

**ausDoCC**  
australian disorders of the corpus callosum



**July 1 2019 to June 30 2020**

**AUSDOCC INC. ANNUAL REPORT**



## **AusDoCC Vision**

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

## **AusDoCC Mission**

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

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 fledgeling organisation. Over the years the committee diversity has grown to include dads, partners, friends and adults with agenesis of the corpus callosum (ACC).

Our aims were clear. We all wanted better recognition for everyone affected by ACC and their families. We all wanted the professionals to know more about ACC. We wanted to connect all these isolated groups and have them connect 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. We ROAR for Recognition, Opportunities, Access and Resources.

## **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

## **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 among any individuals, families and caregivers and the general public who are affected by a disorder of the corpus callosum.

Relief is offered through advocating (raising community awareness, promoting inclusion), educating (broad based information), informing (resources including financial, emotional, therapeutic and social support 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 health care workers and other organisations, will enable them to appropriately support individuals, families and caregivers affected by a DCC.

Partnerships will be formed with key research organisations, who are completing ethically approved research focusing on DCC and through the completion of data collection and a database of research volunteers. Raising community awareness of DCC will be a focal point. AusDoCC is a registered charity with 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.

# CONTENTS

Our vision	[page 2]
Our mission	[page 2]
Our history and purpose	[page 2]
<b>Section 1 – An overview of AusDoCC Inc</b>	
About AusDoCC Inc	[page 4]
Our people	[page 5-6]
Looking ahead	[page 7-8]
Evolution of Edna	[page 9]
What our members say	[page 10-13]
<b>Section 2 – Governance &amp; Operations</b>	
Structure & management	[page 14]
President's report	[page 15]
Our objectives and activities	[page 16-17]
2020 Committee role reports	[page 18-21]
<b>Section 3 – Our Finances</b>	
Our financial supporter - donors, grants & sponsors & grants	[page 22]
Treasurer's report and financials	[page 23-26]
Auditor's statement & Declaration	[page 27-29]
<b>Section 4 – Our other important information</b>	
Partners, associations & umbrella organisations	[page 30]
How you can help	[page 31]
Contact Us	[page 32]

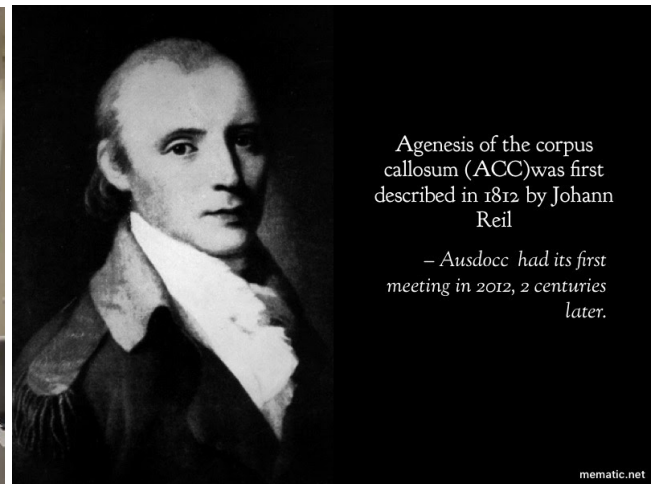




## ABOUT AUSDOCC INC

We are a grassroots committee of volunteers who are passionate about supporting and informing everyone affected by a corpus callosum disorder. That includes adults and kids with a DCC and their families, professionals, friends and the wider local and global community.

The Committee meets monthly and talks constantly on our Facebook group to hatch up plans and projects and work out ways to access money to fund all our ideas and those of our members. Corpus callosum disorders are heterogeneous in cause and presentation which means there are many causes, many ways they affect people and many different needs for everyone involved. For a long time families and professionals had very little accurate information or support. Our quest is to change that and ROAR for Recognition, Opportunities, Access and Resources.



## OUR PEOPLE

### AusDoCC Patron - Professor Linda Richards AO



Congratulations to Professor Linda Richards who has been recognised for her expertise in brain formation and wiring and developmental disorders. Linda has been appointed 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.

<https://medicine.wustl.edu/news/richards-named-head-of-neuroscience/>

### Professional Advisors

Name	Position	Dates acted
Professor Linda Richards	Chief Scientific Advisor	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	Nov 13 -
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 and laboratory research	whole year
Dr Natasha Alexander	Sexuality & Relationships Advisor	whole year










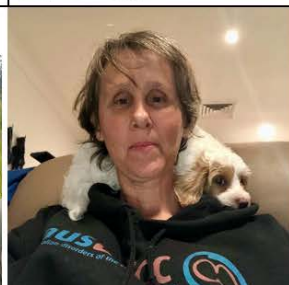

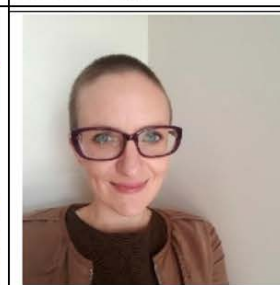
## Volunteer Committee of management 2019/2020

Name	Position	Dates acted
Kristina Coburn	President	whole year
Maree Maxfield	Secretary	whole year
Maja Palacios	Treasurer	whole year
Nicole Harrison	Vice President	whole year
Michael Shanahan	Vice President	whole year
Tanya Smith	General Committee Member	whole year
Anna Uther	General Committee Member	whole year
John Jonker	General Committee Member	whole year
Abbie Kinniburgh	General Committee Member	whole year
Pieta Shakes	General Committee Member	whole year

## Volunteer Committee of Management

The everyday running of AusDoCC Inc is the responsibility of our Management Committee, which is composed of elected, voluntary members. All committee members have individual, designated roles and also belong to subcommittees. Committee members have been from all over Australia and also from New Zealand.

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 available from the secretary. The online 2019 AGM was held on August 13, 2019.

				
Kristina Coburn President Social Media	Maree Maxfield Secretary Communications	Maja Palacios Treasurer Graphic Design	Niki Harrison Vice President Celebrations	Michael Shanahan Vice President Research Page
				
Abbie Kinniburgh Adult Planning	Tanya Smith Awareness Day	Anna Uther Adults Peer Support	John Jonker Partner Peer Support	Pieta Shakes Grants

## Looking Ahead - AusDoCC Committee of Management 2020/21

AusDoCC continues 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. 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.

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 were extended to introduce the concept and program "Friends of AusDoCC" in 2019. This was renamed Diamonds of AusDoCC to reflect the high value of our volunteers.

Diamonds can take on tasks or roles in a volunteer capacity without the full commitment of being on Committee. The Diamonds group will be run by a liaison officer and will operate as a Facebook group to keep the communication flowing between Committee and the Diamonds. Members are free to commit as much or as little time as they wish. Diamonds is evolving but COVID19 has had a massive impact on all our operations. Hopeful 2021 will be kinder.

