



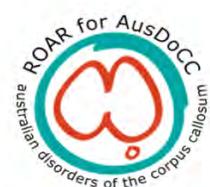
## AUSDOCC INC. ANNUAL REPORT

**July 1, 2020 to June 30, 2021**



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AusDoCC – ROAR for Recognition, Opportunities, Access & Resources



## Table of Contents

<b>Introduction .....</b>	<b>3</b>
AusDoCC Vision.....	3
AusDoCC Mission .....	3
Our History.....	3
Association Name.....	4
Our Purpose .....	4
<b>SECTION 1: AN OVERVIEW OF AusDoCC Inc .....</b>	<b>5</b>
<b>About AusDoCC Inc .....</b>	<b>5</b>
.....	5
.....	5
Social Circles of AusDoCC.....	6
<b>Our People .....</b>	<b>7</b>
<b>AusDoCC Committee of Management 2020/21 .....</b>	<b>8</b>
General AusDoCC Operations .....	8
Meet the Committee .....	9
2021 Committee Role Reports.....	9
Evolution of Edna The Fat Tailed Dunnart.....	15
The Big Reveal.....	16
Edna, Edna is a star. S. T. A. R. .....	18
<b>AusDoCC Community Feedback.....</b>	<b>19</b>
AusDoCC Online Info Day Outcomes Report .....	19
2020/2021 Testimonials .....	22
.....	22
<b>SECTION 2: GOVERNANCE.....</b>	<b>23</b>
<b>Management Structure and Activities.....</b>	<b>23</b>
President's Report - Kristina Coburn.....	23
Strategic Plan .....	26
<b>Activities Completed for 2020/2021 .....</b>	<b>27</b>
Brisbane Family fun Day .....	28
WedChats and SatChats via Zoom .....	29
Awareness Day 2020.....	30
CCD Research .....	31
Connecting Through Social Media .....	33
My People 2021 .....	34
AQUA – Asking Questions, Understanding Answers.....	37
<b>SECTION 3: OUR FINANCES.....</b>	<b>38</b>
<b>AusDoCC Inc Financial Report 2020-2021 .....</b>	<b>38</b>
A Word from the Treasurer .....	38
Balance Sheet.....	40
Profit and Loss Statement.....	41
General Ledger: Summary .....	42
Independent Auditor Report .....	43
Auditor's Independence Declaration .....	46
Schedule 1, Regulation 15 Declaration .....	47
<b>Financial Supporters .....</b>	<b>48</b>

<b>SECTION 4: OTHER IMPORTANT INFORMATION .....</b>	<b>49</b>
<b>Associates and Organisations .....</b>	<b>49</b>
<b>How You Can Help .....</b>	<b>50</b>
<b>CONTACT US.....</b>	<b>50</b>

## Introduction

### AusDoCC Vision

Recognition, Opportunities, Access and Resources (ROAR) for all people with a corpus callosum disorder (CCD).

### AusDoCC Mission

To support individuals, families and caregivers affected by a corpus callosum disorder (CCD).

To influence health professionals, communities, service providers, educators and governments to achieve our vision

### Our History

AusDoCC began from humble beginnings when a group of mums from around Australia attended an online meeting in April 2012 and formed a fledgling organisation. Over the years the committee diversity has grown to include dads, partners, friends and adults with corpus callosum disorder (CCD).

Our aims were clear. We all wanted better recognition for everyone affected by a CCD and their families. We all wanted the professionals to know more about CCDs. We wanted to connect all these isolated groups and have them communicate with and learn from one another. We wanted to make ‘corpus callosum’ a household word.

With social media, a website, professional advisors, conferences, information days, newsletters, connecting globally with similar groups and the scientists and with sheer passion and determination we are achieving all of that and more. Our foundations were strong and we continue to build on them.

We want our organisation to reach more people and have the impact that is needed. As we grow, we are becoming more professional but we will always be guided by our humble beginnings and never lose sight of our original reason for being. We began by advocating, uniting and supporting and we continue by adding some volume. At AusDoCC we **ROAR** for **R**ecognition, **O**pportunities, **A**ccess and **R**esources.

### **Association Name**

AUS DOCC Incorporated, also known as Australian Disorders of the Corpus Callosum or

AusDoCC

Incorporations registration number: A0057821R

Australian Business Number: 54 754 767 674

Registered for Deductible Gift Recipient (DGR) status

### **Our Purpose**

To operate AUS DOCC INC as a charitable institution founded to provide support for individuals,families and caregivers affected by a disorder of the corpus callosum (DCC).

Support is offered through connections with individuals, families and caregivers and the general public who are affected by a corpus callosum disorder.

Relief is offered through advocating (raising community awareness, promoting inclusion), educating (broad based information), informing (resources including financial, emotional, therapeutic and socialsupport networks) and connecting those affected by a diagnosis (reducing the impact of isolation experienced with a rare condition).

The provision of broad-based education resources for service providers, including healthcare workers and other organisations, will enable them to appropriately support individuals, families and caregivers affected by a CCD.

Partnerships will be formed with key research organisations, who are completing evidence based, ethically approved research, focusing on CCD. Research includes the completion of data collection and a database of research volunteers. Raising community awareness of CCD will be a focal point. AusDoCC is a registered charitywith the ACNC and displays the logo with pride. The ACNC Registered Charity Tick is reflective of the ACNC's commitment to being a contemporary, friendly and engaging organisation. The bold coloured ribbons on the logo convey support, pride, spirit and unity.



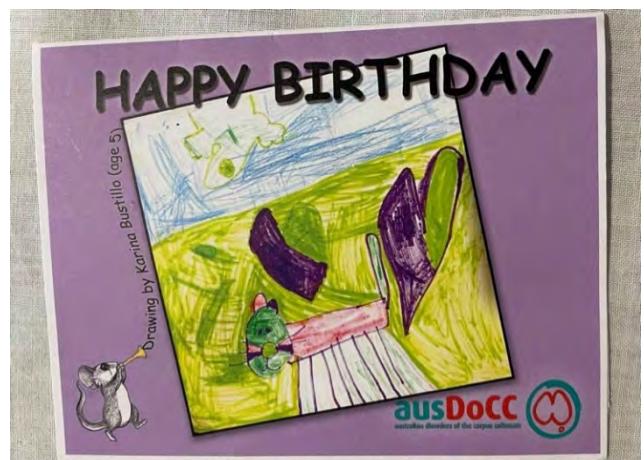
## SECTION 1: AN OVERVIEW OF AusDoCC Inc

### About AusDoCC Inc.

We are a grassroots committee of volunteers who are passionate about supporting and informing everyone affected by a corpus callosum disorder (CCD). That includes adults and kids with a CCD and their families, professionals, friends and the wider local and global community. Our approach to action and evaluation is qualitative and inclusive and we aim to give a voice to both affected individuals and our whole community.

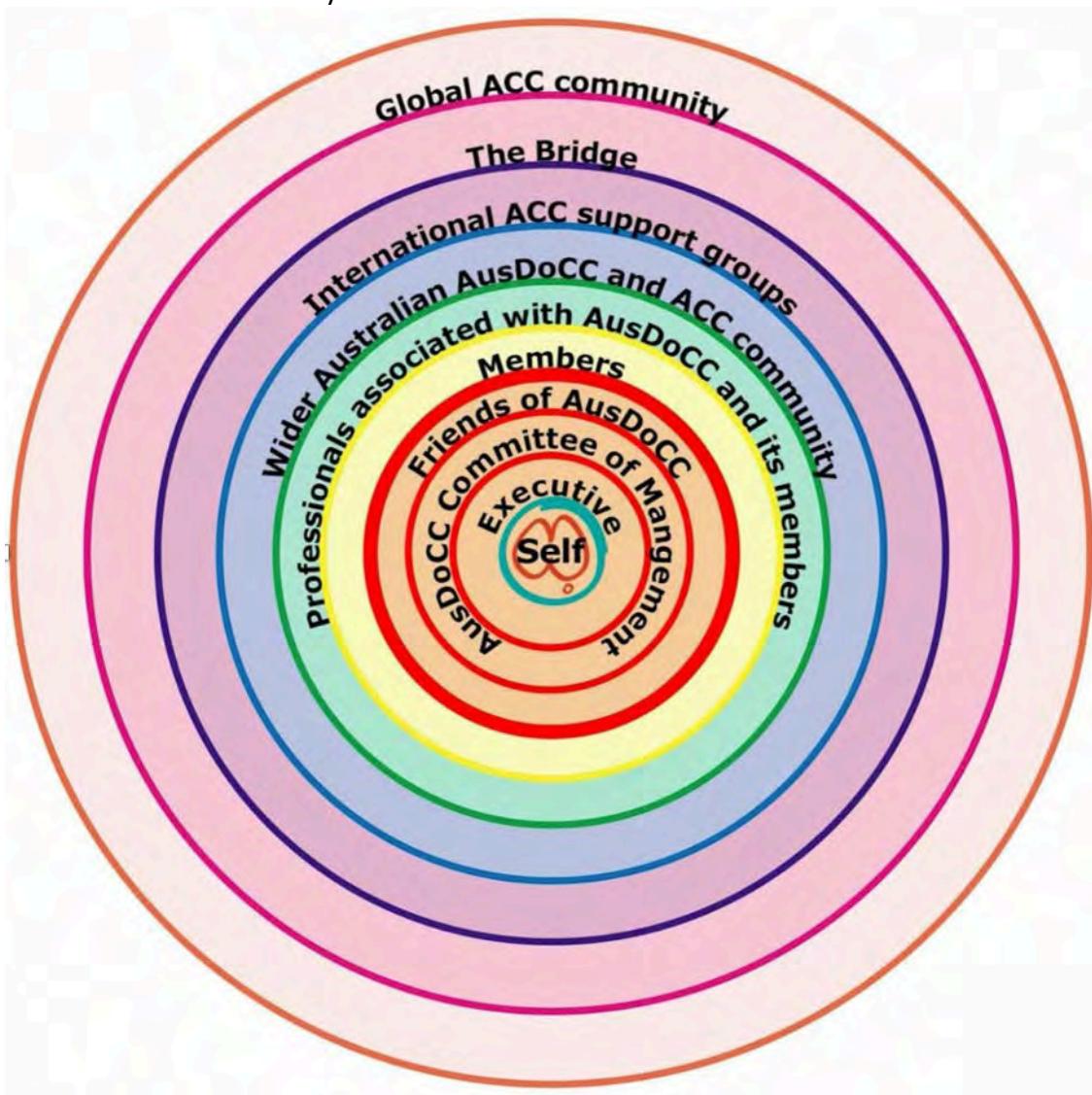
The Committee meets monthly and talks constantly on our Facebook group to 'hatch' plans and projects and work out ways to access money to fund our ideas and those of our members and other supporters. Corpus callosum disorders (CCD) are heterogeneous in cause and presentation, which means there are many causes, many ways they affect people and many different needs for everyone involved. There is very little evidence based information to assist supporting professionals and families, causing longterm, inappropriate management and recognition.

