



Australian Disorders of the Corpus Callosum (AusDoCC) presents

# CONNECTIONS 2019

where **AMAZING BRAINS CONNECT**

## Official Program

# Australian Conference & Family Camp

10-12 May, 2019 Point Walter Recreation Centre, Perth WA



International Research Consortium for the  
Corpus Callosum and Cerebral Connectivity



Australian Government

Department of Social Services

ACN 15 88 26 147 ABN 54 754 767 674 Reg. Org A0057821R

# Welcome to (Camp) Connections 2019

- Have a marvellous time making new memories and friends and catching up with old ones.
- Please wear your **lanyard nametags** at all times. This identifies you as a conference attendee.
- AusDoCC **Committee members** are available to assist and are easily identified by their black and orange AusDoCC shirts. Volunteers will be wearing rainbow T-shirts or aqua AusDoCC shirts.
- Please **be seated** ready for conference sessions to start on time and be in the dining room at the scheduled meal times.
- Have your **phones on silent** during sessions. If you need to answer a call, please leave the room before beginning the conversation.
- Take care with your room keys and belongings. Everybody is responsible for their own **security**.
- Please let a committee member know if you notice **anyone on the grounds** who shouldn't be there
- The campsite is fully fenced but please **be aware of where your children are** when not in Kids Club. Take particular care near any **car parking areas** or roads and watch out for **snakes**.
- Please be patient if there are any glitches. We are **all human**, even the technology!
- If you have a **one-to-one appointment** with a key professional, please be at the designated meeting place 10 minutes before your appointment time. A volunteer will escort you to your appointment. Appointments are strictly 20. minutes.
- **Bedding** (and a towel) is supplied for each person in the room and you can choose your beds and make them up.
- **Alcohol** is not permitted at the camp. This is an alcohol-free event under our insurance requirements.
- **Smoking** is only allowed in the designated area. Please make sure your butts are fully extinguished when finished.
- Anyone participating in **Zumba** must wear comfortable and suitable footwear and have a water bottle and sweat towel. Bare feet will not be permitted.
- Familiarise yourself with the **emergency muster area**
- **If you leave** the camp area, children must not be left behind under supervision of camp or childcare staff. Please keep clear of the childcare areas during Kids Club times unless contacted by staff.
- Try not to **lock yourself out** of your room!
- **Emergency contact numbers:** (please try to find the person before ringing)
- **This AusDoCC conference is funded by the generosity of many and small donations, some one off grants and the tireless work of the committee fundraising efforts.**  
Please spread the word to share the load.

## AusDoCC Executive - Team Leaders:

All conference programs/sessions: Maree 0428 579 216

Venue/accommodation: Maja 0409 994 706

Childcare: Kristina 0438 990 345

Raffles/merchandise: Niki 0421 379 097

## Assistance Officers

Grounds: John 0417 285 876

First Aid: Tina F 0412 939 725. Anna 0415 766 128. John 0417 285 876

Companions/support workers: Margie 0455 903 050

IT: Hamish Coburn 043450576714

**Boom gate Code 7445**





# AusDoCC Committee 2019

## Kristina (Tina) Coburn (President)

Kristina is the mother of three amazing young men, Connor, Hamish and Kyle. Connor (born in 1998) and Kyle (born 2006) both have agenesis of the corpus callosum and coincidentally they also share a birthday. Tina lives in Perth, Western Australia. She has a background in childcare and is a passionate advocate for her sons. They all share their mother's crazy sense of humor. Kristina is the current AusDoCC President and coordinates our social media section. She also has an alter ego known as AusDoCC Screening where she screens people before entering our Facebook group and keeps the group safe and spam free.



## Niki Harrison (Vice President)

Niki is AusDoCC vice president and has been with AusDoCC since its inception. Niki has played a big role in raising funds for AusDoCC over the years. Niki lives in Tooradin, Victoria, with her husband Steve and three children Brodie (20), Tahlia (18) and her youngest, Abby (10). Abby is their ACCer.

She has an underdeveloped corpus callosum. Abby doesn't walk or talk but is a happy little girl. Niki loves to help people less fortunate in her spare time by donating goods and helping at warehouse. She also helps disadvantaged communities when holidaying in her second home, Bali.



## Maja Palacios (Treasurer)

Maja lives in Perth with her husband, Andrew and two daughters Eva and Andie. Andie has complete agenesis of the corpus callosum (ACC) and a suspected undiagnosed syndrome. Until discovering AusDoCC in 2013 the family was isolated and had very little knowledge of ACC. Maja

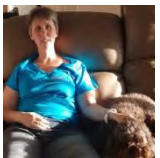
has a background in applied science and now runs a mobile heavy haulage company with her husband. Maja is a motivated person with an artistic flair who has been AusDoCC's treasurer since 2017. Having an undiagnosed child with complex needs, motivates Maja to contribute to raising awareness about AusDoCC and help bridging the obvious gaps in the system.



## Pieta Shakes

Pieta stepped into the role of Grants Officer in 2018 hoping to help raise the needed funds for AusDoCC to reach the next goals of support and advocacy. Pieta is a mental health nurse who facilitates child development, research methods, mental health promotion and mental health &

illness units at Deakin University. A current PhD candidate exploring the experience of receiving a prenatal diagnosis of a disorder of the corpus callosum, Pieta is motivated by lived experience and the awesome little human that calls her "Ma".



## Anna Uther

Anna was seen as being different from her siblings and despite her parents trying to get answers, it wasn't until she was 18 that she was diagnosed with complete ACC. For Anna, this diagnosis didn't change anything in relation to her struggles with her HSC & University degree. As far as she was

aware, she was the only adult in the country with this disorder, until 2015, when she found AusDoCC. She is now a voice for the adults with a DCC on the Committee. Anna presents as neurotypical when you first meet her and uses that to her advantage when talking about ACC and its impacts on her life.



