AusDoCC CONNECTS

Quarterly Newsletter

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Read Lisa’s story

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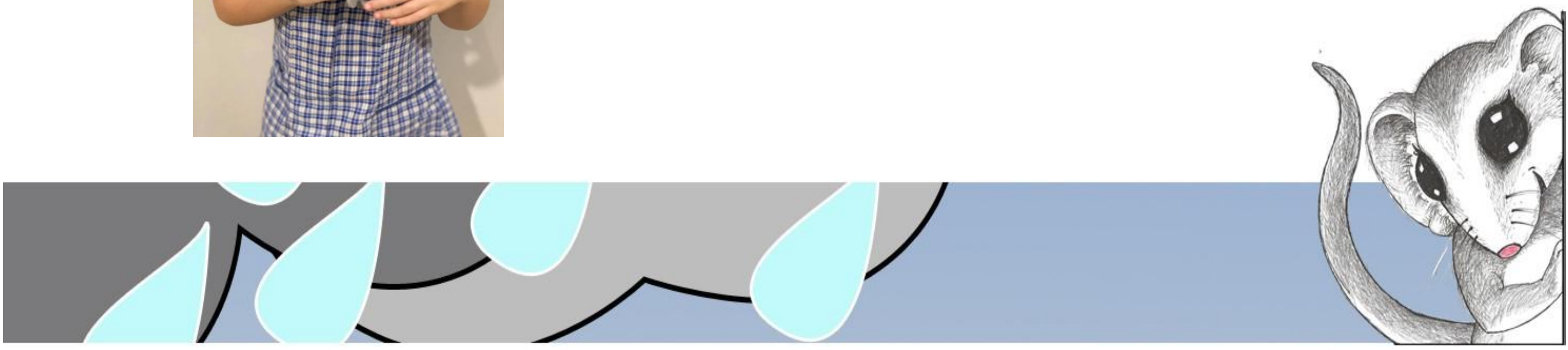
Meet Tracy in The Meeting

Place on page 13

Congratulations Karina.

See page 21



PRESIDENT'S REPORT

Welcome to winter everyone. I hope you are all managing to keep well and stay Covid safe. On the website you will find an official statement on Covid 19 that you may be interested in reading. It was compiled by our AusDoCC advisors.

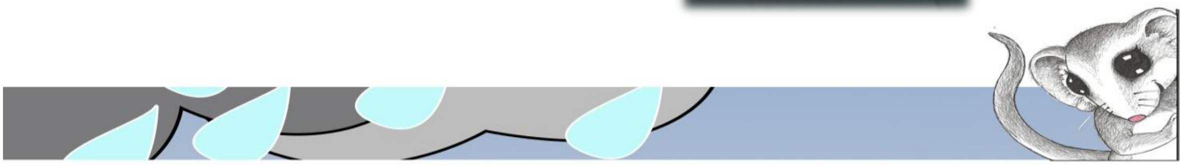
Over the past few months, we have had a few projects on the go, our ACC and Me Books in schools, ZOOM Along with AusDoCC with the ACC adults, media releases and Awareness Day.

During the month of July look out for our new video resources from the Connections 2017 conference and our Top Ten Tips print outs for all life stages. Subscribe to our YouTube channel – AusDoCC Videos. Watch out for Movie Mondays and Top Ten Tip Tuesdays.

AusDoCC's little furry marsupial Edna the fat tailed dunnart has a BIG surprise coming. Edna can be purchased from our online shop, Brain Sells. www.ausdocc.org.au/shop

Until next time,

Love and light
Tina ♡



ACC IN AN AGED CARE SETTING

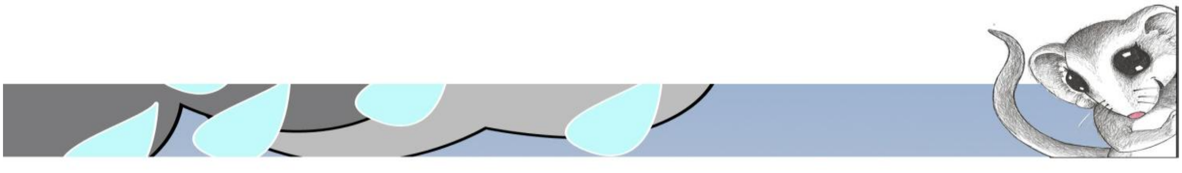
Having worked in the aged care industry in multiple roles for the past 13 years, I have come across many different people with different conditions. However, I have only just been introduced to conditions relating to Disorders of the Corpus Callosum. My role at Hardi Aged Care is specifically entailed to promote the optimal wellbeing for our residents. This often includes finding strategies to provide best practice care, that is individualised relating to residents who may be experiencing behaviours of concern.

The purpose of this article began upon meeting a gentleman aged 69 years old who was admitted into one of our care homes. He had previously lived in another aged care home with a different Provider however, was asked to leave due to “behavioural concerns”. He had been seen by a multitude of external specialists including mental health teams.

He was admitted into our home on respite and admittedly, there were incidents that occurred that had raised questions as to whether we too could accommodate and care for him.

After discovering his diagnosis of Agenesis of the Corpus Callosum, I began doing additional research into the condition. In the aged care environment, we care for a large population of people who are living with dementia. Generally speaking, any behaviours of concern that are observed are usually due to the individual having an unmet need. This quite often can relate to pain, anxiety, boredom, etc. Without knowing too much about Agenesis of the Corpus Callosum, it was difficult to identify what the unmet needs of this gentleman were. He enjoys participating in activities and has been provided with lifestyle choices specific to him; he has good rapport with staff and has even made friends with other residents living in the home. Yet he would still have moments of sudden emotional distress which would result in him expressing frustration towards staff and residents physically. It was often very impulsive and without warning – or so we thought.

I searched through many articles and websites for more information about this condition but this proved very difficult and often didn’t include information relating to older people with this specific condition. I came across the AusDoCC website and decided to make contact and Maree Maxfield from AusDoCC called me. This conversation was an eye-opening moment and really helped me to understand the condition and the needs of a person experiencing it.



ACC IN AN AGED CARE SETTING

This conversation helped me to identify that the times the incidents of verbal and physical agitation occurred; the gentleman was experiencing anxiety. His anxiety often related to the unknown, other people watching him doing a particular task that he is aware can be difficult for him, and a change in routine that he is used to.

The anxiety came down to communication, as I have learned, communication is also something that can be difficult. I had a conversation with him and when asked if he feels anxious and what makes him feel anxious, he simply replied “I get nervous that I can’t get my words out and that I won’t be understood”. He followed this statement with “I get anxious when I have to talk which makes me more anxious and makes it even harder to talk”. Bingo (excuse the aged care content); knowing this key piece of information allowed me to reflect on each incident that had occurred and made me realise that this did not just include verbal communication, but also body language.

