AusDoCC CONNECTS

Quarterly Newsletter

SUMMER 2022

Contents

PRESIDENT'S REPORT

Hi Folks

Welcome back everyone I hope you all survived the Christmas/New Year period. Summer is well and truly here. Once again Covid is running rampant in most states, I hope you are all managing to stay safe. These are definitely worrying times.

In November we held our AGM, where we welcomed a new committee. We farewelled Melo and were joined by Alex Andrews and Jade Wright. Our executive committee continues to remain the same, myself as President, Michael as Vice President, Maree as Secretary and Maja as Treasurer, with Abbie, Georgie, Hilary, Margaret and Tanya returning to their roles.

We have recently introduced our "Welcome to the World" program where we not only welcome new babies in the newsletter, but we send them a card and small gift. If you have a new baby who you would like to introduce, please send your details to kristinacoburnt@gmail.com

On April 11 AusDoCC celebrates 10 years since our first meeting in 2012. This is a huge accomplishment. We started as a small Facebook group and have grown into a wonderful charity supporting individuals and families with a Corpus Callosum Disorder (CCD). Our journey has not been without its challenges but with the backing of community as well Professor Linda Richards we remain strong and are here to tell the tale.

With school returning soon, check out our website, under the teachers' tab there is a CCD resource sheet that will help the teacher further understand your child.
https://www.ausdocc.org.au/for-families/teacher-information-mainstream-school/

Our face to face meet ups remain on hold in many states but we are always here for our members. Who would have thought that a crazy virus would determine our every move?

Please remember in a world where you can be anything, Be kind.

Cheers, Tina

🎂

This year AusDoCC celebrates a milestone - the 10-year anniversary. This is a huge accomplishment. We were born on April 11, 2012 when a small group of 9 mums with big plans met together for the first time over a very poor Skype connection. We have grown into an incorporated, registered charity and key corpus callosum support organisation, providing information, resources, support and connection for Australian and New Zealand individuals and families affected by a corpus callosum disorder (CCD).

Over 10 years, we have produced CCD resources, created a website, distributed a regular newsletter, shared the ups and downs on Facebook groups, established close links with global support groups, health professionals and researchers and held gatherings where our members could finally meet others face to face, often for the very first time. We've also embraced our very own life-sized mascot, Edna the Fat Tailed Dunnart, who, like other marsupials, has no corpus callosum.

Thank you one and all for your support and involvement over the past decade.

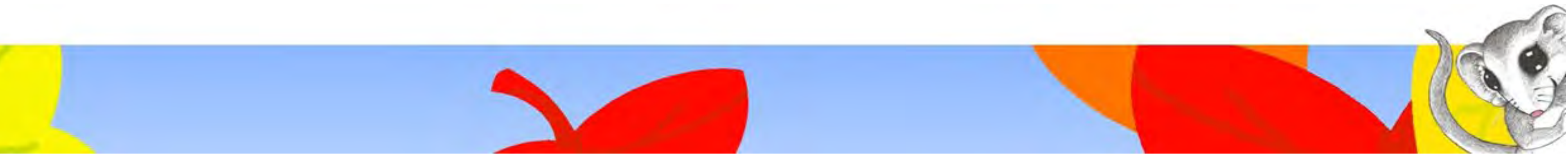
The Pointy End - $

AusDoCC is entirely 100% operated by an annually elected volunteer committee of parents and adults with a CCD. We have no recurrent funding and rely on grants and the generosity of our donors.

You can become a Decade Donor:

1. **10 for 10**. We are asking people to donate $10 for the 10 years ($1 for every year we have been around).
2. **100 for 10**. If you would like to donate more, please consider a $100 donation to receive a unique commemorative pin celebrating our milestone.

All donations over $2 are tax deductible and 100 % of our donations go to supporting our AusDoCC community programs and resources.



LETTERS FROM LINDA IN ST LOUIS

From Professor Linda Richards in the US.

Happy New Year! I'm in St Louis, US.

The team have been busy and we have produced our first paper working with Peter Dayan. Although it has been submitted to a journal, it has not yet been peer reviewed. However, you can read a preprint by clicking here

Essentially, we found evidence that people with (Corpus Callosum Dysgenesis/Disorders) CCD are susceptible to increased persuadability and credulity. Interestingly, this is independent of how they scored on a measure of autism that we administered. We're planning several more papers this year on the work we did with some of the CCD adults at the My People conference and using the tasks we sent out afterwards, so this is just the first study. We are still analyzing the results of the other studies and collecting additional data from neurotypical individuals to compare.

I'm really excited about this work.

On a completely different note, I'm attaching a few photos of elk, reindeer and buffalo that we took at a park near where we are living in St Louis. This is not a zoo but a national park nearby.

AUSTRALIAN CORPUS CALLOSUM DISORDERS (CCD) RESEARCH PROJECTS

Huge thanks to everyone who has participated in Australian corpus callosum research so far. We look forward to other participants from our Australian community. This research is vital to grow the knowledge about the impacts of CCD and assist with advocacy to gain greater understanding, recognition and supports. **You may be eligible for either or both the projects described in this newsletter.**

Project 1: Adults with a CCD - Current

A Good Life: Exploring the personal wellbeing of Australian adults with corpus callosum disorders (CCD)

This project explores how the impacts of a corpus callosum disorder (CCD) affect the personal wellbeing of adults.

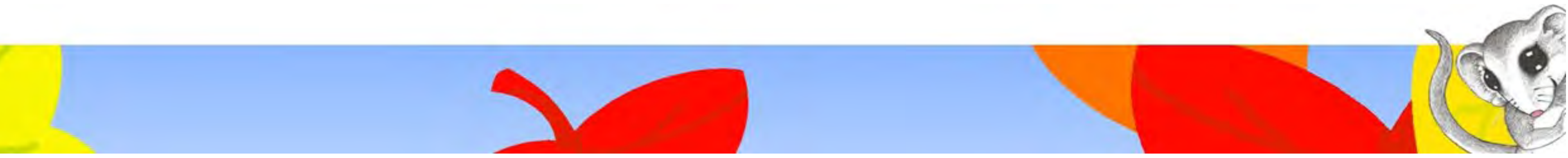
Our team will explore ways in which adults with a CCD can most effectively communicate their needs related to subjective quality of life (also known as personal wellbeing or happiness). It is codesigned and implemented in collaboration with three adults in the CCD community as co-researchers (Michael Shanahan, Tanya Carroll and Margaret Krutli).