## Margie Slater

During her employment Margie worked as a support person for people with a disability and/or special needs. She has an Advanced Diploma in Disability Work and has also taught students studying Education Support. She is now retired from the workforce. As a committee member of

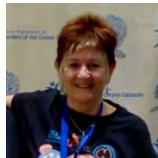
AusDoCC, she is the editor of the quarterly newsletter. Margie has no family members who have a DCC. Her connection to AusDoCC is through a longtime, close friendship with a young adult who has a corpus callosum disorder.



## Lisa McNally

Lisa hails from South Australia. Lisa is mum to two adorable girls, Aggie (5) and Harrie (2) and wife to Christopher. She joined AusDoCC when Aggie was first diagnosed in 2013. Aggie has hypoplasia of the corpus callosum and a number of other conditions suspected to be an undiagnosed syndrome. Lisa

has a Bachelor of Nursing and has worked in aged and community care settings for most of her career as a nurse, educator and manager. She currently works in the areas of compliance, quality and professional coaching. Lisa brings her passion for sharing knowledge and her determination to work alongside others to the AusDoCC table.



## Maree Maxfield (Secretary)

Maree is mother to Abbie (pACC), 28 and is the grandma of the group. She has a long experience of ACC, in which many years were spent in (not so) blissful ignorance. Discovering Linda Richards at QBI in 2010 began the unravelling of many mysteries. This has led her to 4 US ACC conferences and inspired her

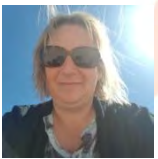
to coordinate Australian conferences for AusDoCC, where she is the current secretary. Maree will complete a Masters of Public Health at Melbourne Uni this year, after 7 years. She will continue PhD research into the lived experience of adults with DCC and aspires to be that "sweet" little old lady with a walking stick, accepting her future uni degrees in a puffy hat.



## Abbie Kinniburgh

Abbie is 28 and has partial agenesis of the corpus callosum (pACC) and panhypopituitarism. The impacts of her ACC were ignored and unknown until attending the NODCC, US conference in 2010. This significant, lifechanging event motivated Abbie to join AusDoCC and help gather other adults together from across the

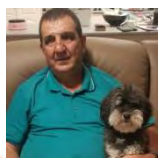
country to promote opportunities for adults with ACC to meet one another and find their 'tribe.' Abbie has been a Committee member for 5 years and continues to be a voice for adults with ACC. She lives in a converted old shop in Melbourne with her Mum and best friend Miss (naughty mini foxie) Scout.



## Tanya Smith

Tanya has 2 children aged 15 and 13. Her 13 year old was diagnosed with language delays, low tone and hypotonia at age 2. He was then diagnosed with Autism and epilepsy at 4. A few months later he had an MRI which revealed P-ACC and colpocephaly. Not long after that, Kristina Coburn found Tanya – lost in the big

wide world. In 2015, Tanya and her family participated in the research project with Queensland Brain Institute (QBI). This research revealed that she and her children all have a deleted gene which causes mirror movement and can cause DCC. The journey has been an interesting one.



## John Jonker

John is the only partner of someone with ACC on the Committee. John works for a local Sydney council. He has the Committee role of partner peer support and will be our groundskeeper and first aid person at the conference. John lives with Anna Uther, who has ACC and he supports Anna with assistance if she requires it.

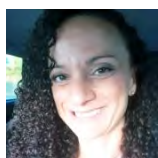
John and Anna attended the NODCC corpus callosum conference in America in 2018.



## Michael Shanahan

Michael is a pACCer on the AusDoCC management committee and co-manages the 'AusDoCC: Disorders of the AusDoCC Corpus Callosum Research Findings' page on Facebook. Michael is a Registered Nurse working in oncology and palliative care on the Sunshine Coast in Queensland and is currently completing a Masters

Degree in nursing, focusing his research component on ACC. Michael was diagnosed with Obsessive Compulsive Disorder at 16 and incidentally with ACC at 19. Michael is passionate about disseminating healthcare research findings for the public and being involved in ACC research.

