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PRESIDENT'S REPORT

Autumn is upon us and this year is already rushing by. Easter and the first term of school are done and dusted.

AusDoCC's plans are still a little restricted due to Covid but slowly the wheels are still turning.

Our second My People conference for Adults with ACC will be held in Brisbane in June. Preparations are well under way. Please remember to check and respond to any emails that you may receive.

Our biennial Connections conference has once again been put on hold with the uncertainty of Covid. It has now been pushed back to May 2023. So, fingers crossed.

Please keep a look out for our Meet ups that will be happening either on Zoom or in person.

Our International Awareness Day is held on July 2nd. We have a special guest arriving on this day so keep an eye out.

We are currently running a program called AusDoCC AQUA- Asking Questions, Understanding Answers.

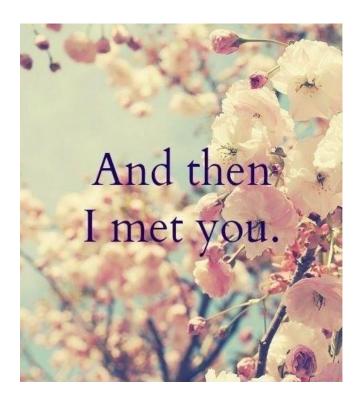
It involves information/discussion sessions with a professional in their area for adults with a disorder of the corpus callosum (DCC). If successful, the program will be extended to Parents of a person with a DCC.

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

Sometimes this journey can be lonely, I found this little saying on the internet and it seems to ring true and it makes me feel a little less alone, "And then I met you"!

Love and Light

Tina. x





Become an AusDoCC member today



As most of you know we have a very informative website as well as our interactive Facebook groups

Did you know you can become an AusDoCC member?

Click here to join today

A one off payment of \$20 per person gives you AusDoCC membership for life.

When you become an AusDoCC member you'll receive a membership pack of resource sheets, copies of our DCC info brochure, small information cards and a few other goodies. You then join our email list to receive our quarterly newsletter and other important information and offers.

As a member you will also be assisting us to support all individuals with a DCC and their families and friends.





PROFESSIONAL ARTICLE

The Speech Pathologist's Role

Speech pathologists are well placed to provide services to people with Agenesis of the Corpus Callosum (AAC) having academic training and professional experience in understanding the neurological function of brain structures in relation speech, communication and swallowing (Love and Webb, 1992). Research has suggested that when the two hemispheres of the brain are not effectively linked, as with AAC; shortfalls in processing speed, executive functions, paralinguistics, pragmatics, working memory, and phonological awareness may be present (Kellmeyer et al., 2019 and Marco et al., 2012).

When the neural pathways in the brain are interrupted the above skills may be impacted and then, in turn, impact further skills. An example of this would be; when experiencing a reduced overall processing speed, executive functioning skills such as interpreting social cues or planning and formulating phrases will also be effected (Melogno et al., 2021).

Speech Pathology in Practice

I began working with Jasmine* in early 2020. Jasmine presented as reserved, but welcoming, and showed complex and descriptive expressive language skills when given extended time to respond. Jasmine reported communication breakdowns with those close to her and with allied health professionals in terms of word finding, constructing her sentences, interpreting others' communications, and social communication for friendships. Alongside these difficulties Jasmine also reported difficulty in advocating for her ideas and opinions. Jasmine was in her late 20's, presented with partial ACC, ASD, anxiety and depression and had not accessed Speech Pathology services previously.

We quickly established session ground rules:

- Jasmine would let me know (either verbally or with facial cues) to rephrase if I had not made tasks clear and would attempt a little bit of homework once in a while.
- I would regularly check in to gauge understanding and be supportively persistent and curious when Jasmine used her habitual phrase 'I don't know' as a response.
- Most importantly we agreed to go at Jasmine's pace, allowing ample processing and formulating time in sessions.

Borrowing from and adapting social communication and neurological rehabilitation interventions, strategies used throughout the year to assist communication were:

- Scripting Writing down thoughts, feelings, and questions to take into health appointments. This reduces the cognitive load of formulating and planning 'on the spot' or when in stressful situations.
- Semantic feature analysis and paraphrasing- To assist with word finding and understanding others ideas by putting into your own words.
- Emotional recognition and inferencing Inferring an emotional state and its potential trigger from a photo stimulus.
- Motivation interpretation Inferring motivations by dissecting non-literal written statements.
- Assertive Language –To increase self-advocacy skills.