It was identified that anything spoken to this gentleman, he took literally and that included body language and his perception of the body language. So, every joke we shared with him needed to be followed up with “I’m only joking” for him to be able to appreciate the joke and have a laugh.

There are multiple layers to this and yet some still to be revealed. Knowing this key information has guided me to look at the environment and how this could be modified to reduce our resident’s anxiety. Our biggest challenge is making the home comfortable for all living there, not just from a physical aspect, but emotionally. People living with dementia may have more difficulty in verbalising and responding, and their body language or the body language of others will not always provide a response for this gentleman to understand. This contributes to his anxiety and increases the risk of him feeling the need to display agitation physically. For example, when he walks with the physiotherapist to build up his mobility capacity, if he sees a resident walking in front or behind him who he knows can be a little confused or disorientated, he fears that this may interrupt his ability to walk, putting him at risk of falling so his instant reaction is to try and move that person out of his way to avoid it.

Taking on board everything to date I have learnt about this condition, training and education for staff has commenced and will be ongoing as we learn more about this condition. We still need to work very hard at this but knowing the possible contributing factors is a starting point. I was surprised to find out that he himself did not know much about this condition as he was diagnosed later in his life, so he too was very responsive to finding out more information.

ACC IN AN AGED CARE SETTING

Although we still have a long way to go, this gentleman now enjoys working within the facility by cleaning and assisting our maintenance worker. He adores our cat Wendy who lives at the home and feeds her daily. He is also supported by NDIS carers and enjoys our bus outings.

This gentleman has chosen to reside in our home permanently. Hardi Aged Care believes that everyone deserves a home and deserves to feel secure. We feel that awareness of Agenesis of the Corpus Callosum is extremely important, particularly for older people living with the condition. We are striving to better understand this condition and improve practice in aged care so that we can offer a good quality of life for people living with this condition and they can be assured that even later in life they will be cared for and have a place to go where their wellbeing is of the upmost importance and that we are skilled to support them.

We are looking forward to supporting AusDoCC to increase awareness and to work together to provide the care that everyone should have access to. Everyone deserves a home, and to feel safe and loved – regardless of age or condition they may be living with.

Francesca Glamorgan
Executive Wellbeing Manager
www.hardiagedcare.com.au

HARDI
AGED CARE

BLACKTOWN GUILDFORD MANLY VALE PENRITH SEVEN HILLS SUMMER HILL

LISA'S LIFE LIVED STORY

Hello readers.
My name is Lisa Doodeman. I'm 50 years old, born in July 1969.
My mother first discovered I had ACC when I was 6 months old.
My nan took me to the royal women's hospital in Sydney where I was tested. You can imagine how testing was back then. Very little was known then and to this day. My mum could not name what tests were done. The story has it that half of my face was growing faster than the other half of my face. My mum was told to just rotate me, and it should correct itself. Today I have a noticeable difference when comparing one side of my face to the other. I don’t like photos of myself, unless my hair is straightened, and I have a face full of make up on. I have a noticeable gap between my teeth.

At the age of 4 years, 1973, I was sent to a place in Parramatta NSW to undergo what would seem an easy test now. But a 4-year-old. An impossibility. Grabbing shapes and putting them into the correct shape holes. Putting things in order/sequencing. The diagnosis was that I have a Processing and Sequencing disorder and would struggle through school.

Sitting with my Big Bear (Grandad), him trying to teach me to count money. Grandad “why is $1 more than 5c?” 1 is less than 5 in a child's mind. But really all I wanted to do was keep the money, so my mother said.

I was held back from Kindergarten, so I started in 1975 instead of 1974.
Primary school was tough. I looked different, felt different and scholastically I was behind.

LISA'S LIFE LIVED STORY

In Year 7 I was in the special AO class. But the work was too easy. I moved schools. Years 8 to year 10 were even worse. I had more crosses in my maths book for 3 years especially in years 9 and 10 at Camden High school. Maths was hard. I could not understand the information.

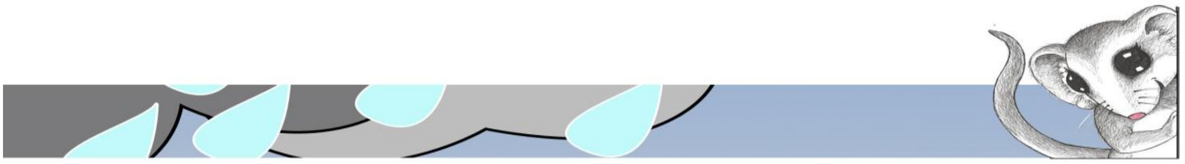
I was the one always picked on. That is when I stayed right at the back of the classroom, quiet as a mouse and I made sure I slumped behind my other classmates. To make myself invisible. But somehow the teacher always stood over me and made me feel uncomfortable. Little did I know in 1993 I would run into him and I quote these words he said.... “I knew you would not amount to anything”. I was a single mother. That hurt me so deeply. I love my son.

I was very tall and skinny. I was very athletic, did gymnastics, long distance running, could hit a ball and was always the outfielder with a good throw arm in softball. I was always the last one to be picked for a team sport. I loved my own company and did not mix well with other kids. Apparently, I was too blonde, too dumb for them. I was not in with the “in crowd”.

I went on to be married and had 2 other children. My daughter Jade was diagnosed with Epilepsy at age 4 and has a cyst on her brain. My last child a Nathan was born with a missing pituitary gland, Polydactyl syndrome, cleft lip and palate, cerebral palsy, a micro penis as well as Diabetes Insipidus (diabetes salt) and other problems. He passed away years ago aged 25.
Doctors said it was a freak of nature. I did not do any substance abuse, but I had food poisoning before I was 3 months pregnant. There were so many if's and but's that not even a paediatrician had the answers. Just treat what we see and know.

Every so often I get really bad headaches, my hearing starts to pop, and my vision is blurred. I wear glasses all the time.

I have tried to put myself through an Accounting course for MYOB. I had to start off with the basic knowledge. It became too overwhelming and impossible to understand. I dropped out. I passed a course with Pittman script shorthand at 50 wpm and can transcribe back to English. I can still touch type to this day.



LISA'S LIFE LIVED STORY

Then I tried Adult Basic education at TAFE. I enjoyed it that much I enrolled for an extra 6 months. I topped my class. I gave presentations on Cerebral Palsy. I worked out that if I've lived the experience that's when I'm at my best teaching others. I found myself in that 12 months. An awakening. I even made the Illawarra newspaper. It showed me that I was not hopeless.