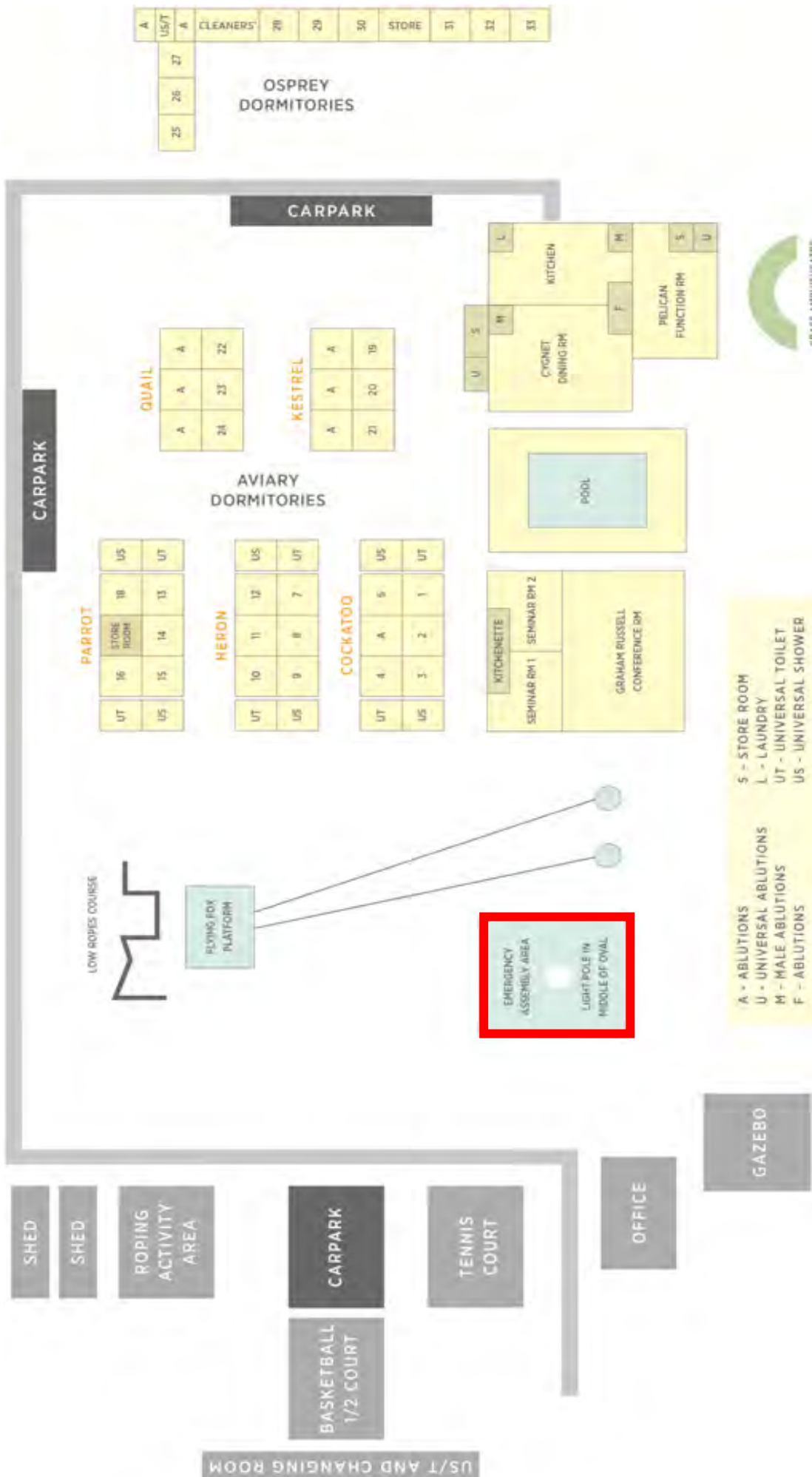


## Maggie Nolan

Maggie lives in Brisbane with her husband and three children. Her amazing 7 year old boy, Charlie, was born with complete ACC and hydrocephalus. Maggie is a full-time remedial massage therapist and business owner. These have been her passion for over 25 years. Her role in the Committee is to bring people together

to share stories and relate to one another through coordinating meet ups Australia wide. Running a meet up in your state is a great way to meet kids and adults with a disorder of the corpus callosum and their families and friends. Contact Maggie if you'd like to.

# Point Walter Recreation site map



## ROOM ALLOCATIONS

- AVIARY DORMS**
- COCKATOO**
- Room 1 : McNally x2
  - Room 2 : Andrew x4
  - Room 3 : Kelsall x4
  - Room 4 : MacKay x3
  - Room 6 : Aronsson x3
- HERON**
- Room 7 : Coburn x3
  - Room 8 : Baric x2
  - Room 9 : Coburn x2
  - Room 10 : Harrison x3
  - Room 11 : Benson x3
  - Room 12 : Benson x3
- PARROT**
- Room 13 : Johnson x4
  - Room 14 : Johnson x4
  - Room 15 : Johnson x3
  - Room 16 : Carr x1
  - Room 18:McGogganx2
- KESTREL**
- Room 19 : Shakes x2
  - Room 20 : Boydell x3
  - Room 21 : Uther x3
- QUAIL**
- Room 22:Kinniburghx2
  - Room 23 : Hancock x2
  - Room 24 : Moore x2
- OSPREY DORMS**
- Room 25 : Harrison x1
  - Room 26 : McAuliffe x4
  - Room 27 : Maxfield x1
  - Room 28 :Alexander x1
  - Room 29 : Furse x1
  - Room 30 : Kent x1
  - Room 31 :McDonaldx1
  - Room 32 :Shanahanx1

# Conference Menu

## FRIDAY MAY 10 – DINNER 6.30PM

**Chef's Carvery:** Selected Roasted Meats with Roasted & Steamed Seasonal Vege and or Salads & Produce to Complement, Bread Basket with Butter, Chef's Special Dessert  
Beef: with Gravy, Mustards & Horseradish  
Pork: with Gravy Crackle and Apple Sauce

## SATURDAY MAY 11

### Breakfast: Continental Breakfast: 7.30AM

Whole Seasonal Fruit, Fruit in Natural Juice, Yogurts, Home Made Muesli, Cereals, Multigrain, Wholemeal and White Bread, Butter, Spreads

### Morning tea: From the Bakehouse: 10:30AM

Homemade Scones, Whipped Cream & Jam

### Lunch: Sandwich Buffet - Make Your Own: 12.30PM

Fresh Rolls and Bread Selections, Ham, Chicken, Tuna, Cheese, Egg, Beetroot, Lettuce, Tomato, Cucumber, Grated Carrot, Red Onion, Condiments

### Fresh & Seasonal Fruit Options: 2:30PM

Fruit and Vegetable Stix Platter

### Plus extra option added of:

Trio of Cookies – Oven Fresh Choc Chip, Shortbread and Anzac's

### Dinner BBQ Sanga Chook n' Burger: 6:30PM

Beef Sausage, Chicken Steak, Beef Pattie, Onions, 3 Homemade Chefs Salads, Beetroot, Shredded Cheese, Fresh Rolls, Sauces, Chutneys and Mustards, Fresh Fruit Bowl