The pace of therapy changed depending on Jasmine's affect, however, we found that even on the quieter days we could weave learning opportunities into our sessions. Jasmine's confidence in her communicative abilities grew each session and her verbal responses became faster and more succinct each week. Jasmine is beginning to use assertive language strategies to ask for clarification and to dispute in session. After repetitive practise Jasmine is beginning use the strategies above independently and outside the therapy space. Jasmine will often report back on how she has been applying these strategies to her everyday life which shows fantastic progress.

At Jasmine's pace, we will continue to work on the above strategies this year to promote an increase in her health care participation, decision making and social connection. I am very excited to see Jasmine's skill and confidence levels continue to grow steadily and to where these new skills will lead her.

If you would like to know more about the services a Speech Pathologist could provide you, please explore our peak body website https://www.speechpathologyaustralia.org.au/ for further information.



Brigitte Amos

Speech Pathologist

M.Sp.Path, B.Hlth.Sci, CPSP

GRP Speech Pathology (Victoria)

www.grpspeechpathology.com.au

click here to make a referral.

Brigitte Amos Speech Pathology (Sunshine Coast) www.brigitteamosspeech.com.au

References

Kellmeyer, P., Vry, MS., and Ball, T. (2019). A transcallosal fibre system between homotopic inferior frontal regions supports complex linguistic processing. European Journal of Neuroscience. (50): 3544-3556. https://doi.org/10.1111/enj.14486

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Melogno, S., Printo, MA., Scalisi, T.G., Badolato, F., and Parisi, P. (2021). *Case Report: Theory of mind and figurative language in a child with agenesis of the corpus callosum*. Frontiers in Psychology, (11): 1-9. https://doi.10.3389/fpsyg.2020.596804



FAMILY STORY - Margaret Krutli

I joined the AusDoCC in June 2018 and my first Conference was in Perth 2019. It is wonderful to connect with people who can understand the challenges we all experience.

I joined the Committee to help adults with ACC and parents who have children with ACC, in South Australia, connect with each other.

In 1995, aged 40, I had a seizure and was rushed to hospital. After having an MRI, the complete ACC was discovered. I was also diagnosed with epilepsy. After reading extensively, I realized that the complete ACC was the reason for many experiences in my growing years.

I was born and grew up in Broken Hill, NSW. I found Primary School education not too difficult. High School was more challenging. I was more comfortable with numbers than words. I was learning French, but after 2 years I failed and they switched me to Commerce (bookkeeping etc.) which I found a lot easier.

I went to Technical College to do full-time Secretarial Studies. I could handle typing and bookkeeping but not shorthand, as they required 60 wpm. I was awarded a "Commercial" Certificate, not a "Secretarial" Certificate.

In 1972, my first job was with the Commonwealth Bank. They put you on for a probationary period without an interview. If you don't meet their standards, they let you go, which is what happened to me.

In 1973, I got a job as a 'Girl Friday' in a small business, which was an agency for travel, real estate, property management and insurance. My duties included answering the phone, typing letters, receiving money over the counter for various companies that the business represented, as well as reconciling the day's takings with the receipt book and banking.

I met my husband Chris in 1974 and we were married in 1977. We decided to move to Adelaide straight after the wedding.

I gave up work before my first child was born, and a part-time job fell into my lap when my second child started school. The job was perfect for me, as I worked 2 days a week and didn't work in the school holidays. It lasted 10 years, until the company went out of business.

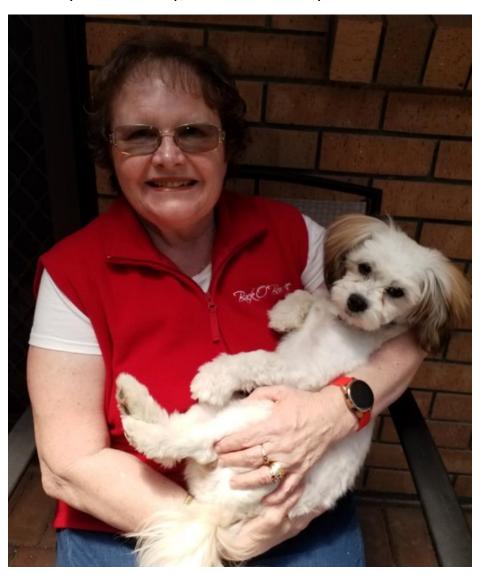


From 1984 until 2016 I have done voluntary work. This included school fundraising committees, secretary of a cricket club and association and in more recent years, I have volunteered in aged care and a local hospital.