Life certainly got the best and worst of me from there.
I sat for my driver's knowledge test, 4 attempts and I got it. I passed my driver's first go. But getting from my green P's to my blacks was a challenge. Several attempts and 15 years later, when the law changed it clicked over naturally. Now I've been on my black for 10 months, let me tell you, that is a relief and I own my own car.

I suffer with high blood pressure, have obsessive compulsive disorder, and suffer badly with anxiety.
I cook and clean... I am self-taught and I have raised a family on and off, with and without a partner.
For the next 20 years I felt good and bad. At my worst I was suicidal, my psychology stint with counsellors and Shoalhaven area mental health hospital was a lifesaver. I'm still in recovery.

I've worked at “House With No Steps” as an employee and loved it, but something snapped in me. I found myself overwhelmed by people's comments and personal experiences with my youngest child really clouded my thoughts. I was then not able to function mentally. So, I left.

I have now been an aged care nurse for nearly 3 years. Revealing my ACC was never an option. I want to be treated as an equal. My roles are caring for the elderly on a day to day basis and kitchen duties. I do not do medications. Why?.... Simply because I sat to do my online exam and found that after a while, after failing many attempts, I lost hope. My confidence went out the window. The comprehension parts were too cryptic. I still have my job. I have gained strategies to cope, eg: going to work early and starting, setting up, trying to not let my co-worker down. This is almost like an approval thing to me. But it works. I do find however that some nurses take advantage of me, it gets me down. I don't do confrontation.

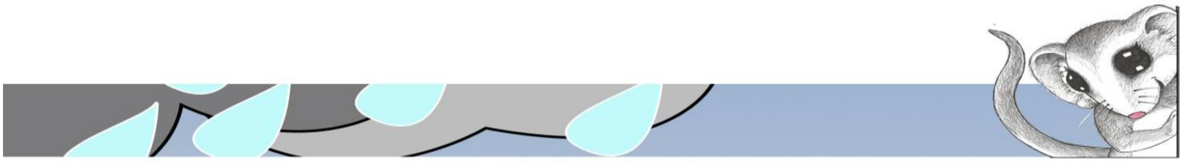
LISA'S LIFE LIVED STORY

My daughter has said that I am very hard on myself. I'm friendly and I treat people how I want to be treated. Sometimes my anxieties get the better of me and I spend the day obsessing about it and crying. As I am right now. This is all too real.

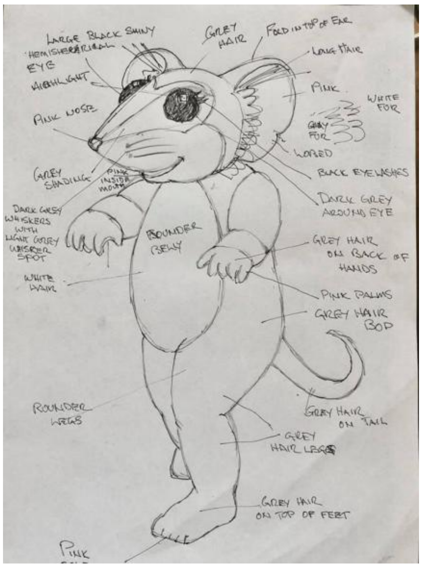
Tomorrow I have an appointment with my GP. I am going to ask about an MRI or CT scan as I want to know more about my brain malformation. As I've said, it was my mother who always told me about ACC and due to non-existent technology back then, I need visual proof. I'm good at advocating and relaying medical jargon to some degree and if I'm unsure I research.

I enjoy photography with my Nikon camera, have a good eye for detail when composing a photo shot. Playing darts is good and I like to score darts. My strategy is to add up in 10's then subtract to get the number. I know that 3 x 19 is 57 by the time the dart lands on the board. Sometimes I come unstuck but that's ok. I love driving by myself to Shep's Mound at Sydney International Airport, near runway 16, on General Holmes Drive, watching the planes. My ultimate dream is to be in the cockpit of a plane on take-off and landing. Reaching 140 kph and rotating. I am just obsessed about flying. It is also my go to place to think and relax. I love cooking with my granddaughters but understanding their homework is beyond me. All I know is 1A + 2A= 3A and that's it.In closing. My life has never been an easy one. Strategies have been the key in navigating life. I have a loving husband and my children. My future daughter in law and granddaughters mean the world to me. I made a promise to always support them, no matter what life brings. Even though life has its challenges I will not be defined by my condition. I am a survivor and an advocate.

By Lisa Doodeman



EDNA'S UPDATE



July 2 was very special day for me.

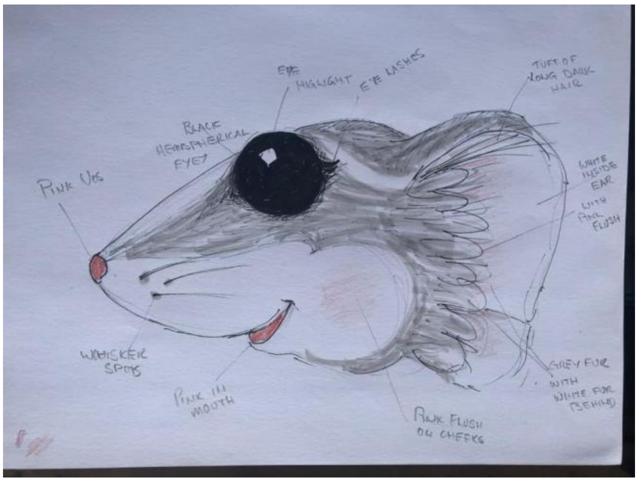
It was all about me and my corpus callosum that isn't there.

I am very excited because I am a legend in my own lunchbox. AusDoCC has made a really, really, big Edna. I had to go and have a photo shoot and do lots of modelling. I got very tired.

I am showing you some photos of how they make a big Edna and a photo of the little Edna that is in the AusDoCC shop. I feel like a movie star because I have my own merch.

Mum says, "Don't get a big head about this Edna or you won't fit through the door." I looked very hard at the photos of Big Edna and I said, "Mum, I think it's a little bit late."

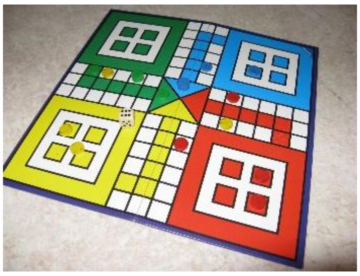
I am so excited for you to meet Big Edna, the super cool gal with no corpus callosum (and maybe a big head!)



