



Crohn's & Colitis  
AUSTRALIA

*making life more liveable*



Annual Review

**2019**

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## Our Vision

### Who is CCA?

Crohn's & Colitis Australia (CCA) is a national, not-for-profit organisation playing a leading role in driving change to support 85,000 Australians living with Crohn's disease and ulcerative colitis, collectively known as inflammatory bowel disease (IBD). Since 1985, CCA has been helping to make life more liveable for Australians living with IBD, for which there is no known cure.

### Our Vision

We empower people to live life at full potential as we search for a cause and cure for Crohn's and colitis.

### Our Purpose

- System change and improvement in quality of care
- Engage with, empower and educate people living with Crohn's and colitis, health care professionals and carers
- Raise awareness of Crohn's and colitis and promote gut health within the community
- Build research capacity in the search for a cause or cure

### Our Values

Our values underpin everything we do and provide a moral compass in our response to opportunities/challenges and decision making:

- Connection with the Crohn's and colitis community
- Innovation and life-long learning
- Agility
- Social and fiscal responsibility

### Our Goals

We continue to:

- improve quality of care for people living with IBD
- strengthen our research scholarship program
- nationalise our support services and networks
- build substantive awareness and broad engagement on IBD
- ensure CCA is financially sustainable and is a long term capable not-for-profit organisation



# Our Strategic Priorities 2020-2022

## Empowering our community

- Increase national profile, support services and volunteers in each State and Territory
- Strengthen relationships with stakeholders nationally
- Keep support service and membership offerings under review, trial and implement new initiatives
- Become a leader within the international community

## Advancing Quality of Care

- Drive priorities in the IBD National Action Plan
- Communicate findings from quality of care projects
- Advocate for improvements in IBD care, treatments & services
- Keep IBD quality standards under review
- Undertake hospital audits on a 2 year cycle and expand audit program

## Building IBD research capacity

- Establish and grow research fund
- Increase volume of research scholarships for IBD projects
- Award a post-doctoral scholarship in IBD
- Partner with researchers and research organisations in quality research projects

## Strengthening our fundraising and brand

- Launch and grow Gut Smart enterprise on e-commerce platform
- Measure and grow consumer awareness of IBD and reputation of CCAs brands
- Increase digital and third-party fundraising activities
- Expand funding partnerships across corporate, government and philanthropy where there is brand alignment and value

## Reinforcing a healthy culture and people

- Engage with the right people who have the right skills/ attitudes aligned with culture and organisation values
- Drive best practice corporate governance with skills based board conducting evaluations of performance every 2 years

## Growing organisational sustainability

- Create and implement an organisation risk management plan
- Grow a lean organisation achieving budget targets and KPI's
- Increase financial reserves for investment in support services, research and digital capability
- Develop a data-driven organisation with strong digital capability



# From the Chair & CEO

**This year heralded the beginning of an exciting new era for Crohn's & Colitis Australia (CCA) and the near 100,000 people who are living with Inflammatory bowel disease in Australia.**

In March, the Minister for Health, The Hon Greg Hunt launched the IBD National Action Plan (NAP). CCA led the project to develop the plan in collaboration with the IBD community, peak medical organisations and members of CCA's Scientific, Medical and Quality of Care Advisory Committee. The plan outlined 8 priorities to improve quality of care for people living with IBD, who are at the heart of everything we do.

The \$2M government funding package to be delivered over 4 years will kick start some short to medium term initiatives helping to grow the quality of care advocacy platform in three areas: IBD community education and self-management, IBD education for General Practice and a paediatric audit to focus on quality of healthcare services for children. CCA continues to work to find solutions to the first priority in the IBD NAP - a skilled and accessible multidisciplinary workforce with increased access to specialist IBD nurses and allied health professionals.

Our support programs have grown in number and reach becoming more innovative throughout the year:

1. Crohn's and Colitis NurseLine launched in July to support our community in navigating the health system. The 3 year project, conducted with the Centre for Community-Driven Research and funded by the Australian Department of Health, will be evaluated.
2. Youth and children's programs expanded with our first Kid's Fun Day held at the Wildlife Sydney Zoo with over 40 attendees, lots of fun and networking amongst parents. We launched our first podcast, the Bottom end and held Camp Fearless in Brisbane in July. Many young people and their families make life-long connections through these programs as they can stay connected via social media after the events. These events can empower both the child and parent capability in dealing with their disease.
3. Community support groups have spread around regional and urban Australia with four new support groups established in 2019, bringing the total to 21 groups all led by trained volunteers living with IBD.

Given the success of our inaugural Research Appeal we were able to announce the establishment of a Research Fund for these donations and another IBD Research Grant named in honour of our founder, Angela McAvoy AM. The optimism and hope generated by the search for better treatments and a cure for IBD remain top of mind. We also selected 4



recipients for the CCA Ferring IBD Clinical Project Award. These grants of \$15,000 encourage innovation and clinical excellence in IBD Clinical practice.

Our Crohn's & Colitis Awareness Month Campaign in May **#FlushtheStigma** emphasised the importance of mental health and psychological wellbeing. Launched by our fabulous Ambassadors, Jacinta Parsons and Amy Benn, we highlighted an insight from our IBD Experience Study where over 1 in 2 people living with inflammatory bowel disease were in psychological distress when completing the survey. We saw the emergence of the purple ribbon to spark an IBD conversation and 25 light up building sites across Australia. Thanks to our partners at the Vivid Festival, on World IBD Day, Sydney city and harbour turned purple in spectacular recognition of our cause.

In 2019 we invested in a digital transformation, moving to the cloud with a significant improvement in access to data and reliability. We developed an organisational dashboard to improve decision making and introduced a quarterly planning and reporting cycle. Our financial performance was strong with an increased surplus, an 8% increase in income and an increase in net equity from \$678,179 in 2018 to \$835,128 for this year.

Importantly, we also updated our vision and strategy plan which you will see in this report. We are committed to empower people living with Crohn's or colitis to live life fearlessly whilst we support actions to find a cause and cure for these diseases. Our strategy is dedicated to these outcomes.

We are deeply grateful for the support from our corporate sponsors, our board and committee members and our staff thanking them all for their unstinting efforts in 2019. We also wish to thank our IBD community - volunteers, members, ambassadors, donors, fundraisers, and social media followers. With over 35,000 people in the immediate CCA IBD community we relate to at least 35% of the total population living with Crohn's and colitis in Australia. We will work to increase and deepen this relationship by expanding our networks.