We know that CCDs are extremely heterogeneous. This means that they have many different causes and presentations with a broad range of impacts, from mild to severe. We know that adults diagnosed with a congenital CCD may face cognitive, physical and psychological challenges.

There is no evidence-based research about quality of life or personal wellbeing of adults with a CCD. We want to understand the elements that help to have a good life and identify the barriers faced. The best way to know more about the lives of people with a CCD is to ask those who live them.

In 2022 we will conduct the first study, measuring personal wellbeing using the Personal Wellbeing Index.
Click here to take the **Personal Wellbeing Index** survey.
Click here to **access the research website** and learn more about the research and the team.
Click here to **read a research article** on the lived experience of Australian adults with a CCD.

For more information: *Contact lead researcher, Maree Maxfield,* m.maxfield@student.unimelb.edu.au
PhD candidate | Melbourne School of Population and Global Health | University of Melbourne



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 Institute

What we want to do

We want to learn more about how satisfied 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 after having 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..

Any questions? *Contact researcher, Maree Maxfield* m.maxfield@student.unimelb.edu.au

?

WANT TO KNOW MORE?

CLICK HERE

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TO REGISTER YOUR INTEREST CLICK HERE

◎

TO TAKE THE SURVEY

CLICK HERE

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 aged 18 years or older

THE UNIVERSITY OF MELBOURNE

Centre for Health Equity.
School of Population & Global Health.

Ethics Approval No.
2021-20393-17872-2

V16. 211130 MM

EDNA THE BRAVE ONE

Edna the lucky, Brave One, (that's me), had a great time at Christmas because there were presents. We couldn't see lots of people because of Covid but there were still presents. My best present was some floating jellyfish. They are not real jellyfish but they look like they are and the water changes colour.

When we go out, we wear a mask and we don't go to crowded places. Mum says, "Wear your mask Edna unless you're eating." The best place to go out was in the car and we drove around and looked at all the Christmas lights. I didn't have to wear my mask in the car.

Last week I got my Covid vaccination. I was very brave. Soon it will be school again. Yippeeeeee!

Have a great rest of summer everyone and stay away from the Covid monster.

Love from Edna (The Brave One)

WORDSEARCH
CARING FOR EACH OTHER

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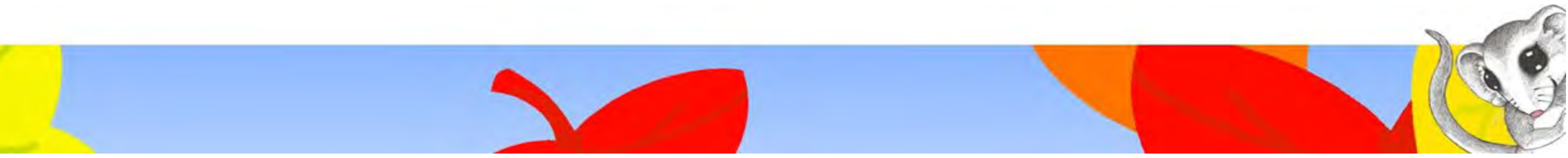
S	P	K	L	L	L	A	U	G	H	T	E	R	B	M
T	U	D	I	B	X	P	F	R	T	Q	A	E	G	D
F	S	E	H	T	L	A	E	H	A	Y	F	A	H	U
D	N	W	Y	E	L	J	Q	O	Y	G	R	K	V	C
T	M	A	H	C	P	M	O	J	U	X	E	E	G	Y

CARE	CHEERFUL	ENCOURAGE
FAITHFUL	GENEROUS	GENTLE
HEALTH	HELP	HONEST
HOPE	KIND	LAUGHTER
LISTEN	LOVE	RESILIENT
SHARE	STRENGTH	SUPPORT
TRUST	WELLBEING	

These words can show our thoughts and care for others.
How many of these words are about you?
Can you find these words in the grid above?
They may be forward, backwards, up, down or across. Good luck!



JOAN’S STORY

After a normal pregnancy Joan came into the world. Shortly after being born, she had respiratory distress and went into the special care unit for a week. One of the nurses said she looked a bit ‘undercooked.’ She had a premature look about her even though she was quite big.

Joan didn’t meet the usual milestones of lifting her head, rolling and crawling and at the age of one she had an MRI. The doctor told us that most of Joan’s Corpus Callosum was missing. We were referred to a physiotherapist who worked with us over the next 12 months to get Joan walking, which happened just after her second birthday.

We went into overdrive researching the condition and were very lucky to find AusDoCC and Professor Linda Richards. A trip to Melbourne to see Dr Rick Leventer and Dr George McGillivray helped us a lot. We went to the first AusDoCC conference in Brisbane, it was so good to meet others with a CCD, I could see that people live a full and meaningful life with this condition.

We recently received the results of genetic testing. Joan has a genetic condition called an NFIA related disorder. The main feature of this condition is a Corpus Callosum Disorder (CCD).

Joan has low muscle tone, difficulties with speech and some issues with her jaw alignment. She wore a Herbst appliance last year and her jaw is now looking much better.

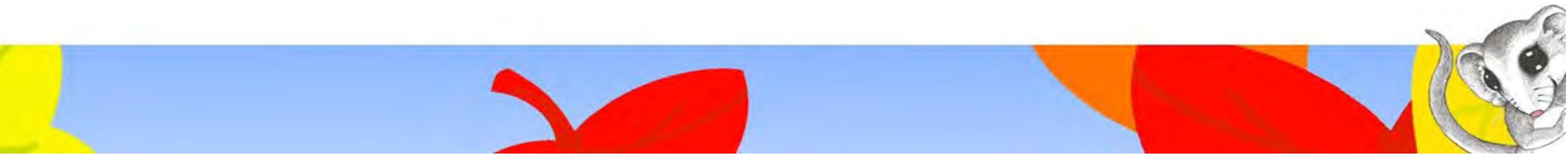
Joan is now eleven and leads a very full life with lots of swimming, playing with her pets (2 guinea pigs, a cat and a dog), her friends and her brother Patrick who is 13. Patrick and Joan like playing video games together.