WORDSEARCH

FUN AND GAMES

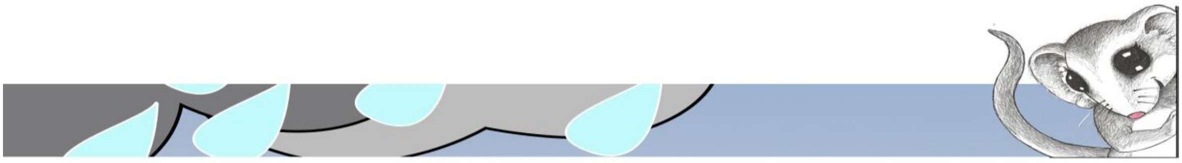
S N Y A D J C E Y P G C G E T S
M N A R E O L L A N O S U L R D
S O A N A B M R U N F X E B I R
M Q G K U N T I N E H D S B V O
N A M O E E O E N I D W S A I W
L T R N S S C I H O G O W R A P
B T M U S T A C T O E D H C L O
P G O Y F P A N S C R S O S P R
H M L O Q C X I D G I V F M U D
F B U K I M M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



Can you find these words in the grid above? Games that have two or more words in the name eg: Trivial Pursuit, will not have a space between words in the grid.They may be forward, backwards, up, down or across. Good luck!

BACKGAMMON
CHECKERS
CHESS
CLUEDO
CONNECTFOUR
DOMINOES
DROPWORDS
GUESSWHO
JENGA
MONOPOLY
MOUSETRAP
PICTIONARY
RUMMIKUB
SCRABBLE
SNAKESANDLADDERS
SNAP
TRIVIALPURSUIT
TROUBLE
TWISTER
UNO

If you would like to send me your favourite photo, story or poem about Winter, please email it to editor@ausdocc.org.au
before 30th September 2020 for inclusion in the next newsletter and please don't forget to put your name on it.



ARE YOU READY TO ZOOM ALONG WITH AUSDOCC?

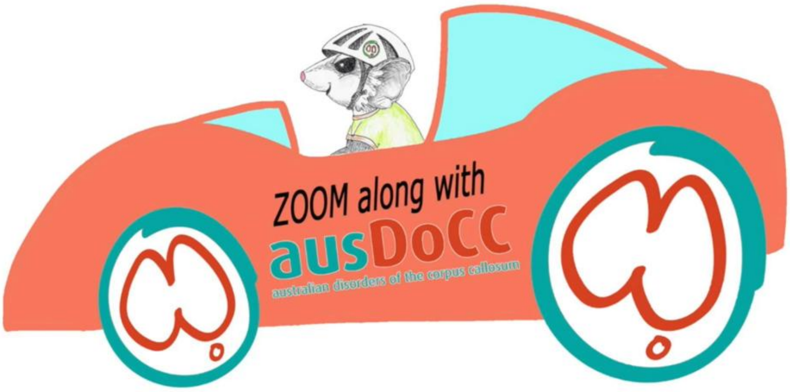
Thanks to the NDIS Information, Linkages and Capacity Building (ILC) grant funding, AusDoCC has been offering zoom training to adults with ACC and Committee members. We know that the best form of connection is to bring our community together in person but we also know that our world has changed dramatically because of Covid 19.

We hope that these trainings will fill part of the gap that is created by not being able to bring everyone together. It won't be permanent but may be something we can use to enhance our future gatherings.

Our Information Technology (IT) guru, Andrew, is running sessions for basic and more advanced training to help people get the basic skills need to chant and join in sessions. We will also hold training for people who would like to host a Zoom session. This will help to develop skills for our adult community to build peer leadership and support.

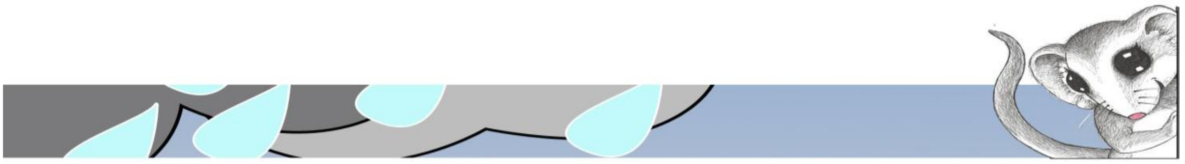
When we have some people all skilled up there will be AusDoCC Zoom Cafes for people to get together and have a chat over a cuppa. We also plan to run some information webinars and some Question and Answer (QandA) sessions where people can ask professionals or peers questions and hear and discuss the answers.

If you would like to join in a training session, follow this link to check out all the different options. All trainings are free. http://connections.ausdocc.org.au/zoom-july/



If you have any suggestions for topics or know any great people who would be suitable to include in QandA sessions, please email info@ausdocc.org.au

Maree Maxfield (AusDoCC Secretary)



MEETING PLACE

ausDoCC
australian disorders of the corpus callosum

This month
at the **'Meeting Place'** Q&A we meet

Tracy Dunbabin

Where do you live?	Doreen, Victoria	**How old are you?**	54
My DCC diagnosis:	Complete ACC	**When were you diagnosed?**	30/9/2002.

Q. What is one of or some of your biggest challenge/s with your DCC (Disorder of the Corpus Callosum)?

A. Not knowing whether life's challenges are due to my ACC (Agenesis of the Corpus Callosum) or other reasons

Q. What do you like doing?

A. Playing sport. Hanging out with family and friends

Q. What/ who are your main supports for you with your DCC?

A. I don't really need any

Q. What do you do with your days?

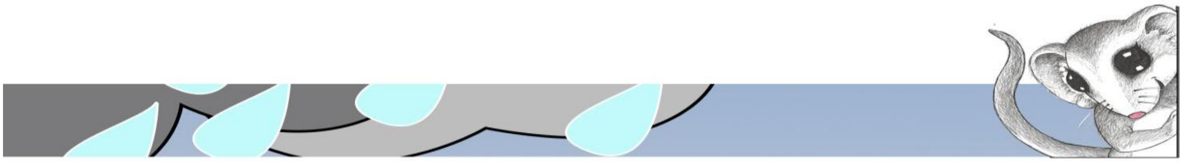
A. I work as a nurse, but I currently have a back injury so am doing lots of walking and strengthening exercises.

Q. What are your interests?

A. Playing netball, reading, watching AFL and learning new things.

Q. What is something unique/special about you BECAUSE of your DCC, or otherwise?

A. I am very caring for others and I have an amazing number recall.



Q. Do you have any pets? Tell me about them.

A. I have an 8 month old puppy called Luna, a cross American Bulldog and English Staffy.

Q. What is your favorite book and/or author and why?

A. I like Jodi Picoult. She writes about some pretty hard topics and really evokes strong feelings.

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

A. Everyone is different and has different strengths and weaknesses. Do the best you can and don't let self-doubt stop you from enjoying life.