Our quest is to bring about change and **ROAR** for Recognition, Opportunities, Access and Resources.



## Social Circles of AusDoCC

1. Self- the individual
2. Executive - President Secretary Treasurer and Vice President
3. AusDoCC Committee of management - volunteer operating body of 10 ongoing working members with key operational roles and responsibilities (includes 4 adults with acc). Attends monthly meetings.
4. Friends of AusDoCC - fringe volunteer operating body of up to 53 of casual member workers who assist or manage specific projects or once off activities when available or interested.
5. Members - all registered members of AusDoCC Inc.
6. Professionals associated with AusDoCC and its members - IRC5, advisors, other researchers, clinicians and educators
7. Wider Australian AusDoCC and CCD community - includes Facebook members, family friends and supporters
8. International CCD support groups - peak bodies in each country.
9. The Bridge
10. Global CCD community



## Our People

### AusDoCC Patron - Professor Linda Richards AO



Congratulations to Professor Linda Richards AO who has been begun her appointment as head of the Department of Neuroscience and the Edison Professor of Neurobiology at Washington University School of Medicine in St Louis, USA. She will continue to be involved with AusDoCC in her roles. Linda returned to Australia to attend the My People event in June. You can find out more about Linda [here](#)

### Professional Advisors

Name	Position	Active
Professor Linda Richards	Chief Scientific Advisor, Patron	whole year
A/Professor Richard Leventer	Paediatric Neurological Advisor	whole year
A/Professor Simone Mandelstam	Imaging Advisor	whole year
Dr Megan Spencer-Smith	Research Advisor	whole year
Dr Lynn Paul	Psychology Advisor	whole year
Professor Mark Walterfang	Adults with DCC Advisor	whole year
Dr Monica Cooper	Paediatric Advisor	whole year
A/Professor Paul Lockhart	Scientific Advisor - Genetics & laboratory research	whole year
Dr Natasha Alexander	Sexuality & Relationships Advisor	whole year



## AusDoCC Committee of Management 2020/21

Name	Position	Active
Kristina Coburn	President	whole year
Maree Maxfield	Secretary	whole year
Maja Palacios	Treasurer	whole year
Michael Shanahan	Vice President	whole year
Tanya Smith	General Committee Member	whole year
Abbie Kinniburgh	General Committee Member	whole year
Margaret Krutli	General Committee Member	partial year*
Hilary Bustillo	General Committee Member	partial year*
Georgie Lamb	General Committee Member	partial year*
Melo Kalemkeridis	General Committee Member	partial year*

\* partial year – new members at Nov 10, 2020 AGM election

### General AusDoCC Operations

The past twelve months have been severely affected by COVID 19. The global pandemic has restricted travel and face to face activities across the country. The CCD community struggled without the opportunities for personal connections and support. This exacerbated the isolation of our community and highlighted the fact that it is vital that we offer activities where people can gather together in person. Zoom became our method of connecting with one another but it was no substitute for personal connection.

AusDoCC maintains its strong grassroots tradition as an organisation where the majority of the operational planning and implementation is carried out by the Committee of Management members. At the Annual General Meeting (AGM), financial members of AusDoCC elect our committee for a period of 12 months. Members are entitled to a vote at this meeting either by their attendance or by a proxy vote. The online 2020 AGM was held on November 10, 2020.

Committee members are passionate about their individual roles and AusDoCC as a whole. The Executive continues to take leading responsibilities for key events, operations and policy implementation and construction. For the first time in our history the Committee of ten members included four adults with a corpus callosum disorder. This gives strong representation for the community of adults with a CCD who have been typically under-represented and unsupported in society in the past.

The elected Committee members have several ongoing commitments and attend monthly meetings. Individual roles are carried out in our scattered locations across the country with collaboration when possible and as required. The Circles of AusDoCC continues to be our model, allowing for inclusion and diversity. The concentric pattern of circles represents the social and stakeholder communities we embrace and expands from individual to global.

The Bridge is one of our global communities made up of representatives from family support groups. It aims to provide a link between the key global scientists of the [IRC5](#) who research the corpus callosum and the individuals and families who belong to the global support groups. Like the corpus callosum it allows the flow of information and communication to effectively move backwards and forwards. AusDoCC has strong representation on The Bridge and our representative, Maree, is the chair of the committee of 16 countries.

### Meet the Committee

				
Kristina Coburn President Meetups Social Media	Michael Shanahan Vice President Research Liaison Qld Adults with CCD	Maja Palacios Treasurer Graphic Design WA coordinator	Maree Maxfield Secretary Major Events Website	Tanya Smith General Committee Awareness Day Teens Program
				
Abbie Kinniburgh General Committee Newsletter (adults) Vic Adults with CCD	Hilary Bustillo General Committee Qld coordinator Media Officer	Margaret Krutli General Committee SA coordinator Zoom host	Georgie Lamb General Committee Birthday greetings Adults with CCD Awareness of CCD	Melo Kalemkeridis General Committee Pastoral care events Parents Program

### 2021 Committee Role Reports

#### Kristina Coburn - President

I am a mother of 2 sons with a CCD and I'm the current President. My presidential role includes chairing our committee meetings and overseeing the operational side of AusDoCC. I work closely with the secretary, treasurer and vice president.

I am overseeing our social media platforms, screening Facebook members through the AusDoCC Screening profile and maintaining a Facebook database. I reach out to people on Facebook and connect them with other families in Australia and New Zealand.

As Meetups coordinator I oversee the arrangement of meetups and collect the reports and evaluations. In Perth we have had two coffee mornings for the AusDoCC community. We also held a family Meetup day where we introduced our special guest, Edna the Fat Tailed Dunnart, our mascot, in full costume. In Brisbane we held a family fun day and in due to lockdown in Melbourne our planned face to face information day was converted to an online event.

#### **Michael Shanahan - Vice President**

In my role as the research officer, I have maintained an AusDoCC, research-focused social media page and have ongoing conversations about producing content for our community aimed at dispelling misinformation on the internet.

In my role as host of monthly Zoom Chats for adults with a CCD we have seen the growth and success of this new project and the use of different media by our community to connect with one another. New members have had a way of connecting during the COVID19 lockdowns when they would not have otherwise had the opportunity. Friendships have been fostered by these events, by allowing opportunities for social connection.

I have participated and facilitated at the My People Brisbane 2021 event which involved running two sessions and introducing guests. I have also assisted with establishing a Mental Health steering committee and attended planning meetings, in addition to the Teens group sub-committee which has launched its initial Zoom session.

I have taken on the responsibility of coordinating the progress reports for our major Individual Linkages and Capacity Building (ILC) grant funding.

#### **Maja Palacios - Treasurer**

There has been some interesting and exciting work in graphic design this year, with Jocelyn Palacios assisting as a volunteer. AusDoCC Inc.'s mascot, Edna, has actually come alive. We worked closely with designers, Character Costumes and have been waiting for face to face events to become possible so that Edna could be revealed to our community.

We engaged an up and coming film production company in Perth, WA, to produce a short film about Edna's arrival and her Big Reveal when meeting her peers and AusDoCC families at a special WA Cohunu Koala Park event. All the graphics were created and produced by us.

For Awareness Day we simplified the international logo to be more inclusive of our worldwide counterparts. That will be likely to evolve as terminology and new groups arise around the world. We also created some fantastic new memes, a slideshow and some graphics, many of which were shared throughout Australia and the world.

We created graphics for My People in Brisbane, which included World Café graphics, lanyard labels and posters. Karina Bustillo, one of our kids with a CCD, submitted the winning entry for the birthday card competition which we also featured in a new design.

I have provided the necessary documents for grant applications and have worked closely with Executive Committee to ensure that our organisation's licensing and legal obligations were met. I assisted and supported the My People event in Brisbane. Treasury has run fairly smoothly and all operations are up to date. The financial reports have been sent and evaluated by the auditor for 2020/21 and are included in this document.

#### **Maree Maxfield – Secretary**

I am mother to Abbie, 31, who has partial agenesis of the corpus callosum. I am secretary of AusDoCC and have a few additional roles. Like all members of our committee, my roles are carried out in a voluntary capacity.

As secretary I manage the incoming and outgoing correspondence and maintain the membership database and distribution of Welcome Packs to new members. I also do some of the advertising, in conjunction with our graphics guru, Maja and liaise with our team of professional advisors.

With Maja and Jocelyn, I am a 'Ma' in the MaMaJo production crew that produces Edna's activities, supported by the rest of the Committee. One of my jobs in this capacity is to help Edna write her newsletter articles because she is still learning. She's making amazing progress but like many with a corpus callosum disorder (CCD), things sometimes take a little longer.

As website manager, I maintain the website and keep the old one limping along while we are constructing the new one with our IT support person, Andrew. We have found that this is a long and arduous process but when we finish next year, it will be a fabulous one stop place for a wide range of information and resources.

I coordinate our major events such as the national Connections family events and My People event for adults with a CCD. In the past 12 months we have only been able to hold one face-to-face major event which was My People, in Brisbane, in June. With a willing crew from the AusDoCC Committee, it was amazing to connect another group of adults, some of whom had never met another adult with a CCD in their lives. One of the major advances at this conference was the leadership shown by members of the community of adults with a CCD and the increase in peer supported and peer led activities.

Because of COVID19 interrupting our lives, we were fortunate to gain a grant to help the adults maintain connection using the online platform, Zoom. In conjunction with adult community members, we have produced the Chat and AQUA (Asking Questions Understanding Answers) programs. They have been very successful but nothing and I mean nothing, will ever replace the connection our community needs through face-to-face activities. I hope these will begin again very soon, when it becomes safe.

#### **Tanya Smith – Committee member**

In my role during the last financial year, I supported Kristina in our social media platforms by sharing information and creating theme day posts to encourage our members to

engage with one another.

We had a successful Awareness Day, despite our plans being changed due to COVID19. We created memes and shared interesting facts about corpus callosum disorders (CCD).

I co-hosted a Zoom meeting for the parents of children with CCD and also for the teens with a CCD. These were well received by those who attended.

I attended the "My People" event for adults with a CCD, that was held in Brisbane. My role was as support person for a member, to ensure that needs were met and participation in an important event for the adults was achieved. I also facilitated sessions with accompanying carers and provided their first opportunity to compare their lived experiences and support one another. The feedback was very positive.

**Abbie Kinniburgh - Committee member**

AusDoCC adults with a corpus callosum disorder (CCD) representative (Victoria and Australia)

Over the past 12 months, we have managed to adapt our events and the workings of our committee to fit in with the COVID-19 risks and restrictions. We have still been able to provide much needed connection, advocacy and support for adults with a CCD. We have held most of our events online, providing information, peer support and some consistent connection. However, it has been extremely difficult for many adults to attend the online sessions. This is due to the challenges of having a CCD, coupled with the challenges of working the technology and the online set up. Given the cohort we are working with, it is much preferred that we organise and run face to face events as soon as it is safe and possible to do so.