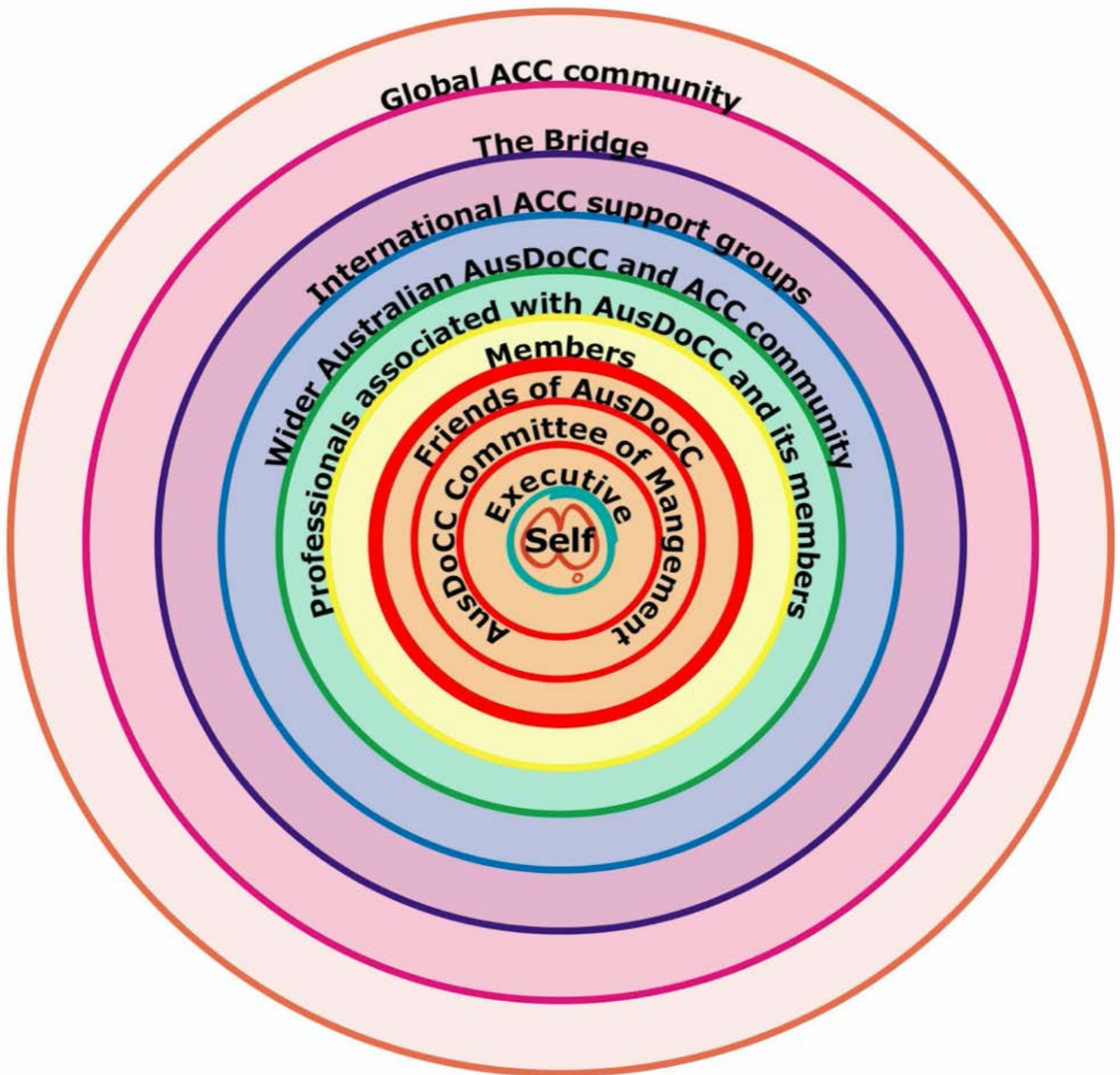
The social and stakeholder circles of our group continue in a concentric pattern to reach global communities.

### **Social Circles of AusDoCC - Groups**

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



## Social Circles of AusDoCC







**WHAT OUR MEMBERS SAY** - Member register total @ June 30, 2020 = 295

## **Survey #1. All AusDoCC Members - Help us Plan Ahead (August 2019)**

### **DEMOGRAPHICS**

This survey was sent in August 2019 to AusDoCC members, aged 18 or over. This included 16 adults diagnosed with a disorder of the corpus callosum. Other roles noted by respondents were clinician, carer and partner of someone with a DCC (one each). No one completing the survey identified as an educator.

### **CONFERENCE**

Over half of respondents indicated intention to attend Connections 2021, including 12 adults with ACC. Eight respondents have attended all three Connections conferences (2 ACC adults and two committee members have also attended all adult conferences).

21 respondents indicated they had not attended any conference so far. Of those, about half intend to attend Connections 2021, and one-third for Bridging the Gap 2020.

Overall, 21 respondents plan to attend Bridging the Gap 2020. Looking at the data, it does appear that some of this number refers to adult children of the respondents. .

Respondents generally said that location (eg being close to home), financial considerations, having plenty of notice for planning, and childcare were factors that may make it easier to attend an AusDoCC conference.

Nearly half of respondents said they would prefer a conference venue and hotel style accommodation, while about 10% would prefer a camp. Half of those surveyed said they would like a balance of presenters, workshops and social activities. About a quarter of respondents said they would like assistance to gain NDIS funding.

### **MEETUPS**

Just over one-third have attended a meetup and a similar number indicated they would like to do so. Over 60% say that meetups are valuable. There is a clear preference for meetups to be held on weekends. It can be difficult for members in regional areas to attend. There was a suggestion of holding more meetups for adults.

### **INFORMATION DAYS**

About one-quarter have attended an information day. About 40% say they are valuable. It is difficult to interpret the intention of future attendance at information days based on the data collected, but it is probably at least 40%. Again, weekends are the preferred time. As with the main conferences as noted above, location and childcare availability can also be barriers to attendance at information days.

### **SATISFACTION**

Generally, all but a couple of respondents were satisfied with the AusDoCC Newsletter, "Edna" Mascot, Facebook Groups, Accounting, Brain Sells shop, Website.