Q. If you could give one bit of advice to your child SELF to make things different/ easier, what would it be?

A. Don't put too much pressure on yourself. Everything doesn't have to be perfect.

Q. What is your favorite song, band, singer (or all of these) and why?

A. I like Queen, 'We are the Champions'. It's about overcoming hurdles and being victorious. I'm fairly competitive.

Q. Do you have any siblings? Tell me about them.

A. I have 2 older sisters who I don't believe have any DCC (Disorder of the Corpus Callosum) issues, but they have never been tested.

Q. Was there anything you wished you would be or do when you grew up? Has it

happened?

A. Yes, A nurse

Q. What is your favorite movie or TV show (or both) and why?A. I love Neighbours. It's a great escape from my own life dramas

This is me

International Awareness Day 2020

As July2nd is the middle day of the year, there is not a better day to celebrate and raise awareness for the significant middle part of the brain – The Corpus Callosum.

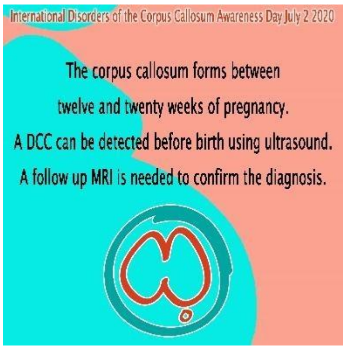
This year we were truly fortunate to have media outlets help us raise awareness of Disorders of Corpus Callosum with some fabulous TV interviews and newspaper outlets publishing articles. We would like to thank our members who participated in these opportunities. You did make a difference, thank you.

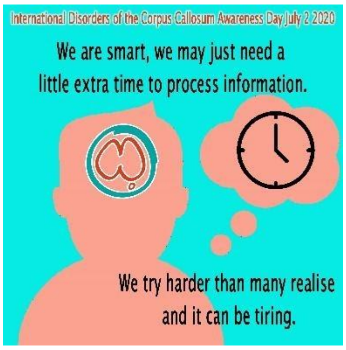
On July 2nd we celebrated birthdays of 5 of our ACCers and we welcomed into the world another tiny ACCer born in New Zealand.

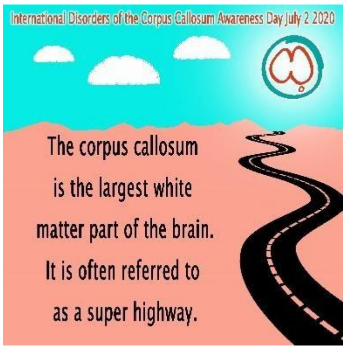
A social media campaign was run using Facebook, Instagram, and Twitter to share with the world, some facts about Disorders of Corpus Callosum.

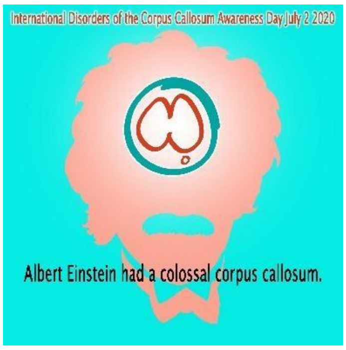
A special thankyou to those who took part in our "Tatts and T's" campaign, and for allowing us to use those photos in our slideshow. Being able to show the world the human side behind AusDoCC is especially important in bringing awareness to the disorder. Cannot wait for next year when we should be able to celebrate by being together.

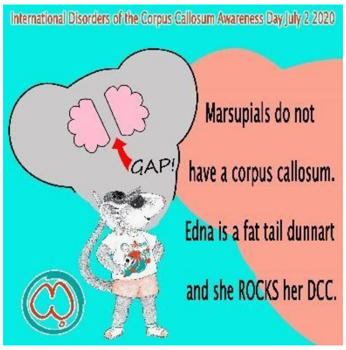
By Tanya Smith

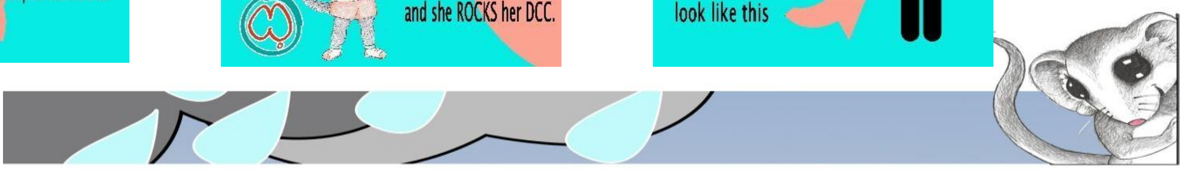












BORN ON JULY 2 – the middle day of the year.

Celebrating International Disorders of the Corpus Callosum Awareness Day.

HAPPY BIRTHDAY to:

Amanda 18+
My name is Amanda. I got diagnosed with agenesis of the corpus callosum (ACC) at one month old. I have four generations with ACC in my family. My mother got diagnosed at 28 years old that she had ACC. I was a month old and my younger sister got diagnosed in the womb.

I struggled with learning through school. I am the mother of two children, Harrison four years old and Maddison seven years old. Maddison has the same disability as me but only moderate. Back in March last year I married my soulmate and husband, Brad, after many years together. Brad has an acquired brain injury.

I live in New South Wales in Lake Macquarie, Newcastle. I am currently working in disability. My own disability doesn't put me down and I am a support worker doing my Certificate 4 in disability. As a mother with a disability and also full-time carer of my daughter and husband I have been through so much but I have overcome it. Nothing is going to put me down.

Shaun 18
Shaun is celebrating his 18th birthday this year so it's going to be a big year all round as we approach the end of year 12 and look forward to what new challenges lay ahead. Shaun loves spending time on his play station so whilst isolation has been challenging for lots of people Shaun has been very happy!! When not 'gaming' Shaun enjoys getting outside for walks and cooking. He is currently working towards completing Cert 3 in kitchen operations.

BORN ON JULY 2 – the middle day of the year.

