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story on page 15

PRESIDENT'S REPORT

Hi Folks 🤝

You might have noticed it's been a while since our last newsletter. I trust you are well. Those crisp mornings are starting to disappear and the sun is making a welcome appearance once again.

In June we held the second My People conference in Brisbane for the adults with a DCC. Thankfully after a few potholes (mostly due to that curse word Covid) it came together beautifully. All credit goes to Maree and her awesome team.

This year, in the lead up to our International Disorders of the Corpus Callosum Awareness Day, the international science conference, Cortical Connections 2021, was held online. Daily seminars ran over six days bringing together clinicians and individuals with callosal malformations and their families. Special thanks to the organisers of this amazing event, the IRC5 (International Research Consortium for the Corpus Callosum and Cerebral Connectivity). Recordings of the sessions are now available here <https://www.irc5.org>

On Awareness Day we introduced a surprise guest, Edna, our friendly, furry, life sized fat tailed dunnart. To see Edna's arrival, click the link: <https://youtu.be/f9d-o-81-OY>
Interesting fact, all marsupials are missing their corpus callosum. The fat tailed dunnart is a favourite with Professor Linda Richards and her research team at Queensland Brain Institute and Washington University.

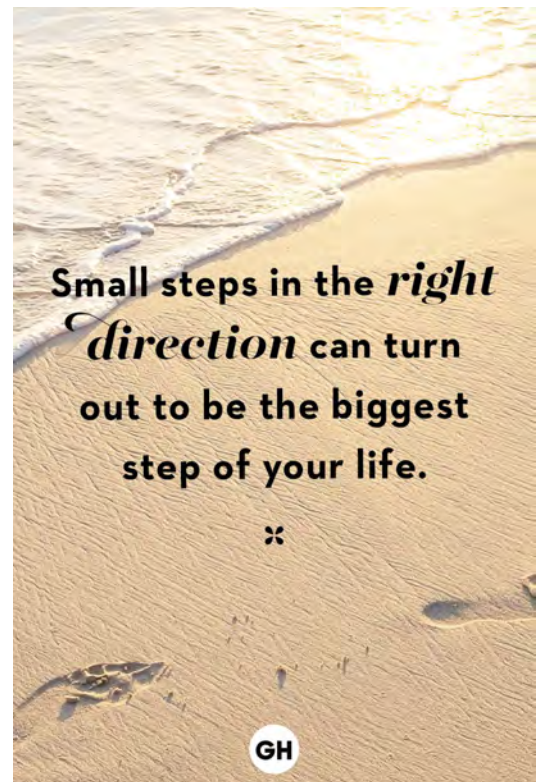
Remember to check our Facebook groups and your emails for any upcoming Zoom Events or Coffee Mornings.

A reminder if you have anything you would like to share in our newsletter, please email editor@ausdocc.org.au

Please, if you are struggling due to Covid or for any reason at all please reach out to us. We are always here to listen. One step at a time.

Peace

Tina.



OT experience of understanding how to improve mental health for someone with ACC/DCC

At Get Your Future Together (GYFT), our work is to enable ordinary people to do extraordinary things. As OTs, it has been our challenge to think about what enables someone to truly function in life on their own terms, and what it takes to experience good mental health.

Understanding the experience of the individual, who they really are, and a world where someone can be at the centre, comprises of a number of areas:

- A person's mood – and how certain emotions can trigger a change in mood, usually related to something that has occurred
- Typical rhythms and routines during the day and across a week - when energy peaks or is low and what types of activities a person would engage in
- Connectedness to their own body – whether there are any medical, disability or previous experiences of trauma which might exacerbate or inhibit a physical response and knowing how someone feels in their own body. Often a person may require additional support to understand what their own body might be telling them in relation to their body, this could be things such as appetite, pain or discomfort, stress or anxiety, temperature
- Fears – there can be many fears of the unknown for a person, of not having control or being able to know or communicate their needs in new or vulnerable situations
- Physical environment, relationships, occupations and abilities/skills. The meaning and function of each of these on a person as it applies to - belonging, connection, work/life balance, growth, financial security, contribution, intellectual stimulation, recognition
- A person's hopes and dreams for themselves, as well as values and beliefs about the world