Despite its challenges, we have been able to organise and run monthly information sessions with different professionals. We have held fortnightly zoom chats run *by* adults with a CCD *for* adults with a CCD. We have also held information and training sessions for adults using Zoom. We have been able to provide the opportunities and run successful events online.

We were *extremely* lucky to plan and run a residential face to face event for 17 adults over three days in Brisbane earlier this year. As a representative for adults with a CCD, I helped plan the program, organise and run the event. With high uncertainty whether the event would go ahead and many hurdles along the way due to COVID-19, it was a major accomplishment to pull off, and huge highlight for the adults who could attend.

As part of my role on the AusDoCC committee, I have been putting together a regular item for the AusDoCC newsletter called 'The Meeting Place'. This is a Q&A article from different adults with a CCD. It provides a snapshot of the lives of adults with a CCD.

We have also increased our number of adults with a CCD on our working committee. This means more of us can connect regularly, work on resources and events, and liaise between the committee and the wider community of adults with a CCD. With help from

a mentor and the wider AusDoCC committee, we have been able to keep up the connection in our small but growing community of adults with a CCD.

#### **Georgie Lamb - Committee member**

I am a 41 year old adult with partial agenesis of the corpus callosum (ACC). I enjoy playing my PS4 and watching YouTube puzzle videos and walk-throughs. I also like to challenge myself with complex puzzles.

As a Committee Member, I post birthday messages to adults with a CCD via social media. This is part of the program run by Niki, who sends birthday cards to members of AusDoCC.

I have attended the 2021 My People event in Brisbane and various Zoom Chats and AQUA sessions.

My future plans as a Committee Member are to hold a New South Wales meet up and an Awareness Day stall in my local shopping centre, on July 2, International Corpus Callosum Awareness Day.

#### **Margaret Krutli - Committee member**

This is my first year on the Committee. I joined AusDoCC in June 2018 and experienced my first Connections Conference in Perth in March 2019. My complete ACC was discovered in 1995, at the age of 40. The Perth conference was the first time I had met other adults and families with ACC.

When the COVID lockdowns started, I was asked to host Zoom Chat sessions for adults over 40, with another adult as co-host. Another Committee member hosted a Chat session for the under 50's. The sessions evolved into 2 Chats involving everyone once a month. I was then asked to join the Committee. I met more adults in June this year, when I attended the My People event in Brisbane.

I live in Adelaide, SA and hope to bring the South Australian CCD community together, once we can move more freely.

#### **Hilary Bustillo - Committee member**

As a new member of the committee, I have taken on the roles of Queensland meetup coordinator and media assistant.

This past year has been somewhat challenging with organising face to face meetups. However, we did have a very successful family fun day in March 2020, at a local pool centre with several Brisbane families. In my role as medical officer, I was also involved with the Brisbane "My People" event held in June, in which adults with a CCD travelled to Brisbane and connected with peers.

As media assistant, I have been in contact with the NDIS and had a social media story shared in their platform for Corpus Callosum Awareness Day, and been involved with the International Day for People with People with Disability project.

### Melo Kalemkeridis - Committee member

Melo re-joined the AusDoCC Committee at the last election and was welcomed back. Melo attended the My People conference in Brisbane as a pastoral care officer and was instrumental in supporting the group and individual adults as the need arose.

Melo also introduced some new parenting concepts and options for AusDoCC to consider in the future when we hold online parent forums and training.

Unfortunately, due to pressing personal commitments Melo could not continue for the full term. We thank him for his contribution.

**Congratulations** to the winners of the competition to design the next birthday card - Andie McAuliffe and Tahlia Raftery. Both received a cuddly Edna and AusDoCC cap. Their designs will feature on the new round of birthday cards.



## **Evolution of Edna The Fat Tailed Dunnart**

After reading that the American opossum has no corpus callosum the search began for a similar Australian native animal. The search revealed that all marsupials have no corpus callosum. A conversation with QBI researcher, Tim Edwards, identified the fat tailed dunnart as 'one of their favourites.' So began the search to find someone who would make us a toy one. Eventually we located Jozzies and the first prototype arrived. She had a little name tag with Edna on it and so 'Edna' became our mascot.

After an extensive photo shoot with her on her travels to AusDoCC, she was adopted by everyone and much loved. Not long after that several of her cousins arrived and began to be adopted out to families who had a child or an adult with a corpus callosum disorder (CCD).

Edna has become quite a celebrity and features widely on all resource material. In 2020, a larger-than-life Edna arrived at AusDoCC Central in a huge box. Currently she is making the best of lockdown to write her book and pose for photos and artist impressions when allowed. Edna has become very much part of AusDoCC and is a friend to all. The next exciting stage of her journey follows.



## The Big Reveal

During the past 12 months, our much loved mascot, Edna the fat tailed dunnart, has evolved from that gorgeous custom made soft toy to a human sized mascot.

It's an interesting fact that our Advisor, Professor Linda Richards and her Australian and US team, study fat tailed dunnarts because marsupials are born without a corpus callosum. That made her a great choice.

The Edna designs and tales are produced by MaMaJo Productions. With the amazing illustrations created by our talented volunteer artist, Jocelyn Palacios (Jo), we have been able to create many Edna graphics and items for our community to enjoy over the years. Edna has become an important tool in helping to promote awareness and also in creating peer support for children, adults and families impacted by corpus callosum disorders (CCDs). Edna writes a regular column in the AusDoCC newsletter and features on our cards, programs, website, posters and more.

In 2019, Committee Member, Tanya, introduced the concept of a human sized Edna mascot. Tanya and the MaMaJo team worked closely with Character Costumes, based in NSW, to create a mascot made to our exact specifications. It was a very exciting project.

AusDoCC Inc. had planned to introduce Edna on the 2020, July 2, Awareness Day. Unfortunately, due to the unexpected impacts of COVID 19 we postponed the 2020 release to enable a face to face event in 2021. We were lucky to have a change of circumstances with our funding guidelines, which allowed our Edna mascot project to be funded under the Australian Government's Information Linkages and Capacity Building program. That gave us another year to prepare the surprise arrival of Edna. Many Australian states were still not able to hold face to face events due to COVID19, so we decided that a film of 'the big reveal' would allow the best reach.

We engaged an up and coming film production company in Perth WA called Airborne Apes. They were a group of students and TAFE graduates who very enthusiastically assisted Maja to produce a small film about Edna's arrival. That led to her 'Big Reveal' where she was the special mystery guest at an AusDoCC Meetup held at Cohunu Koala Park in WA. Edna met her peers and AusDoCC families. Members were invited to attend the event and feature in a unique film. It was a hugely successful event. The film was completed in June 2020 ready for release on our 2021 Awareness Day.





## **Edna, Edna is a star. S. T. A. R.**

Edna is a movie star. Yes she is. Edna. I'm the star. It's me!

For Awareness Day on July 2, we made movie about me. Yes, Me!

Awareness Day is on the middle day of the year. It is like the corpus callosum in the middle of the brain.

I had to fly in a big plane from Melbourne to Perth.

I was very good at social distancing and wearing my mask.

I was in quarantine for 2 weeks. That was soooooo boring.

Then I went to a koala park and met lots of AusDoCC people.

It was sooooo fun. I got lots of hugs.

I wonder if I will win an Oscar?

Stay safe my AusDoCC family.

## **Love from Edna.**

p.s. Click [here](#) to watch my movie.



## AusDoCC Community Feedback

### AusDoCC Online Info Day Outcomes Report

**Summary:** On August 23, 2020, AusDoCC held their first online information session. The event was held online, via Zoom after the cancellation of all face to face events due to COVID19. The event ran for 2.5 hours, with a total of five speakers, each allocated a 30 minute slot for the presentation and questions. Questions were invited through the 'chat' function and a host read these out during question time. Registration and communication with attendees were maintained through Eventbrite. Attendees were sent the requested slides and links after the presentation.

**Hosts:** Pieta Shakes and Michael Shanahan

**Speakers:** Dr Lynn Paul, Dr Megan Spencer-Smith, A/Prof Paul Lockhart, Louise Di Pietro and Clare Keogh

Attendees:

Adult with a DCC	6
Adolescent with a DCC	1
Family member or carer of a person with a DCC	26
Therapist or health professional	11
Other/ prefer not to say	6
Total	50

#### What worked well:

The platforms Eventbrite, Zoom and Survey Monkey used for the registration, session and feedback. All worked well. The event was advertised in the Facebook groups, AusDoCC newsletter and the Facebook page closer to the event. Timely reminders were set up to automatically send through to attendees. Having two hosts was beneficial.

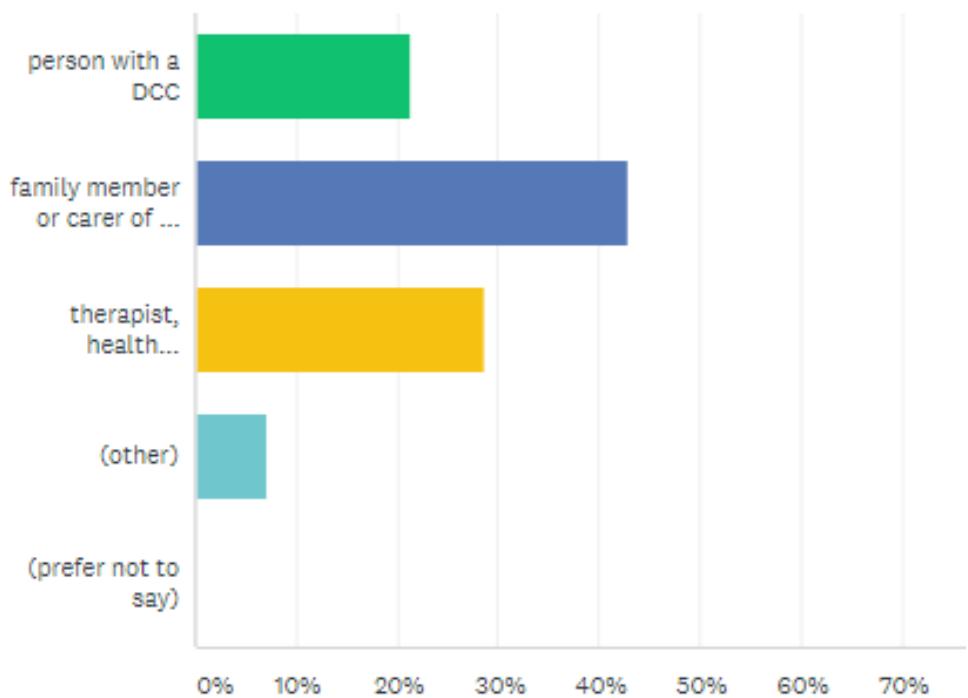
#### What could be improved:

Wider advertising of the event, such as Twitter or through other networks such as GSNV may be beneficial. One speaker had difficulty sharing her screen, while this was solved pre-event, as she had a PDF presentation with the notes on it, rather than separate, she found it difficult to show the presentation and hide her notes. Having the feedback survey available for the end of the session and a link may have encouraged more people to complete it. Breaks would be helpful, and while the host had an initial welcome screen, this was changed quickly to the first speaker's slides therefore the welcome message was lost.