## Survey #2. Adults with DCC - Input to Events policy for adults with DCC

### ADULTS WITH DCC EVENT POLICY

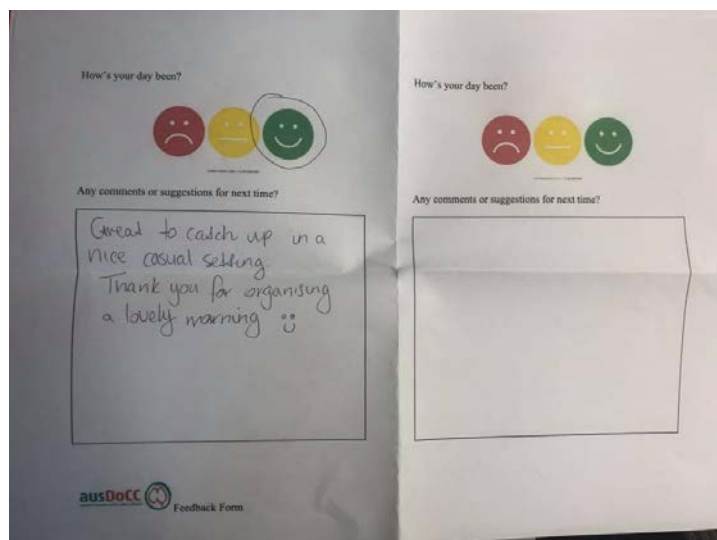
Policy Guidelines ○ SURVEY RESULTS 2019



Q	Topic	Response	Suggested outcome
1	Collected information	<ol style="list-style-type: none"> <li>1. Most respondents believed that almost all listed information should be collected</li> <li>2. Those not ticked generally included that of a medical nature such as Medicare number, medications, ambulance and private health insurance.</li> <li>3. Only 40% selected being able to seek medical consent where communication is impracticable.</li> <li>4. Some didn't select concession card information such as Companion Cards and Half price taxi cards</li> <li>5. 70% selected agreeing to terms and conditions</li> <li>6. 50% selected education levels</li> </ol>	<ol style="list-style-type: none"> <li>1. All majority responses should be included</li> <li>2. Accurate medical information is essential in the event of an accident requiring an ambulance or hospital admission. Private health insurance status is probably not necessary</li> <li>3. If communication is impossible and urgent medical help is required this gives consent. Without it we may not be able to seek the right medical assistance</li> <li>4. Concessions information allows for transport and entry planning to reduce group costs</li> <li>5. Terms and Conditions cover us legally so written agreement is important.</li> <li>6. Education levels help with planning appropriate sessions and content &amp; minimise embarrassment</li> </ol>
2	Cognitive abilities range strategies	<ol style="list-style-type: none"> <li>1. Sensory toys and alternative seating options. Alternative quiet space to access if needed</li> <li>2. Adjusted lighting and sounds</li> <li>3. Have carers on standby rather compromising other group members to assist</li> <li>4. Assistance from facilitators or assistance from other group members</li> <li>5. Alternative or inclusive strategies to help overcome and assist with any cognitive related difficulties. Allowing time and strategies for all to voice opinions and make contributions.</li> </ol>	<ol style="list-style-type: none"> <li>1. Adjustments to be made for maximising comfort and minimising sensory overloads.</li> <li>2. Venue to be fully accessible and willing to agree to requests for things such as lighting control, hand dryers off, alternative seating, sensory toys</li> <li>3. Carers may be utilised if appropriate</li> <li>4. Assistance should not compromise other group members' experiences unless fully cooperative learning is part of the session aim and expectations clear</li> <li>5. Strategies need to be inclusive so that all members have an opportunity to contribute. A minority may not dominate or set too fast a pace. Some activities may require grouping</li> </ol>
3	Physical abilities range strategies	<ol style="list-style-type: none"> <li>1. Fully accessible venue. Consideration of information in room set up</li> <li>2. Carers on standby at all times</li> <li>3. Awareness and inclusion at all times. Awareness of associated conditions and needs</li> <li>4. Use facilitators to assist</li> </ol>	<ol style="list-style-type: none"> <li>1. Advance venue accessibility checks, for full compliance</li> <li>2. Carers to be onsite, contactable and available during all sessions (not necessarily in the session room)</li> <li>3. Develop awareness of ableism and a way for participants to express accommodations needed</li> <li>4. Facilitators to assist where appropriate.</li> </ol>
4	General expectations	<ol style="list-style-type: none"> <li>1. Most respondents agreed with most statements.</li> <li>2. Some question of Companion Card acceptance and evaluation</li> <li>3. 60% agreed with expected attendance at sessions</li> </ol>	<ol style="list-style-type: none"> <li>1. Most statements to be included but maybe simplified and some merged with similar statements. Not as prioritised items but are all important</li> <li>2. Companion Cards are only given to those in need after evaluation. Do we have the skill/right to re-evaluate?</li> <li>3. If AusDoCC is paying/subsidising and running the event, people would be expected to attend unless unwell or overloaded. If participants are self funded it would encouraged but not compulsory. Non attendance can upset the rest of the group and may not be in the spirit of attendance and participation. People should come understanding and expecting to participate.</li> </ol>
5	Priorities	<ol style="list-style-type: none"> <li>1. Decisions in the best interests of all adults w DCC</li> <li>2. Adults with DCC should be consulted at all stages</li> <li>3. Accessibility and diversity recognised</li> <li>4. Companion Cards accepted</li> <li>5. Respect for closed/private sessions</li> <li>6. Some sessions closed to carers/support workers</li> <li>7. SW/Carers are not participants in activities</li> <li>8. Adults w DCC are expected to participate unless unwell or unable</li> <li>9. Withdrawal space will be provided</li> <li>10. Events are alcohol free unless otherwise stated</li> <li>11. Grievance policies will ultimately resolve disputes</li> <li>12. Grant money is spent according to grant regulations with accurate acquittals</li> </ol>	That all items are included but do not need to be noted as having any priority. If they are included they are important!
6	Enforcing privacy in closed sessions	<ul style="list-style-type: none"> <li>• State the facts</li> <li>• Give advanced warning. Include it in the terms and conditions</li> <li>• Signage</li> <li>• Inform presenters</li> <li>• Check that group is ok before starting session</li> </ul>	"This session is closed for privacy reasons to allow people to speak and ask questions without judgment." All suggestions could be included at the planning and information stage and implemented during events.