## SUNDAY MAY 12

### Breakfast Cooked Breakfast: 7:30AM

Whole Seasonal Fruit, Bacon, Chipolatas, Cage Free Eggs, Baked Beans, Multigrain, Wholemeal and White Bread, Butter, Spreads and Hash Browns

### Morning Tea: Moist Cake Selections: 10.30AM

White Chocolate and Raspberry

### Lunch: Gourmet Open Burger: 12.30PM

Stack your own Burger with your choice of Onions, Cheese, Beetroot, Lettuce, Tomato, Cucumber, Grated Carrot, Sauces, Chutneys and Mustards

### Afternoon tea: New Zealand Natural Pleasure Pot: Approx 3.00PM (out on camp grounds)

Assorted Individual Ice-cream Tubs to include  
Vanilla, Chocolate Ecstasy, Cookies & Cream, Strawberry Ice-cream or Mango Sorbet or Forest Berry Frozen Yoghurt. 100% Natural - No Artificial Flavours

\*\*\*Beverages: Served with All Meals - Orange and Apple Juice (from concentrate) Tea, Coffee (Instant & Plunger) and a Fresh Seasonal Fruit Bowl\*\*\*

### Special Diet notes:

No Nut Policy: We do not use any nuts in our School or Community Menus. Please Note: Accolade cannot guarantee that traces of nuts will not be in some products.

Halal: With the exception of bacon (served at breakfast) and ham (served at lunch) all other meat is Halal. Our beef and chicken is sourced from any of the following Halal Accredited Abattoirs Goodchilds (Beef) and Steggles (Chicken)

Lactose and Dairy: We provide soy and lactose free milks, Nuttlex as butter alternative and other dairy free products.

Vegetarian and Vegan Vegetarian: We provide vegetarian meal alternative selections including vegan.

Gluten Free: We provide gluten free meal alternates throughout our menu.

Preservatives: We do not use any preservatives in our cooking.

Egg: We provide egg free alternative cakes and biscuits





# AUSDOCC CONNECTIONS 2019 CONFERENCE FRIDAY PROGRAM (Program subject to change without notice)

FRIDAY MAY 10, 2019

2.00-5.00pm	Arrivals and check in. Registration. <i>Location: Graham Russell.</i> Room allocations. Room entry times depend on cleaning after previous camp group.
5.00pm Open 6.00pm	All seated by 5.30. Welcome/Housekeeping/Introductions. <i>Location: Cygnet dining</i> Evening meal- food served. <i>Location: Cygnet dining</i>
7.00-9.00pm	Night activities: African drumming. Kids: 7pm. Adults 7.35pm <i>Location: Pelican, Campfire (weather permitting),</i> Chatting, Games & Raffles <i>Location: Graham Russell &amp; Cygnet Dining Room, Adults with a DCC quiet space. Location:</i> <i>Seminar 1</i>

KEY: GR = Graham Russell Conference Room. PFR = Pelican Function Room CDR = Cygnet Dining Room  
Program subject to change at any time ©AusDoCC Inc 2019

## Kids Club

### Providers

6 Owl Eyes staff along with 4 volunteers will be providing care for children whilst you attend the conference sessions. There will be craft activities, outdoor activities and an animal farm for the under 10s and the over 10s will have an opportunity to participate in various activities such as archery and ultimate sports. It will be located in the Cygnet Dining Room.

### Directions

Kids will need enclosed shoes and hats for some activities, Sun cream will be available.

Clearly label your child's belongings. We are not responsible for any misplaced items.

Please have your phones on vibrate in the event that the kids club staff need to contact you.

The staff are qualified, however should they experience behavioural or medical issues with your child you will be called. Staff will assist with nappy changes and toileting.

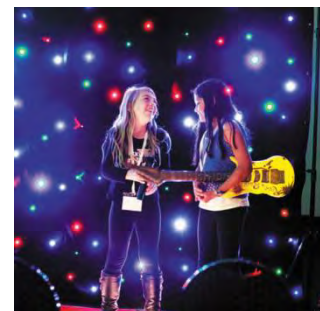
\*\*\*Parents need to be on the camp grounds and at the conference to use this service.

Should parents leave the camp grounds for any reason they will need to collect their child prior\*\*\*

### Kids Club times

Saturday: 8.20am - 2.30pm

Sunday: 8.20am - 12.30pm



# Session Notes

## SATURDAY

Professor Linda Richards: **How is the brain rewired in corpus callosum dysgenesis compared to split brain syndrome?**

“Split brain” was a term given to the cognitive changes that occurred in people that had undergone surgical resection of their corpus callosum (called a callosotomy) because of severe epilepsy. These cognitive changes are different from those seen in people with corpus callosum dysgenesis (CCD). This talk will present our results from work in mouse models studying the brain rewiring changes that occur in congenital DCC and callosotomy.

Dr Maina Kava: **Agenesis of the Corpus Callosum- Clinical and Radiological Spectrum**

Dr Maina Kava, a paediatric neurologist at Perth Children's Hospital, will be talking about the variable clinical presentations in children with agenesis of the corpus callosum, (ACC) and will review the radiological/imaging findings and management of comorbidities associated with ACC

A/Professor Paul Lockhart: **Identifying Genes influencing corpus callosum development**

This presentation discusses genetics and how it can be used to understand the causes and potentially identify future therapies for conditions affecting brain development and function.