To support a person to live life on their own terms, it often boils down to safety and success. Examples of this would be supporting a person to:

- Communicate their needs and preferences in different situations
- Identify and find the right level of supports needed to improve their day to day experience of life
- Be informed, plan and prepare for new situations
- Plan for changes without overwhelming and creating additional chaos and stress for a person in their life



- Including the person's informal and formal networks/supports in a shared vision, sharing insights and valuable knowledge together as a team
- Unpack how situations can trigger certain emotions – what strategies and tools someone could learn to care for themselves when distressed
- Learn meaningful skills for a sense of purpose, achievement and being a part of something
- Understand rules and expectations for how different systems work, so a person can feel like they're able to ask for what they need and what they have a right to, as a client, customer or citizen

Catherine Phan – Occupational Therapist

Catherine is the founder of GYFT, an organisation that help ordinary people do extraordinary things. She feels strongly about developing people and helping them to create the sense of identity and a life that works, regardless of the starting point.

Catherine is an OT who also focuses on mental health, aiming not just to change people's lives but introduce a holistic approach to change the industry.

She is currently working closely with an adult with a DCC.

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BRISBANE 'MY PEOPLE' CONFERENCE JUNE 2021

There were 17 adults with a DCC brought together to meet each other face to face at the Hotel Diana, Woolloongabba. Most states & territories were represented. For some it 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 & breathing techniques to stimulate our brains & relax our bodies.

Then we had a session with Samantha, a disability rights activist, who is very knowledgeable about the NDIS & 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 electives, where we could be in small groups & ask more personalised questions. Kieren spoke about body, brain, health & fitness. Samantha spoke about the challenges with the NDIS. Michael spoke about journaling & 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 & her team. Professor Richards gave a summary of the research that is being conducted on Adults with a DCC & introduced her team, who spoke about their areas of research they are focused on. After enjoying an afternoon tea & chatting to the team at the QBI, we headed back to the hotel & went to dinner at Boos 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, a psychologist, specialising in relationships & mental health, helping people with intellectual & cognitive disabilities. Then Toby, from the University Psychology Department. He is working on how anxiety affects people with a DCC. Toby spoke about managing anxiety & answered questions.

The 4 electives on day 2 consisted of Professor Richards answering questions of research & genetics, Michael speaking on managing our time, Toby speaking about our anxious moments & Natasha giving us advice on relationship difficulties. After lunch we participated in the World Café. Hosted by Maree, we



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

Sunday morning, we had the opportunity to speak to Natasha & 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 & board a Riverboat Dinner Cruise & enjoy the lights of Brisbane. It was a beautiful evening, in more ways than one. Getting to know new friends a lot more & 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 & proud they were, with a degree of tiredness. Others, including first-timers, said they had found their tribe, family & new friends. One used the word 'whanau'. Māori for extended family. A few older people in the group were delighted & content, meeting friends, both old & new. A few also described being overwhelmed & 'brain blown'. One of us had an 'assistance dog' with them, which made everybody happy & calm.

The aims & purposes of the Conference were:

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

As a group we aim to remember the 5 C's

Connection, Communication, Collaboration, Community, Capacity

Report by Margaret Krutli – conference attendee & AusDoCC Committee member





at the *'Meeting Place'* Q&A we meet....

Clare Keogh

Q. What is one of, or some of your biggest challenges due to your corpus callosal disorder?

A. My challenges include social communication in different contexts, decision making, auditory processing and emotional Processing.