		<ul style="list-style-type: none"> <li>Provide additional small group/individual alternatives for anyone unable to participate without carers</li> <li>Consult the adults with DCC and produce appropriate policy</li> <li>A person who is not a facilitator or person with ACC should not be present even if only one person in the group desires this. No justification is needed.</li> </ul>	<ul style="list-style-type: none"> <li>This issue will take some time to establish boundaries. There will be some who need time and training to understand that they are not exceptions. Although they may insist on involvement out of love and caring, the adults have the right to insist on privacy. Planning diplomacy and clear guidelines will eventually pave the way.</li> </ul>
7	Person requiring a support person in closed sessions	<ul style="list-style-type: none"> <li>Establish needs and whether facilitator can perform basic assistance or alert support person if needed.</li> <li>Other group members to assist</li> <li>Hire external, independent trained staff member</li> <li>Offer alternative sessions with presenter and support person</li> <li>Offer 2 concurrent sessions – one with SW and one without. Swap.</li> <li>They are attending knowing the conditions</li> </ul>	<p>Conditions would be made clear in advance</p> <p>Efforts would be made to offer alternatives probably in the form of break out choices or an alternative concurrent session to cater for both groups</p> <p>Hired personnel are an added expense and still may not understand all people's needs</p>
8	Assistance types	<ol style="list-style-type: none"> <li>General agreement that those with financial needs or personnel support needs should not be excluded or disadvantaged.</li> <li>Companion Cards are generally recognised for registration at events</li> <li>Travel assistance should be provided if possible</li> <li>Concession prices should be available for Pension/Healthcare Card holders</li> <li>Consider extenuating circumstances</li> <li>Accommodation requests for single rooms</li> </ol>	<ol style="list-style-type: none"> <li>Full inclusion a consideration in financial planning</li> <li>Companion Cards generally for all registrations and possibly other costs</li> <li>Travel assistance where possible</li> <li>Concession prices for those on low Centrelink incomes with concession cards. Concession to the card holder only.</li> <li>Extenuating circumstances can be requested and considered</li> <li>Accommodation requests considered and met where possible. Sometimes this may not be possible</li> <li>Peer support available for Companion Card holders but not just "bring a friend" unless appropriate and part of the planning</li> </ol>
9	Applications exceed places	<p>Many mixed responses including:</p> <ul style="list-style-type: none"> <li>Members first</li> <li>New people first followed by those who have attended least</li> <li>First in first served (applications)</li> <li>First to pay</li> </ul>	<p>Members generally get priority. Non members given plenty of opportunity to join.</p> <p>Sometimes excluding those who have been to many events may be unfair .e.g. If they have paid for many events and then they are excluded form a subsidised one</p>
		<ul style="list-style-type: none"> <li>Those with fewer needs or demands</li> <li>Those who are independent</li> <li>Those who meet clear deadlines</li> <li>Preference given to people more active on Facebook group</li> <li>Ranking system on rotation</li> <li>Best reasons for attending</li> <li>Ballot – lucky draw</li> <li>Waiting list</li> </ul>	<ul style="list-style-type: none"> <li>This may need to be decided for each event.</li> </ul>
10	Other	<ol style="list-style-type: none"> <li>Grant conditions are legislation and not a choice</li> <li>Have someone there who is not a parent as mediator and first point of contact</li> <li>As numbers grow we may have to hold some events split into younger and older adults</li> <li>Participant fee may be a minimum contribution but offsets costs and allows more people to attend</li> <li>Some people may not have a Companion Card but may need a carer. Consider for future.</li> <li>Run sessions for support workers and carers</li> <li>Need clear rules and guidelines</li> <li>Be firm</li> <li>Have someone willing to make the tough choices and inform people.</li> </ol>	<ul style="list-style-type: none"> <li>Conference, activities, events need to have clear aims</li> <li>Personnel managing and operating the event and activities will be considered depending on their skills and experience, the nature of the event and activities and costs.</li> <li>Different exclusions and groupings may be considered as numbers increase</li> <li>Sessions may be run for Support Workers/Carers attending.</li> <li>Policy document will be made and available to all. Each event will have its own guidelines and Terms and Conditions based on the policy</li> <li>Guidelines will be given to participants, operational personnel and involved guests</li> <li>Adults and organisers will continually review guidelines and revise as appropriate.</li> </ul>



### Survey #3 Adults with DCC - Survey of preferred events and Zoom operations

The survey results for “Adults with ACC events survey 2020” a survey of people with agenesis of the corpus callosum over 18 years of age regarding meet ups in-person and online are outlined below.

Fifteen respondents completed the survey, most respondents wanted an in-person meet up less than monthly (i.e. 2<sup>nd</sup> or 3<sup>rd</sup> monthly), several people cited mobility issues, sensory issues, crowded venues and concerns about social settings (e.g. social anxiety) as issues they may have with an in-person event, one respondent added a concern of their own and several people skipped this question.

Many examples of events were provided for respondents to choose from, the most popular options selected were, meet up at a café/pub, bowling, river cruise, mini-golf, although there was a wide spread of interest over other options as well, and three respondents added to the list.

Participants were asked to give an alternate name to “adults with ACC” for which there were a mix of responses. There was significant interest in taking part in research about ACC conducted by professionals.

The remainder of questions were about using ZOOM for meeting up online.

When asked how comfortable they were with using ZOOM there were mixed responses. When asked what kind of session they would like, many responses were popular. The most popular were hearing a presentation from a professional, group chat with peers, chat with and have questions answered by a professional, two respondents added to the list of options.

Training from an IT professional was offered and the level of training asked with respondents giving mixed results. Most wanted to learn the basics of zoom, some wanted one-on-one training, some stated they wanted to learn advanced skills, to have support with the process from a support worker or parent. Four respondents added additional thoughts.

Concerns about in-person meet ups will be used to make decisions about where events are held and what adaptations are needed. Questions about ZOOM will be used to more effectively deliver training offers and help prioritisation of session types.



**STRUCTURE & MANAGEMENT**

AusDoCC is governed by a Committee of Management which currently has 10 members. It includes 5 office bearers and each Committee member has a 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 accordance with the Incorporations Act 2012.

We have a Policy and Procedures Document and members' code of conduct with descriptions of expected behaviours and underlying values.

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





## PRESIDENT'S REPORT - Kristina Coburn

At our last AGM in August 2019 we elected a total of 10 committee members. Executive remained the same with Maree Maxfield as secretary, Maja Palacios as treasurer and Niki Harrison as vice president. Michael Shanahan was added to the executive as a co-vice president and became the first adult with a DCC to hold an executive position. We said goodbye to 3 committee members, Maggie Nolan, Lisa McNally and Margie Slater and thanked them for their contributions. Margie kindly agreed to continue the role of newsletter editor and always produces an outstanding newsletter.

In October we met for our annual face-to-face meeting with all of the new committee in tow. We were ready for another hard-working year ahead of us. The executive committee spent Wednesday reviewing our strategic plan and going through our first ILC grant with consultant, Catherine McAlpine. Then the whole committee came together over the next few days to discuss leadership, advocacy, problem solving, IT skills and the year ahead.

Our plans included getting members together for AusDoCC Meet Ups and Information Days that were fully funded, including transport costs from those traveling from isolated parts of the country. We began our plans for the second My People, Brisbane conference for our adult members with a DCC.

Suddenly everything came to a standstill with the terrible bushfires that ravaged the country. Australia was burning. Meet Ups and Info Days around the country were put on hold. WA and Brisbane managed to slip in a Meet Up in November but that was it.

Just as the country stopped burning, who would have guessed a global pandemic would change the world. Borders everywhere shut - nobody in, nobody out, a bit like Willy Wonka's Chocolate factory. We could no longer do anything that we had planned. Covid 19 changed everything, in every way. We had to get creative and make some changes to our plans and our grant funding. We posted 300 mini care packs out to all members amidst the first wave of the pandemic. The project was called "Love Letters." This was purely to let people know that they were not alone and to reach out if need be. Books in Schools made another successful return. We sent 25 ACC and Me books out to the classes of children beginning school.