Dr Lynn Paul: **The impacts of the corpus callosum on interpreting social situations**

Human beings tend to presume that behaviour, attitudes, and emotions are a direct result of an individual's personality. In this session, we will discuss ways that a disorder of the corpus callosum (DCC) may impact one's ability to think about social situations. Participants will be challenged to consider alternative ways of interpreting and responding to the "personality" of their loved one with a DCC.

Dr Natasha Alexander: **Concerns and strategies for protection in relationships**

This is a delicate topic that Dr Natasha is used to handling sensitively. She talks about the concerns that some parents and carers have and possible strategies for ensuring that children and young people with DCC are protected but not overprotected to the extent that they are put at further risk of sexual exploitation. She will discuss protective behaviours, puberty, teenagers' issues and relationships, and how to have some of these conversations at home.

### 4 Discussion Groups:

Choose a discussion group depending on your relationship to the person with a DCC: Mums, Dads or Other Family and Friends. Each group discussion will be facilitated and everyone will be welcome to participate or just listen. These groups provide an opportunity to speak openly with others about any concerns or aspects of DCC that you would like to share. The information shared in these sessions is strictly confidential.

\*Family & Friends – there will be a question box to add any questions prior to the session.

Professionals can join the AusDoCC president and secretary to brainstorm some ideas for moving forward with DCC awareness. What can AusDoCC do for you? What can you do for AusDoCC? What can we all do for DCC?

## SUNDAY

### All About Adults with DCC

Neuropsychologist, Lynn Paul, will present findings from her most recent research publication, “The neuropsychological syndrome of agenesis of the corpus callosum.” Following that, you will gain rare insights from 3 adults with a DCC, Emily, Margaret and Anna. They will describe the impacts of DCC on their lives as adults with a corpus callosum disorder and share their experiences & challenges growing up with undiagnosed ACC & the determination to live an inclusive life.

### Epilepsy.

Epilepsy is widely associated with DCC. This session includes a presentation and discussion covering diagnosis, seizure types, treatments, safety and any management issues the group would like to address.

### Medical Management

Hear from a GP and a paediatrician as they share insights into the medical management of individuals with ACC. Then share your own insights as we work together to workshop solutions for navigating health services. Effective collaboration will help us to consolidate information and ideas through combining professional knowledge with parents' experiences and insights. This may form the basis for resources to help other parents and professionals navigate the systems.

....Cont

# Session Notes

## NDIS

Samantha Connor, cofounder of the 46,000 strong, NDIS Grassroots Discussion Facebook group, will share her experiences in disability, advocacy and activism and alert us to some of the dos and don'ts of the NDIS. Andrea Johnson will follow on and describe the collaborative approach and supports she has established using NDIS. She will introduce the E-Team, who support Emily Johnson, an adult with a DCC who is rocking the NDIS (consent obtained from Emily).

## Anxiety, Autism & education

Connecting to the right support is essential for the learner's needs. This session is an exploration of potential educational needs, barriers to learning and strategies to support learners with ACC, autism and/or anxiety. This session will cover the social model, tried and tested supports, the neuropsychological perspective including the use of assessments to identify individual needs and a personal account of learning as a person with ACC.

## Therapies and supports

Discover how Occupational and Physiological Therapies can assist those with a DCC. Hear how one mum has built on innovation and ingenuity to access DCC supports in a remote WA community.





## AUSDOCC CONNECTIONS 2019 CONFERENCE SATURDAY SESSIONS PROGRAM

(Program subject to change without notice)