Joan goes to a mainstream school and does struggle academically and socially at times. She needs a fair amount of support. She is kind and generous but also very much her own person and doesn’t put up with people being mean to her. In fact, she is generally quite good at telling people where they are going wrong (including me).

Whilst Joan struggles academically, she has some significant strengths. She has a very good visual memory and she can be very resourceful.

Joan is now reading fairly well. However, the pace is slow, she gets distracted very easily and needs help staying focused. The ABC Reading Eggs helped a lot in the beginning. I was quite anxious about Joan’s school progress in the early years. I’m more relaxed now taking the view that she is continuously improving in all areas, just not at the same pace as the other kids.

Joan has had some difficulty socially at school, some kids don’t like difference and we have found this very hard to accept. In 2021 Joan joined Girl Guides, this has been fantastic for her. She has met a great group of girls who are really caring and supportive. She has been on two camps and has had other exciting girl guide adventures.



We love our family holidays on Stradbroke Island in Queensland and think that the swimming, walking and chasing soldier crabs is the best therapy ever. Joan is much loved in our family and wider community, and we feel very positive about her future.

Alex Andrews (Joan's mum)

AUSTRALIAN CORPUS CALLOSUM DISORDERS (CCD) RESEARCH

Project 2 – Mothers of babies with a CCD – from February 28, 2022

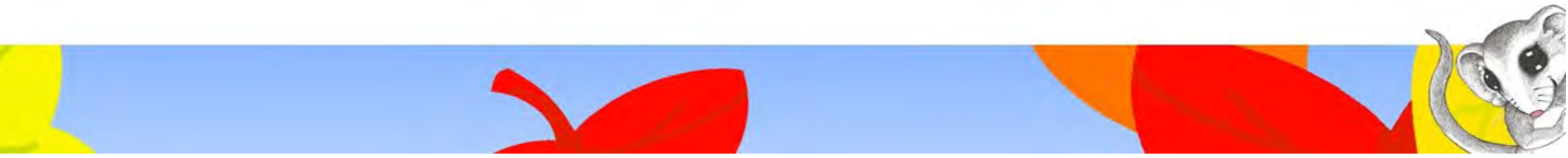
Experiences of mothers who were told that their unborn baby had an issue with their corpus callosum

CALL FOR PARTICIPANTS

Thank you to AusDoCC for again sharing this call for participants! I am a PhD Candidate currently undertaking a study into the experiences that mothers go through when they are told that their unborn baby has an absent or underdeveloped corpus callosum. So far, I have held interviews with mothers from Australia, USA and UK, and held two focus groups online. I will be holding a third focus group from ***February the 28th 2022****. The groups are online and run like a private discussion forum where eight mothers post anonymously over a five-day period. There will be topics about the experience of receiving a prenatal diagnosis, to see if this resonates with your own experience.*

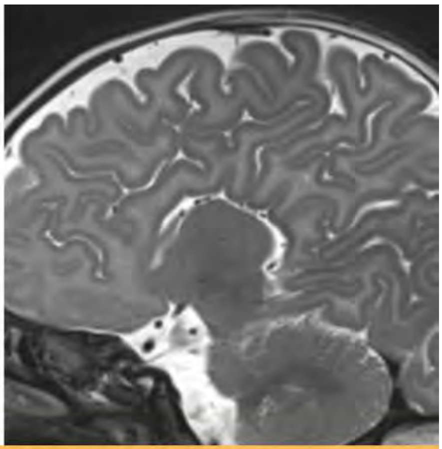
To participate you must be the mother of a child with an absent or underdeveloped corpus callosum who received a diagnosis before birth. The child must be older than 6 months and younger than 4 years old. Mothers with a first language of English, who live in Australia, New Zealand, USA, UK or Canada can join in, and as the focus group is online, you should have technology to access to join the online forum at times that suit you over the five-day group period.

If you would like to take part, please email me at p.shakes.10@student.scu.edu.au so that I can forward the study information sheet and consent form.



SHARE YOUR STORY

Were you pregnant when you were told that your baby's **corpus callosum is different to the typical?**



We are seeking mothers for a study that hopes to capture their experiences from when they were told that their unborn baby has an issue with their corpus callosum, through until the birth of their child.

To be eligible to participate, you must:

- be the biological mother of a child who was diagnosed with an atypical corpus callosum, before birth and is between 6 months and 3 years old when signing up to the study
- speak English as your first language
- live in Australia, New Zealand, The USA, The UK or Canada
- have access to participate through online conferencing or access the online forum
- be over 18 years of age &
- provide consent

The study will involve:

One-to-one interviews held over online conferencing

Online focus groups held within a private online forum

You can choose to take part in either or both

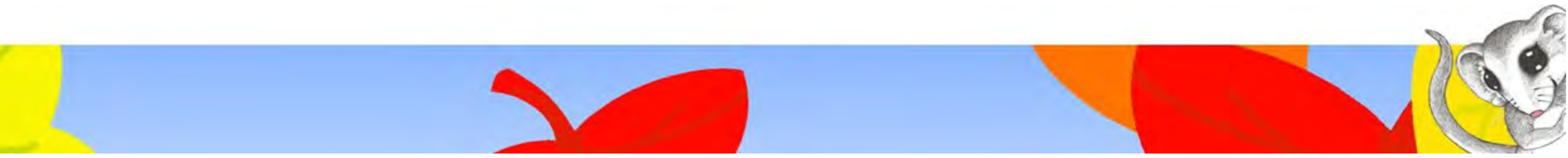
For this study, the atypical corpus callosum could be:
missing/ absent (agenesis),
partial agenesis,
thin (hypoplasia),
dysgenesis or hypogenesis.

This research has been approved by the Human Research Ethics Committee at Southern Cross University. The approval number is ECN-19-200

If you want to take part, or would like further information, please email Pieta Shakes at p.shakes.10@student.scu.edu.au

Southern Cross University

This research is supported by an Australian Government Research Training Program (RTP) Scholarship



EARLY DIAGNOSIS OF CORPUS CALLOSUM DISORDERS

Why do some people find out about their baby's corpus callosum disorder (CCD) during pregnancy, while others receive a diagnosis after birth?

Corpus callosum disorders are considered one of the more common brain anomalies found through ultrasound during pregnancy, although some people only find out after birth. The reason for this is the challenge in identifying corpus callosum disorders through prenatal ultrasound.