Celebrating International Disorders of the Corpus Callosum Awareness Day

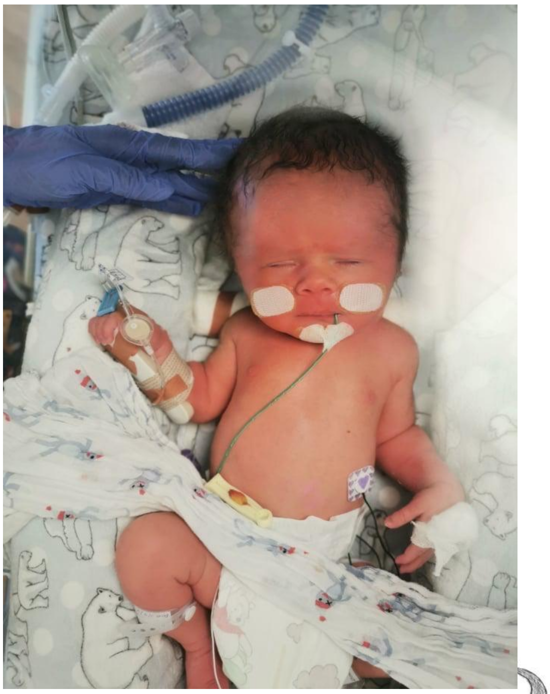
Brooklyn 8
Brooklyn is a cheerful girl, always happy and smiling. She brightens every room with the most amazing smile and giggle. She loves the outdoors, four wheel driving and bumpy boat trips. Brooklyn's birthday is extra special because it is the same date as the International Disorders of the Corpus Callosum Awareness Day; 2nd July.

Oliver 7
This is Oliver, age 7. He’s in first grade and absolutely loves going to school. He is a fantastic reader and speller and continuously amazes us with what he knows. He is a very affectionate and gentle soul and loves spending time with his family. Right now, he’s learning how to ride a bicycle.

BORN ON JULY 2 – the middle day of the year.

Celebrating International Disorders of the Corpus Callosum Awareness Day.

Jagger 6
We can't believe Jagger is turning six on International Corpus Callosum Awareness Day.
He's been in school now for 18 months and has reached so many milestones. He is happiest when rolling around in "Wheels" his wheelchair and "Beetroot" which is his wheelchair accessible vehicle. He's become so chatty and knows his left and right. We couldn't be prouder or love him any more than we do.



Daxton 0
We welcomed Daxton to the world on July 2, 2020, on international disorders of the Corpus Callosum awareness day. The name, Daxton, means warrior who conquers great obstacles which seems very fitting for our little man

THE CURIOUS CASE OF CORPUS CALLOSUM CONDITIONS

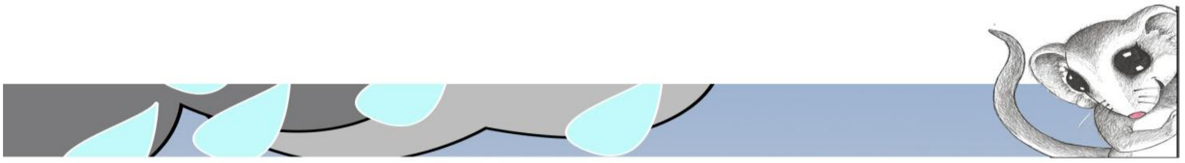
One of the most curious aspects of disorders of the corpus callosum is that affected individuals may exhibit a wide variety of possible structural alterations in brain connectivity. It is this variability, coupled with a lower rate of incidence (affecting only one in four thousand individuals), that has posed one of the greatest difficulties for researchers endeavouring to understand the causes and consequences of this neurodevelopmental condition. Animal models, such as laboratory bred mice, have historically been used to help address some of these challenges as they provide an opportunity to directly study brain connectivity in a controlled system.

The Brain Development and Disorders Laboratory, led by Prof. Linda Richards, has used a number of mouse models over the years that have complete agenesis of the corpus callosum. However, until recently, we had no model to study partial agenesis of the corpus callosum. We use the collective term corpus callosum dysgenesis to encompass all disorders of the corpus callosum including both complete and partial agenesis as well as any other changes to the corpus callosum (for example in its thickness), that are significantly different from the neurotypical size and shape of the corpus callosum observed by magnetic resonance imaging (MRI) at the midline.

Drs Edwards and Fenlon, and their colleagues at the University of Queensland, the University of California San Francisco, and the International Research Consortium for the Corpus Callosum and Cerebral Connectivity (IRC^5), have been investigating the generation of mouse models that would be useful for accelerating research into corpus callosum dysgenesis (CCD). Excitingly, as reported in May 2020 in the peer-reviewed and internationally renowned research journal NeuroImage, they have been successful in characterising a new line of mice known as BTBR x C57Bl/6 N2 (or BTBR N2). These mice, unlike other mouse strains, express the full range of possible corpus callosum disorders, including mice with complete and partial CCD, as well as animals with a neurotypical corpus callosum.

The investigators extensively examined the neuroanatomy and brain connectivity patterns of the BTBR N2 mice, employing methods that have been traditionally used to characterise human CCD, such as high-resolution diffusion MRI tractography. Crucially, the authors were able to validate their MRI tractography findings via a method that fluorescently labelled a small number of neurons in the brain, allowing their precise patterns of connectivity to be directly observed under a microscope. This histological investigation also proved the existence of a neural tract exclusive to individuals with partial CCD known as the sigmoid bundle, which had been predicted to exist based on MRI tractographic findings in some, but not all, people with partial agenesis of the corpus callosum but had not been verified in animal models. The BTBR N2 mouse line will be valuable for future anatomical studies of CCD, and will provide a firm foundation from which other investigators might study the underlying causes of these neurodevelopmental disorders of brain connectivity.