**SATURDAY MAY 11, 2019**

Time	Parents Plus/ General Attendees	Adults with DCC 18+	Kids Club/Teen Machine. 3-17
7.30-8.00am	Breakfast. <i>Location: Cygnet dining</i>	Breakfast. <i>Location: Cygnet dining</i>	Breakfast. <i>Location: Cygnet dining</i>
8.45-10.30am	<b>Welcome.</b> <i>Location: Pelican function.</i> <b>5 Keynote speakers.</b> 1. Prof. Linda Richards - Rewiring the brain - a comparison 2. Dr Maina Kava - Clinical & radiological spectrum of DCC 3. A/Prof. Paul Lockhart - What can genetics tell us about DCC? Facilitator: Pieta Shakes	<b>Welcome.</b> <i>Location: Pelican function.</i>  <b>Hello My People.</b> <i>Location: Seminar 2</i> <b>Snap it up.</b> <i>Location Seminar 2</i> <b>Let's talk about... safety in relationships</b> - Dr Natasha Alexander. <i>Location: Seminar 2</i>	<i>Location: Cygnet dining</i> <b>Welcome to Kids Club</b> <b>Welcome to Teen Machine</b> Activities
10.30-11.00am	Morning tea. <i>Location: Pelican function</i>	Morning tea. <i>Location: Pelican function</i>	Morning Tea. <i>Location: Cygnet dining</i>
11.00-12.30pm	<b>5 Keynote speakers (cont.)</b> <i>Location: Pelican function.</i> 4. Dr. Lynn Paul - DCC, social impacts and personality 5. Dr Natasha Alexander - Concerns & strategies for relationships <b>Panel of 5 keynote speakers</b> - QandA Facilitators: Maree Maxfield and Pieta Shakes	<b>Let's talk about... spreading the word</b> <i>Location: Seminar 2</i> <b>Let's move it or make it (11.45)</b> Zumba - Kristie. <i>Location: Graham Russell</i> Art Therapy Materials available - <i>Seminar 2.</i>	<i>Location: Cygnet dining</i> <b>Kids Club/Teen Machine</b> - Activities <b>10+ - Games/team building</b> - (PW) <i>Location: Graham Russell. Teens with DCC -</i> <b>Zumba with adults with DCC</b>
12.30-1.15pm	Lunch. <i>Location: Cygnet dining</i>	Lunch. <i>Location: Cygnet dining</i>	Lunch. <i>Location: Cygnet dining</i>
1.15-2.15pm	<b>Discussion groups</b> <b>Mums</b> - Tina Furse, Andrea Johnson. <i>Location: Pelican</i> <b>Dads</b> - Dr Natasha Alexander, FC. <i>Location: Gazebo</i> <b>Family and friends</b> - Margie Slater. <i>Location: Seminar 1</i> <b>Health &amp; education clinicians &amp; researchers</b> - Maree Maxfield, Tina Coburn <i>Location: Graham Russell</i>	<i>Location: Seminar 2</i> <b>Let's talk about... science and DCC</b> (50 mins). Genetics - A/Prof Paul Lockhart DCC research - Prof Linda Richards <b>Let's talk about... The Parking Lot</b> (10mins)	<i>Location: Cygnet dining and outdoors</i> <b>Kids Club/Teen Machine</b> <b>3 - 9</b> - Old Macdonald's farm <b>10-12</b> - Archery/Old Macdonald's farm <b>Teens with ACC</b> - 20 mins with Lynn Paul -> Archery <b>Siblings</b> - Archery -> 20 mins with Lynn Paul <b>All teens</b> -> Archery/Old Macdonald's farm
2.15-2.45pm	Afternoon Tea. <i>Location: Cygnet dining</i>	Afternoon Tea. <i>Location: Cygnet dining</i>	Afternoon Tea. <i>Location: Cygnet dining</i>
2.00-6.00pm	<b>EVENT: Amazing Brains Connect.</b> (IRC5 event for professionals.)Registration essential. Includes refreshments @2.00pm. 1st speaker @2.30pm <i>Location: Pelican</i>		
3:00-6.00pm	<b>Family adventure activities.</b> <i>Location: campgrounds</i>	<b>Adults with DCC - Optional Art activity</b> - Ana Palacios. 3-5pm <i>Location: Seminar 2</i>	<b>Kids-</b> old & young: Animal Farm
6.00pm (open) 6.30pm (meal)	Open for seating - wandering magician. <i>Location: Cygnet Dining</i> Evening meal - food served. <i>Location: Cygnet dining</i>		
7.30-9.30pm	Night Activities: Magic Show <i>Location: Graham Russell.</i> Zumba <i>Location: Pelican,</i> Henna tattoos, Photobooth, Chatting, Games & Raffles <i>Location: Graham Russell &amp; Cygnet Dining Room.</i> Adults with a DCC quiet space. <i>Location: Seminar 1</i>		

**KEY: GR = Graham Russell Conference Room. PFR = Pelican Function Room CDR = Cygnet Dining Room Program subject to change at any time ©AusDoCC Inc 2019**

## Key Speakers



**Dr Lynn Paul**

Lynn K. Paul, PhD, is a clinical psychologist and neuroscientist who has been studying disorders of the corpus callosum (DCC) for over 25 years. To people with DCC, Dr. Paul may be most familiar as a co-author of the picture story book, "ACC and Me." In collaboration with families in the DCC community, Dr. Paul helped create the NODCC in 2003. In 2015, she joined with other researchers to co-found the IRC<sup>5</sup>.

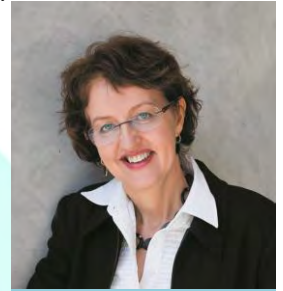
Dr. Paul is currently serving as Senior Research Scientist at California Institute of Technology, where she is directing a research program studying brain-structure, cognition and social processing in DCC. She recently began a longitudinal study of behaviour in infants with ACC. For more information or to enrol, please visit <http://emotion.caltech.edu/research/agcc/>.

Dr. Paul received her PhD in Clinical Psychology from Fuller Graduate School of Psychology working with Dr. Warren Brown and completed a post-doctoral fellowship in clinical neuropsychology from the Department of Neurology, UCLA. She also maintains a small private practice, through which she provides consultations and neuropsychological assessment for individuals with DCC. Dr Paul is AusDoCC's International Psychology Advisor.

Linda J. Richards, PhD, FAA, FAHMS is a Professor of Neuroscience and Deputy Director (Research) of the Queensland Brain Institute (QBI) at The University of Queensland, Brisbane, Australia. She is a Fellow of both the Australian Academy of Science and the Australian Academy of Health and Medical Sciences and is a National Health and Medical Research Council Principal Research Fellow. She is Past President of the Australasian Neuroscience Society and Co-chair and spokesperson of the Australian Brain Alliance, as well as a member of the International Brain Initiative and Spokesperson for its Initial Strategy Committee.

Professor Richards is head of the brain development and developmental disorders laboratory at QBI. Her laboratory team strives to understand how the brain forms during development and how these processes are disrupted causing human developmental brain disorders and brain cancer.

Professor Richards is a leading expert on the formation of the corpus callosum and is scientific advisor and patron for Australian Disorders of the Corpus Callosum (AusDoCC).



**Prof Linda J. Richards**



**Dr Maina Kava**

Dr Maina Kava is a consultant paediatric neurologist at Perth Children's Hospital and practices privately at Paedswest. She is a Fellow of the Royal Australasian College of Physicians. Maina is an active member of the Australia and New Zealand Child Neurology Society (ANZCNS).

