her heart – and the Life Fearless Golf challenge was born!

Charlotte, who has strong links to the golfing community through her family business, approached CCA with her idea to run a fundraising golf tournament including games, refreshments and golf! She did an amazing job planning her event and securing support to make it a resounding success (despite the weather!), raising nearly \$30,000.

"Charlotte is a brilliant ambassador for those living with Crohn's and Colitis. We're grateful for our fearless ambassadors like Charlotte who are proud to speak about their experiences and share their struggles. We are thrilled with how many golfers and golfing brands were supportive of this inaugural event and we hope it only grows in number and awareness in the following years. Thank you" Leanne Raven CEO CCA.

"Thank you to everyone who made our first ever, Live Fearless Golf Challenge in support of Crohn's and Colitis Australia, such an amazing success. We battled hurricane-like winds and torrential rain, but the day was incredible, and it was wonderful to see everyone eager to put their wet weather gear on to support for such a vital organisation," said Charlotte.

Every swing, every putt, and every moment shared during the golf challenge had a tremendous impact.

LIVE FEARLESS GOLF CHALLEN BROUGHT TO YOU BY



# ✓ Get involved✓ Find out more✓ Donate today



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