Bruce Rosengarten, Chair



A/Prof Leanne Raven, CEO

# A year of highlights



## Fundraising



Total fundraised amount  
Raised from appeals

**3,877**

donations to the Live Fearless Challenge

**\$2m**

grants through the IBD National Action Plan



## Volunteers & Supporters

**2,693**

members and volunteers in 2019



**10%**

increase in new membership



## Programs & Services



**617**

Crohn's and Colitis Helpline calls & NurseLine assessments



**61**

attendees at youth programs



**558**

attendees at IBD Information Forums



**23%**

increase in new support groups



## Events



**25**

light up sites on May 19, World IBD Day



**6,000+**

stream views of Facebook Live Awareness Month Q&A

live **fearless**™ challenge

**62,000+**

kilometres covered during the 2019 Live Fearless Challenge



## Web & Social Media

**259,513**

website visitors to [crohnsandcolitis.com.au](http://crohnsandcolitis.com.au)



**26,539**

followers across all social media



**19,317**



**5,272**



**1,638**



**312**

# Programs and Services

CCA provides a diverse range of support programs and services for the IBD community to enhance knowledge and awareness of Crohn's and colitis.

In 2019, there was increased usage of the services we offer, and the subsequent positive feedback has encouraged CCA to further develop forums and support groups so that everyone across Australia has access.

## Information Forums

IBD Information Forums are CCA's flagship program. Their popularity over the years has increased, with both people with IBD and health professionals considering these programs to be an excellent vehicle to educate and support.

CCA hosted 11 information forums in 2019:

Location	Specialty Topic	Date
Melbourne: Royal Children's Hospital	Mental Health	February 20
Melbourne: The Alfred Hospital	CCA AGM	March 23
Brisbane: Mater Hospital	Microbiome	May 8
Online: Facebook Live Q&A		May 29
Sydney: Randwick Children's Hospital	Youth	July 24
Sydney: Blacktown Hospital		August 13
Perth: Royal Perth Hospital	Pregnancy, Medications	August 21
Sydney: Liverpool Hospital	e-Book launch	October 17
Melbourne: Eastern Health - Box Hill Hospital	Surgery	October 23
Canberra: Canberra Hospital	Research	November 20
Adelaide: Women's & Children's Hospital	Diet	December 5



**11** forums - both online and face to face



**558** attendees at face-to-face forums



**43** speakers across all forums



**6,000+** stream views of our Facebook Live Q&A during Awareness Month

## Support Groups

Support groups are a very important service provided by CCA and have been an integral program for many years. Our goal is to continue to nurture and grow this program to meet the needs of the thousands of people who value face-to-face connections and sharing lived experiences.

CCA would like to thank all the volunteers who lead our support groups and who have enabled the formation of new support groups in 2019 in:

- Newcastle
- Sunshine Coast
- Geelong
- Perth



**21**

support groups across Australia



**31**

support group facilitators



### iConnect

This service provides online support for people living with Crohn's disease or colitis, their families and friends, by providing linkages with peers and IBD nurses for a confidential, one-on-one conversation.

### CCA Helplines

#### Crohn's and Colitis Helpline

Our Crohn's and Colitis helpline offers individual support, information and guidance on living with Crohn's disease or ulcerative colitis, provided by our expert peer Helpline Coordinator.

Often people living with Crohn's or colitis turn to our helpline for support when they are newly diagnosed, are interested in new treatments or are seeking suitable health professionals. Our helpline is there for patients and their carers, friends or colleagues as a way to provide supportive listening, as well as reliable information to divert people away from potentially questionable internet advice. The Crohn's and Colitis Helpline provided 585 episodes of support and information, mostly by telephone but also through email and social media. Callers included people living with IBD, their family and friends, people who suspected they may have IBD but were yet to be diagnosed, and international callers planning to visit Australia.

#### Crohn's and Colitis NurseLine

The Crohn's and Colitis NurseLine is a new service launched in June 2019 and funded by the Australian Government, with an IBD nurse providing telephone-based information, support and personalised care planning. CCA is now working with the Centre for Community-Driven Research to evaluate this service.

### Can't Wait Card

The Can't Wait Card program engages program affiliates, businesses and community venues to provide access to their toilets for CCA members living with IBD. By showing the card, IBD patients are able to discreetly access toilets without embarrassment or distressing questions.

The campaign is also a business and consumer awareness campaign, with dedicated collateral available to businesses and their staff alerting members of the public and key business decision makers about the disease and its symptoms.

A plan to expand the program in 2020 was launched at the Silver Lining Lunch in Sydney with guest speaker and toilet access advocate, Ally Bain, the person behind "Ally's Law," otherwise known as the Restroom Access Act in the United States.



**40%**  
increased usage of  
iConnect, with volunteers  
responding to over 160  
emails



**463**  
calls answered on Crohn's  
and Colitis Helpline



**32**  
care plans prepared  
via Crohn's and Colitis  
NurseLine



**750+**  
business premises  
involved in the  
Can't Wait Program



**10,000+**  
people benefitted from  
the Can't Wait Card

# Youth and Children's Programs

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

In 2019, CCA ran youth and children's programs in Queensland, New South Wales and Victoria.

## Kids Fun Day

CCA's first Kids Fun Day (KFD) was held in Sydney in 2019. The idea for the event came from a young 10-year-old member who had never met someone his age living with IBD.

Held at Wildlife Zoo Sydney, the KFD was an opportunity for young children living with IBD to meet others just like them, and for parents to participate in an information session presented by staff from the Westmead Children's Hospital.

CCA would like to thank CCA volunteers, as well as staff from the Westmead Children's Hospital who gave their time to ensure a successful event.

***"It was comforting to be around families that understand IBD. It was such a joyful day with no judgement. But what we really liked the most was that our son got to see for himself that kids with Crohn's look like regular kids, up until then he felt different and isolated."***

*Parent of Kids Fun Day attendee*

***"I now feel more comfortable, because most of the kids looked like people I would see every day. I had a great time and hope we can do it another time in the future."***

*Kid's Fun Day attendee*

## The Bottom End podcast

A podcast series for young people living with IBD which can be downloaded on iTunes or Spotify was created in 2019. *The Bottom End* podcast series features CCA ambassadors, Luke Escombe and Brittani Nicholl, as well as fellow Crohn's patient, Justan Singh who all share their deeply personal stories of their journey with IBD.