Maina graduated from University of Mumbai with several distinctions and a gold medal. She completed her paediatric training with a gold medal and paediatric neurology training from India, Australia, and Canada. She is a senior clinical lecturer affiliated with the School of Paediatrics and Child Health, University of Western Australia.

Maina's special interests are paediatric neuromuscular and neurometabolic diseases. Maina is the state clinical lead for the mitochondrial flagship associated with the Australian Genomics Health Alliance and is involved in several clinical research projects.

Dr Natasha Alexander is an experienced clinical psychologist from the UK, who is now settled in Brisbane. In her own words, she 'ran away' from government disability services to set up Consentability. This is a service based in Brisbane, for people with intellectual or cognitive disabilities and their support networks, in the areas of sexuality, relationships, consent and safeguarding. She also works with other people where there is a concern about their capacity to consent to relationships.

Dr Natasha has experience in providing individual and couples therapy sessions, training and consultation in mental health and disability contexts. She is passionate about this area and has 'infectious enthusiasm' when talking about people's rights and responsibilities around sexual pleasure.

Dr Natasha has recently undertaken further training in somatic sex education. Having been fortunate to have experienced a variety of education and learning on her own sexuality journey, she is keen to empower and support others.



**Dr Natasha Alexander**



**Associate Professor Paul Lockhart**

Associate Professor Paul Lockhart was awarded his PhD by the University of Melbourne in 2000 and completed postdoctoral training in Neurogenetics at the Mayo Clinic (USA).

Dr Lockhart was appointed group leader of Neurogenetics Research at the Murdoch Children's Research Institute in 2005 and co-Director of the Bruce Lefroy Centre in 2009. The Centre has a focus on research into genetic diseases that affect the nervous system as well as research into genetic testing, ethics in clinical genetics and study of genetic syndromes. A major focus of the research is gene discovery using powerful modern genomic technologies and functional characterisation of proteins contributing to neurodevelopmental and neurogenetic disorders such as autism, brain malformations, Parkinson's disease and ataxia.

Dr Lockhart works in close collaboration with the Victorian Clinical Genetics Service and Royal Children's Hospital to identify and understand the genetics behind families presenting to the clinic. His team is actively investigating disorders of the corpus callosum. In collaboration with national and international colleagues, he recently described the genetic basis of syndromes defined by alterations to the structure or function of the corpus callosum. Dr Lockhart is a Scientific Advisor to AusDoCC in the areas of genetics and laboratory research.



## Saturday Speakers and Facilitators

### Tina Furse

Tina Furse is a Clinical Nurse Specialist in paediatric epilepsy who has worked for Epilepsy Action Australia for over 8 years. She has over 25 years of epilepsy experience in caring, nursing and educating children, families and carers. Tina completed her paediatric nursing and epilepsy qualifications while living in the UK, and recently achieved a post graduate qualification in epilepsy via distance learning. This not only consolidated her epilepsy knowledge but also developed skills in self-discipline and time management. Tina is passionate about helping families gain the best seizure control possible and improving their quality of life. Tina will conduct the discussion for Mums, coordinate an elective about epilepsy and is attending the camp in the role of advisory nurse.



### Andrea Johnson

Andrea Johnson is a mum and step mum who has worn a few hats in her life. As a teacher she's had a keen interest in the development and wellbeing of young people. Becoming a step mum and then a mum brought new challenges and saw her experience with disability and brain development take on a whole new direction. She's a fan of Self Managing for NDIS participants, as it's given freedom to make choice and control a reality. Andrea will coordinate the E-Team in the NDIS session.



### Margie Slater

During her employment, Margie Slater worked as a support person for people with a disability and/or special needs. She achieved an Advanced Diploma in Disability Work and also taught students studying Education Support. She is now retired from the workforce. As a committee member of AusDoCC, she is the editor of the quarterly newsletter. Margie has no family members who have a DCC. Her connection to AusDoCC is through friendship with a young adult who has a disorder of the corpus callosum. Margie will facilitate the discussion group for friends and family members.



### Maree Maxfield

Having spent the first 20 years in the dark, as the mother of a now 28 year old daughter with pACC, Maree alleviated her frustrations by trying to make sense of it all. This led to involvement in setting up AusDoCC, a Master of Public Health and the current journey, a PhD researching the impacts of corpus callosum disorders on key life domains of adults. These ventures are the source of great elation and not something she expected to do in her 60s but she has no grandchildren and is a hopeless knitter, so it seems like the logical choice! Maree will coordinate a workshop with health and educational professionals to see how we can work collaboratively for ACC enhancement



## Friday and Saturday Entertainers

### Toby Z. - Perth professional close-up magician

Birthday party, wedding and corporate event magician, with over 10 years experience in magic. Toby is also member of W.A.S.M (West Australia Society of Magicians. one of the oldest magician's club in Australia). Toby is one of the few polyglot magician in Western Australia, He is the only magician representing the leading Asian media company in Perth – 'MOSTWA'.



### Zumba with Kristie

Hello! I'm Kristie Anderson, and I live in Perth, WA. I've been a ZIN™ Member since Sep 2015 and I absolutely love teaching Zumba classes. The reason is simple: Every class feels like a party! I am currently licensed to teach Zumba, Zumba® Toning, Zumba Gold®, Zumba® Kids & Kids Jr. Come join me, I guarantee you will have a blast!



### Henna Tattoo by Sue Cudlipp



Choose from amazing designs for your temporary tattoo.

### Avalon DJs Perth

We offer comparably affordable photobooth hire with our specially designed, fully enclosed curtain photobooth. Our photobooth is equipped with a high end Nikon DSLR camera which combined with our professional studio halo ring lighting produce amazing images. After your session you can choose from a wide variety of instagram style filters to be applied.