After finding the CACC, I felt a "huge weight lift off my shoulders". This is the reason for bumping into door jambs and knocking a glass of water over as I go to pick it up. With my left hand my fine motor skills are non-existent. I will often drop items as I'm not holding securely. I wish I could concentrate on more than 2 jobs at a time. I also feel more comfortable seeing information and lists in alphabetical, date or number order.

Over the years, I have put myself into situations, where I have to read in public, to make myself more confident.

Meet my new fur baby, 7 month old Ruby.





ADULTS' CONFERENCE

17 - 21st June

My People. Brisbane. June 2021.

Adults with a disorder of the corpus callosum (DCC) will meet in Brisbane in June for the 2nd My People gathering.

This will be a great first opportunity for people with a DCC to meet up in person since Covid began and will be a great learning opportunity with presenters from various fields.

My People is about building our community, crafting our own identity, and strengthening our skills to advocate for our community and achieve our goals.

It is a residential event where adults with a DCC, some Carers and AusDoCC committee organisers work together to bring change for adults with a DCC and awareness in the wider community. Topics covered will include the NDIS, sexuality and relationships, teambuilding, the science of the corpus callosum, ageing with a DCC, advocacy, staying healthy, anxiety and of course a lot of socialising.

Melbourne will also host a My People residential event in November. More news to come.



My People 2018



EDNA'S UPDATE

Hi AusDoCCers,

Well, summer holidays have finished and we have all gone back to school. I hope the Covid doesn't close our schools again. It was pretty fun to be back at school and we have some new kids and new teachers. So many peoples. So many words. So many new things.

Sometimes I go to speech therapy because I have lots of things in my head but they won't come out my mouth. Sometimes people say things to me and it gets all jumbled. If they say too many things all at the same time it's like a big bowl of spaghetti in my head.





I like to just listen to one thing at a time and work out what it means. Then I work out my answer. I have to use my hands a lot because sometimes the words can't come out my mouth.

I am learning to use an iPad with lots of pictures to tell people what I want.

I love my iPad. Do you have an iPad? iPads are cool and so is my speech therapist. She says, "Good job, Edna," and gives me a high five.

Love from Edna xx



Colour me in.



Look at me. I did up my own buttons. Edna for the win. High five.

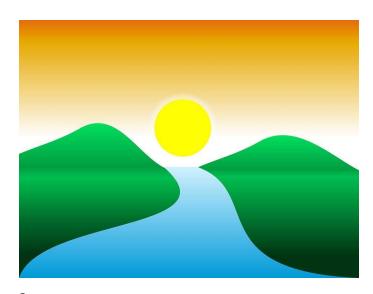


AUTUMN WORDSEARCH

RIVERS IN AUSTRALIA

Р	Р	В	Υ	Z	Α	F	L	Н	G	Ε	М	Ν	В	J
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W	G	Ν	Ε	Ν	Υ	М	D	Ν	М	L	L	А	F	R
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Υ	I	U	Н	Р	К	S	R	0	Р	Ε	R	А	L	В
Ε	Ν	I	М	А	D	Ν	0	\subset	D	К	F	\subset	D	L
А	I	R	0	Т	\subset	I	V	Ν	R	W	G	Р	Н	I

Barwon	Gwydir
Darling	Mitchell
Finke	Ord
Goulburn	Victoria
Loddon	Condamine
Murrumbidgee	Drysdale
Roper	Gilbert
Bullo	Lachlan
Diamantina	Murchison
Flinders	Paroo



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 your favourite photo, story or poem about Autumn, please email it to editor@ausdocc.org.au before 30th June 2021 for inclusion in the next newsletter and please don't forget to put your name on it.





Special School District of St. Louis County

Logan Novotny

When in doubt, Logan Novotny likes to say "let's give it a try." Now a fifth-grade student at Oak Brook Elementary in Parkway Schools, Logan was born with Agenesis of Corpus Callosum, a rare medical condition that means he is missing the connective tissue between the two hemispheres of his brain. When he came to Oak Brook as a kindergartener, his team wasn't sure how he would do with school academics or what his social programming would look like. But at every step of the process, Logan was open to new opportunities—willing to give it a try.