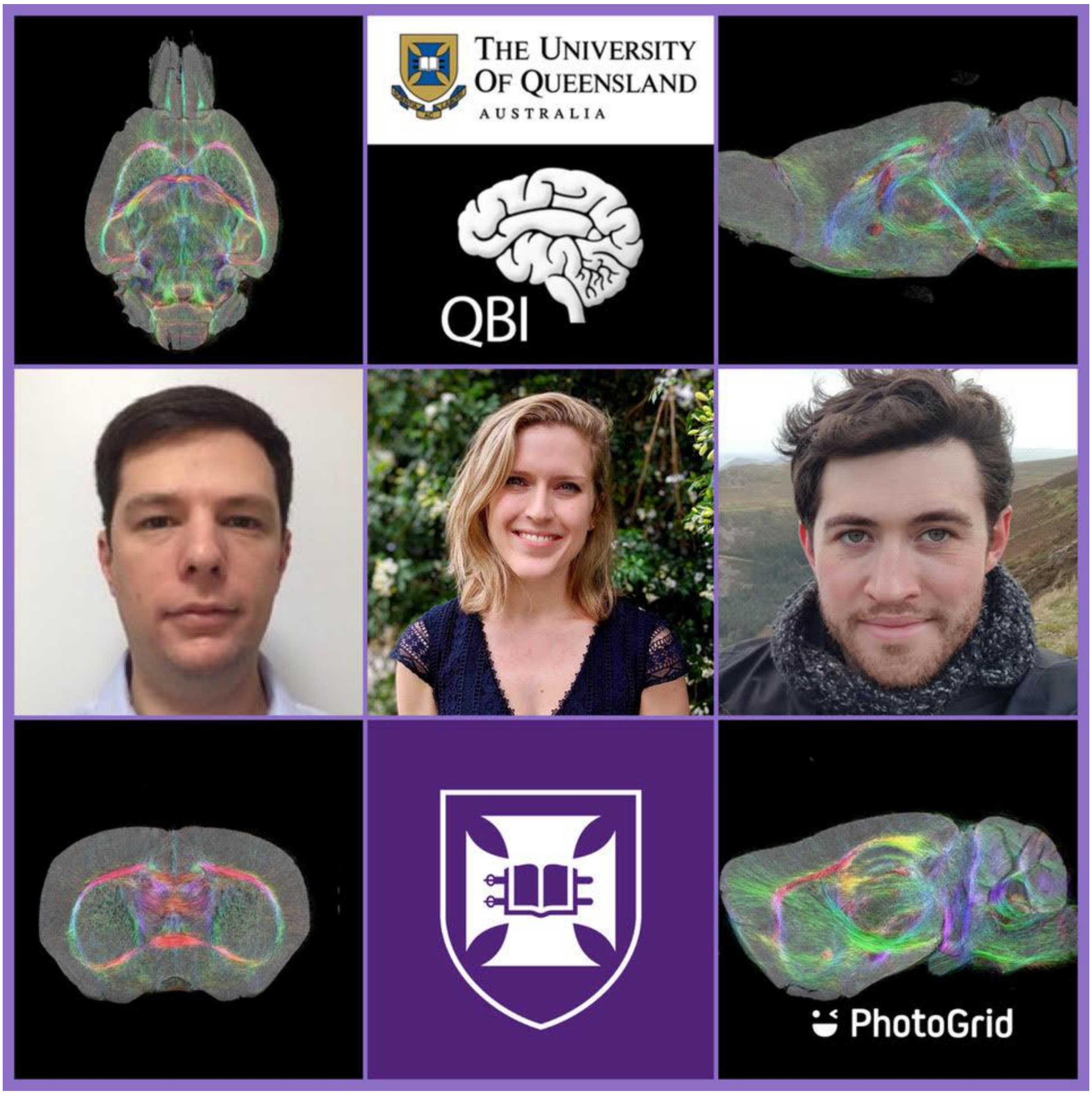
Dr Ryan Dean Queensland Brain Institute (QBI), Brisbane.



THE CURIOUS CASE OF CORPUS CALLOSUM CONDITIONS

Mouse brain images: Dr Timothy Edwards

Note re mouse brain images:The images are of whole brain tractography of a partial CCD mouse.



Dear Karina,

Thank you for your beautiful drawing of the birthday cat.

Guess what?

We love it and you are the **winner** of the competition.

Your picture will be on our birthday cards for the next year.

Congratulations!

You are a very good artist. Keep up the great work.

Love from

The AusDoCC Team and Edna
May 2020

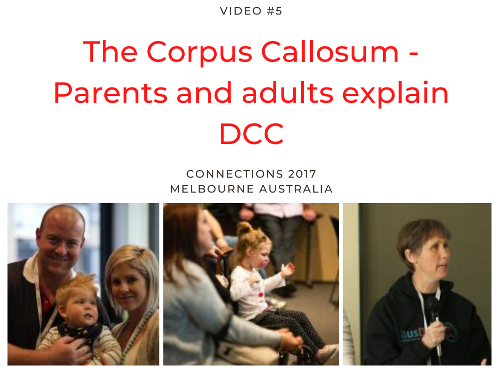
Australian Disorders of the Corpus Callosum
ROAR - Recognition Opportunities Access Resources

CONGRATULATIONS KARINA

AusDoCC VIDEOS ON YOUTUBE

We would love everyone to check out and **subscribe** to our YouTube channel – **AusDoCC Videos.**

Beginning in July we will have **Movie Mondays** and will release a new video every Monday for four weeks. There are seven in the series and the have been made from footage collected at the **Connections 2017** conference



#1 Globally renowned corpus callosum researchers

#2 rRising the profile of corpus callosum disorders

#3 4 Australian clinicians answer 5 DCC questions

#4. DCC and Autism

#5 The Corpus Callosum - Parents and adults explain DCC

#6 The Corpus Callosum with Professor Linda Richards AO

#7 The Psychosocial Aspects of DCC with Dr Lynn Paul

Follow this link to subscribe and check out these and other AusDoCC videos.
https://www.youtube.com/channel/UCEXKFie6Qj75GGNyON8tOpQ/videos

Funded by ndis
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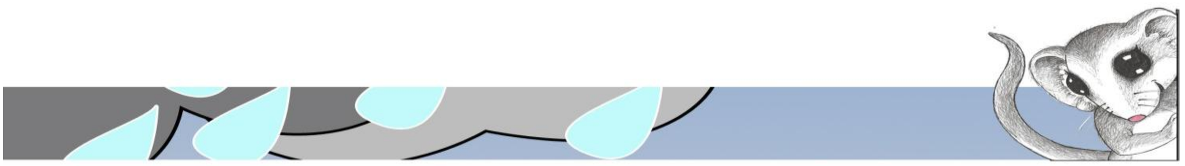


IMPORTANT DATES TO STICK IN YOUR DIARY

2020

23rd August	Information Day - Online

2021

30 April – 2 May	Conference

INFORMATION DAY

The AusDoCC Information Day is going ONLINE!

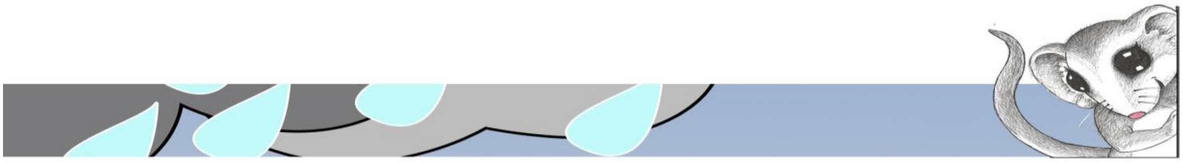
At the beginning of this year, AusDoCC had a goal to hold Information Days in most states and territories around Australia. Unfortunately, COVID-19 came along and we needed to cancel the face to face events. As time has passed and we are finding our way around ZOOM, the AusDoCC committee have decided to hold the very first Information Webinar.