Our brand new Birthday cards, designed by competition winner Karina Bustillo, arrived along with our new Thank You cards and little information cards. Getting an Edna mascot costume made was a highlight and she will be introduced soon. But shhh it's a secret.


We discovered Zoom was the newest online platform. So began Zoom. The Zoom sub committee was formed and Zooming began. We found that our committee meetings became more efficient because we could finally see and hear one another. Thank you to all of our amazing committee over this past year.

I think I would describe this year as the year of tolerance.



# OUR OBJECTIVES AND ACTIVITIES

DRAFT - AUSTRALIAN DISORDERS OF THE CORPUS CALLOSUM STRATEGIC PLAN					
Vision	<b>Recognition, Opportunities, Access and Resources for People with Disorders of the Corpus Callosum (DCC)</b>				
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				
About Us	<b>Our Values</b> - <b>We show respect</b> : We actively listen, promote choice and are empathetic - <b>We show commitment</b> : We act with integrity by doing what we say we will - <b>We are leaders</b> : We act within accountability in a united, cohesive and transparent way - <b>We are inclusive</b> : We accept and value everyone and actively promote opportunities for engagement - <b>We are passionate</b> : We are driven by our vision and focused on delivering our mission			<b>Our key stakeholders</b> • Individuals with a DCC • Members & Families of those with a DCC • Health Professionals & researchers • Educators • Financial supporters • Government and other organisations • Volunteers	
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.	Publish and promote credible and current information regularly  Update the website with more resources, research and information  Half to full day information seminars in each state  Resources to include contributions from all perspectives	Provide national camps and conferences  Hold regular meet ups in each state and NZ  Ask a professional Skype sessions  Provide support for new parents  Provide opportunities for adults with DCC to gather independently	Gain greater recognition of ACC by medical practitioners as a primary diagnosis  Promote, participate in and support all Australian corpus callosum research  Encourage people to visit website, join Facebook groups & distribute brochures  Advocate for greater recognition of DCC by health professionals and policy makers	Educate prospective medical professionals at training/academic level  Provide the latest research to members  Provide educational resources for teachers and parents  Build capacity of health professionals and supporters with tools and information	Maintain a coordinated bank of willing volunteers  Actively strengthen the profile of AusDoCC  Maintain sustainable and diverse funding streams  Develop and deliver annual goals  Develop unique items for sale and distribution promoting AusDoCC
How we will know if we are successful	Feedback from users  Increase in membership  Interactions/partnerships with other organisations and professionals  Online web data  Satisfaction expressed in surveys and other evaluation  Contributions to newsletter	Attendance at conferences  Attendance at meetups  Successful grant applications  Increase in membership of AusDoCC and online groups  Interaction and response on Facebook groups  Response of adults to events and activities	Reduced complaints about DCC not being heard and recognised  Increased success in accessing NDIS where DCC is primary condition  Feedback from members who are receiving appropriate DCC management  Evaluation & surveys	Inquiries and requests for information and resources  Feedback from users and professionals re AusDoCC resources  Website/Facebook traffic  More positive feedback from families and individuals with a DCC re consultations and knowledge	Sustained numbers of people willing to help  Feedback from members and professionals with increased recognition in schools and medical & therapeutic practices  Successful grant acquisition & fundraising. Gaining donors. Stable cashflow  Evaluation of goals




**ausDoCC**  
australian disorders of the corpus callosum

## Edna's DCC facts

**AusDoCC Inc is a not for profit organisation formed and run by volunteer parents and adults with a DCC.**

[www.ausdoccc.org.au](http://www.ausdoccc.org.au)



**ausDoCC**  
australian disorders of the corpus callosum

## Edna's DCC facts

**A disorder of the corpus callosum can be described as:**

- ACC/AgCC:** Agenesis or complete absence of the CC.
- pACC:** Partial absence of the CC.
- Hypoplasia/Hypogenesis:** A thin CC
- Dysgenesis:** Incomplete formation of the CC.

[www.ausdoccc.org.au](http://www.ausdoccc.org.au)

## ACTIVITIES COMPLETED FOR 2019/20

- A quarterly newsletter - AusDoCC Connects
- International Corpus Callosum Awareness Day - Memes and slideshow of members
- Growing the adults' support group to plan a second adults with DCC conference and obtained funds
- Initial planning for Connections 2021 in Melbourne (postponed to 2022)
- Drafting a picture story book about Edna (mascot) at Connections 19
- Planning coordinated meet ups in each state
- Competitions for designing new AusDoCC cards
- Improving and maintaining our website to be a valuable source of information. Engaging an IT support person.
- Completing Top Ten resource sheets and a DCC fact sheet. Include them in new member Welcome Packs
- Upgraded technology resources and operational equipment for committee members
- Continuing to liaise closely with AusDoCC advisors. Appoint new research advisor
- 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 settings
- Advocating to government bodies to gain better recognition for DCC, as a key diagnosis
- Exploring the NDIS and meeting with Access Managers to create greater awareness of ACC and AusDoCC
- Maintaining a YouTube channel with AusDoCC videos
- Successfully applying for 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 through chairing the The Bridge, designing a logo and building policy
- Team building, leadership and planning activities for Committee members
- Maintaining Brain Sells shop with AusDoCC merch.
- Maintain social media sites - 2 Facebook groups, a Facebook Page and Twitter
- Establishing a volunteers group called Diamonds of AusDoCC
- Connecting with families and schools by sending Care Packs and ACC and Me Books
- Survey members about needs and suggestions to improve AusDoCC
- **ROAR** for everyone associated with disorders of the corpus callosum to gain **Recognition, Opportunities, Access and Resources**



## **2020 COMMITTEE ROLE REPORTS**

### **ABBIE KINNIBURGH** - AusDoCC Adults with a DCC representative (Victoria and Australia)

Over the last year or so in the AusDoCC committee, I have assisted with planning and organising online events on Zoom for adults with a DCC. This has helped continue to build our community and maintain some connection for adults with a DCC in the challenging time of COVID-19.

I have also been sourcing and putting together a regular Q&A article from an adult with a DCC for each AusDoCC newsletter, to learn a bit about our different adults with a DCC. I am an admin on the Australian ACC Adults Facebook group and often post information about upcoming events or programs on behalf of AusDoCC or for our adults with a DCC community.

Unfortunately, the unexpected and life altering times of COVID have meant some big change of plans for AusDoCC and the adults with a DCC. It meant having to cancel our much anticipated 'My People' conference in Brisbane, which was disappointing for all. It also meant fewer state meetups or events for adults with a DCC in Victoria. Although it has not been the same as face to face meet ups or without challenges, many adults with a DCC have been able to compromise and attend some events on Zoom, run by AusDoCC over the COVID period.