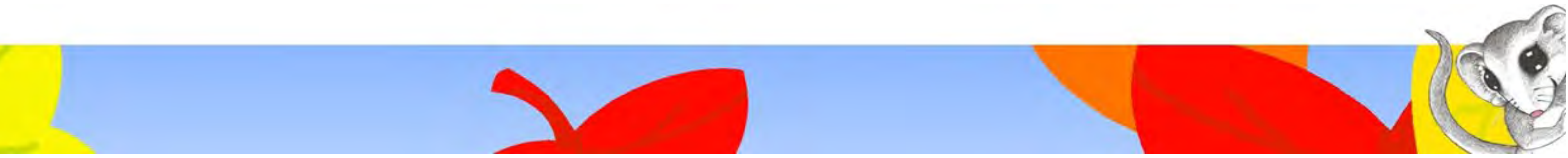
International and Australian guidelines for the mid-gestation ultrasound (between 18-20 weeks) do not specifically recommend an assessment of the corpus callosum.[1,2,3] In fact, the guidelines published before 2020 do not even mention the corpus callosum at all.

There are other parts of the head and brain that are measured or viewed as standard, including the cavum spectrum pellucidum (CSP) and the lateral ventricles. The most recent international ultrasound guidelines, published in 2020, highlight that when the CSP can't be seen or is a different shape than usual, this can be an indirect sign of corpus callosum dysgenesis.[2]

The guidelines also mention that a missing CSP may be noted alongside "tear-drop shaped" lateral ventricles, known as colpocephaly.[2] The lateral ventricles are two fluid-filled spaces in the brain. When these spaces look larger than usual and have a distinct disproportionate shape, then colpocephaly can be diagnosed. This enlargement may be caused by the lack of the usually thick rear part of the corpus callosum and the difference to the position of the hippocampus common in corpus callosum dysgenesis.[4] Some clinicians and researchers use the term ventriculomegaly instead of colpocephaly, which also refers to dilated (enlarged) lateral ventricles.[5] Like many terms in the world of corpus callosum disorders, different teams use different terms, which can make things confusing.

While different terms can create confusion, we know with more certainty that other parts of the brain may develop differently when there is corpus callosum dysgenesis. During pregnancy ultrasounds, it is often these other differences that lead to a suspicion or diagnosis of corpus callosum dysgenesis. The axons that become the corpus callosum cross the midline of the brain between weeks 13 and 19, hence the structure cannot be seen in full prior to 19 weeks gestation. Even at this time, the corpus callosum is hard to visualise, but is frequently attempted now due to more knowledge and better technology. The 2021 published guidelines for "targeted fetal neurosonography" due to an increased chance of neuroanatomical differences, includes an assessment of the corpus callosum but this type of ultrasound requires expertise.[6]

Even with the best knowledge and technology, prenatal diagnosis can be hard as the "indirect signs" of a corpus callosum disorder are not always clear. The CSP may indeed look typical when part of the corpus callosum has formed, and another structure can sometimes mimic the CSP, so can look like it's there. Despite corpus callosum dysgenesis, the lateral ventricles can also be the typical size at the mid-gestation scan. While the ventricles commonly increase in size as pregnancy continues when there is a corpus callosum disorder,[7] this doesn't happen for every baby, and many people don't have ultrasounds after the mid-gestation scan anyway.



With all these challenges, there will be some families who receive a diagnosis in the middle of their pregnancy, some who find out late pregnancy and others who first learn about a diagnosis after birth, sometimes many years down the line.

References

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2. Malinger, G., et al., *ISUOG Practice Guidelines (updated): sonographic examination of the fetal central nervous system. Part 1: performance of screening examination and indications for targeted neurosonography.* Ultrasound in Obstetrics & Gynecology, 2020. **56**(3): p. 476-484.
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4. Poduri, A. and J.J. Volpe, *Neuronal Migration*, in *Volpe's Neurology of the Newborn*. 2018, Elsevier. p. 120-144.
5. Shakes, P., A. Cashin, and J. Hurley, *Scoping review of the prenatal diagnosis of agenesis of the corpus callosum.* Journal of Obstetric, Gynecologic, & Neonatal Nursing, 2020. **49**: p. 423-436.
6. Paladini, D., et al., *ISUOG Practice Guidelines (updated): sonographic examination of the fetal central nervous system. Part 2: performance of targeted neurosonography.* Ultrasound in Obstetrics & Gynecology, 2021. **57**(4): p. 661-671.
7. Masmejan, S., et al., *Natural history of ventriculomegaly in fetal agenesis of the corpus callosum.* Journal of Ultrasound in Medicine, 2019. **39**(3): p. 483-488.

About the authors.

Pieta Shakes is a Lecturer and currently undertaking her PhD research into the experience of mothers after learning their unborn baby has corpus callosum dysgenesis and has published several related papers. Her PhD topic was inspired by her own lived experience as a mother of a child with CCD.

Dr Samantha Thomas and Alison Deslandes are accredited and qualified obstetric sonographers who work clinically, within research and education. Sam was recently awarded *ASUM Sonographer of the Year* for her ongoing work to improve communication within obstetric sonography.

Pieta, Sam and Ali are board members of *Through the Unexpected*, a registered charity with the vision that all people are informed, supported and empowered through the experience of prenatal diagnosis.

Note. Images are from “The challenges for patients and sonographers when complex obstetric anomalies are identified” by P. Shakes & A. Deslandes, 2021, *Sonography, 8*(2), p.66 (https://onlinelibrary.wiley.com/doi/abs/10.1002/sono.12260)