Q. What do you like doing?

A. I like reading, writing and listening to music.

Where do you live?	Melbourne, Victoria	How old are you?	25
My DCC diagnosis:	Agenesis of the Corpus Callosum	When were you diagnosed?	In utero. Confirmed after birth- Nov 1995

Q. What is, or who are your main supports for you with you corpus callosal disorder?

A. My main supports are my partner whom I live with, as well as my psychologist and speech therapist.

Q. What do you do with your days?

A. I work part-time as a paediatric occupational therapist. Otherwise I'm usually reading or writing stuff.



Q. What are your interests?

A. I love Star Wars and writing fanfiction. I also like singing, listening to music and reading.

Q. If you could give one bit of advice to a child with a corpus callosal disorder who asked you for support, what would you tell them?

A. Your brain is unique, and that's cool. Don't let others tell you otherwise. It also means you need support, even if others might think you don't. If support and help is offered, it is worth exploring.

This is me...



WELCOME TO THE WORLD

Edan Freddie Gonzalez

17/02/2021

2.630 kg.

Other than struggling to breastfeed Edan was perfectly happy and healthy, just on the small side. At 10 weeks, due to his small head circumference, we were advised to have a head ultrasound which led then to an MRI. The MRI showed Edan had partial Agenesis of the corpus callosum.

At the moment he is hitting his milestones, and it's a case of "if we didn't know, we wouldn't know".



WELCOME TO THE WORLD

Sofia Morales

4 March 2021

She's our daughter Sofia Morales, born on March 4th, 2021, in Ontario, Canada. She was diagnosed with complete agenesis of the corpus callosum and epilepsy when she was 4 weeks old. Later on we found out she has a variation on gene ARX.

Now let's talk about the important things... she's the happiest baby ever! Loves new toys, talking to Dad, cuddling with Mom, pulling her big sister's hair and going out for a walk. She loves watching up the tree leaves when she's on her stroller. She's starting to roll over and is learning how to use her body at her own pace.

There are no words to describe how much we love this little munchkin!



WELCOME TO THE WORLD

Bonnie

3/4/2021

7.03 lbs

50cm

Bonnie and I had the most beautiful natural water birth here in New Zealand. She had apneas post birth which led onto millions of tests which then showed us she has ACC and INVDUPDEL 8p Chromosome, which is incredibly rare. Currently you would never know, she is doing everything an 11 week baby should be, she is truly beautiful and we have already learnt more lessons to life than we could have imagined.



How best to support your young child to cope with the COVID-19 pandemic

Should I talk to my child about the COVID-19 pandemic?

Yes. Most advisors suggest an open, honest and age-appropriate discussion about the pandemic. A good starting place is to ask your child what they know about it and if they are worried. There is no need to have all the answers.

Be aware of the conversations that children hear between adults, older siblings and from the television. Consider how you react as a parent in discussion with other adults. Young children can be really in tune with their parents' emotional responses. For this reason, it is important to stay calm, reliable and in some ways keeps things business as usual. Your child may need more cuddles. Your children want to feel safe and loved.

Should I be worried about their learning?

Stop stressing about academic progression. The kids will be fine. Online learning provides structure, distraction and entertainment. All the kids are in the same boat. They will catch up to where they would have been. We will look back at this time when we are busy and spending too much time in cars again and we will miss it. There is so much to learn just from being at home: how to prepare for dinner, do the laundry and to see how a household is run; enjoying the simple things, like the tree in the backyard, a slower pace, hearing the birds outside, seeing the flowers; sharing in the small delights as a family—eating lunch together, learning to ride a bike, learning how to bake cupcakes and how to care for a garden.

Kids thrive on routine; there is safety in it, and expectations that are met with routine. However, there needs to be fun too. To quote Maree Maxfield, "My tendency as a teacher is to say stop stressing about replication of the classroom in home education under extreme conditions. Give them ice cream for breakfast, build a cubby fort, learn all the timetables, compose a song and read them your favourite book chapter by chapter....I think it would work. Kids learn best when they're happy."

What are other options?

It may (and should) be possible to send your child to school if the home environment is not safe. Discuss this with your child's doctor and their school.