The Information Webinar will include several speakers who research disorders of the corpus callosum or provide clinical support to people in our community. More information will come once the speakers are locked in, but for now please make a note in your calendar if you would like to Zoom in.

When: Sunday the 23rd of August, from 1pm (Melbourne time)

Where: ONLINE! Via Zoom

RSVP: By the 20th of August – email **ausdoccgrants@gmail.com** so you can be sent the link to join in.
We are taking questions for the speakers in advance and on the day. If you know in advance what you will ask, please send it through with your RSVP and we will forward that to the speakers.



NDIS JOINS THE PACK

and ROARS for AusDoCC and PEER SUPPORT

When the committee first heard about the National Disability Insurance Scheme grants, we thought we wouldn’t have a chance at getting one. The Information Linkages and Capacity Building grants seemed out of reach for a small volunteer-led grassroots organisation. The committee put in an application, crossed our fingers and hoped for the best. We were shocked to learn that the NDIS did indeed want to help us ROAR for the DCC community.

ROAR stands for Recognition, Opportunities, Access and Resources.

Through two grants from the NDIS, our organisation has been able to do many things to ROAR. Some of things funded include:

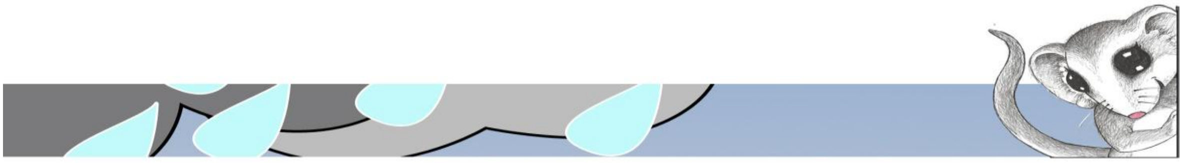
ndis

Funded by the National Disability Insurance Agency

- The human-sized Edna costume made up for events and awareness,
- Building committee skills and processes to make things run smoother and safer,
- Meet ups and information days (before COVID-19!),
- Surveys so we can hear what our members want and need,
- Developed a Zoom training program for people with a DCC,
- An online Information Webinar,
- Mailed out care packages during the pandemic isolation time,
- Birthday cards,
- More information resources, such as the business card size information and top tips for different life-stages sheets,
- Information and awareness videos from the footage we had from past events,
- Further peer support groups,
- The continued development of the online resources and website,
- Support a representative in ‘The Bridge’ – the international support group and IRC5 link,
- The mail out of the ‘ACC and me’ picture books to schools with a child with a DCC in their first year, and more surprises yet to come!

Some of the funding from the grants also goes toward the Adults My People event and the biennial Connections event, where we all get to come together and share stories, laughter and at times, therapeutic tears.

- The support from the NDIS has been and continues to be a great opportunity for AusDoCC. In turn, the support helps the AusDoCC support you, the people of the DCC community, the reason AusDoCC continues to ROAR.



CORPUS CALLOSUM DISORDERS FACT SHEET

1. The corpus callosum is the **major nerve structure** connecting the two sides (hemispheres) of the brain. It allows communication between the hemispheres.

2. People with a disorder of the corpus callosum (DCC) are born missing part or all of their corpus callosum. This may be called **agenesis, dysgenesis, hyperplasia or hypoplasia** of the corpus callosum. It is a lifelong condition. Causes can be genetic, environmental or unknown. There are more than 200 medical conditions or syndromes that have a DCC as one component of the clinical features.

3. DCCs are a relatively common brain abnormality in newborns and occur in approximately **1:4000 live births**, affecting approximately 6500 Australians. Some research estimates that it may be as common as 1:3000 live births.

4. The ICD10 (International Statistical Classification of Diseases) code is **Q04.0.**

5. A DCC diagnosis is **confirmed by MRI or CT imaging**. Advancements in imaging have enabled DCCs to be diagnosed in utero. There are relatively high termination rates. Diagnoses may also be made in childhood or in adulthood after an incidental MRI or CT scan.

6. Corpus callosum disorders are **heterogeneous** in cause, presentation and management. People with apparently the same DCC may have very different impacts, requiring a holistic approach to management.

7. Professional expertise, knowledge and experience with DCC are generally limited and sporadic. **Accurate information can be difficult to access** but there is growing body of research.

8. A DCC affects the speed and transfer of sensory-motor processing information, complex reasoning and problem solving skills and cognitive processing. **Early intervention** is effective in helping babies, children and adults meet milestones.

9. A DCC can have **cognitive, behavioural and social impacts ranging from mild to severe**. A minority of people will have very mild impacts and not need support. Most will benefit from support even if symptoms are not always apparent from simple 'bedside assessments.' Many people will display obvious impacts requiring targeted supports.

10. Adults with ACC in Australia have been typically under supported and under recognised. This can contribute to isolation, mental health issues and reduced capacity to achieve in education, employment and relationships. Although the introduction of the NDIS improves access to support, many adults experience **difficulties finding health professionals who understand** DCC.

References

Brown, W.S. and L.K. Paul, The Neuropsychological Syndrome of Agenesis of the Corpus Callosum. Journal of the International Neuropsychological Society, 2019. ***25****(3): p. 324-330.*
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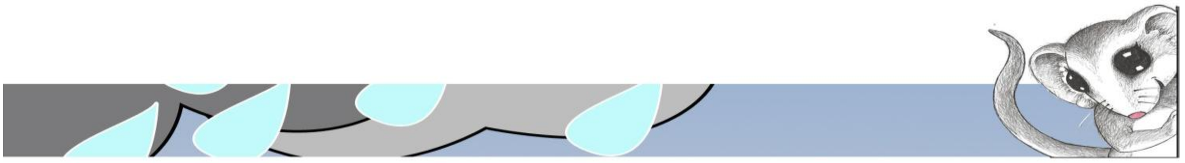

BRAIN SELLS SHOP

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

MEET THE AUSDOCC COMMITTEE

Kristina Coburn
AusDoCC President, Social Media Officer

Maree Maxfield
AusDoCC Secretary, Website Officer

Maja Palacios
AusDoCC Treasurer, Design Officer

Niki Harrison
Vice President, Sponsorship Officer

Abbie Kinniburgh
Adult Programs Officer

Michael Shanahan
Research Officer

Tanya Smith
Volunteer’s Coordinator

John Jonker
Community Fundraising Officer

Anna Uther
Peer Support Officer

Pieta Shakes
Grants Officer

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 September 2020.

I hope that you are safe and well during this difficult time.

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 groups ADULTS –
https://www.facebook.com/groups/355338714574689/?fref=ts

Facebook page –https://www.facebook.com/AusDoccInc

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