This last year has had me and others experiencing many ongoing challenges, on top of this very long COVID period. AusDoCC does an amazing job to support each other through many hurdles and rollercoaster rides on our working committee. AusDoCC works for and caters to people and families with a diverse range of needs and situations. AusDoCC is run by people with a diverse range of needs and situations. This is what helps make it an extremely accommodating, compassionate and understanding working committee to be part of. It enables me to continue my role of representing adults with a DCC.

Thank you.

### **PIETA SHAKES** – Grants Officer

This past 12 months has presented successes and challenges within my committee role as the grants officer. Further NDIS ILC funding has continued to provide the opportunity for AusDoCC to grow in capacity as an organisation to reach, connect and support a greater number of people within the DCC community. COVID19 required adaptation of grant programs and despite disruptions and alterations the grant activities, outcomes and reporting have been achieved on time. While a successful applicant for the NDCI, the committee declined acceptance as the pandemic meant the event could no longer be held in the required timeframe, demonstrating responsible governance.

Other activities of which I have enjoyed over the year include my involvement within the Mental Health Working Group, the research sharing Facebook page, resource development, risk management, advocacy and the online information session. Due to my other commitments, I am finishing up within my role on the

committee. I look forward to watching and supporting the amazing things to come, from the position of a 'Diamond' and wish the committee all the success.

#### **MAREE MAXFELD** – Secretary & Communications Officer

The 2019-2020 term has been an unusual one but also productive. We planned a bumper conference for adults in Brisbane for May 2020. Unfortunately, we have had to postpone it twice. We also postponed the CONNECTIONS 21 conference until 2021. In some ways this provided a break from the constant demands of high level organisation by a group of people punching way above their weight. Hopefully 2021 will see some borders open and we can gather people together in person once again, which is a key feature of our operational goals.

My contributions during this term have been to organise a couple of Face2Face planning weekends, grow the presence of our mascot, Edna, maintain the website whilst building the content for the new website, refine and release some resources such as the Top Tens, videos and policy documents. I have continued to build networks with key local and global professionals and researchers. As AusDoCC secretary I keep the minutes for Committee meetings and deal with correspondence and our ever increasing member base. I was fortunate to secure a couple grants and helped to keep records for the reporting and acquittal of the major ILC grants and related media publicity.

Never a dull moment at AusDoCC Central!

#### **MAJA PALACIOS** – Treasurer & Graphic Design Officer

It has been an interesting year for graphic design, with Jocelyn Palacios assisting as a volunteer we have designed and created an amazing Edna mascot which will be revealed when face to face events can be held. Awareness day was a great success with our original memes and images shared worldwide.

I have assisted Maree and other committee members by creating graphics for documents over the year. I have provided Pieta with the required documents for grant applications and reporting obligations. I have worked closely with Executive Committee to ensure that our organisation's licensing and legal obligations were met.

While our planned conferences and events were postponed due to covid19 they are scheduled to be held in the near future.

Treasury and accounts have run smoothly and are up to date. The financials have been audited for 2019/20.

#### **NIKI HARRISON** - Vice President & Celebrations Officer

My job is to send birthday cards to all our members who have a disorder of the corpus callosum. Before each month commences I send a text message to the member and confirm the date of birth and the address. This keeps our database up to date and also makes sure the card is going where it needs to go. I then get all cards ready for the month and send 3 to 5 days prior to the birth date of each person. I also help the president and executive with anything else needed.

### **TANYA SMITH** – Awareness Day Officer

This year in my role, I contributed to the creation of the Edna mascot costume. We successfully created a Covid-safe awareness day campaign on July 2nd with great media attention and memes that went around the world on social media. People sent us photos which were put together for the annual slideshow.

The beginnings of a teen friendship group are underway and we have a plan which will be expanded upon into the future.

Various social media platforms have been used to provide support and information to our financial members and the wider community.

### **MICHAEL SHANAHAN** – Vice President & Research Awareness Officer

In the financial year 2019/20 I held events in Queensland for members in Brisbane, participated in training at two committee Face-to-Face meetings, participated in the Mental Health Steering Committee and prior to the COVID-19 lockdown, I worked on the Adults members database and the adults' My People event before its postponement. I have continued to work on the AusDoCC DCC research page on Facebook. I floated the idea of an Indigenous resource to address the needs of Indigenous Australians in our community and finding an Indigenous member of the community who can be the leader of that.

I held three events for families/adults with a DCC in Queensland to socialise, prior to the Covid-19 lockdown, and after that I participated in Zoom training to host future events online.

### **JOHN JONKER** – Partner peer support

My role is to offer peer support for partners and other family members who are not parents. I am usually involved in organising NSW Meetups and we had begun to plan a NSW information day. Due to Covid19 there have been no meetups or other in person meetings other than zoom.

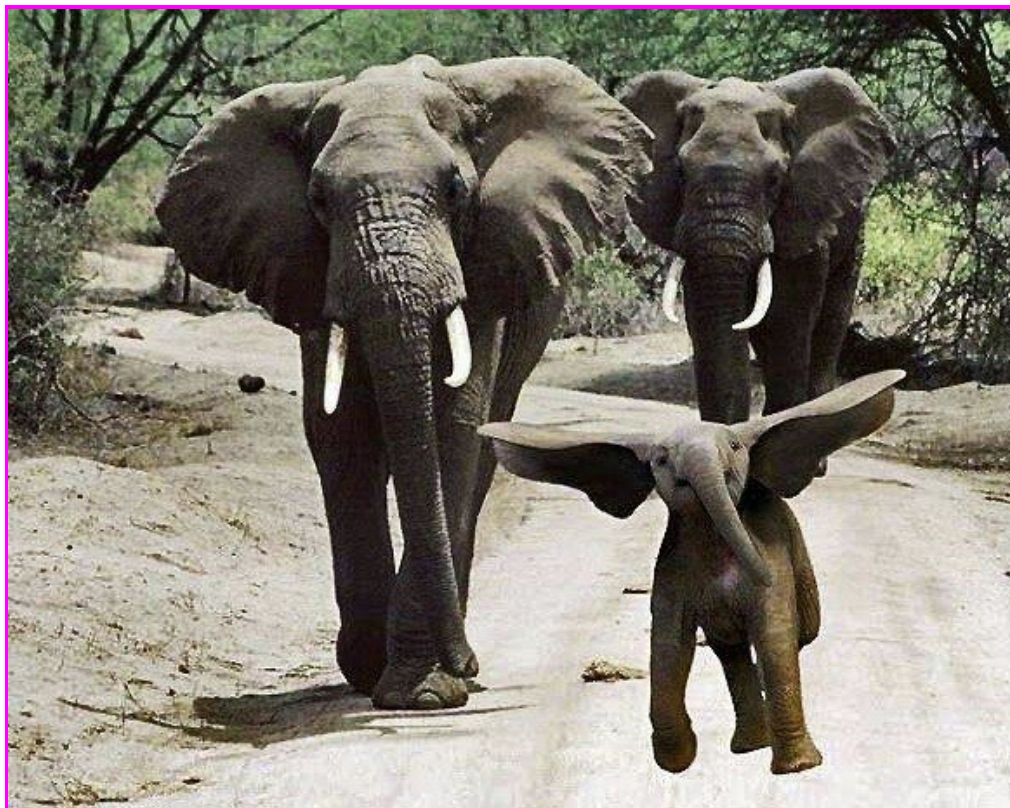
### **ANNA UTHER** – Adult peer support

I am an Adult diagnosed with complete ACC. I was diagnosed as a young adult. I live in NSW. My role on the committee is to represent other adults with a DCC, especially those who live in NSW. I also hope to be part of a support network for other adults whether they are newly diagnosed or have known for a while. My jobs have been to welcome new Facebook group members and acknowledge birthdays. Due to Covid19 and other personal happenings it has been a disrupted year