Dr Monica Cooper, RCH, Melbourne



FAMILY STORY

Matt and I are big believers to be open about the tough times to inspire or help others that are going through tough times or in tough times to come to know we are here to listen and to support! Here's our story...



We had the most magical natural birth. Two hours post birth Bonnie had an apnea and went totally blue, it happened again 4 hours later.

We were transferred to Tauranga hospital and started running millions of tests, got treated for all sorts of infections and her apnea's continued and we were then ambulated to Waikato hospital.

More tests were run on our wee 1 day old babe and they truly were so hard to watch. We then found out she is missing her corpus callosum (CACC). After a week in Waikato we were then transferred to Tauranga.

Bonnie was doing incredible no more apnea's, we were about to go home and then she had 3 more the next day. These were very scary and kept us in hospital for another week.

From there we had genetic testing done on Bonnie and we have now found out that her 8p chromosome is inverted, duplicated and deleted and this is also the cause for her missing corpus callosum.

This is incredibly rare and there is not many people in the world with this (around 350 people diagnosed) We have been told that she may never walk, talk, developmental delays, she may have many health issues that range from heart, spine, sight and kidney issues.

But every person that has 8p appears very different from severe to mild and no person is the same.

Right now Bonnie is presenting perfectly, she is doing everything a little new born should be doing.

We are holding onto hope and no matter what Bonnies journey is, we will be there with her, celebrating every win and navigating this journey with love, compassion and joy.

This journey has taught us more about life than we have ever known.

It has shown to us that we can choose our mind set and how we want to deal with situations. It has shown and teaching us the importance of being present.

It has given us a whole new respect for parents and children that have walked a similar path. These kids have super powers to help teach us about what truly matters in life.



BIRTHDAY CARDS COMPETITION UPDATE.

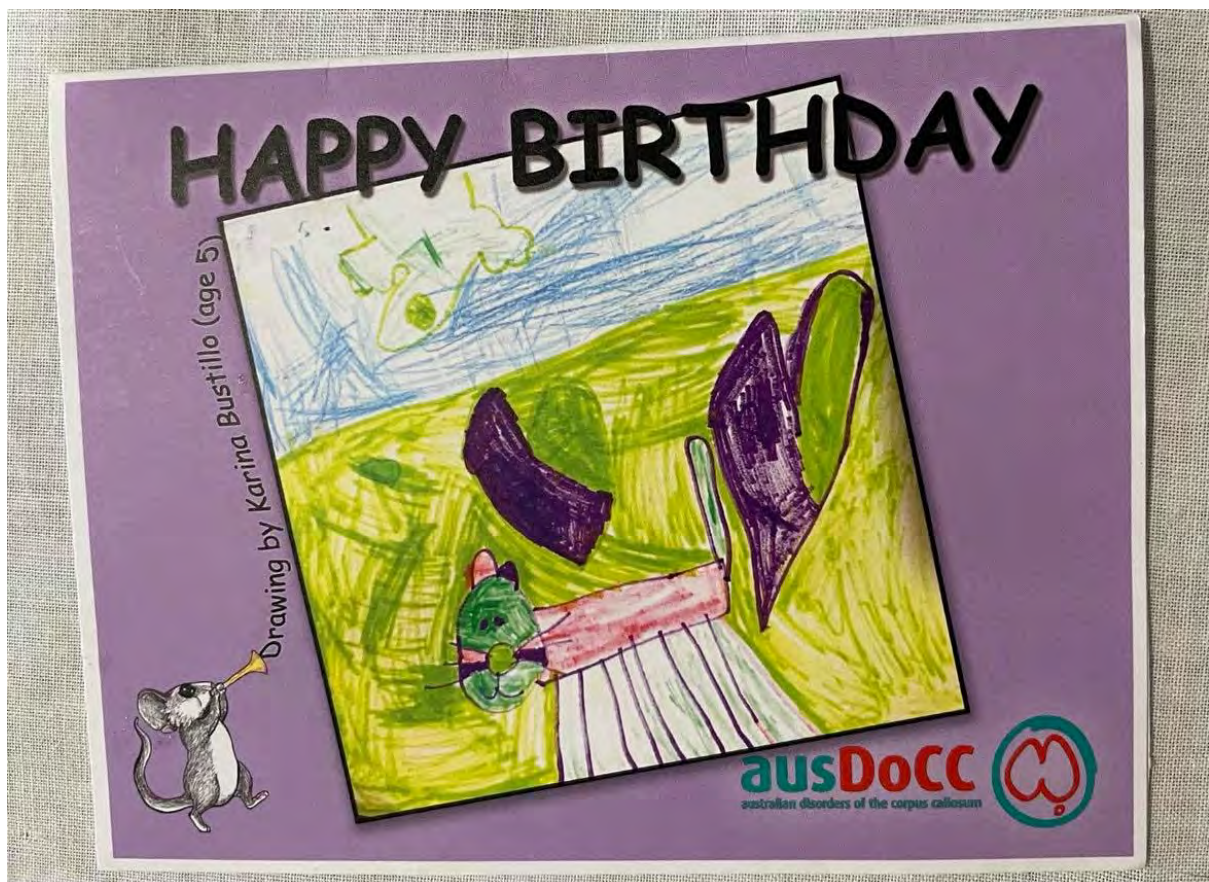
Congratulations Andie and Tahlia. The birthday cards have been printed.