Even though learning can be difficult for him, Logan never gives up. He keeps a positive attitude and combines it with a healthy thirst



for knowledge. He loves science and social studies, and he has become an expert on topics such as the Titanic, the musical group Queen, Washington DC, and Abraham Lincoln, just to name a few. He even learned to roller blade at school.

"After a few tries, he was on his own with the entire gym cheering for him and celebrating his success," said his teacher, Leslie Frasca.

Outside of school, Logan spreads his warmth and kindness. He takes part in Tae Kwon Do, baseball games with his Challengers team, and musical performances with his School of Rock band, as well as family events. Even with a significant medical condition that impacts his muscle tone, agility, balance and coordination, he pursues new things and excels at them.

"This is all possible because of his positive and charismatic attitude," Frasca said. "There is not a person that Logan has met that is not affected by him. He shows kindness to everyone. He shows integrity with his daily choices. He shows perseverance academically, personally and socially every day."

To see the full article

2021 Rosemary Zander Awards / Logan Novotny (ssdmo.org)



ANNA SHARES HER EXPERIENCE

This is the company that my Exercise Physiologist Daniel works for. I have found that the combination of weekly physio and twice weekly exercise training with Daniel has really lowered my sick days at work, due to the usual muscle aches and pains that come from my low muscle tone/ hyper mobility and poor spatial awareness. Daniel is also helping - where he can, with reducing the likelihood of falls from my agility, and finding innovative ways to help me with some of the more physically demanding tasks I have to do at work.

Longevity do utilise Telehealth, and they have about three or four locations across Sydney.

Anna Uther

How Can An Exercise Physiologist Help Someone You Know?

Who Do You Know Who We Can Help!

Here at Longevity, we see a whole range of people with different health conditions and goals.

To put it simply, anyone who is looking to make a health-related lifestyle change should consult an exercise physiologist.

Check out our blog today to find out more how an exercise physiologist can help someone you know!

Written By: Georgia Wassall







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Why Should I Choose Individualised Exercise Sessions?

One of our core concepts at Longevity is client-centred care. This means that we are dedicated to providing the best treatment options for you and your health, and it is our duty to help deliver those to you.

Today's blog highlights the main benefits of doing individualised exercise physiology sessions and how we can help you achieve all your health goals by being in a 1-1 setting.





Written By: Jackie Cheung

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Our mailing address is: info@longevitypt.com.au





This month

at the 'Meeting Place' Q and A we meet....

Michael Gilbert

Where do you live?	Brisbane, Queensland	How old are you?	31
My DCC diagnosis:	Complete Agenesis of the Corpus Callosum	When were you diagnosed?	23 years old

- Q. What is one of or some of your biggest challenges with your CCD (Corpus Callosal Disorder)
- A. I have challenges with socialisation, problem solving and emotional understanding.
- Q. What do you like doing?
- A. I like researching and reading modern history. I also like watching and playing cricket.
- Q. What/ who are your main supports for you with your DCC?
- A. My wife.
- Q. What do you do with your days?
- A. I work as an interstate truck driver. I work around the house and I spend every moment I can with my daughter.
- Q. What are your interests?
- A. My interests are modern history, cricket, AFL and collecting memorabilia.
- Q. What is something unique/special about you BECAUSE of your DCC, or otherwise?
- A. Something special about me is I have a broad general knowledge and can retain information I read. This makes quizzes and game show answers quite easy for me.
- Q. Do you have any pets? Tell me about them.
- A. Yes. I have 2 Bull Arab dogs
- Q. What is your favourite book and/or author and why?
- A. 'God is Not Great' by Christopher Hitchens

- 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. Don't push your limitations. It only leads to unnecessary stress.
- Q. If you could give one bit of advice to your child SELF to make things different/ easier, what would it be?
- A. I wish I had known about my condition early in life. It would have made a world of difference to understand my situation.
- Q. What is your favorite song, band, singer (or all of these) and why?
- A. 'Oh no not you again' by Australian Crawl. I enjoy classic Aussie music.
- Q. Do you have any siblings? Tell me about them.
- A. Yes. I have one younger sister. It is known if she has a DCC (Disorder of the Corpus Callosum) or not.
- Q. Was there anything you wished you would be or do when you grew up? Has it happened?
- A. I didn't aspire to anything when I was younger.
- Q. What is your favorite movie or TV show (or both) and why?
- A. 'That 70's Show' was my favourite show as a teenager.