Their candid conversations delve into the reality of day-to-day life with IBD, each offering their own uplifting insights, encouragement and advice to others who find themselves in the same situation.

Each episode also features balanced commentary from a healthcare professional, courtesy of Melbourne-based paediatric gastroenterologist, Dr. Ed Giles.





### **YEP! Youth Empowerment Program**

YEP! is unique program that brings together a professional IBD advocate speaker and mentors from the CCA community who share their experiences to inform and guide their younger peers in managing their condition. After a successful pilot in 2018, YEP! was held in Melbourne in 2019.

CCA would like to thank our volunteers who mentored participants on the day and shared their experiences of living with IBD, as well as Luke Escombe for speaking at the event.

***"The best part of YEP! was hearing that I am not alone, talking about experiences with others, finding out ways to manage it through life"***

*YEP! attendee*

***"I just wanted to thank the people involved in organizing the day at Latitude. My daughter had a fantastic time and was so grateful to finally meet some other people with Crohn's disease, who understood what she is going through"***

*Parent of YEP! attendee*

### **Camp Fearless**

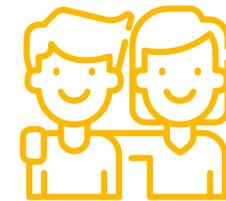
Camp Fearless is an adventure weekend for teens living with IBD, with the purpose of the camp to bring young people together to share their experiences and to build social connections with other teens. A successful camp was held at Redland Bay, QLD in July and CCA would like to thank the volunteers that supported staff and attendees throughout the weekend.

***"It has meant a lot to me to be able to connect with people who understand me and my condition, especially in my age group."***

*Camp Fearless attendee*

***"My daughter had a great time on camp and didn't want to come home. Thanks to the organisers, volunteers and camp staff who made this weekend so special"***

*Parent of Camp Fearless attendee*



**61**

attendees across all children and youth programs

# 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.

In 2019, we were fortunate to see an increase in both the number of volunteers and hours spent supporting the organisation. We would like to extend a special thank you to both new supporters and long-time volunteers for your time and effort.

## Volunteer Service & Recognition

In 2019, CCA recognised outstanding volunteer service for 3 of our volunteers:

Anita Reilly	30 years
Cassandra Anslow	5 years
Stefan Norman	5 years

## Corporate volunteers

CCA would also like to thank volunteers from ANZ, NBN, Deloitte and Suncorp who spent the day at the CCA as part of their workplace volunteer program.

## Ambassadors

A big thank you to CCA Ambassadors for spreading the word both through their own publicity, events and social media as well as CCA's organised events and publications, especially during Awareness Month and the Live Fearless Challenge.

## Local Champions

CCA's Local Champions are an important part of achieving our awareness goals, with these volunteers applying their lived experience of IBD to educate the community and advocate for increased support for patients.

In 2019, our local champions spoke at awareness month events, organised fundraisers and met with local council members and federal MPs to discuss how government can better support Australians living with IBD.

## The Power of Local Champions

Whilst CCA has been advocating for funding from government and philanthropy to support IBD nurse education and positions, our Local Champion Melita Griffin (pictured right) has successfully lobbied to secure an IBD Nurse position at the Royal Hobart hospital in Tasmania. With over 2,000 patients on the waiting list and no IBD nurse in Tasmania, Melita's persistence resulted in questions being asked in the Tasmanian Parliament and the State government has now funded a full-time IBD nurse at the hospital.



**140+**  
number of volunteers,  
up 46% from 2018



**1,500+**  
volunteer hours donated,  
up 38% from 2018



**12**  
CCA Ambassadors



**7**  
CCA Local Champions



**15**  
Live Fearless Challenge  
Ambassadors





## Membership

In a continuing effort to improve the membership experience, CCA conducted a member survey with more than 300 previous and current members providing feedback on our membership program. The following recommendations from these findings were identified, and will be implemented in 2020:

- Focus on improving member retention
- Continue to provide quality content through our 'Inside Insight' magazine
- Provide more ways for members to pay their annual fee (e.g. direct deposit)
- Provide greater clarity on member benefits page as to what is exclusive vs non-exclusive
- In the long-term, we need to look at how membership works within the website to provide a better user experience

From the survey, CCA was also able to conclude that the most valued benefits for our members were our publications ('Inside Insight' magazine & CCA Member e-News) and the Can't Wait Card. Many members showed their support for CCA with feedback including:

*"it is invaluable to me"*

*"thankful to be in the loop"*

*"you are most comprehensive with your services"*

## Membership renewal process

CCA has begun implementing SMS technology to facilitate a reminder two weeks prior to membership expiry. This is to provide an extra point of contact to ensure renewing membership remains top-of-mind and is easy to complete.

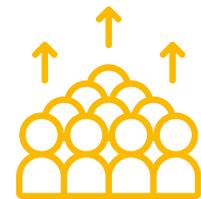
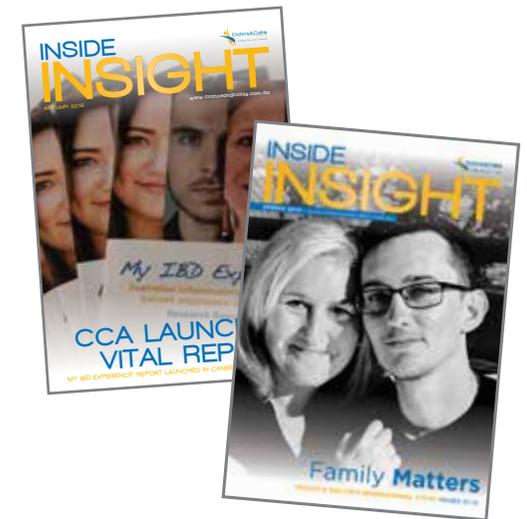
2019 has seen CCA increase its digital approach to communication. Though members can still choose to receive their correspondence by post, CCA is now using email for default communication. This is relevant for membership renewal information and receipting, as well as the magazine and new fortnightly member e-News.

A new benefit in 2019, CCA Member e-News streamlined communications to members in one easy-to-access format, ensuring the Crohn's and colitis community is more regularly kept up to date on a range of news and issues.