#### Attendee feedback:

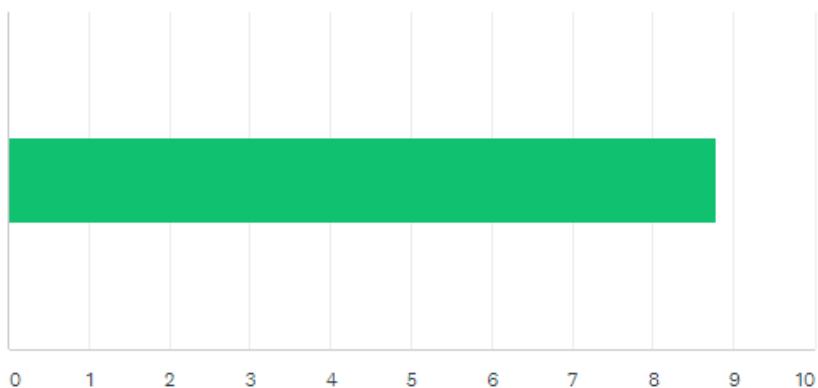
An online survey link via survey monkey was sent to the registration email for all attendees. The five question survey was completed by 14 participants and no incomplete responses were received.

1/ You are a: (select all that apply)



2.What rating would you give the event, on a scale of 1 to 10? (1 being the worst, 10 being the best) (Select number)

Answered: 14 Skipped: 0



3. What did you like most about the event? (Open text box)

Most of the participants commented that their highlight was Clare's lived experience/OT presentation or hearing from Dr Lynn Paul, both offered daily living information and strategies of which participants appeared to highly value. A few other comments spoke of the ease of access to the session, the variety of speakers and the relevance of topics.

4. What did you like least about the event? (Open text box)

The genetics and “science” sessions were described as difficult to understand, some people found them interesting despite being “over my head”, while one participant said they found the genetics sessions boring. Several people commented that there was

“nothing” for this question suggesting a positive response to the session. Other infrequent comments noted that the question time felt rushed, and one person shared their preference for DCC to be considered within the neurodiversity paradigm as a difference opposed to using the language of malformation.

##### 5. How could we improve the online information session next time? (Open text box)

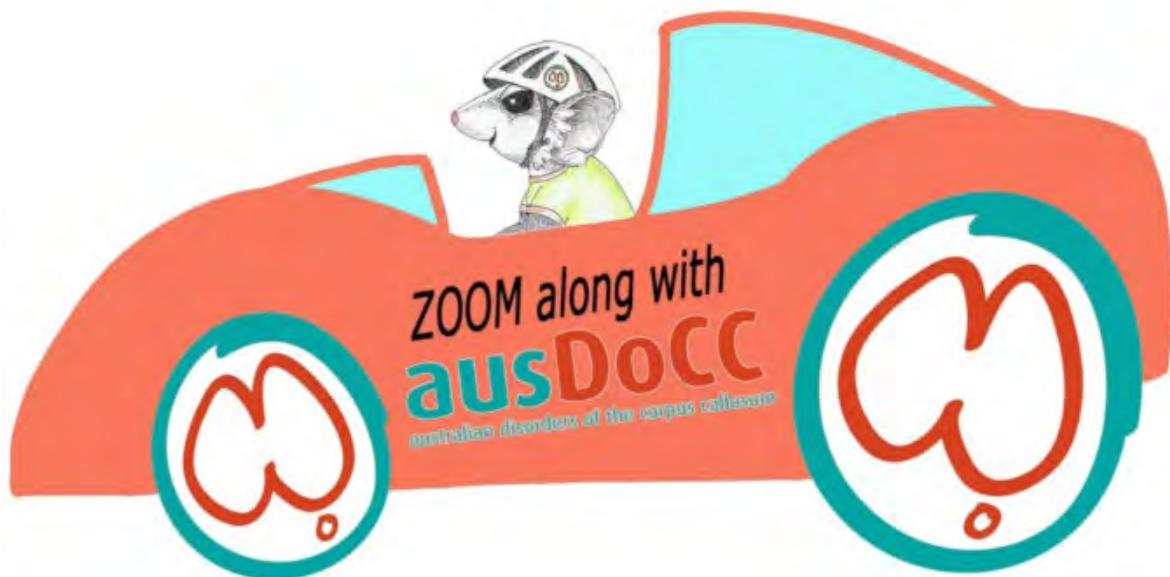
The most common response received was a suggestion to add breaks into the program. There was a strong interest in more lived experience or day-to-day aspects of DCCs and strategies to support a person with a DCC. There was support for the event being online, although one participant reported difficulty hearing the speakers. One participant recommended seeking a wider audience and one suggested the event was too long.

#### Conclusion

Information days provide an opportunity to get together and learn about disorders of the corpus callosum, the basics and any updates in the research. After having to cancel all the face-to-face events this year, the committee decided to venture into the online world and hold the first Online Information Session.

A big thank you to all involved and a special thank you to the attendees who completed the feedback survey. Your responses help the volunteer committee understand the things you would like to hear more of and how we should go about things. Many of you asked for more lived experience presentations and strategies for managing day-to-day life with ACC after finding Clare’s talk so meaningful. Your feedback is valued and yes, we will add breaks into the next online event!

We hope to Zoom along with you soon.



## 2020/2021 Testimonials

Dear Lisa

Would you kindly convey to Maree Maxfield and her team for convening a most successful convention WELCOME to "My People" held recently. From the short time I was able to be with you, I know it must have been a wonderful experience for family members to hear an exceptional team of experts lead by Professor Linda Richards. In the name of BICARE (Brain Injured Children's Aftercare Recovery Endeavours) I am privileged to be a small part of the support team of

AusDoCC. I was also touched by Linda's acknowledgement of BICARE and quite overwhelmed by the gift of a most beautiful cyclamen at the close of the day's activity. Sincere thanks and all good wishes for the future of AusDoCC  
Dorothy Stringer OAM

Very welcoming group. Great connecting to obtain information. Thanks!

Absolutely lovely catch up with AusDoCC families.

The best feeling in the whole world is getting together with my tribe.

Just a perfect time spent with everyone

I just wanted to thank and congratulate you for the "My People" gathering. You and the committee must have put such a huge effort into it.

It was such a positive experience for [name], she had a wonderful time. From the time she met [names] in the taxi she seemed to open up. I feel sure she has grown in confidence as a result of her time in Brisbane. It's also great that she now has a group of friends on Facebook So well done everyone! As far as [name] and myself are concerned it was a great success

## **SECTION 2: GOVERNANCE**

### **Management Structure and Activities**

AusDoCC is governed by a Committee of Management which currently has 10 members. It includes four office bearers and six general members. Each Committee member has one or more roles role of responsibility.

AusDoCC Inc is registered with the Australian Charities and Not-for-profits Commission (ACNC).

We operate under our Own Rules which are predominantly those supplied by our Incorporations body, Victorian Consumer Affairs, in compliance with the Incorporations Act 2012.

We have created our own Policy and Procedures manual which includes a members' code of conduct with descriptions of expected behaviours and underlying values. This is a living document that is updated regularly.

All Committee members and volunteers are required to sign a Statement of Undertaking when volunteering for AusDoCC.

#### **President's Report - Kristina Coburn**

In November we held our Annual General Meeting where we elected a new committee. I was pleased to be elected President again and we have Maree as Secretary, Michael as Vice President, Maja as Treasurer and our general committee members Abbie, Tanya, Melo, Hilary, Georgie and Margaret. We farewelled Niki Harrison, Anna Uther, John Jonker and Pieta Harris and thanked them for volunteering their time to AusDoCC. Margie Slater kindly continued as our newsletter editor and Niki Harrison with our birthday card program, Birthday Bonanza.

Generally, after an AGM the new committee would meet in Melbourne for a face to face gathering but for the second year running we were once again affected by COVID19. With COVID19 dictating the way we operated we knew we would need to quickly adapt and change. The Executive Committee members worked on peer support guidelines that would better accommodate our incoming committee. Our new committee members were introduced over Zoom where each was given a formal induction with a step by step guide to follow. We applied a new method of giving information to our peers through a mentoring system, where each new committee member was paired up with an executive committee member. This was the first time in the history of AusDoCC that 40% of the new committee had a CCD.

Our organisation relies heavily on donations and grants. I'm pleased to say that due to COVID19, we were successful in our request for extensions on most of our current grants.

Although meet ups were still not permitted in many states, we were able to keep in touch with our members through social media. Members were also well informed though eNews and the website. Our quarterly newsletter, AusDoCC Connects, is sent to over 350 members. We have a very informative website with a lot of information and resources to help individuals with a CCD, parents, carers, educators and health care professionals.

As web based platforms became necessary most things were done over Zoom. We created a set of Zoom guidelines and etiquette and held trainings in hosting and “How to Successfully Zoom.” Trainings also covered peer support and leadership. Zoom Along with AusDoCC was created as an umbrella term to cover our new Zoom programs. Programs such as Zoom Chats and AQUA were programs designed to enable isolated adults to connect. The adults with a CCD held regular Zoom chats with their peers and spin off teen and parent Zooms have also begun.

AQUA (Asking Questions, Understanding Answers) is another successful recently created Zoom program. AQUA sessions are facilitated chats where a professional clinician provides information about a topic, followed by a ‘question and answer’ session with the opportunity of pre-registered and live questions. These sessions are currently for adults with a CCD. However, we are hoping to extend these to parents/families and teens with a CCD.

Our Melbourne based Information Day had to be changed to an online forum due to COVID19 restrictions. It was a huge success, with many of our AusDoCC advisors taking part and offering their expertise in their given area. It also featured one of the adults with a CCD who gave a presentation about paediatric occupational therapy .

On July 2, 2020, our International Awareness Day was extremely successfully. We released professionally edited, videos from our 2017 conference and featured national television media releases featuring some of our children and adults with a CCD. All of these are available on our popular YouTube channel, [AusDoCC Videos](#).

Facebook is a major part of AusDoCC. We are able to reach families and stay connected with our community. We have two Facebook groups and two Facebook pages. Our main Facebook group has grown to over 700 people and we now have over 2000 likes on our Facebook page, which is not bad for a rare brain condition. We encourage families and individuals to become registered, financial members of AusDoCC. An AusDoCC membership is a once off payment of \$20 per person. Members have extra benefits, as well as assisting us to support families with a CCD. This year our 300th member received a special spot prize.

Our major priority is holding events where individuals and families can meet in person. Often at our MeetUps individuals and families are meeting their peers for the first time ever. We find that face to face meetings are invaluable for our CCD community. Having peers to connect with is extremely important at any age. Our large biennial gathering, Connections, allows us to connect our community while giving them valuable, accurate information about corpus callosum disorders. Sadly, this event has been postponed twice

due to COVID19. We did manage to hold a couple of exciting MeetUps and one amazing adults' residential event.