AusDoCC sends birthday cards to all members with a DCC.

This year's birthday card competition had joint winners. Winning designs by Andie McAuliffe and Tahlia Raftery will feature on birthday cards for the next 12 months. The competition runs annually and is open to all kids under 13 who have a DCC.

We will keep the designs a secret so that everyone gets a lovely surprise on their birthday.

Last year's winner was Karina Bustillo with this design featuring a birthday cat.



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 soooooo fun. I got lots of hugs.

I wonder if I will win an Oscar?
Click [here](#) to watch my movie.



Stay safe my AusDoCC family.

Love from Edna.

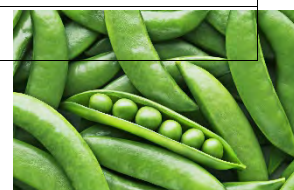




B R I L O Z B M U C I S P A C
 C E Y D N U R R U T Q K F B W
 C B A T I C O P I N S R A P P
 M M Q N O C C R C L X T A A B
 W U H E N H C S F T H C R E C
 J C E G E I O T O B A S I L P
 H U N A Y N L W T B L M C H Y
 T C B S P I I V B E K B C M N
 N O T H Y M E A Y A D A V M N
 P S R E R T G T R W N L P A E
 E E O R I E M Y O I G C C L V
 V E F Y A K R I P M U X A F O
 L E T T U C E S N U A K E D Z
 Q U H S S U W Z X T N T G Q O
 L K B E Z U Q V H Q L F O U U

basil	bean	broccoli	cabbage	capsicum
carrot	cucumber	kale	lettuce	mint
onion	parsley	parsnip	pea	sage
spinach	thyme	tomato	zucchini	

Can you find these words in the grid above?
 They may be forward, backwards, up, down or across. Good luck!



If you would like to send me a photo, story or poem please email it to editor@ausdocc.org.au before 30th
 December 2021 for inclusion in the next newsletter and please don't forget to put your name on it.



Are you an adult with a Disorder of the Corpus Callosum?

Would you like to take part in a study about your satisfaction with life?

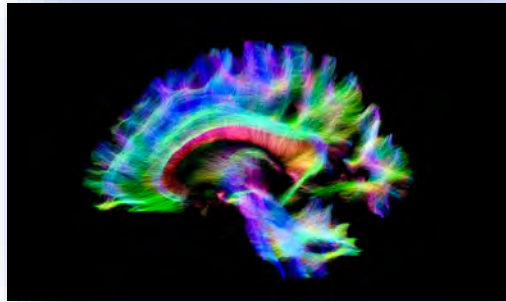


Image courtesy Queensland Brain

What we want to do

We want to learn more about how satisfied Australian adults with a disorder of corpus callosum (DCC) are with their quality of life.