# 2,527

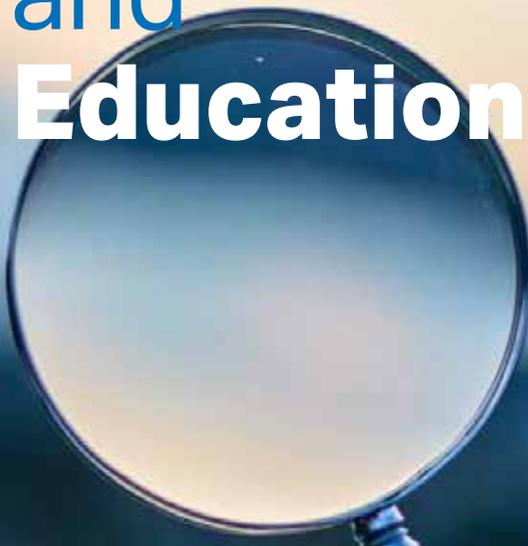
active CCA Members



# 10.6%

increase in new membership from 2018

# Research and Education



CCA is committed to building IBD research capacity through its annual Scholarship and Clinical Project grants. Research is a priority of the IBD National Action Plan 2019 for people living with IBD, health professionals, scientists and stakeholders.

## Quality of Care

CCA continued to focus on improving quality of care through leadership of IBD stakeholders, advocating for funding, publishing evidence and providing consumer friendly materials.

CCA lead IBD stakeholders to develop the IBD National Action Plan published by the Australian Government Department of Health. Launched by Minister for Health Greg Hunt in March, the plan sets out priorities to improve care and resulted in \$2M dollars of funding being allocated for IBD projects. CCA was selected to deliver one of these projects, with \$1M to improve consumer awareness and education materials focusing on self-management over the next four years.

We continued to strengthen the evidence about quality of IBD care in Australia by publishing two articles and a conference abstract in peer reviewed healthcare medical journals, presenting the findings of the My IBD Story patient experience survey.

## Scholarships

CCA awarded four CCA-Ferring IBD Clinical Project Awards and the Angela McAvoy Research Scholarship in 2019, increasing our focus on research capacity building. The post-graduate IBD research scholarship, named after CCA's founder, was entirely funded from donations by the members and supporters of CCA.

Research applications were received from 23 Australian researchers, and topics funded included:

- Sulphide reducing diet for people with ulcerative colitis
- Gut-directed hypnotherapy for patients with Crohn's disease
- The role of IL-37 (a substance in humans that can inhibit inflammation)
- Reducing thiopurine medication for people with ulcerative colitis taking the biologic therapy Vedolizumab
- Concentrated albumin infusion prior to Infliximab for people with Acute Severe Ulcerative Colitis (ASUC).

## Asia-Pacific IBD Alliance (APIBDA)

CCA is a member of the APIBDA and our CEO Chaired 3 successful meetings this year. The first in Bangkok with representatives from Japan, China, Thailand, Taiwan, Korea, Singapore and New Zealand and the other 2 via video conferencing.

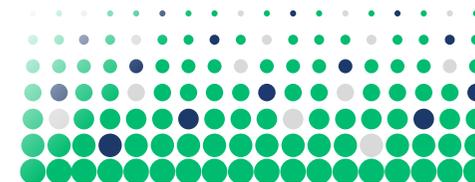
A poster was presented at the Taiwan IBD medical conference in June - *Hand in Hand: tackling the burden of mental health issues in those living with IBD in Asia Pacific.*



Australian Government  
Department of Health

## INFLAMMATORY BOWEL DISEASE NATIONAL ACTION PLAN 2019

March 2019



# \$135,000

total value of grants and scholarships



### Crohn's & Colitis Hub

The Crohn's & Colitis Hub (CC Hub) is the go-to information portal for everything you need to know about living well with Crohn's disease and ulcerative colitis.

Articles and research studies are freely available and sourced from reputable online publications to provide a comprehensive resource of the best available information on IBD and gut health.

### Research Videos

Our Online Research Updates series provides members with the opportunity to hear new research findings directly from researchers. These videos feature interviews with health professionals, specialists, researchers and academics and are delivered exclusively to CCA members through email and CCA's private YouTube channel.

### Current Research

CCA promotes various research studies run by Australian and international universities as well as sponsored research trials to help recruit participants and raise awareness around emerging research. In 2019, CCA promoted 11 IBD research studies covering topics such as the microbiome, exercise, wellbeing and diet.

### New initiative: GutSmart

GutSmart is the next step in CCA's mission to ensure that people living with IBD receive the best possible care.

Everyone deserves to have access to treatment and support that maximises their physical and mental wellbeing. Yet even with the incredible strides that have been made in the quality and breadth of services available, our My IBD Experience: Research Report 2018 found that fewer than 1 in 3 patients had a dietitian as part of their treatment team, and only 12% had a psychologist.

Additionally, the necessity of IBD-specific training was highlighted in the Inflammatory Bowel Disease National Action Plan 2019 as a priority action point to ensure that every patient has access to a multi-disciplinary treatment team.

GutSmart is our solution - work has commenced and the digital education platform will be launched in 2020.

We are deeply grateful for the funding provided by **The Eva & Les Erdi Humanitarian Charitable Foundation**, the founding innovation partner for GutSmart.



**20,421**

unique visitors to  
Crohn's & Colitis Hub



**15%**

return visitation



**2** research videos  
**582** video views



# Events and Community Fundraising



## Silver Lining Events

In 2019, CCA hosted two of our ever-popular Silver Lining Lunch events, one in Melbourne in May, and the other in Sydney in December.

The objective of Silver Lining events is to continue to raise awareness of IBD at the highest level of business and government, providing a relaxed and informative forum, as well as providing a networking platform for future partnerships.

The key message of CCA Silver Lining events is one of encouraging positivity and hope for the Crohn's and colitis community, to assist people living with IBD to overcome challenges and find the silver lining to live a happier and healthier life whilst working towards a cure for tomorrow.



**194**

Silver Lining Lunch attendees across 2 events



**\$31,171**

funds raised from Silver Lining Lunches in 2019

Fundraising is vital to CCA, and is the primary way in which our organisation generates funds to provide IBD research scholarships and support services across Australia.

Fundraising events held by individuals within the community are especially valued by CCA, and are also important in raising awareness and initiating conversations on Crohn's and colitis.





### Live Fearless Challenge

Studies have shown that low impact exercise can have a positive health benefit on people living with Crohn's and colitis, and in September 2019, CCA conducted its 2nd Live Fearless Challenge, our largest national digital campaign encouraging participants to walk, run, cycle or swim 150km during September.