In March we held a family fun day in Brisbane that included swimming, a sausage sizzle and a brief appearance from Federal MP for Bonner, Ross Vasta. During June a family day was held in Perth at Cohunu Koala Park. This is where we introduced our life sized mascot Edna, to the AusDoCC community. Like all marsupials, Edna the Fat Tailed Dunnart happens to be missing her corpus callosum. Filming *Tales of Edna - The Arrival*, took place in the surroundings of the koala park on the day. Both days were a huge success.

After much uncertainty surrounding the My People conference due to COVID 19, we were finally given the 'all clear' to go ahead. Some AusDoCC Committee members, a group of adults with a CCD and some of their carers travelled to Brisbane to participate. The five day event included information sessions, Q & A sessions, socialising and connecting with peers as well as lots of fun and eating, it seems. Some participants stayed on to take part in the ongoing research program at Queensland Brain Institute (QBI).

Moving forward we want to be able to connect with more families through not only our online and social media platforms but face to face events as well. Behind the scenes we will be working on Connections 2023, My People 2022, Committee peer training, giving our website a facelift and expanding our program to welcome new babies with a CCD. We will continue to offer support for individuals and their families with a CCD and we are always contactable via [info@ausdooc.org.au](mailto:info@ausdooc.org.au)

## DRAFT - AUSTRALIAN DISORDERS OF THE CORPUS CALLOSUM STRATEGIC PLAN

Vision		Recognition, Opportunities, Access and Resources for People with Disorders of the Corpus Callosum (DCC)				
Mission	We influence health professionals, communities, service providers, educators and Government to achieve our vision We support families, individuals and care-givers affected by disorders of the corpus callosum					
Our Values		<ul style="list-style-type: none"> <li>- We show respect : We actively listen, promote choice and are empathetic</li> <li>- We show commitment: We act with integrity by doing what we say we will</li> <li>- We are leaders: We act within accountability in a united, cohesive and transparent way</li> <li>- We are inclusive: We accept and value everyone and actively promote opportunities for engagement</li> <li>- We are passionate: We are driven by our vision and focused on delivering our mission</li> </ul>		<b>Our key stakeholders</b> <ul style="list-style-type: none"> <li>• Individuals with a DCC</li> <li>• Members &amp; Families of those with a DCC</li> <li>• Health Professionals &amp; researchers</li> <li>• Educators</li> <li>• Financial supporters</li> <li>• Government and other organisations</li> <li>• Volunteers</li> </ul>		
Strategic Objectives	To communicate	To connect people	To be heard	To educate	To be effective	
What critical actions are we taking to deliver these objectives.	<p>Publish and promote credible and current information regularly</p> <p>Update the website with more resources, research and information</p> <p>Half to full day information seminars in each state</p> <p>Resources to include contributions from all perspectives</p>	<p>Provide national camps and conferences</p> <p>Hold regular meet ups in each state and NZ</p> <p>Ask a professional Skype sessions</p> <p>Provide support for new parents</p> <p>Provide opportunities for adults with DCC to gather independently</p>	<p>Gain greater recognition of ACC by medical practitioners as a primary diagnosis</p> <p>Promote, participate in and support all Australian corpus callosum research</p> <p>Encourage people to visit website, join Facebook groups &amp; distribute brochures</p> <p>Advocate for greater recognition of DCC by health professionals and policy makers</p>	<p>Educate prospective medical professionals at training/academic level</p> <p>Provide the latest research to members.</p> <p>Provide educational resources for teachers and parents</p> <p>Build capacity of health professionals and supporters with tools and information</p>	<p>Maintain a coordinated bank of willing volunteers</p> <p>Actively strengthen the profile of AusDoCC</p> <p>Maintain sustainable and diverse funding streams</p> <p>Develop and deliver annual goals</p> <p>Develop unique items for sale and distribution promoting AusDoCC</p>	
How we will know if we are successful	<p>Feedback from users</p> <p>Increase in membership</p> <p>Interactions/partnerships with other organisations and professionals</p> <p>Online web data</p> <p>Satisfaction expressed in surveys and other evaluation</p> <p>Contributions to newsletter</p>		<p>Attendance at conferences</p> <p>Attendance at meetups</p> <p>Successful grant applications</p> <p>Increase in membership of AusDoCC and online groups</p> <p>Interaction and response on Facebook groups</p> <p>Response of adults to events and activities</p>	<p>Reduced complaints about DCC not being heard and recognised</p> <p>Increased success in accessing NDIS where DCC is primary condition</p> <p>Feedback from members who are receiving appropriate DCC management</p> <p>Evaluation &amp; surveys</p>	<p>Inquiries and requests for information and resources</p> <p>Feedback from users and professionals re AusDoCC resources</p> <p>Website/Facebook traffic</p> <p>More positive feedback from families and individuals with a DCC re consultations and knowledge</p>	<p>Sustained numbers of people willing to help</p> <p>Feedback from members and professionals with increased recognition in schools and medical &amp; therapeutic practices</p> <p>Successful grant acquisition &amp; fundraising.</p> <p>Gaining donors, Stable cashflow</p> <p>Evaluation of goals</p>

## Activities Completed for 2020/2021

- A quarterly newsletter - AusDoCC Connects
- International Corpus Callosum Awareness Day – Memes, [YouTube videos](#) and slideshow
  - Growing the community of adults with a corpus callosum disorder
  - Initial planning for Connections 2021 in Melbourne (postponed to 2023)
  - Drafting a picture story book about Edna
  - Planning coordinated meet ups in each state depending on COVID19 restrictions
  - Competitions for designing new AusDoCC birthday cards
  - Developing our website as a valuable source of information. Engaged an IT support person.
- Completing Top Ten resource sheets & [DCC fact sheet](#) for new member Welcome Packs
- Upgrading computer hardware, software and printing equipment for committee members
- Continuing to liaise closely with [AusDoCC advisors](#).
- Holding an afternoon tea gathering for advisors and other invited guests to meet Committee
  - Planning an [information day](#) for parents and adults with DCC.
  - Face to Face Executive meeting in Melbourne to develop policy and procedures
  - Training volunteer committee members to build skills and effectively grow the organisation
  - Advocating for greater awareness of DCC in health and education policy settings
  - Advocating to government bodies to gain better recognition for DCC, as a key diagnosis
  - Exploring NDIS & meeting Access Managers for greater awareness of DCC and AusDoCC.
- Maintaining a [YouTube channel](#) with AusDoCC videos
- Successfully grants to build individual and organisational capacity and fund conferences
  - Sending birthday cards to everyone with a DCC
  - Increasing international collaboration with the global support groups and science/research community. Leading the global community via The Bridge, designing a logo and building policy
- Team building, leadership and planning activities for Committee members
- Maintaining [Brain Sells shop](#) with AusDoCC merchandise.
- Maintaining social media sites - Facebook groups, Facebook Pages, Instagram and Twitter
  - Maintaining a volunteers group called [Diamonds of AusDoCC](#)
  - Connecting with families and schools by sending resources and [ACC and Me Books](#)
- Evaluations from members about activities, needs and suggestions to improve AusDoCC
- Establishing awareness via a national media in mainstream television and newspaper outlets
- Creating a Zoom platform and presence to connect to all AusDoCC members
- Creating AQUA and Zoom chats to connect parents, and teens and adults with a

CCD, funded by ILC grant

- My People conference in Brisbane
- Creating a movie to introduce life sized Edna
- Birthday card design competition
- Constructing policy for COVID management, Zoom delivery, Committee peer support, and session hosting and updating existing policies and procedures
- Small personalized information cards printed for the adults
- Release of new book, *Agenesis of the Corpus Callosum*, written by Rhonda Booth of Corpal
- Peer support, technology and leadership training for Committee and other AusDoCC community members
- Establishing a Mental Health Working Group
- ROAR for Recognition, Opportunities, Access and Resources

### Brisbane Family fun Day

On the 6<sup>th</sup> March 2021, AusDoCC held a Brisbane family fun day at the Clem Jones Swim Centre in Carina. The event was attended by families and individuals with a CCD, who enjoyed activities including a BBQ lunch, swimming and a waterslide area, face painting and lawn games.

The local Lions Club assisted with the BBQ lunch and the event was also attended by Federal member for Bonner, MP Ross Vasta.

The event was well attended and received positive feedback from AusDoCC attendees.



### **WedChats and SatChats via Zoom**

The Adults with Corpus Callosum Disorders (CCD) have the opportunity to come together, via Zoom, on the 4<sup>th</sup> Wednesday of each month to share our challenges and how we can overcome them.

We talk about our day-to-day living with an invisible disability, as well as our hobbies and our strategies to overcome the difficulties we encounter. Members share activities that make them have a more positive outlook and be more relaxed. They also share their challenges, which other members can give them advice on, as they have experienced similar situations. This gives all members more confidence to deal with their daily living. We've got the time to share our relaxation techniques when we become stressed out in certain situations.

Each month we encourage all members to join our Zoom Chats, especially new members, as they have found their community. We welcome all adults with a CCD, who would like to share their story and get to know other members of the AusDoCC community. We also run SatChats as a social get together and discussion forum on Saturday nights on the 2<sup>nd</sup> Saturday night of each month.

Members look forward to hearing about others' new experiences. These may be new relaxation techniques and activities, new hobbies and recent holidays. They also look forward to discovering and sharing recent and up to date published studies about Corpus Callosum Disorders.

Through these Zoom Chats we have got to know each other very well and formed lasting friendships.

The chats are advertised on the adults Facebook group and known adults with a CCD are notified by mail.

*Let's Chat  
with  
Michael Sharahan*



ROAR for AusDoCC  
Supporting adults with  
disorders of the corpus callosum

**FOR ADULTS WITH DCC, BY ADULTS WITH DCC  
ZOOM CHAT GROUPS 2021  
2ND SATURDAY OF EACH MONTH  
7.30PM  
EVERYONE WELCOME**

Join Michael and other adults with DCC to chat about DCCs, the health and disability systems, advocacy and other things that affect you.

*Let's Chat  
with  
Margaret Krutli*



ROAR for AusDoCC  
Supporting adults with  
disorders of the corpus callosum

**FOR ADULTS WITH DCC, BY ADULTS WITH DCC  
ZOOM CHAT GROUPS 2021  
4TH WEDNESDAY OF EACH MONTH  
7.30PM  
EVERYONE WELCOME**

Join Margaret and other adults with DCC to chat about things that interest you.

## Awareness Day 2020

We had an amazing [Awareness Day 2020](#) despite the COVID restrictions. What a fabulous day we had. The feedback has been awesome and we feel that the corpus callosum is edging ever closer to becoming a household name. We continue to focus on the positives but must not ignore the challenges.