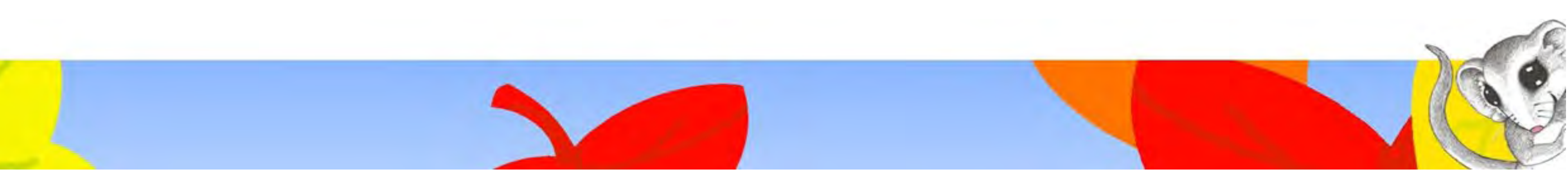
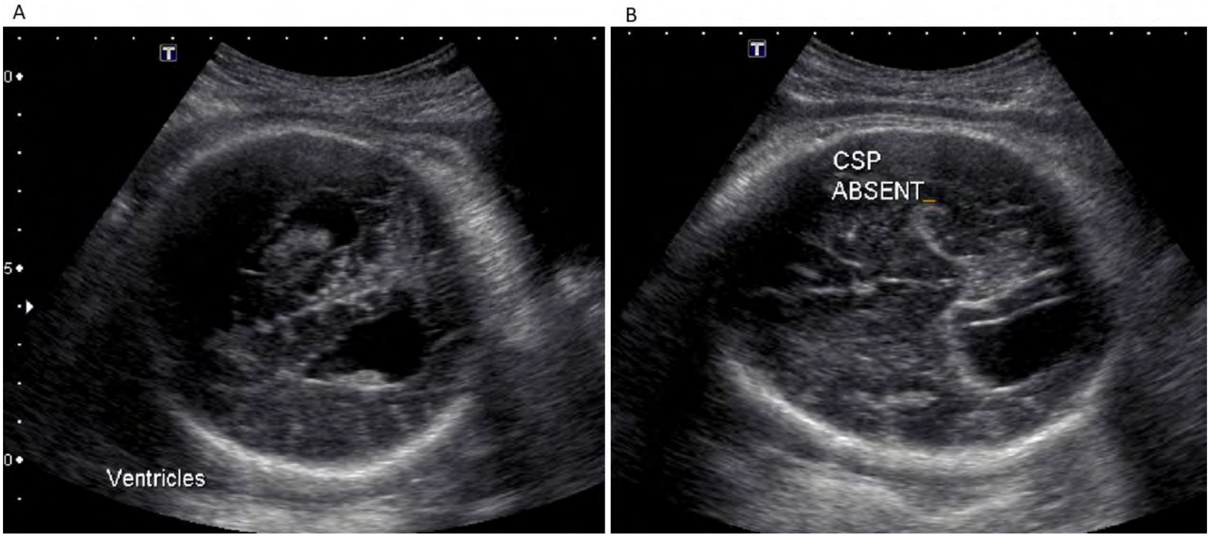
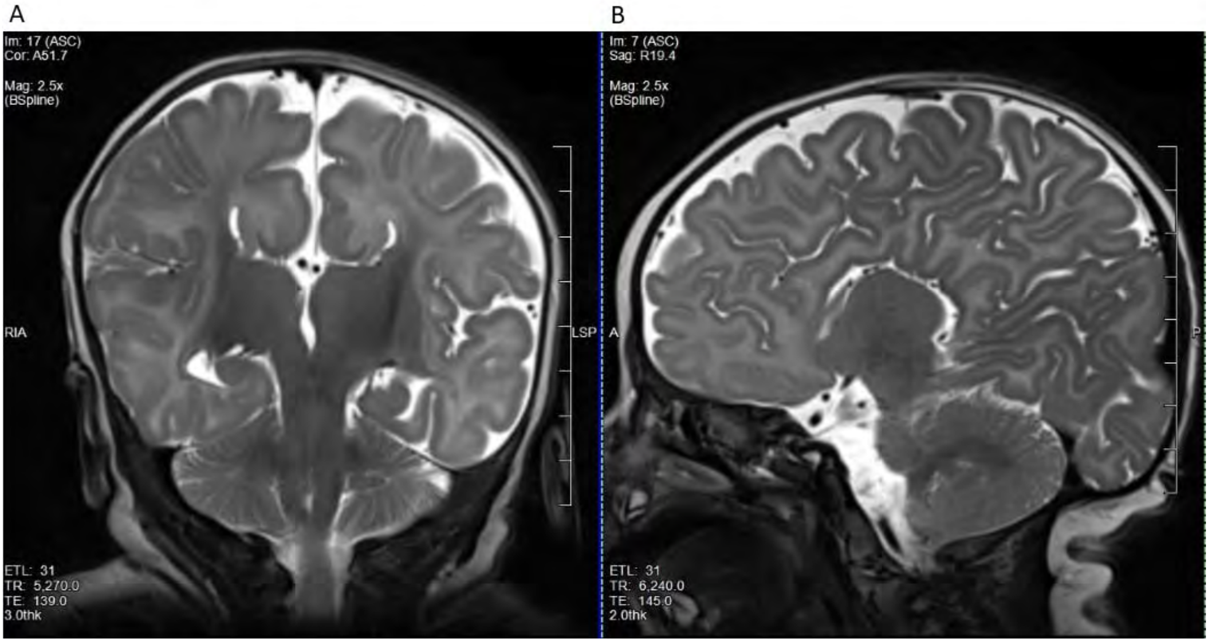


Figure 3:



An ultrasound of the fetal head at 37 weeks and two days. The white arrows indicate bilateral ventriculomegaly (A) and an absence of the cavum septum pellucidum (CSP) (B). It should be noted that in typically developing fetuses, the CSP may not be seen late in the third trimester.



MRI images performed on the infant at three months of age confirming the absence of the corpus callosum in the coronal (A) and sagittal (B) planes. The corpus callosum should be seen in the regions of the white arrows but in this case, is absent

This month at the ‘Meeting Place’ Q&A we meet….

Lynette McGoggan

Where do you live?	Melton West, Victoria	**How old are you?**	53
My DCC diagnosis:	Complete Agenesis of the corpus callosum	**When were you diagnosed?**	Age 40

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

A. I have depression and anxiety issues. I get overwhelmed easily, I can only do one task at a time and I get upset really easily.

Q. What do you like doing?

A. I love to cook, listen to my favourite music, gardening and swimming in my pool.

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

A. Donna (my bestie) and her family.

My four boys- Alex, Christ, Will and Josh.

Q. What do you do with your days?

A. I spend a lot of time in the garden. I cook a lot. I do everyday chores. I play Uno and Scrabble with my youngest son Josh.