The Live Fearless Challenge encourages participation regardless of fitness level, and can be completed by teams or individuals at their own pace.

The objective of the campaign is to empower people with Crohn's and colitis to share their experiences with others, such as their friends, family and work colleagues, to increase the reach and understanding of invisible illnesses beyond the patient community.

In 2019, 115 teams registered for the Live Fearless Challenge - a combination of family & friendship teams and corporate teams.

#### Top Fundraisers (Individuals)

Bruce Rosengarten	\$9,000
Simone Spaulding	\$8,400
Jason Brennan	\$8,100
Daniel Concannon	\$6,000
Lachlan Pike	\$5,300
Jack Lehrer	\$3,000
Julie Weldon	\$2,800
Julie Lonard	\$2,500
Jarrold Sinclair	\$2,500
Kara Mullarvey	\$2,257

#### Top Fundraisers (Teams)

Tummy Bugs	\$11,700
The Semi Colons	\$10,800
Marshall Day Acoustics	\$4,200
Ain't nothing going to break our stride	\$4,000
We're Stronger Together: Let's Do This!	\$3,100
Don't Walk on Bys	\$2,800
Team Takeda	\$2,700
Gold Coast Bowels on Bikes	\$2,600
I B DID that!	\$2,500
We Thought This Was Pub Trivia	\$2,100



**650**  
participants



**4,500**  
total people involved



**\$206,771**  
funds raised during the  
Live Fearless Challenge



**62,000km**  
kilometres travelled by  
participants in 2019



**107,828**  
pageviews on the Live Fearless  
Challenge website



### Crohn's and Colitis Awareness Month

Each May, in conjunction with World IBD Awareness Day, Crohn's & Colitis Australia delivers a month-long national awareness campaign.

In 2019, Crohn's & Colitis Australia ran **#FlushTheStigma**, an awareness campaign with an emphasis on the importance of psychological wellbeing, an often overlooked aspect of IBD.

Crohn's and Colitis Awareness Month aims to:

- Increase awareness within the broader community of the quality of life issues faced by people living with Crohn's and colitis
- Destigmatise these invisible illnesses and empower the Crohn's and colitis community to speak up and share their stories
- Communicate beyond the patient community so that the wider community have a better understanding of Crohn's and colitis
- Communicate with newly diagnosed patients to spread awareness of CCA's programs and support services

We are deeply grateful for support from our sponsors to raise IBD awareness during 2019 Crohn's and Colitis Awareness Month and World IBD Day:

- Janssen Australia and New Zealand (silver sponsor)
- Takeda (bronze sponsor)
- Aspen Pharma (bronze sponsor)
- Emerge Health (bronze sponsor)



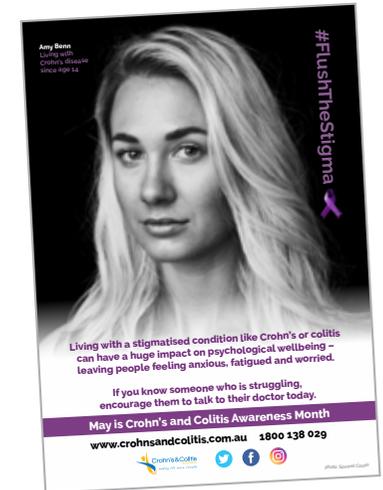
# 8%

increase in Instagram followers during Awareness Month



# 241,804

Facebook reach during Awareness Month



# 600

posters distributed

# 1,400

flyers distributed



### World IBD Day: May 19

Each year, the CCA formally joins with international colleagues to participate in World IBD Day through the **#WorldIBDDay** campaign, raising awareness by lighting up major iconic buildings around the world in purple, the international colour for IBD.

The Sydney Harbour Bridge and surrounding buildings were lit up purple and featured on 9News Sydney.

As well as the light-up campaign, CCA seeks to promote a larger and broader communications message through:

1. Media and PR: A press release will be distributed to appropriate media outlets to raise awareness, and case studies will be presented to provide comment and real-life experiences.
2. Digital Campaign: A World IBD Day social media campaign will extend the campaign's reach and relevance.
3. General Media & Social Media: CCA will continue to leverage its inspirational ambassadors to promote the campaign.
4. Print Collateral - Posters and Flyers: CCA will distribute posters and flyers to its key stakeholders and major IBD sites such as hospitals to promote the awareness month campaign.
5. Purple Awareness Ribbon: CCA now has purple awareness ribbons to spark conversations about IBD, and these are available for purchase from our website all year round.



**25**

iconic sites around  
Australia lit up in purple  
for World IBD Day



**423**

Awareness  
Ribbons sold



### CCA Representation at Industry Conferences and Forums

Representatives from CCA participated in a number of conferences including during Australian Gastroenterology Week, the Australian Patient Organisation Network Conference, and at the Pharmaceutical Benefits Advisory Committee.

A poster was presented at AGW-GESA conference 'Patient experience of quality of care for people with IBD'.

Our CEO delivered the keynote address at GENCA (Gastroenterological Nurses College of Australia) in Melbourne and spoke at the GESA conference in Adelaide.

### Community Fundraising

Our community fundraisers took on wonderful challenges across Australia in 2019, whether they were diagnosed themselves, advocating for a friend or family member, or were striving to achieve a new personal best.

In support of the Crohn's and colitis community, their fundraising events included participating in fun-runs and marathons, a trek in Nepal, local sausage sizzles and a home piano recital, with many ready to embark upon their next fundraising and personal goals for the year ahead.

We thank our community fundraisers for their commitment and dedication to raising awareness of IBD in their local communities, and championing their own personal experiences with others.

### Final Melbourne Fidelio Concert

With nearly all concerts sold out, the three-year CCA-Fidelio Quartet collaboration came to a close at the end of 2019.

The Quartet performed their final show in September, with concerts enjoyed by the Crohn's and colitis community in Melbourne.

### Hand-in-Hand campaign

In recognising the significant association between symptoms of depression and/or anxiety and flare ups in IBD, CCA undertook a project to develop resources to help initiate a conversation with an IBD clinical team.

Our IBD experience survey found that over half who responded were in psychological distress at the time of completing the survey and only 16% had been asked about their psychological health by their doctor. The Wellbeing Checklist can be used to start this conversation and can be downloaded from the Crohn's and Colitis Hub.