Why we want to do it

We want to see how their quality of life compares with other Australian adults.

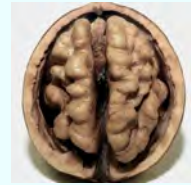
Who we want to take part

Australian adults aged 18 or older, who have been diagnosed with a disorder of the corpus callosum with a CT scan or MRI.

How we hope it will help

It will show us how adults with a DCC feel their quality of life is going. It will help to plan research where adults with a DCC and researchers can explore the lives of adults together. We can tell the people who design policies and provide supports what adults with a DCC need to improve their quality of life.

*Click [here](#) to contact Maree Maxfield for more information.



You can join this study if you are diagnosed with

*Agenesis
*Partial Agenesis
*Dysgenesis or
*Hypoplasia of the Corpus Callosum

18

You can join this study if you are an Australian adult aged 18 years or older, with a DCC



University of Melbourne
Centre for Health Equity.

School of Population & Global Health.

Ethics Approval No.
2021-20393-17872-2

1

WANT TO KNOW
MORE?
CLICK [HERE](#)

2

TO REGISTER
YOUR INTEREST
CLICK [HERE](#)

3

ANY
QUESTIONS?
EMAIL [HERE](#)





Online Research with Professor Linda Richards

Linda and her team are seeking participants with a DCC to complete online research over 2 sessions.

In the first session participants will be asked to complete some questionnaires and then complete two computer 'games' - one with cards and the other moving dots. This will take a bit over 1 hour and you will receive \$25.00 by direct deposit into your bank account

The second session involves a similar computer 'game' where players search through doors for a reward item. This will take around 1 hour and you will receive \$20.00 by direct deposit into your bank account.

If you would like further information, please contact Lisa via email at
corpuscallosumresearch@uq.edu.au

CALLING ALL PARENTS OF TEENS WITH A DCC

Did you know that when your teen reaches 18 they can become a full member of AusDoCC?

This is an important step as they reach the next stage of life – adulthood.

Membership is free.

By becoming a member in their own right, they belong to a unique group of their peers as well as the broader AusDoCC family.

Please click [here](#) to join, sometime leading up to that big birthday.

For anyone else wishing to become a member, a small fee of \$20 gives lifetime membership. Members get this awesome quarterly newsletter as well as discounts to events and first access to offers. Members also support us to be the peak organisation connecting kids and adults with a DCC and their families.



IMPORTANT DATES TO STICK IN YOUR DIARY

2023

AusDoCC Conference

BRAIN SELLS SHOP



Brain Sells

The AusDoCC Shop

www.ausdocc.org.au/shop



You can order AusDoCC merchandise at www.ausdocc.org.au/shop



MEET THE AusDoCC COMMITTEE



Kristina Coburn

AusDoCC President, Social Media Officer



Michael Shanahan

AusDoCC Vice President, Research Officer



Maree Maxfield

AusDoCC Secretary, Website Officer



Maja Palacios

AusDoCC Treasurer, Design Officer



Abbie Kinniburgh

Adult Programs Officer



Tanya Smith

Volunteer's Coordinator



Georgie Lamb



Melo Kalemkeridis



Margaret Krutli



Hilary Bustillo



NOTE FROM THE EDITOR

Thanks again to everyone who contributed articles to this edition of the newsletter and to the team behind the scenes who help to present it. If you have a story or photos that you would like to share in the next edition, please email to editor@ausdocc.org.au by 30th December 2021.

*Enjoy reading
Cheers Margie*



For more information about AusDoCC
visit www.ausdocc.org.au

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

Facebook support group for ADULTS –
<https://www.facebook.com/groups/355338714574689/?fref=ts>

AusDoCC Facebook page – <https://www.facebook.com/AusDoccInc>

AusDoCC research Facebook page
https://www.facebook.com/DCCresearchACT_DETAILS

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