This is me...





ACC Infant Study



AGENESIS OF THE CORPUS



OUR GOAL

We are seeking better ways to help children with ACC grow into their full potential, by studying mental and behavioral development in infants with ACC.



WHO CAN PARTICIPATE?

PARTICIPANTS WILL **NEED TO PROVIDE**

- Information about their child's development and their own well-being via on-line surveys and phone-based interviews. at up to 6 timepoints before the child turns
- · Copies of their child's brain scans and/or
- Saliva samples.

PARTICIPANTS WILL RECEIVE

- Financial compensation at each timepoint.
- Direct behavioral assessment at University of Minnesota, all travel expenses paid. (Only available for some participants in North America.)

Caltech IRB Protocol 19-0896 UMN IRB Protocol Study 00005484

ENROLL NOW accinfantstudy.com

MORE INFORMATION Email: admin@accinfantstudy.com



ACC Infant Study

Does your child have Agenesis of the Corpus Callosum?

The California Institute of Technology and University of Minnesota are examining behavioral development in infants (6 to 36 months) with Agenesis or Dysgenesis of the Corpus Callosum (ACC). Ultimately, this understanding can be used to more effective intervention techniques and supports for individuals with ACC. If you are interested in participating and would like more information, please click on the following

link: https://emotioncaltech.co1.qualtrics.com/jfe/form/SV_9Xr1cy47DnsOHiJ

To find out more about the study visit: www.accinfantstudy.com

Longitudinal Study of Behavior and Development in Infants and Toddlers with ACC

This is the first study examining behavioral development in children with Agenesis / Dysgenesis of the Corpus Callosum (ACC) from birth into early childhood. We cannot begin to truly appreciate the potential for early intervention in ACC until we understand how these diagnoses are influencing behavior and neurological development during this critical period of time.

<u>Study Goals</u>: Our aim is to characterize/describe the behavior development of children with agenesis/dysgenesis of the corpus callosum. Ultimately, this understanding can be used to create more effective intervention techniques and supports for children and adults with ACC.

Who can participate? Parents / primary caregivers of a child who is less than 36 months of age and who has received a clinical diagnosis of corpus callosum malformation via MRI, CT, or ultrasound. On medical reports this malformation is typically called dysgenesis of the corpus callosum, complete or partial agenesis of the corpus callosum or hypoplasia of the corpus callosum. Caregivers must be 18 years or older and must be proficient in reading and speaking English.

What are participants asked to do? Parents will be asked to complete online questionnaires about themselves and their child's behavior. Parent's will also be interviewed by phone/skype about their family and child's behavior. Most families will participate on multiple occasions (up to 5 times between 6 and 36 months of age) and some families will be invited to fly to the University of Minnesota for a direct behavioral assessment (all travel expenses paid). Nominal compensation will be provided for your time (\$20 US for each long-distance assessment and \$50 US for direct assessments).

To enrol visit: https://emotioncaltech.co1.qualtrics.com/jfe/form/SV 9Xr1cy47DnsOHiJ

To find out more about the study visit: www.accinfantstudy.com

Is your child over 36 months of age? We are also recruiting anyone up to the age of 18 for our child study.

To enrol visit: https://emotioncaltech.co1.qualtrics.com/jfe/form/SV_9Xr1cy47DnsOHiJ



WELCOME TO THE WORLD

Anika. 28/12/20 3.7kgs

Anika was diagnosed with ACC in her mum's womb. Her parents think she's such a blessing! Each time she smiles and coos, it just takes their worries away! She loves music and cuddling with her daddy. She's daddy's lucky charm!





Congratulations to the winners of the competition to design the next birthday card - Andie McAuliffe and Tahlia Raftery.

Both received a cuddly Edna and AusDoCC cap. Their designs will feature on the next round of birthday cards.



Andie's design features our mascot, Edna the fat tailed dunnart, who has no corpus callosum. Andie Enjoys performing as a singer with Music Rocks.



Congratulations

Tahlia loves to dance and is all set to wear her new cap and take Edna for a dancing lesson. Tahlia's design features a dancer and an acrostic poem using the letters of AusDoCC.