# \$160,000+

funds raised by the  
Crohn's and colitis community

*"It was so heart-warming to us when people came up to us and said things like "oh great cause," "I know someone with Crohn's - good on you" and another runner came up to us and said "next year I'm running for CCA because I'm a Crohn's sufferer myself."*

*Stephanie McCamley participated in the 2019 Sun-Herald City2Surf with her best friend, raising over \$530.*

*"The people I met, beautiful scenery I hiked through and the ability to do some good for our community and CCA made it the most impactful experience I've ever had."*

*Brad McAuliffe (pictured left) set himself a physical challenge in trekking in Nepal, which raised over \$2,000 for the Crohn's and colitis community.*



# \$3,282

raised from Fidelio  
Quartet concerts



# 340

attendees

# Publications

## Inside Insight magazine

CCA produced four full colour, quality magazines in 2019 made available in both print and digital formats. A total of 15,000 copies were distributed to CCA members, IBD clinics, nurses and gastroenterologists.



# 15,000

distribution of Inside  
Insight magazine

Articles included research updates, latest trends and developments in IBD, features on nutrition as well as human interest stories.

## Member e-News

CCA introduced a fortnightly e-news for members in March 2019. These regular updates have proved to be popular with members, with an average open rate of 51% each fortnight and strong interest in stories, with an average 8% click rate.



# 51%

average e-Newsletter  
open rate

## e-Books

Working closely with people living with IBD, CCA produced a consumer-friendly version of the Australian IBD Standards – *My Partner in Care*.

Launched at the Liverpool Hospital IBD Information forum in October, this booklet and social media campaign were designed to help people living with IBD to get the best out of their care. Hundreds of people have viewed the social media campaign and eBook.



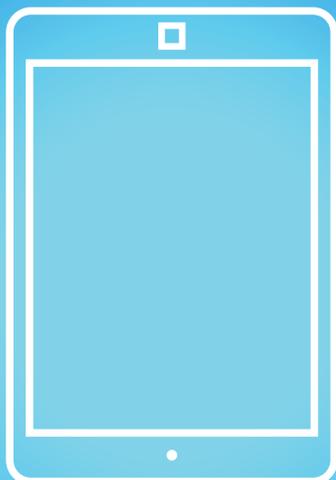
# 2,500

copies of 'My Partner in  
Care' distributed

A new e-Book series on the Crohn's & Colitis Hub commenced in 2019 with the first e-Book - 'Ostomies & IBD' - published. In conjunction with Crohn's and Colitis Awareness Month in May, CCA also published a Psychological Wellbeing Toolkit e-Book which offers a range of tips and guidance on managing your mental health while living with IBD.



# Digital & Organisation Transformation



## Data Storage, Security and Reporting

During 2019 we moved to the cloud, creating secure and reliable access to information. IT security was reviewed with new anti-virus and firewall solutions to be implemented in 2020.

A dashboard reporting framework was implemented, designed to inform board and management decision making, reporting quarterly on data from:

- Membership and earned revenue initiatives
- Support programs
- Quality of care and research
- Fundraising
- Marketing and communications

## Digital Enhancements

We have increased our engagement with members and stakeholders by using SMS functionality to send notifications.

All company documents have been transferred to Cloud storage to increase productivity, collaboration and security, actively functioning as a company intranet resource. Additionally, a standardised Microsoft version is being utilised across CCA, a conference phone has been installed, and cost savings have been made by upgrading the multi functional unit (printer) and switching mobile phone and internet providers.

## Organisation Restructure

A review of the organisation structure was undertaken leveraging our volunteer network as a new recruitment pipeline. New positions were created at the management level and part-time project officer roles within teams. Our structure remains lean and flat utilising an agile contingent work force model where expertise is brought in when required.

## How we work at CCA

In 2019, we introduced a 90-day business planning cycle where the plan is updated each quarter to ensure alignment with strategic priorities. Everything we do at CCA is underpinned by strengthening our business to achieve our goals and living our organisational values. Our values shine through our everyday actions working within the CCA team to create a healthy culture and organisation.

## Team Communication

Team communication and decision making have been enhanced by introducing:

- Quarterly Review meetings
- Fortnightly Management Team meetings
- Full CCA Team meetings post board meetings

Our culture is described by FACTS:

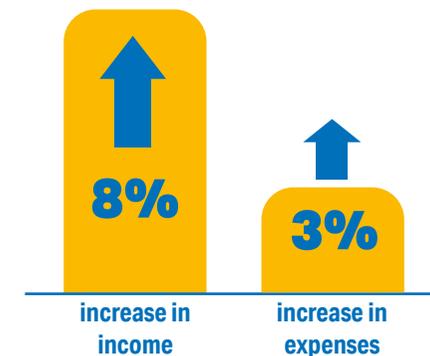
<b>FAST</b>	Responsive to new ideas we are quick to act in ways that empower our people and community
<b>AGILE</b>	Our agility helps us to drive change and ensure social and fiscal responsibility
<b>CONNECTED</b>	We are connected to the Crohn's and colitis community, we strive to deepen this connection and we value feedback on how we can empower people living with IBD
<b>TRANSPARENT</b>	We are proud of what we do, aim to showcase our achievements, disclose our failures and learn from our experiences
<b>SMART</b>	We innovate through taking up new initiatives, adding value and sharing our learnings

# Financial Report

This report is for the 12 months ended December 2019. The financial surplus of \$156,949 has increased by \$65,814 compared with the previous year.

This has been attributed to the growth of our IBD research capacity and research appeal introduced in 2019, growth of our third-party fundraising activities, and the continued success of the Live Fearless Challenge and other community events which continue to empower our IBD community.

We are pleased to report that the subsequent increase in income of 8% has been matched by a modest increase in expenses of 3%, allowing us to establish a dedicated research fund in 2019.



Our cash position has improved this year as a result of the research appeal, and from securing a federal government grant to allow us to accelerate and advance our quality of care over the next 4 years.

The drop in the liquidity ratio vs. 2018, is driven by additional balance sheet reporting as a result of the accounting standards changes for leases (AASB 16).

With a stronger balance sheet, we can report an increase in net equity to \$835,128 for this year, compared with \$678,179 in 2018.

**A full audited financial report is available on request or can be accessed via our website.**

## Asset Register

The Company Asset Register was reviewed and updated.

## Risk Management Framework

During 2019 work has commenced on the development of a Risk Management Plan with the assessment of risk appetite and ongoing identification of emerging risks and mitigation plans.