Q. What are your interests?

A. My interests are reading romantic novels, cooking and gardening.

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

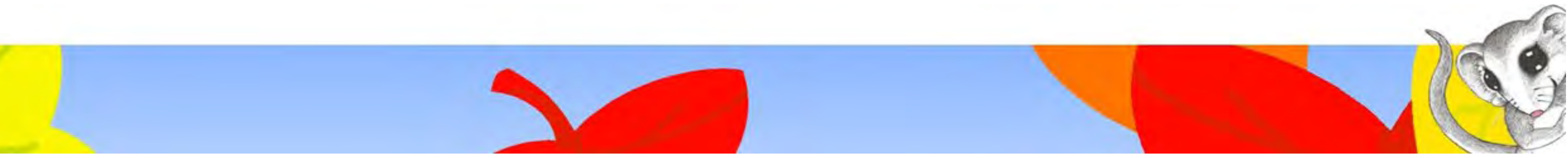
A. I can play a song on the keyboard after hearing it once. I am very good at drawing landscapes.

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

A. We have 4 pets.

1 male cat called Smooch, 2 female cats called Bella and Mia,

1 bird, a lorikeet called Squawker



Q. Do you have a favorite joke? What is it?

A. Knock knock…

Who's there?

Alice….

Alice who?

Alice Springs! Lol.

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

A. At the moment I'm reading 'Twilight, Breaking Dawn' by Stephanie Meyer. I love reading a story of romance that includes vampires.

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

A. Always do your best. Be happy with yourself that you can achieve or are achieving what you want to do.

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

A. Routine is always a plus. Always focus on things you are good at, no matter how big or small it is. Learn to love yourself because we are special.

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

A. My favourite band is Abba. My favourite song is Ring Ring. It puts me in a happy mood.

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

A. I have a younger brother Steve, and adoptive older brother Richard and an adoptive younger sister Suzanne. I don't have any contact with them or get any support from them. To them, I'm a 'retard.'

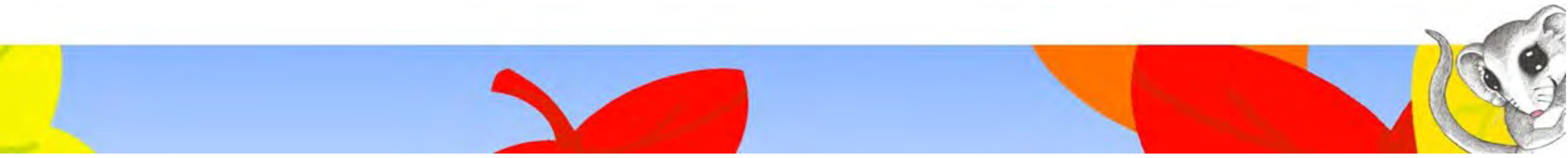
Q. Was there anything you wished you would do or be when you grew up? Has it happened?

A. I wanted to become a nurse, but had no support from my adoptive parents on my future. They were solely focused on my siblings.

Q. What is your favourite movie and/or TV show and why?

A. I love 'The Sound of Music', because it's a movie with lots of singing.

This is me…



COMMITTEE TRAINING – THE NDIS

AusDoCC Committee members recently had a very informative NDIS AQUA (Asking Questions, Understanding Answers) session. The guest expert was Kirsten Deane AOM, Manager at the Melbourne Disability Institute and formerly one of the driving forces behind the NDIS campaign, Every Australian Counts.

There was a lot of discussion about the frustrations experienced by some of our families and adults with a corpus callosum disorder (CCD). The heterogeneity and lack of recognition of CCDs can present many problems accessing and maintaining a plan.

After the session Kirsten sent us some links to valuable resources that she thought may be helpful. We would like to share these with our AusDoCC community.

- **The Valid guide for allied health professionals writing reports for the NDIS** - https://valid.org.au/resources-and-media/resources/10-steps-excellent-ndis-therapy-reports/

- **Queenslanders with Disability Network - Guide for GPs to the NDIS** - https://qdn.org.au/wp-content/uploads/2021/07/BNPHN_Understanding_Your_Role_NDIS_GP_Toolkit_May2018_FINAL_WEB-optimized.pdf

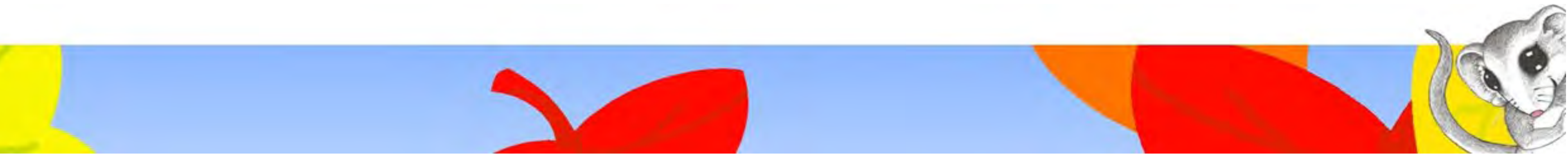
(Not just useful for GPs but all medical professionals trying to get their heads around the NDIS and providing evidence for access requests and planning meetings).

- **QDN also have a resource called "Getting on the grid" to help people access the NDIS** - https://qdn.org.au/our-advocacy/ndis/

- **Every Australian Counts (EAC) has some planning resources here** - https://everyaustraliancounts.com.au/what-is-the-ndis/pre-planning/

- **They have top ten tips for people first applying here** - https://everyaustraliancounts.com.au/what-is-the-ndis/top-10-tips/

- **EAC also has a really comprehensive list of NDIS resources from across the web.** They are in alphabetical order so it can take a while to scroll but there are lots of useful resources there - https://everyaustraliancounts.com.au/what-is-the-ndis/resources-2/



ZOOM ALONG WITH AUSDOCC

During the pandemic AusDoCC has tried to keep our community connected by holding online Zoom sessions. We know these are not the same as being together and we are hopeful that all our in-person activities that are on hold will be able to happen sooner rather than later. We miss you!