We hope everybody enjoyed the wonderful bombardment of Awareness Day media. We had some excellent mainstream media coverage on national television and in major newspapers. AusDoCC produced fabulous memes and we collected amazing photos to make a slide show. With the assistance of Ellen Carpenter, a NDIA senior media officer, we were fortunate to have national coverage of a very high quality. (Put links) One of the stories about Karina and the Bustillo family became the most successful story ever on the NDIA website with xxx numbers of views.

Our memberships jumped up to over 300 full members and our Facebook sites gained many more members and likes. We discovered new kids and adults with DCC. We didn't know about them but more importantly they didn't know about us. They discovered a whole new community to connect with.

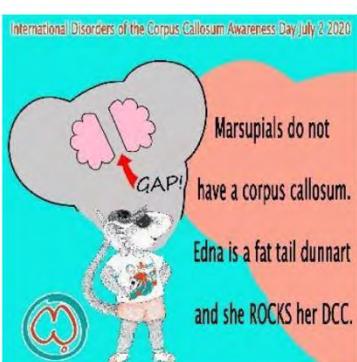
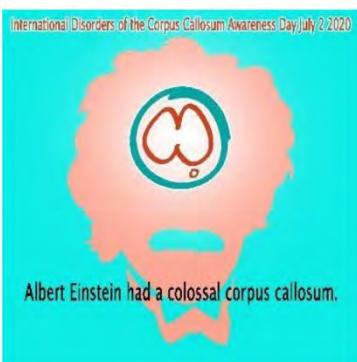
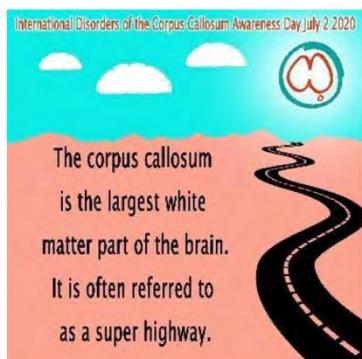
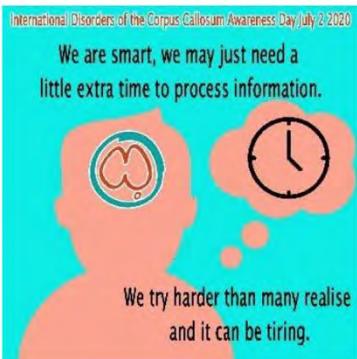
For the month of July we continued to raise awareness for DCC. Funded by our NDIS grant we released new Top 10 tips resources (Top Ten Tuesdays), a series of movies (Movie Mondays) and a slideshow (Saturday) of all the photos from our wonderful community on Awareness Day.

But it doesn't have to end there... One video from a session at the 2017 Connections conference, focused on [raising the profile](#) of corpus callosum disorders. Much progress has been made but we need more. Over the next 3 years, AusdoCC will focus on continuing to do this, particularly to improve access to the NDIS and greater awareness in the community.

Thank you to the wonderful AusDoCC committee and community who continue to amaze us.

See Karina's story [here](#)

See Georgie's story [here](#)



## CCD Research

Corpus Callosum Disorder (CCD) research is essential for the future of our community and a growing area. AusDoCC has supported the CCD community in getting involved in research that will improve the lives of those in the community.

The [University of Queensland](#) has liaised with AusDoCC to reach out to our members to recruit for a study focusing on decision making processes headed by Prof. Linda Richards AO.

Similarly, Maree Maxfield at the University of Melbourne has liaised with AusDoCC for a qualitative [study of quality of life](#) in the adult CCD population.

Pieta Shakes at Southern Cross University is researching maternal experiences of an [in-utero diagnosis](#) of CCD and has connected with AusDoCC to support this.

Dr. Lynn Paul at California Institute of Technology (Caltech) is recruiting parents for interview studies over the course of their [child infancy](#).

All of these studies benefit from having AusDoCC available to connect them with people wanting to engage with the research community, and the CCD community benefits from gaining much needed information about itself from these studies.



## Connecting Through Social Media

Once again social media and the online world were a major form of interaction this year. Now that most people have become more familiar with all things online, communicating has never been easier.

Facebook is a large part of our organisation that keeps our members connected and informed. In total, we have four public profiles - two Facebook groups, the AusDoCC Inc. Facebook page and the AusDoCC research page. Our main Facebook group has grown to over 700 members and we have over 2000 followers on our AusDoCC Facebook page. We also have a group that is just for adults with a CCD and a research focused profile.

Twitter (@AusdoccInc) and Instagram are primarily used for our annual international Corpus Callosum Awareness Day.

Our YouTube channel, 'AusDoCC Videos' has all our latest clips ready to view. You can subscribe

[here](#)

We maintain a Facebook database that helps us to connect our families, parents and adults with a DCC.

Find our groups at the following addresses:

Ausdocc- Australian disorders of the corpus callosum

<https://www.facebook.com/groups/ausdocc/>

Australia and New Zealand ACC Adults

<https://www.facebook.com/groups/355338714574689/?ref=share>

Ausdocc Inc <https://www.facebook.com/AusDoccInc/>

Ausdocc Disorders of the Corpus Callosum Research Findings

<https://www.facebook.com/DCCresearch/>

Ausdocc Twitter (@AusdoccInc) <https://twitter.com/ausdoccinc?s=21>

Ausdocc Instagram [https://instagram.com/ausdocc?utm\\_medium=copy\\_link](https://instagram.com/ausdocc?utm_medium=copy_link)



# CONNECTIONS 2021

Natio  
April 30

POSTPONED

m Symposium  
ell City, Melbourne VIC



Funded by the National Disability Insurance Agency



## My People 2021

There were 17 adults with a corpus callosum disorder (CCD) brought together to meet each other face to face at the Hotel Diana, Woolloongabba. Most states and territories were represented. For some it was their very first conference. It began Thursday afternoon, with an informal meet and greet, before we walked to the Brewhouse for a pub dinner.

Friday morning began with Kieran, a Fitness expert from Science of Fitness, taking us through a series of exercises and breathing techniques to stimulate our brains and relax our bodies. Then we had a session with Samantha Connor, a disability rights activist, who is very knowledgeable about the NDIS and how to manoeuvre through the system. A few adults, who were “too old” for the NDIS, were taken through different aspects of the Aged Care system, to know how to acquire all your entitlements.

Then we had a choice of 4 workshops, where we could be in small groups and ask more personalised questions. Kieran MacGuire spoke about body, brain, health and fitness. Samantha spoke about the challenges with the NDIS. Michael spoke about journaling and how we can use it. Maree spoke about constructing a personal profile to use when we consult professionals.

Friday afternoon we travelled to the Queensland Brain Institute, to meet Professor Linda Richards and her team. Professor Richards gave a summary of the research that is being conducted on adults with a DCC and introduced her team, who spoke about their areas of research they are focused on. After enjoying an afternoon tea and chatting to the team at the QBI, we headed back to the hotel and went to dinner at Boo’s Thai Restaurant. After dinner we had a fun Trivia night at the Hotel, where PJs were optional.

Saturday began with Francesca, from Science of Fitness, who took us through some exercises to kickstart our brains. The morning consisted of 2 sessions. The first was with Natasha Alexander, a psychologist, specialising in relationships and mental health, helping people with intellectual and cognitive disabilities. Then Toby Reinberger, from the University Psychology Department joined us. He is working on how anxiety affects people with a DCC. Toby spoke about managing anxiety and answered questions.

The 4 electives on day 2 consisted of Professor Richards answering questions about research and genetics, Michael speaking on managing our time, Toby speaking about our anxious moments and Natasha giving us advice on relationship difficulties.

After lunch we participated in the World Café, Hosted by Maree. We gathered in small groups, asked and answered big questions, moving around the room, meeting new friends and connecting with old ones, in a café environment. This was productive and very enjoyable. Dinner was a casual affair with take-away fish and chips or Chinese food. Then we had board games hosted by the QBI team.

Sunday morning, we had the opportunity to speak to Natasha and Samantha on an individual basis. Our time was free to do what we wanted. Some of us walked down to

South Bank to enjoy a lovely lunch. We had many choices of bistros with a wide variety of food. Late afternoon we gathered together to board buses to take us to Eagle Pier and board a Riverboat Dinner Cruise and enjoy the lights of Brisbane. It was a beautiful evening, in more ways than one. Getting to know new friends a lot more and enjoying the Brisbane by night with perfect weather.

Late Sunday we gathered together to share how we felt about our experience at the Conference. Some of us expressed how grateful, honoured, thankful and proud we were, with a degree of tiredness. Others, including first-timers, said they had found their tribe, family and new friends. One used the word 'whanau', Māori for extended family. A few older people in the group were delighted and content, meeting friends, both old and new. A few also described being overwhelmed and 'brain blown'. One of us had an 'assistance dog' with them, which made everybody happy and calm.



#### The aims and purposes of the Conference were:

- To form an identity of self and our collective group.
- Empowering ourselves and our group.
- To learn more about each other
- To reduce the isolation, we may feel
- To exchange ideas, aspirations and share challenges.
- To develop independence
- To learn about our expectations of others and their expectations of us.

As a group we also aim to remember the 5 C's  
Connection, Communication, Collaboration, Community, Capacity

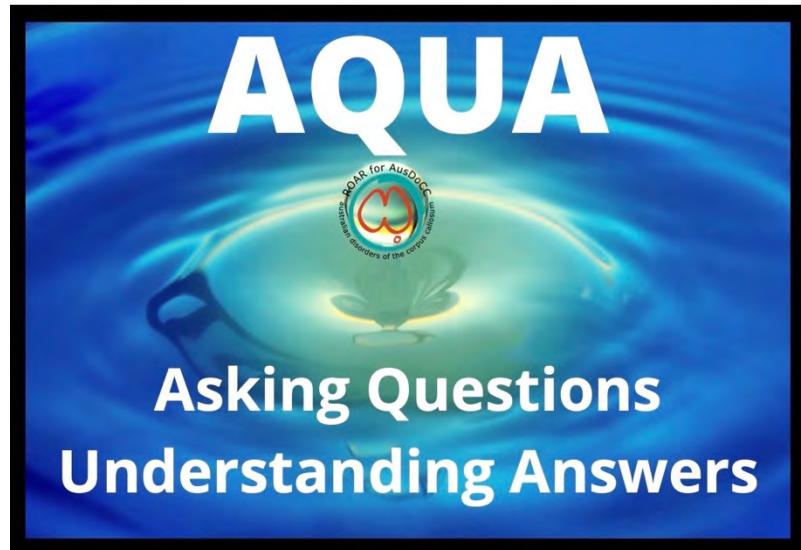


## **AQUA – Asking Questions, Understanding Answers**

Aqua is a program that involves a series of monthly sessions where the Zoom audience can ask questions to a trusted professional. It is up to 60 minutes long and held at different times on different days to include a range of participants.

Firstly, we introduce one of our trusted CCD professionals who describe themselves with a little background and some information about their area of work. Then they answer questions that have been pre-submitted. This is followed by a live question and answer session while time permits.