## Key Financial Indicators

Ratio	Category	Definition	Calculation	Target	2019	2018	2017
Current Ratio	Liquidity	An indicator of the company's liquidity	Current Assets/Current Liabilities	2:1	1.99	2.58	4.30
Return on Investment	Profitability	Indicates how well an organisation is utilising it's equity investment	Net Income/Equity	10-14%	19%	13%	45%
Debt to Assets	Debt/Leverage	Measures the % of assets being financed by liabilities	Total Liabilities/Total Assets	<1	0.49	0.3	0.2

# Board of Directors



**Bruce Rosengarten**  
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), and at Shell (Global Vice President Retail, Marketing) where he led Fuels, Convenience stores, Loyalty, Cards, Marketing and the Shell brand globally. Prior to this, he was Executive Director at Crown, launching Crown locally and internationally and running Tables Games. He spent over 12 years at Coles Myer overseeing regions of Department stores, and additionally, was Managing Director of World 4 Kids.

Bruce has extensive governance experience across a diverse range of organisations including ASX listed, private companies, joint ventures, industry associations and the not for profit sector. Bruce was a Director of Jewish Care Vic 2008-15 and its President/Chair 2009-2012. He has held governance roles in the not for profit sector, including the Singapore Jewish Welfare Board and as a Council Member of Mt Scopus Memorial College. He has also held extensive roles in industry associations including International Committee Chair National Association of Convenience Stores, Australian Institute of Petroleum, VP South Australian Retailer's Association, and was a Rundle Mall Management Committee Member.

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



**Paul Pavli AM**  
Director

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.

He has also served on a number of Federal and Territory government bodies and professional organisations including the Australian Drug Evaluation Committee (ADEC), now the Advisory Committee on Pharmaceutical Medicines (ACPM), the National Health and Medical Research Council (NHMRC), the Royal Australasian College of Physicians, the Gastroenterological Society of Australia and Therapeutic Guidelines.



**David Reckenberg**  
Director, Company Secretary

## **Chair - Governance, Remuneration and Nominations Committee**

David Reckenberg is a lawyer who has worked in the wealth management industry for over 20 years, specialising in superannuation law. Between 2005 and 2009 he also held operational (non-legal) management roles with AXA.

David currently works part time as a special counsel with Hive Legal and as a qualified teacher of English as a second language, he teaches part time. After a family member was diagnosed with Crohn's disease some years ago, David began supporting CCA.



**Greg Moore**  
Director

## **Chair - Scientific, Medical and Quality of Care Advisory Committee**

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

# Board of Directors (cont)



**Daniel Teller OAM**  
Director

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).

He became a Director of both the Group's businesses (Teller Automotive Group & Harlea Properties) and now focuses on the family's long-term property investments.

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

Daniel was a launch participant in the City of Port Phillip's Growing Affordable Housing In My Backyard, was involved with the New Directions for Social Housing – Innovation Round Table Panel, and has been a member of the Community Housing Federation of Victoria.



**Sally Stockbridge**  
Director

Dr Sally Stockbridge has had an extensive career in free to air TV, and film and television compliance. She is an expert in the areas of regulation and classification with media policy and broadcast industry knowledge, and is the Network Classification Manager at Network Ten.

She is a published author in the area of communications and broadcast policy and has served on specialist committees and industry bodies including five years with the former Commonwealth Film Censorship Board.

Sally is a former University lecturer with a PhD in Media Communications. She has a deep interest in politics and in promoting diversity and inclusivity, and is also on the Board of the Sutherland Shire Environment Centre.

Sally has lived with ulcerative colitis her entire adult life.



**James Oliver**  
Director, Treasurer

## Chair - Finance, Audit and Risk Committee

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 that 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.



**Julie Weldon**  
Director

## Chair - Communications and Fundraising Committee

Julie Weldon has worked in corporate communication in both Australia and the UK for nearly 25 years, and has lived with Crohn's disease since 1994.

She is the Managing Director of JAW Communications, a consultancy she founded in 2011, which works across a wide range of industries and sectors, including government, corporates, small businesses and not-for-profit groups.

Julie was previously a director of the International Association of Business Communicators (Victoria), and served on several of IABC's international task-forces and committees.

# Board Advisory Committees

## Scientific, Medical and Quality of Care Advisory Committee

### Associate Professor Greg Moore (Chair)

Professor Paul Pavli  
Professor Jane Andrews  
Stephanie Buckton  
Dr Fergus Gardiner  
Alexandra Sechi  
Associate Professor Leanne Raven  
Dr Emma Halmos  
Dr Simon Knowles  
Dr Ed Giles

## Governance, Nominations and Remuneration Committee

### David Reckenberg (Chair)

Bruce Rosengarten  
Julie Weldon

## Finance, Audit and Risk Committee

### James Oliver (Chair)

Bruce Rosengarten  
Julie Weldon  
David Reckenberg

## Fundraising and Communications Committee

### Julie Weldon (Chair)

Bruce Rosengarten  
Sue Beecher  
Lachlan Pike

# Our Valued 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 those listed below for making a positive difference to those living with inflammatory bowel disease during the 2019 calendar year.**

## General Donations

**\$30,000** Mandy & Ted Yencken, The Eva & Les Erdi Humanitarian Charitable Foundation

**\$5,000 - \$9,999** Worrells Solvency and Forensics Accountants (Sydney), The Jackson Foundation, P & H Butts, Eirene Lucas Foundation

**\$2,000 - \$4,999** K Sandison, G Board, D Reckenberg, S Hillebrand-Roellgen, J Mandel, D Birner, A Maple-Brown

**\$1,000 - \$1,999** S O'Dea, E Tan, A Newman, J Bolderas, P Goldsmith, J Harding, A Kingsford-Smith, K Rogers, P Knight, I Habib, N Barrow, M Bartholomaeus, M McPherson, J Watson, B Thomas, C Azzopardi