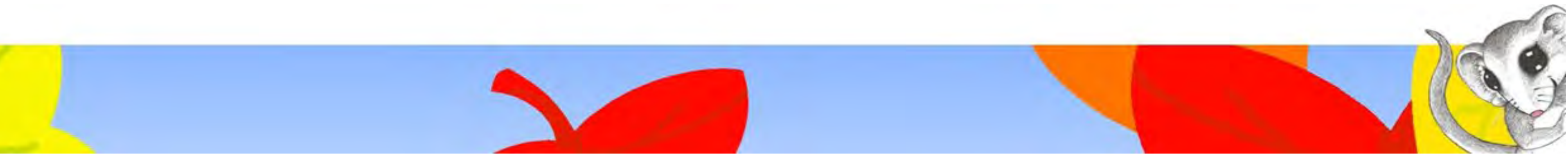
Here are some of the activities we have planned for 2022 and the dates of the first sessions:

AQUA: Asking Questions, Understanding Answers

AQUA sessions are question and answer sessions hosted by AusDoCC Committee members. Invited guest professionals are available for the AusDoCC community to ask questions before the session in writing or at the session. There is usually a different professional each month. So far most of the sessions have been for adults with a Corpus Callosum Disorder (CCD)

ZOOM Chats

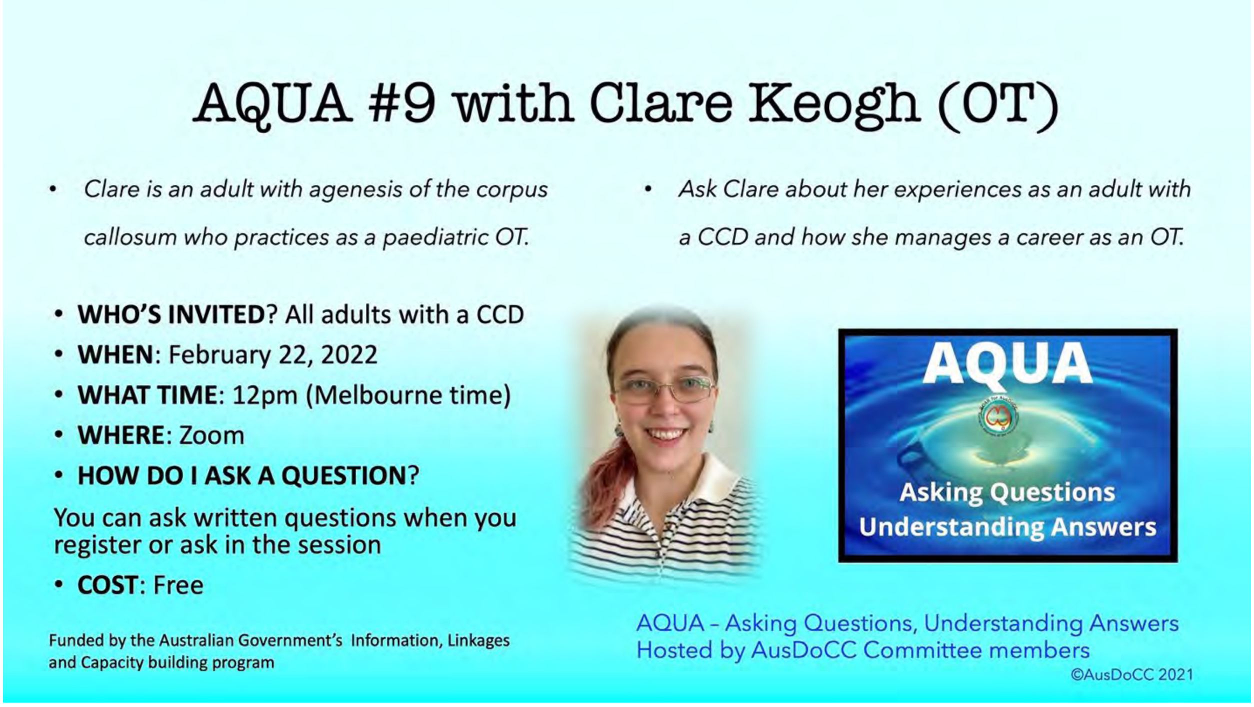
These informal chats are hosted by peers and Committee members. Sometimes they are run according to a theme and for others they are a chance for a general catch up and discussion with some socialising. We have sessions running for the adults and teens and are planning some sessions with parents and kids in 2022.



2022 February Chats & AQUA

All times are AEDT (Melbourne time)

2022	Activity	Host	Audience
Mon., Feb 7, 7.30pm	TeenChat	Tanya Smith	Teens with CCD + support
Sat., Feb 12, 8pm	SatChat	Michael Shanahan	Adults with CCD
Tue., Feb 22, 12pm	AQUA - Clare Keogh	Maree Maxfield	Adults with CCD
Wed., Feb 23, 8pm	WedChat	Margaret Krutli	Adults with CCD
Tue., March 1, 5pm	AcesChat	Abbie K & Georgie L	Adults with CCD + support



AQUA #9 with Clare Keogh (OT)

- *Clare is an adult with agenesis of the corpus callosum who practices as a paediatric OT.*
- *Ask Clare about her experiences as an adult with a CCD and how she manages a career as an OT.*

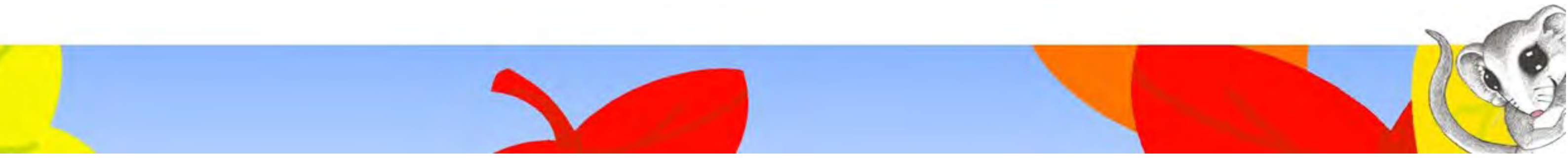
- **WHO'S INVITED**? All adults with a CCD
- **WHEN**: February 22, 2022
- **WHAT TIME**: 12pm (Melbourne time)
- **WHERE**: Zoom
- **HOW DO I ASK A QUESTION?**

You can ask written questions when you register or ask in the session

- **COST**: Free

Funded by the Australian Government's Information, Linkages and Capacity building program

AQUA – Asking Questions, Understanding Answers
Hosted by AusDoCC Committee members



Let's Chat with Tanya Smith

TEENCHAT - FOR TEENS WITH A CCD

DATE: MONDAY, FEB 7, 2022

TIME: 7.30PM AEDT (MELB)

TOPIC: WELCOME TO 2022

Parents are encouraged to attend as our teens get to know each other.