This year the social media platform has become an essential part of keeping people connected. Online platforms became very popular Zoom being one of them. It's my job to chair the committee meetings and Zoom has been a welcome change. Seeing and hearing everyone has made the meeting more efficient.

Our Facebook groups have increased in number and have been busy with chatter with regular theme days encouraging this. The AusdoCC Inc Facebook page is regularly updated along with the AusDoCC research page. Twitter and Instagram get a workout around our Awareness Day. Our latest AusDoCC videos have been uploaded to our new YouTube channel, AusDoCC Videos. Check it out and subscribe. We have a Facebook database that helps us to connect up families, parents and adults with a DCC. In Perth I assisted Maja with a lovely High Tea meetup that was held in the Swan Valley.



## OUR FINANCIAL SUPPORTERS - DONORS, SPONSORS &amp; GRANTS



Funded by the National Disability Insurance Agency



**Australian Government**  
**Department of Social Services**



UK Online Giving Foundation

**Uther, William**

**Evens, Becky**

**White, Jennifer**

**Chakravarthy, Mahesh**

**Eden, Bonnie**

**Schaefer, Raechelle**

**George, Susan**

**Palacios, Maja**

**Preston, Emma**

**Eggington, Alicia**

**Uther, Penny**

**Richards, Professor Linda**

**Watkins, Helena**

**Newcastle Disability Service**

## TREASURER'S REPORT



Maja Palacios

### AusDoCC Inc Financial Report 2019-2020

#### Contents

1. Cover
2. Contents and notes
3. Balance Sheet [Last Year Analysis] June 2020
4. Profit & Loss Statement July 2019 To June 2020
5. General Ledger [Summary] 1/07/2019 To 30/06/2020
6. Schedule 1 Regulation 15 Form 1

#### Notes

Reported by AusDoCC Treasurer, Maja Palacios

Date\_02/11/2020

Notes: AusDoCC Inc is a registered 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 7 Jan 2014

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

### Trial Balance June 2020

	This Year	Last Year	\$ Difference
<b>Assets</b>			
Cash on Hand			
ANZ BUSINESS Account	\$127,436.99	\$68,897.03	\$58,539.96
ANZ online Saver Account	\$52,013.83	\$51,931.63	\$82.20
PAYPAL ACCOUNT	\$1,485.76	\$1,356.51	\$129.25
General Pool Assets	\$13,244.80	\$2,417.00	\$10,827.80
Acc Deprn General Pool Assets	-\$13,244.80	-\$2,417.00	-\$10,827.80
Total Cash on Hand	\$180,936.58	\$122,185.17	\$58,751.41
Trade Debtors	\$772.19	\$597.19	\$175.00
Total Assets	\$181,708.77	\$122,782.36	\$58,926.41
<b>Liabilities</b>			
Current Liabilities			
Unspent grants at end of FY	\$112,647.64	\$52,069.00	\$60,578.64
Total Current Liabilities	\$112,647.64	\$52,069.00	\$60,578.64
Total Liabilities	\$112,647.64	\$52,069.00	\$60,578.64
Net Assets	\$69,061.13	\$70,713.36	-\$1,652.23
<b>Equity</b>			
Retained Earnings	\$70,713.36	\$54,403.65	\$16,309.71
Current Year Earnings	-\$1,652.23	\$16,309.71	-\$17,961.94



**Profit & Loss Statement**  
**July 2019 To June 2020**

**Income**

Membership Fee	\$440.00	
Sponsorships	\$20.00	
Grants & Fundings	\$55,238.86	
Merchandise	\$510.50	
interest earned	\$82.20	
Donations	\$4,176.73	
Conference	\$5,425.00	
Committee Contributions	\$160.00	
<b>Total Income</b>		<b>\$66,053.29</b>
<b>Gross Profit</b>		<b>\$66,053.29</b>

Expenses

**Administration**

Audit Fees	\$770.00	
Bank Fees	-\$179.38	
Computer & Software	\$1,942.38	
Depreciation - General Pool	\$10,827.80	
Fees & Licenses	\$466.22	
Gifts & Marketing	\$1,292.94	
Insurance	\$2,577.18	
Printing Postage & Stationery	\$2,036.55	
Telephone & Internet	\$209.90	
Website	\$1,462.88	
Volunteer Committee expenses	\$4,389.34	
AGM and Face to Face expenses	\$11,660.59	
PAYPAL FEES	\$63.35	
Committee and Executive Training	\$10,044.33	
<b>Total Administration</b>		<b>\$47,564.08</b>

**Fund Raising**

Brainsells shop supplies	\$2,105.40	
Merch at cost used Events	\$80.00	
Total fundraising	\$2,185.40	
Conference expenses	\$11,717.92	
AusDoCC Function cost	\$5,490.14	
Online AusDoCC programs	\$747.98	
<b>Total Expenses</b>		<b>\$67,705.52</b>
Operating Profit		(-\$1,652.23)
Net Profit/(Loss)		(-\$1,652.23)