**\$200 - \$999** C Cutche, A Etheron, E Leske, J Urquhart, C Azzopardi, C Fransen, D Greenwood, R Legoe, T Linehan, D & K Rechtman, R Tiberi, D Dadon, L Daly, L Walker, B Gray, A Weeks, M Griffin, V Anich, N Barrow, B Bell, G Board, A Bortollon, A Dawson, J Fenton, S Field, P Garwood, M Gibson, S Horler, P Humphreys, R Johnston, C Lehmann, A Lord, S McDonald, J Neldner, P Re, D Royal, A Saraceni, J Thompson, J Voigt, M Watkins, P Zantis, J Andrews, A Baud, B Boyd, M Boyd, E Bray, C Cook, D Cooper, K Costanzo, M Ellis, S Gerrans, N Giles, S Hayward, J Jones, A Junor, P King, J Lax, L Maughan, L McNally, A McWhirter, D Petrie, M Sharp, S Sutton, K Toirkens, C Tonner, N Towns, P Walker, T Whitney, J Zeinstra, Ahrens Group Pty Ltd, V Allen, J Bonivento, J Chan, M Clarke, F Corsetti, H Day, P Fredericks, B Gommers, D Green, G Gunn, B Hayllar, A Kenna, J King, S Klineberg, M Lawless, P Maguire, N McVicar, M Melville, K & D Muckert, A Patane, T Pick, C Poidevin, K Rich, N Schot, M Walker, J Weldon, P Wilson, D Carlisle, M Harrison, A McWhirter, G & M Ryan, B Whitlock, Flight Centre Foundation, N Kruger, M Powell, T Rynne, R Brierley, S Field, E Camarri, Diversified Communications Australia, P McKelvey, L Potok, J Quist, J Pooley, C & P Palan, M Fernyhough, T Pick, D Denham, C Duff, C Vass

## Community Fundraising

**\$5,000 - \$9,999** Order of the Eastern Star - Tamar Chapter No. 178

**\$2,000 - \$4,999** Trevor & Shirley Young, Anthony Concannon, Microba, Farnsworth Investor Relations, Entertainment Publications of Australia

**\$1,000 - \$1,999** Blue Illusion, M Hudson, Social Activities Club - University of Canberra, C Mills, Australian Communities Foundation, G Ball, D Coen, B Kohn, P O'Brien, W Pike, D Caruso, M Riddler

**\$200 - \$999** Cooranga North QCWA, CWA Bendigo Northern Group, Department of Education Queensland, Grill'd Pty Ltd, Gumeracha Medieval Fair Inc, Jinghli Valley QCWA, Landsdale Rose Gardens, W Leeder, A Mander-Jones, QCWA Forrest Branch, QCWA Maleny Branch, Quay Australia, I Roach, Roberts Real Estate, The Posy Story, K Threlfall, J Brinzi, M & C Burcher, R Camard, D Chamberlain, J Darrell, P Douroudis, T Enosa, L Escombe, R George, M Gregory, J Harris, J Hattan, E Imad, Y ShenKhor, T Lai, J Lees, J Lloyd, J Mast, B McAuliffe, H Saab, M & V Samaha, D Sande, D Somerville, S Spiro, Suncorp Group, C & H Thomas, A Worland, J Yousseph, AbbVie Pty Ltd, M Alexander, L Allan, J Allen, A Bailey, A Beacom, S Benjiman, D Bereth, A Biffen, J Billinghamurst, D Breen, S Brilley, J Brinzi, P & T Burgess, E Butcher, R Cargill, D Concannon, C Concannon, J Connell, A-M Convery, N Cope, A & D Cowlshaw, T Crawley, N De Cure, S Debeen, M Dening, N Drake-Brockman, M Edwards, Sheed Electrical, P Fearnside, N Foo, R Gagliardi, C Gardiner, A Giacon, T Gillham, S Ginnivan, L & E Godhino, A Goldstein, A Gray, P Hadlow, J Harrison, G Henwood, J Herbet, A Herberyt, S Hope, S Hughes, G Jacobson, S Kay, J Kiely, I Kiely, KMFC, R Lee, P Little, D Lustig, G Lynch, A Maple-Brown, G Martin, S McKnight, J Menzies, A Miles, H Mitchell, K Munce, C Muprhy, S Ortenburg-Light, N Patterson, K Penn, T Price, L Reimers, H Rendevski, W & J Richardson, M Ristic, L Rowe, A Rubin, P Sewrathan, R Sharpless, K Silvia, S & T Sinclair, S Sowter, A Spaulding, K & W Sweet, M Taylor, P & E Taylor, K Toirkens, J Troc, B Trollope, C & A Vass, S Vescio, P Watson, C Young, D Zehner, S Beslic, M Carmona, E Dellis, J Donohoe, L Fahad, M Griffiths, K Hunt, R Kilpatrick, K Leggat, R Owston, G Prentice, M Verdi, H Verdi

## Donations to Research

**\$25,000** Mandy & Ted Yencken

**\$10,000** C Redman, M & R Winter

**\$5,000 - \$9,999** J Blackford, J Ernst, S Trevor, K Formosa

**\$2,000 - \$4,999** S Conroy, Z Fisher, B Hughes, M Hughes, B Pike, D Birner, N Sonenberg, C Busby, A See

**\$1,000 - \$1,999** E Hatzimanolis, C Thorne, P Crupi, D Gluskie, Lions Club of Morayfield & Dist Inc., D McDermid, J Neill, H M Chew, B Green, C Martin, J Watson

**\$200 - \$999** K Coulson, K Crowe, J Dalton, M Donnelly, P Gordon, C Lloyd, B Purbrick, J Shaw, A Stewart, W Viles, V Antulov, B Backer, K Bedford, L Bowler, C Brodie, E Cremonini, G Culvenor, D Denham, M & L Dumbleton, M Ebb, P Farnan, P Forder, K Gallus, L Gatfield, R Giuliano, D Green, O Grobtuch, M Jarvie, A Jones, B Kelleher, H Koustas, K Lu, W McCrae, D Minns, J Morris, N Nosow, L Potok, N Rogers, N Spitzer, M Sutton, B Thomas, G Webster, W Wise, C Azzopardi, S Chharbra, Country Womens Association of Victoria Inc - Tongala Branch, Double Scotch Pastoral Co, J Forrest, P Gaudry, C Herring, A Hingston, F Jagger, J Knapp, J Kooloos, M Kousins, J & J May, P Meadows, R Moulden, K Osborne, J Page, H Pedretti, QCWA Nebo/Sarina Range Branch, P Re, D & K Rechtman, R Scott, N Spitzer, M Underwood, B Zahra

## Bequests

The Estate of Mrs Esther Alma Larsen  
Pethard Tarax Charitable Trust

## In Memoriam

C Brain, D A Wennerbom, G Dutton, H Millar, H Pavli, J Gilmour, J Smith, L Rooke, M Cox, N Phillips, S Matthews, W Pilley

## In Celebration

A Friedland's Birthday

# Our Valued Partners



Australian Government  
Department of Health