Email Austanya@gmail.com to register

Let's Chat with Abbie and Georgie

New!

AusDoCC AcesChats 2022

For adults with CCD

First Tuesday of each month @ 5pm

Young and old - All welcome

A parent or support person is welcome to assist with access.

Let's Chat with Margaret Krutli

AusDoCC ZOOM WedChats 2022

Adults with CCD

4th Wednesday evening each month

Young and old - All welcome

Day-to-day living, hobbies, interests, positives & challenges.

Chat, share or just listen.

Let's Chat with Michael Shanahan

FOR ADULTS WITH CCD, BY ADULTS WITH CCD

ZOOM CHAT GROUPS 2022

2ND SATURDAY OF EACH MONTH

8PM(AEDT)

EVERYONE WELCOME

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

ausDoCC

This project was funded under the Australian Government's Information Linkages and Capacity Building program.

POSTPONED

AusDoCC
State Meetup

We are excited to invite all AusDoCC families to a local state meet up. Come and enjoy some refreshments while meeting other AusDoCCers.

Location: Footscray Park
40 Maribyrnong Boulevard, Footscray VIC 3011

Contact: Claire on cake[illegible]h3350@gmail.com
Bryan on 0413 448 082

Date: Sunday 23 January 2022

Time: [illegible]pm

Note: This is an opportunity for all members and families to come together and meet others.
We will find some shelter near the playground and will be ordering some hot chips to share as part of afternoon tea.

RSVP: As soon as possible to the contact email above.

Recognition Opportunities Access Resources

Mail: PO Box 533, Altona 3018. Inc Reg A0057821R

IMPORTANT DATES TO STICK IN YOUR DIARY

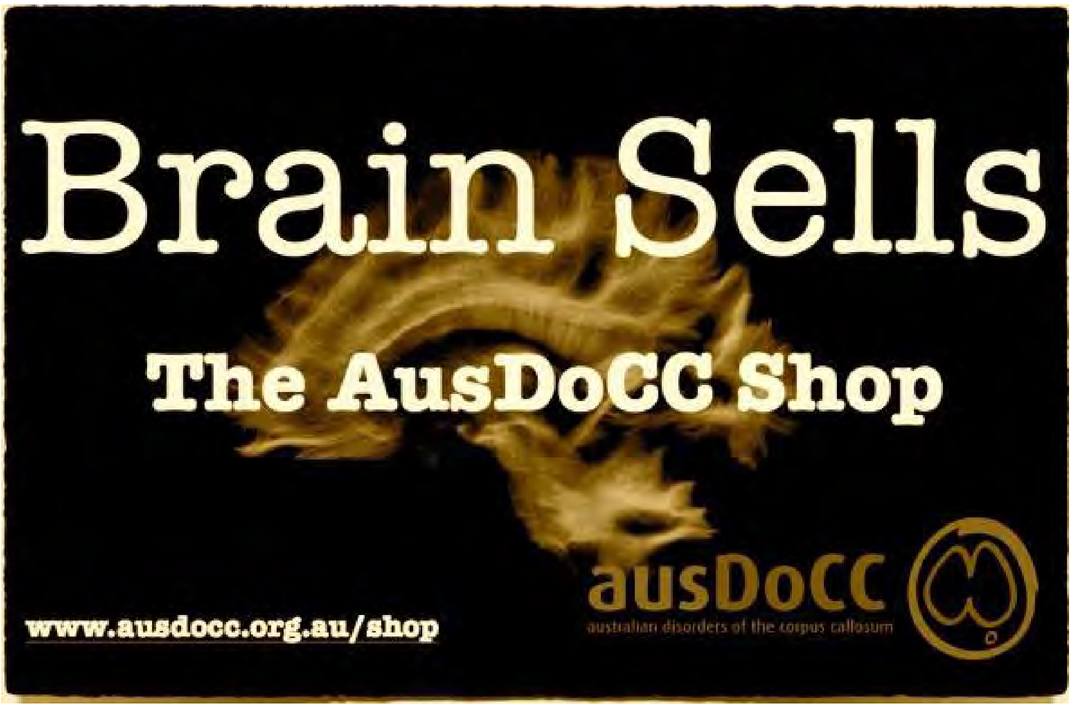
2022

7th February	Teen Chat
12th February	SatChat
22nd February	AQUA
23rd February	WedChat
1st March	AcesChat
11th April	AusDoCC Anniversary
Late 2022	My People Melbourne

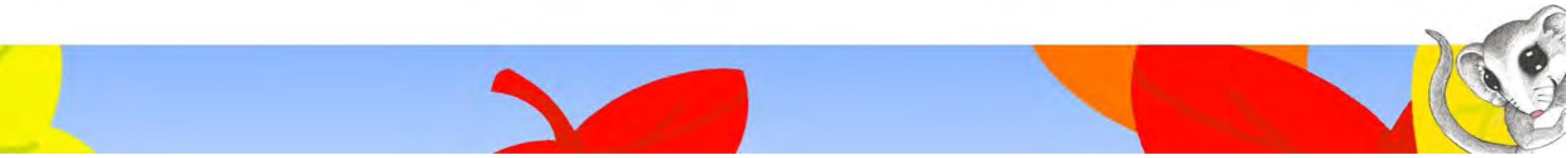
2023

Late 2023	National Conference - Connections 2023

BRAIN SELLS SHOP



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



Meet the AusDoCC Volunteer Committee

Kristina Coburn AusDoCC President, Social Media Officer, W.A. rep

Michael Shanahan AusDoCC Vice President, Research Officer, Qld adults' rep

Maree Maxfield AusDoCC Secretary, Website Officer, Major events co-ordinator

Maja Palacios AusDoCC Treasurer, Design Officer

Abbie Kinniburgh Adult Programs Officer, Vic adults' rep

Tanya Smith Volunteer's Coordinator, NSW rep

Georgie Lamb NSW adults' rep

Margaret Krutli S.A. adults' rep

Hilary Bustillo Qld meetups, Media liaison

Jade Wright W.A adults' rep, website blog

Alex Andrews Grant's 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 15th March 2022.

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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