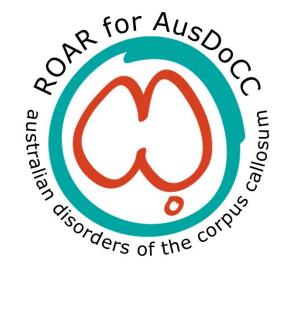
Congratulations to Tahlia and Andie for your dynamic designs.

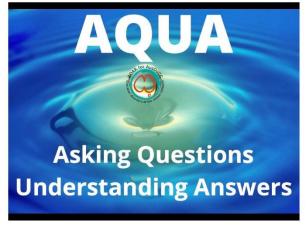


AQUA









AusDoCC Zooming 2021

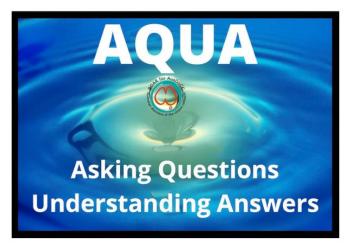


<u>AQUA</u>



Ask Catherine all your questions about occupational therapy and mental health





AQUA - Asking Questions Understanding Answers - Occupational
Therapy - Mental Health - Monday, May 17 at 11:00am AEDT (Melb.
Time)

Catherine is an OT who focuses on exploring ways to improve practical and mental health function that is centered around the person and their needs.



PARTICIPATE IN RESEARCH

Do you have a question about DCC research, or about a particular paper you have read or want to fact-check something you've heard?

Do you want help accessing a full version of a paper or want to keep up with the latest research being published?

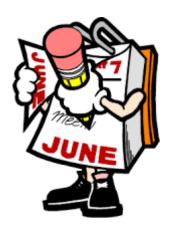
There are a few options:

- 1. You can check out <u>AusDoCC's research page</u> on Facebook where we post the latest published research in DCCs.
- 2. You can also send us a message, comment on the Facebook page or <a href="mailto:ema
- 3. AusDoCC also has advisors who are long standing professionals engaged in clinical practice and research. You can learn more about them here
- 4. You can also check out the <u>IRC5</u>, a global scientific research consortium, investigating all things related to the corpus callosum.
- There are always research projects being carried out around the world. You may like to participate. Contact AusDoCC <u>here</u> if you are interested





IMPORTANT DATES TO STICK IN YOUR DIARY



2021

17th - 21st June Adult's Conference

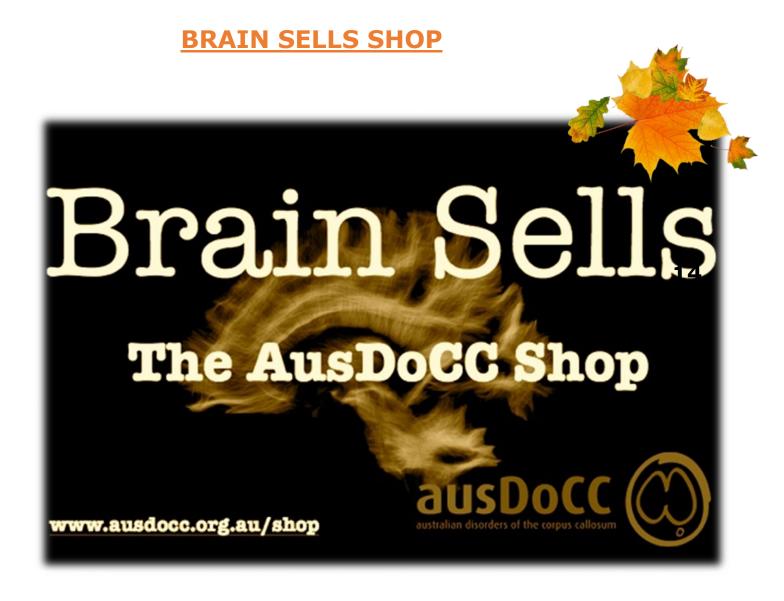
2nd July International Awareness Day

2023

AusDocc Conference







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

MEET THE AusDoCC COMMITTEE



Kristina CoburnAusDoCC President, Social Media Officer



Michael Shanahan AusDoCC Vice President, Research Officer



Maree Maxfield
AusDoCC Secretary, Website Officer



Maja PalaciosAusDoCC 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 June 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 groups ADULTS –

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

Facebook page -https://www.facebook.com/AusDoccinc

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