The first programs involve adults with a CCD but after we have road-tested AQUA and we have people to facilitate more programs, we will expand to other groups such as parents, teens, partners and other family and friends.



## SECTION 3: OUR FINANCES

### AusDoCC Inc Financial Report 2020-2021

#### A Word from the Treasurer

Reported by AusDoCC Treasurer, Maja Palacios

##### Notes:

AusDoCC Inc is a registered, incorporated organisation : A0057821R

AusDoCC Inc receives donations from across Australia and fundraises according to state guidelines.

AusDoCC Inc holds fundraising licenses in WA, VIC, QLD and NSW and completes an independent Audit annually.

AusDoCC Inc is registered by Australian Charities and Non-for-profit Commission as of Jan 7, 2014

All debits from AusDoCC ANZ accounts are authorised by two executives using RSA Security devices.

##### Our finances

For the 2020 to 2021 period AusDoCC Inc. predominantly relied on income from grants. While a small proportion of funds were received from membership fees, merchandise, fundraising and donations, the main income was received from grants. These include:

- National Disability Conference Initiative from the Department of Social Services
- Volunteers Grant from the Department of Social Services
- Individual Capacity Building Grant Round 2019-20 from the Department of Social Services
- NDIS Information Capacity Building 2020-21 from the Department of Social Services

AusDoCC Inc has worked hard during this COVID19 affected year to achieve activities and spending required for these grant conditions.

A very successful peer support focused My People event, focusing on peer support, was held in Brisbane for Adults with a CCD.

Our online Zoom programs AQUA, Wedchat and Satchat have been received well and provided an important connection within the community.

Although most face to face events have been postponed this year, a family MeetUp was held in QLD and a very special MeetUp held in WA to coincide with the filming to reveal AusDoCC's new life sized mascot, Edna the Fat Tailed Dunnart.

The grants have allowed AusDoCC to continue to increase both organisational and

individual capacity. Committee and members have been able to upskill particularly with online forums such as Zoom. A new website is under construction to allow greater reach.

AusDoCC now has access to software subscriptions such as Mail Chimp, Zoom, Survey Monkey, MYOB, Wordpress, Adobe, Photoshop, Office 365 and Eventbrite. These have revolutionised the functioning of AusDoCC Inc in this somewhat online era.

AusDoCC Inc has also been able to support its Volunteer Committee with hardware such as laptops and printers. A small grant from Crown Casino enabled us to purchase some CCD guidance books from our sister UK based group, Corpal, to provide this important source of information to our members.

The committee continually works to streamline and improve operations. Project proposal forms have been introduced for any project and are reviewed and approved at monthly committee meetings. We have also introduced improved recording and evaluation processes to build our organisational capacity.

## Balance Sheet

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**AusDoCC Inc**

10 High St

Seaholme, VIC, 3018

ABN: 54 754 767 674

Email: majapalacios.99@gmail.com

### Balance Sheet [Last Year Analysis]

June 2021

	This Year	Last Year	\$ Difference	% Difference
<b>Assets</b>				
Cash on Hand				
ANZ BUSINESS Account	\$136,340.10	\$127,436.99	\$8,903.11	7.0%
ANZ online Saver Account	\$52,039.81	\$52,013.83	\$25.98	0.0%
PAYPAL ACCOUNT	\$1,963.17	\$1,485.76	\$477.41	32.1%
General Pool Assets	\$15,293.80	\$13,244.80	\$2,049.00	15.5%
Acc Deprn General Pool Assets	-\$15,293.80	-\$13,244.80	-\$2,049.00	(15.5)%
Total Cash on Hand	\$190,343.08	\$180,936.58	\$9,406.50	5.2%
Trade Debtors	\$575.00	\$772.19	-\$197.19	(25.5)%
<b>Total Assets</b>	<b>\$190,918.08</b>	<b>\$181,708.77</b>	<b>\$9,209.31</b>	<b>5.1%</b>
<b>Liabilities</b>				
Current Liabilities				
Unspent grants at end of FY	\$114,270.73	\$112,647.64	\$1,623.09	1.4%
Total Current Liabilities	\$114,270.73	\$112,647.64	\$1,623.09	1.4%
<b>Total Liabilities</b>	<b>\$114,270.73</b>	<b>\$112,647.64</b>	<b>\$1,623.09</b>	<b>1.4%</b>
<b>Net Assets</b>	<b>\$76,647.35</b>	<b>\$69,061.13</b>	<b>\$7,586.22</b>	<b>11.0%</b>
<b>Equity</b>				
Retained Earnings	\$69,061.13	\$70,713.36	-\$1,652.23	(2.3)%
Current Year Earnings	\$7,586.22	-\$1,652.23	\$9,238.45	559.2%
<b>Total Equity</b>	<b>\$76,647.35</b>	<b>\$69,061.13</b>	<b>\$7,586.22</b>	<b>11.0%</b>

This report includes Year-End Adjustments.

Page 1 of 1

## Profit and Loss Statement

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### Profit & Loss Statement

July 2020 To June 2021

**AusDoCC Inc**  
10 High St  
Seaholme, VIC, 3018

ABN: 54 754 767 674  
Email: majapalacios.99@gmail.com

Income	
Membership Fee	\$920.00
Sponsorships	-\$75.00
Grants & Fundings	\$54,135.66
Merchandise	\$886.50
interest earned	\$25.98
Fundraising	\$284.75
Donations	\$4,165.00
Conference	\$957.81
Rebates and Refunds	\$2,514.39
<b>Total Income</b>	<b>\$63,815.09</b>
<b>Gross Profit</b>	<b>\$63,815.09</b>
Expenses	
Administration	
Audit Fees	\$770.00
Computer & Software	\$2,306.33
Depreciation - General Pool	\$2,049.00
Fees & Licenses	\$266.22
Gifts & Marketing	\$500.00
Insurance	\$2,690.00
Office Equipment	\$19.96
Printing Postage & Stationery	\$1,640.07
Website	\$9,354.95
OCB Consultancy	\$860.76
PAYPAL FEES	\$92.62
Committee and Executive Training	\$330.00
<b>Total Administration</b>	<b>\$20,879.91</b>
Fund Raising	
BRAINSELL SHOP SUPPLIES	\$43.70
Merch at cost used Events	\$1,046.30
<b>Total Fund Raising</b>	<b>\$1,090.00</b>
Conference expenses	\$350.00
AusDoCC Function cost	\$2,627.71
Online AusDoCC programs	\$4,735.80
Peer support engagement	\$22,420.62
General IT for AusDoCC	\$4,124.83
<b>Total Expenses</b>	<b>\$56,228.87</b>
<b>Operating Profit</b>	<b>\$7,586.22</b>
<b>Net Profit/(Loss)</b>	<b>\$7,586.22</b>

This report includes Year-End Adjustments.

Page 1 of 1

## General Ledger: Summary

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**AusDoCC Inc**

10 High St

Seaholme, VIC, 3018

ABN: 54 754 767 674

Email: majapalacios.99@gmail.com

### General Ledger [Summary]

1/07/2020 To 30/06/2021

Account No.	Account Name	Beginning Balance	Total Debit	Total Credit	Net Activity	Ending Balance
1-1005	ANZ BUSINESS Account	\$127,436.99	\$61,598.89	\$52,695.78	\$8,903.11	\$136,340.10
1-1006	ANZ online Saver Account	\$52,013.83	\$25.98	\$0.00	\$25.98	\$52,039.81
1-1008	PAYPAL ACCOUNT	\$1,485.76	\$3,450.77	\$2,973.36	\$477.41	\$1,963.17
1-1100	General Pool Assets	\$13,244.80	\$2,049.00	\$0.00	\$2,049.00	\$15,293.80
1-1110	Acc Deprn General Pool Assets	\$13,244.80cr	\$0.00	\$2,049.00	\$2,049.00cr	\$15,293.80cr
1-1200	Trade Debtors	\$772.19	\$6,193.69	\$6,390.88	\$197.19cr	\$575.00
2-1100	Unspent grants at end of FY	\$112,647.64cr	\$112,647.64	\$114,270.73	\$1,623.09cr	\$114,270.73cr
3-8000	Retained Earnings	\$70,713.36cr	\$1,652.23	\$0.00	\$1,652.23	\$69,061.13cr
4-1005	Membership Fee	\$0.00	\$80.00	\$1,000.00	\$920.00cr	\$920.00cr
4-1010	Sponsorships	\$0.00	\$75.00	\$0.00	\$75.00	\$75.00
4-1015	Grants & Fundings	\$0.00	\$114,270.73	\$168,406.39	\$54,135.66cr	\$54,135.66cr
4-1020	Merchandise	\$0.00	\$786.30	\$1,672.80	\$886.50cr	\$886.50cr
4-1025	interest earned	\$0.00	\$0.00	\$25.98	\$25.98cr	\$25.98cr
4-1035	Fundraising	\$0.00	\$0.00	\$284.75	\$284.75cr	\$284.75cr
4-1045	Donations	\$0.00	\$0.00	\$4,165.00	\$4,165.00cr	\$4,165.00cr
4-1055	Conference	\$0.00	\$442.19	\$1,400.00	\$957.81cr	\$957.81cr
4-3000	Rebates and Refunds	\$0.00	\$0.00	\$2,514.39	\$2,514.39cr	\$2,514.39cr
6-1005	Accountant Fees	\$0.00	\$770.00	\$770.00	\$0.00	\$0.00
6-1008	Audit Fees	\$0.00	\$770.00	\$0.00	\$770.00	\$770.00
6-1010	Bank Fees	\$0.00	\$234.39	\$234.39	\$0.00	\$0.00
6-1020	Computer & Software	\$0.00	\$4,575.28	\$2,268.95	\$2,306.33	\$2,306.33
6-1022	Depreciation - General Pool	\$0.00	\$2,049.00	\$0.00	\$2,049.00	\$2,049.00
6-1030	Fees & Licenses	\$0.00	\$266.22	\$0.00	\$266.22	\$266.22
6-1035	Gifts & Marketing	\$0.00	\$500.00	\$0.00	\$500.00	\$500.00
6-1040	Insurance	\$0.00	\$2,690.00	\$0.00	\$2,690.00	\$2,690.00
6-1045	Office Equipment	\$0.00	\$19.96	\$0.00	\$19.96	\$19.96
6-1060	Printing Postage & Stationery	\$0.00	\$1,640.07	\$0.00	\$1,640.07	\$1,640.07
6-1085	Website	\$0.00	\$9,354.95	\$0.00	\$9,354.95	\$9,354.95
6-1100	Volunteer Committee expenses	\$0.00	\$2,000.00	\$2,000.00	\$0.00	\$0.00
6-1111	OCB Consultancy	\$0.00	\$860.76	\$0.00	\$860.76	\$860.76
6-1155	PAYPAL FEES	\$0.00	\$92.62	\$0.00	\$92.62	\$92.62
6-1999	Committee and Executive Training	\$0.00	\$330.00	\$0.00	\$330.00	\$330.00
6-2095	BRAINSELL SHOP SUPPLIES	\$0.00	\$43.70	\$0.00	\$43.70	\$43.70
6-2100	Merch at cost used Events	\$0.00	\$1,046.30	\$0.00	\$1,046.30	\$1,046.30
6-3000	Conference expenses	\$0.00	\$350.00	\$0.00	\$350.00	\$350.00
6-4000	AusDoCC Function cost	\$0.00	\$2,907.71	\$280.00	\$2,627.71	\$2,627.71
6-4500	Online AusDoCC programs	\$0.00	\$4,735.80	\$0.00	\$4,735.80	\$4,735.80
6-5000	Peer support engagement	\$0.00	\$22,420.62	\$0.00	\$22,420.62	\$22,420.62
6-7000	General IT for AusDoCC	\$0.00	\$4,124.83	\$0.00	\$4,124.83	\$4,124.83
Total :		\$365,054.63	\$363,402.40			

This report includes Year-End Adjustments.