## General Ledger [Summary]

1/07/2019 To 30/06/2020

Account Name	Beginning Balance	Total Debit	Total Credit	Net Activity	Ending Balance
ANZ BUSINESS Account	\$68,897.03	\$124,913.67	\$66,373.71	\$58,539.96	\$127,436.99
ANZ online Saver Account	\$51,931.63	\$82.20	\$0.00	\$82.20	\$52,013.83
PAYPAL ACCOUNT	\$1,356.51	\$2,088.00	\$1,958.75	\$129.25	\$1,485.76
General Pool Assets	\$2,417.00	\$10,827.80	\$0.00	\$10,827.80	\$13,244.80
Acc Deprn General Pool Assets	-\$2,417.00	\$0.00	\$10,827.80	-\$10,827.80	-\$13,244.80
Trade Debtors	\$597.19	\$9,471.50	\$9,296.50	\$175.00	\$772.19
Unspent grants end FY	-\$52,069.00	\$52,069.00	\$112,647.64	-\$60,578.64	-\$112,647.64
Retained Earnings	-\$54,403.65	\$0.00	\$16,309.71	-\$16,309.71	-\$70,713.36
Membership Fee	\$0.00	\$0.00	\$440.00	-\$440.00	-\$440.00
Sponsorships	\$0.00	\$0.00	\$20.00	-\$20.00	-\$20.00
Grants & Fundings	\$0.00	\$112,647.64	\$167,886.50	-\$55,238.86	-\$55,238.86
Merchandise	\$0.00	\$0.00	\$510.50	-\$510.50	-\$510.50
interest earned	\$0.00	\$0.00	\$82.20	-\$82.20	-\$82.20
Donations	\$0.00	\$0.00	\$4,176.73	-\$4,176.73	-\$4,176.73
Conference	\$0.00	\$3,236.62	\$8,661.62	-\$5,425.00	-\$5,425.00
Committee Contrib	\$0.00	\$0.00	\$160.00	-\$160.00	-\$160.00
Accountant Fees	\$0.00	\$770.00	\$770.00	\$0.00	\$0.00
Audit Fees	\$0.00	\$770.00	\$0.00	\$770.00	\$770.00
Bank Fees	\$0.00	\$0.00	\$179.38	-\$179.38	-\$179.38
Computer & Software	\$0.00	\$6,451.78	\$4,509.40	\$1,942.38	\$1,942.38
Depre -General Pool	\$0.00	\$10,827.80	\$0.00	\$10,827.80	\$10,827.80
Fees & Licenses	\$0.00	\$466.22	\$0.00	\$466.22	\$466.22
Gifts & Marketing	\$0.00	\$5,555.44	\$4,262.50	\$1,292.94	\$1,292.94
Insurance	\$0.00	\$2,577.18	\$0.00	\$2,577.18	\$2,577.18
Office Equipment	\$0.00	\$2,055.90	\$2,055.90	\$0.00	\$0.00
Printing Post & Stuff	\$0.00	\$2,036.55	\$0.00	\$2,036.55	\$2,036.55
Telephone & Internet	\$0.00	\$209.90	\$0.00	\$209.90	\$209.90
Website	\$0.00	\$1,462.88	\$0.00	\$1,462.88	\$1,462.88
Volunteer Committee expenses	\$0.00	\$4,389.34	\$0.00	\$4,389.34	\$4,389.34
AGM and Face to Face expenses	\$0.00	\$11,660.59	\$0.00	\$11,660.59	\$11,660.59
PayPal fees	\$0.00	\$63.35	\$0.00	\$63.35	\$63.35
Committee and Exec Training	\$0.00	\$10,044.33	\$0.00	\$10,044.33	\$10,044.33
BrainSells shop suppli	\$0.00	\$2,105.40	\$0.00	\$2,105.40	\$2,105.40
Merch at cost Events	\$0.00	\$80.00	\$0.00	\$80.00	\$80.00
Conference expenses	\$0.00	\$12,245.48	\$527.56	\$11,717.92	\$11,717.92
AusDoCC Function cost	\$0.00	\$5,490.14	\$0.00	\$5,490.14	\$5,490.14
Online AusDoCC programs	\$0.00	\$747.98	\$0.00	\$747.98	\$747.98
<b>Total</b>		<b>\$395,346.69</b>	<b>\$411,656.40</b>		

## AUDITOR'S REPORT



57 Ridgehill Rise  
Roleystone WA 6111  
Phone: 9397 9253  
Mobile: 0437 853 253  
Email: [themaclan@bigpond.com](mailto:themaclan@bigpond.com)  
ABN 40 305 326 211

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



10<sup>th</sup> November 2020

Chairperson  
AusDoCC Inc.  
PO Box 533  
Altona VIC 3018

Dear Sirs/Mesdames

### AUDIT FOR THE YEAR ENDED 30 JUNE 2020

In order to carry out our duties and responsibilities as the Association's auditors, Araluen Accountancy is required by ASA 260 "Communication of Audit Matters to those Charged with Governance" (ASA 260), to communicate to you setting out the matters arising from our audit.

My audit was conducted in accordance with the agreement to conduct the audit of the Association for the financial year ended 30 June 2020.

The Board should understand that:


- a. We are responsible for forming and expressing an opinion on the financial report that has been prepared by the Board; and
- b. The audit of the financial report does not relieve the Board of their responsibilities.

Because of the test nature of an audit, there is a risk that some material misstatement, fraud or irregularity may remain undiscovered. The matters noted during the audit that I wish to draw to your attention are set out in the attached report.

It is not intended to be a comprehensive report of all such matters that may exist. Should you wish to discuss any of these matters or require further services, please contact Mr Ray M<sup>e</sup>Manus.

The report is prepared under the terms of our engagement solely for the information of the committee of management of the AusDoCC Inc.

Yours faithfully,  
Araluen Accountancy



Ray M<sup>e</sup>Manus – MIPA AFA

**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 2020 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



Raymund McManus

Date: 10<sup>th</sup> November 2020

Address: 57 Ridgehill Rise,  
Roleystone WA 6111



**Schedule 1**  
**Regulation 15**  
**Form 1**

*Associations Incorporation Reform Act 2012*

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

---

**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  
committee of the Australian Disorders of the Corpus Callosum  
(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, 2020.”

Signed: 

Date: November 10 2020

Signed: 

Date: November 10 2020

**Partners, associates & umbrella organisations**

- Epilepsy Action - WA
- NDIA Partner
- GSNV - Genetic Support Network Victoria
- IRC5 - International research consortium for the corpus callosum and cerebral connectivity
- The Bridge - connecting science and families
- QBI - Queensland Brain Institute
- MCRI - Murdoch Children's Research Institute
- Agenesia de Corpo Caloso - Brasil - ABRDCC (Brazil)- Rubia Mara Oliveira Castro Girao
- Corpal (UK) - 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

#3



## HOW YOU CAN HELP

### Become a member

<https://form.jotform.co/93138440733860>

### Volunteer your time

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

Join Diamonds of AusDoCC <https://www.facebook.com/groups/986410298384706/members/>

### Make a donation

<http://www.ausdocc.org.au/donate/#top>



## CONTACT US

Australian Disorders of the Corpus Callosum  
PO Box 533, Altona, VIC, 3018.  
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

<https://www.facebook.com/groups/ausdocc/> - Main group

<https://www.facebook.com/groups/355338714574689/> - Adults with DCC

<https://www.facebook.com/AusDoccInc/> - Public page

<https://www.facebook.com/DCCresearch/> - Research findings page

<https://www.facebook.com/IRC5-International-Research-Consortium-1512077215594864/> -

IRC5 scientific research consortium

Report prepared by:

Maree Maxfield (Secretary) signed

Kristina Coburn (President) signed

Maja Palacios (Treasurer) signed

AGM November 10, 2020