Page 1 of 1

## Independent Auditor Report



*Liability limited by a scheme approved under Professional Standards Legislation.*



### AusDoCC INCORPORATED INDEPENDENT AUDIT REPORT FOR THE YEAR ENDED JUNE 30<sup>th</sup> 2021

**To the Members of AusDoCC Inc.**

#### **Report on the Audit of the Financial Report**

##### **Opinion**

I have audited the financial report of AusDoCC Inc. which comprises the Profit or Loss Statement and balance Sheet for the financial year ended June 30<sup>th</sup> 2021

In my opinion the financial report of AusDoCC Inc has been prepared in accordance with Division 60 of the Australian Charities and Not-for-profits Commission Act 2012, including:

- a) Giving a true and fair view of the registered entity's financial position as at June 30<sup>th</sup> 2021 and of its financial performance for the year then ended; and
- b) Complying with the Australian Accounting Standards and Division 60 of the Australian Charities and Not-for-profits Regulation 2013.

##### **Basis for Opinion**

I conducted my audit in accordance with Australian Auditing Standards. My responsibilities under those Standards are further described in the *Auditors Responsibility for the Audit of the Financial Report* section of my report. I am independent of the registered entity in accordance with the ethical requirements of the Accounting Professional and Ethical Standards Boards APES 110 *Code of Ethics for Professional Accountants* (the Code) that are relevant to my audit of the financial report in Australia. I have also fulfilled my other ethical responsibilities in accordance with the Code.

I believe that the audit evidence that I have obtained is sufficient and appropriate to provide a basis for my opinion.

##### **Information Other than the Financial Report and Auditor's Report Thereon.**

The responsible entities are responsible for the other information. The other information comprises the information included in the registered entity's annual report for the year ended 30 June 2021 but does not include the financial report and my auditor's report thereon.

My opinion on the financial report does not cover the other information and accordingly I do not express any form of assurance conclusion thereon.

In connection with my audit of the financial report, my responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial report, or my knowledge obtained in the audit or otherwise appears to be materially misstated.

If, based on the work I have performed, I conclude that there is a material misstatement of this other information, I am required to report that fact. I have nothing to report in this regard.

### ***Responsibilities of Responsible Entities for the Financial Report***

The responsible entities of the registered entity are responsible for the preparation and fair presentation of the financial report in accordance with Australian Accounting Standards and the ACNC Act, and for such internal control as the responsible entities determine is necessary to enable the preparation of the financial report that is free from material misstatement, whether due to fraud or error.

In preparing the financial report, responsible entities are responsible for assessing the registered entity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the responsible entities either intends to liquidate the registered entity or to cease operations, or has no realistic alternative but to do so.

The responsible entities are responsible for overseeing the registered entity's financial reporting process.

### ***Auditor's Responsibilities for the Audit of the Financial Report***

My objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes my opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of the financial report.

As part of an audit in accordance with the Australian Auditing Standards, I exercise professional judgement and maintain professional scepticism throughout the audit. I also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for my opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the registered entity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by responsible entities.
- Conclude on the appropriateness of the Committee's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the registered entity's ability to continue as a going concern. If I conclude that a material uncertainty exists, I am required to draw attention in my auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. My conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the registered entity to cease to continue as a going concern.
- Evaluate the overall presentation, structure, and content of the financial report, including the disclosures and whether the financial report represent the underlying transactions and events in a manner that achieves fair presentation.

I communicate with the responsible entities regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that I identify during my audit.

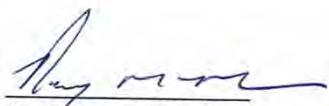
***Basis of Accounting***

The financial report has been prepared to assist AusDoCC Inc. to meet the requirements of its Constitution. As a result, the financial report may not be suitable for another purpose.

***Auditor's Opinion***

In my opinion, the financial report of AusDoCC Inc. presents fairly the assets and liabilities as at 30<sup>th</sup> June 2021 and of its financial performance for the year ended on that date.

Signed at Roleystone this 22<sup>nd</sup> day of November 2021.

  
Ray Manus MIPA AFA

ARALUEN ACCOUNTANCY  
57 Ridgehill Rise  
Roleystone WA 6111

## Auditor's Independence Declaration

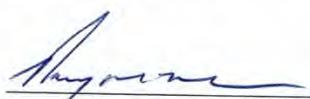
### AUDITORS INDEPENDENCE DECLARATION TO THE EXECUTIVE COMMITTEE OF AusDoCC INC.

I declare that to the best of my knowledge and belief, during the year ended 30 June 2021 there has been:

- (i.) no contraventions of the auditor independence requirements as set out in the Section 69 of the Associations Incorporations Act 2015 in relation to the audit; and
- (ii.) no contraventions of any applicable code of professional conduct in relation to the audit.

Name of Firm: Araluen Accountancy

Name of Principal: Raymund McManus



Date: 19<sup>th</sup> November 2021

Address: 57 Ridgehill Rise,  
Roleystone WA 6111

**Schedule 1, Regulation 15 Declaration**

**Schedule 1  
Regulation 15  
Form 1**

*Associations Incorporation Reform Act 2012*

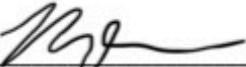
Sections 94 (2)(b), 97 (2)(b) and 100 (2)(b)

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**Annual statements give a true and fair view of financial performance and position  
of incorporated association**

We Kristina Coburn and Maree Maxfield being members of the  
Australian Disorders of the Corpus Callosum  
committee of the (AusDoCC Inc) certify that –

"The statements attached to this certificate give a true and fair view of the financial  
performance and position of the above named association during and at the end of  
the financial year of the association ending June 30, 2021."

Signed: 

Date: November 23 2021

Signed: 

Date: November 23 2021

## Financial Supporters

Our sincere thanks to all these donors. Your generosity supports our AusDoCC existence and the CCD community, beyond measure.

Craig Stanton	Professor Linda Richards
Birgit Pekovich	Teneriffe Lions Club
Melina Gabriel	Diana Uther
Mahesh Chakravarthy	Officeworks Altona Nth
William Uther	Ellington Family
Jolie Kremer	Nadine Katic
The Australian Online Giving Foundation from Benevity platform	



### Associates and Organisations

We have close alliances with many organisations and individuals who we connect with or who support us. Key and directions in the past 12 months have been with:

- Epilepsy Action - WA
- National Disability Insurance Agency (NDIA)
- Department of Social Services (DSS) – Cathlene De Ocampo
- Genetic Support Network Victoria – ([GSNV](#))
- International research consortium for the corpus callosum and cerebral connectivity (IRC5)
- The Bridge - connecting science and families
- Queensland Brain Institute (QBI)
- Murdoch Children's Research Institute (MCRI -)
- Agenesia de Corpo Caloso - Brasil - ABRDCC (Brazil)- Rubia Mara Oliveira Castro Girao
- [Corpal](#) UK DCC support group - Jean Dalton
- Italian Association of ACC patients (ASSACCI) - Sunti Morando
- National Organisation of Disorders of the Corpus Callosum ([NODCC](#)) - Lynn Snyder
- RACCORD (France) - Alexia Gibrat
- Brighter World Consulting – Andrew and Lacey
- Autism CRC – Olivia Gatfield
- Autism Star – Malcolm Mayfield
- Consentability – Natasha Alexander
- Get Your Future Together (GYFT) –Catherine Phan
- Airborne Apes – film crew



National Organization for  
Disorders of the Corpus Callosum



## How You Can Help

### Become a member

Click [here](#) to become a registered member of AusDoCC

### Volunteer your time

Contact Kristina Coburn: [info@ausdocc.org.au](mailto:info@ausdocc.org.au)

Join Diamonds of AusDoCC [here](#)

### Make a donation

You can make a donation [here](#). All donations over two dollars are tax deductible with our DGR status.

### Subscribe to our YouTube channel

Subscribe to AusDoCC videos [here](#)

### Follow us on social media or access a website

Like and follow our AusDoCC Inc. Facebook Page [here](#)

Follow us on Twitter [here](#)

Join or follow a Facebook group.

[Main group](#)

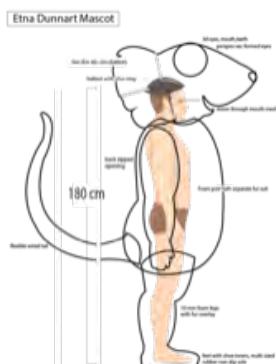
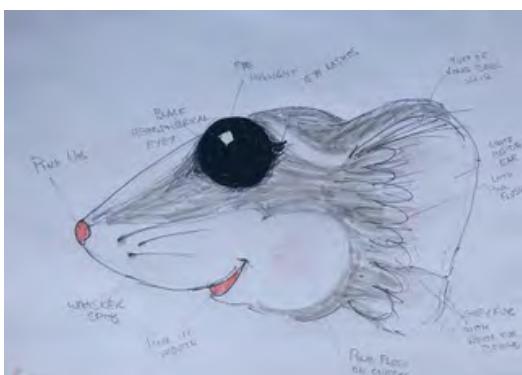
[Australia & New Zealand ACC adults](#)

[Public page](#)

[Research findings page](#)

[IRC5 international research consortium](#)

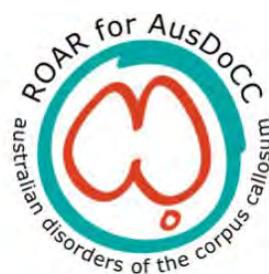
[AusDoCC website](#)



## CONTACT US

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web: [www.ausdocc.org.au](http://www.ausdocc.org.au)  
email: [info@ausdocc.org.au](mailto:info@ausdocc.org.au)  
Inc. Reg. A0057821R

AusDoCC – ROAR for Recognition, Opportunities, Access & Resources



Report prepared by:

**Kristina Coburn (President).**



**Maree Maxfield (Secretary)**



**Maja Palacios (Treasurer)**



*AGM November 23, 2021*

*If you don't know what a corpus callosum is, it's probably because you have one*