### Point Walter Recreation Program

Outdoor recreation programs have been provided to the community by Point Walter since 1996. They have evolved into 13 distinct recreation programs, with a range of program variations, training packages, workplace adventures and custom-developed programs.



### Feel the rhythm, it's in all of us!

Drumming is a perfect way to liven up any event and introduce people to African drumming. Popular with Community programs, Festivals, Corporate teams and schools, our drum circles are guaranteed to get participants grooving to the beat of Africa through singing, clapping, drumming and dancing to African rhythms. An African Oz Drum n dance really sets the scene for any event, as people are drawn to the circle of drums, costumes and infectious smiles they will join the circle.





# AUSDOCC CONNECTIONS 2019 CONFERENCE SUNDAY SESSIONS PROGRAM

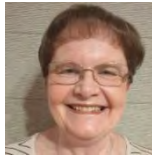
## (Program subject to change without notice)

**SUNDAY MAY 12, 2019**

Time	Parents Plus/ General Attendees	Adults with DCC 18+	Kids Club/Teen Machine. 3-17
7.30-8.00am	Breakfast. <i>Location: Cygnet dining</i>	Breakfast. <i>Location: Cygnet dining</i>	Breakfast. <i>Location: Cygnet dining</i>
9.00-10.30am	<b>Electives</b> 1. <b>All about adults with DCC</b> - Dr Lynn Paul, Emily Johnson, Margaret Krutli, Anna Uther, + other adults with DCC Facilitators: Maree Maxfield, Tina Coburn. <i>Location: Pelican function</i> 2. <b>Epilepsy</b> - Tina Furse, Maja Palacios. <i>Location: Graham Russell</i> 3. <b>Medical management</b> - Pieta Shakes, Dr Morenikeji Komaiya, Dr Ellen MacKinnon. <i>Location: Seminar2</i>	<b>Let's talk about ... life with a DCC</b> <b>Adults with DCC</b> - Dr Lynn Paul, Emily Johnson, Margaret Krutli, Anna Uther, adults with DCC. <i>Location: Pelican function</i>	<b>Kids Club/Teen Machine</b> - Activities <i>Location: Cygnet dining</i> <b>Camp provided equipment available</b> <i>Location: outdoors</i> <b>Teens with DCC 16+: optional - Elective 1</b> - Meet the adults with DCC <i>Location: Pelican function</i>
10.30-11.00am	Morning Tea. <i>Location: Pelican function</i>	Morning Tea. <i>Location: Pelican function</i>	<i>Location: Cygnet dining</i>
11.00-12.30pm	<b>Electives</b> 1. <b>NDIS</b> - Samantha Connor, Andrea Johnson, The E team. Facilitator: Niki Harrison <i>Location: Pelican</i> 2. <b>Anxiety, autism &amp; education</b> - Tania Bianco, Louise Sheehy, Ana Palacios, Claire Deans. Facilitator: Pieta Shakes <i>Location: Graham Russell</i> 3. <b>Therapy &amp; supports</b> - Shannen Stanes, Tahlia Wilson, Sophie Minuta, Jenny Lee-Kelsall. Facilitator: Lisa McNally <i>Location: Seminar 2</i>	<b>Let's talk about ... Anxiety and social impacts of DCC.</b> - Dr Lynn Paul. <i>Location: Seminar 1</i> <b>Let's talk about... the NDIS and how to make it work</b> - Samantha Connor. <i>Location: Seminar 1</i> (Alternative - Gazebo)	<b>Kids Club/Teen Machine</b> - Activities <i>Location: Cygnet dining</i> <b>10+ - Ultimate Sports</b> Pt Walter staff. <i>Location: campgrounds</i>
12.30-1.15pm	Lunch. <i>Location: Cygnet dining</i>	Lunch. <i>Location: Cygnet dining</i>	Lunch. <i>Location: Cygnet dining</i>
1.15- 2.00pm	<b>Finale: Location: Pelican function</b> <b>What the future holds</b> - Prof. Linda Richards <b>Goodbyes can be so tricky</b> - Dr Natasha Alexander <b>Conference slideshow. See you in 2021. Only 731 more sleeps.</b>		
2.00-4.00	Camp provided adventure activities (PW). <i>Location: campgrounds</i> <b>Adults with DCC - Optional:</b> 2-3pm <b>"You can ask that!"</b> - Lynn Paul & Natasha Alexander (60mins)		
3.00pm	Afternoon snacks available. <i>Location: distribution and delivery around campsite</i> 2019		©AusDoCC Inc

## Sunday Presenters

**Margaret Krutli**, 64, lives at Aberfoyle Park, a southern suburb of Adelaide, SA. She is married to Chris & has 2 sons & 1 grandson. Born in Broken Hill, she moved to Adelaide in 1977. After completing year 10 she left school to complete tertiary studies in secretarial procedures. Margaret worked for various clerical companies and has volunteered for a variety of organisations for over 30 years, until 2016. She and Chris love traveling in their caravan every year & their hobby is researching their family history. Margaret will speak about her experiences as an adult with ACC.



**Emily Johnson** is a gutsy young woman in her twenties. In her teen years she began having large seizures. Fearing she was critically ill, doctors sent her for CT scans and discovered that she doesn't have a corpus callosum. It meant that she could finally understand why her life holds a unique set of challenges. It's also helped others to better understand and support her. Now an NDIS participant, with her sister Gabi filling the primary carer role in her life, she is living life her way and dreaming big. You'll find her microenterprise at [goodlookingartandphotography.com](http://goodlookingartandphotography.com) Emily will take you on a tour of her experiences as a young adult with ACC.



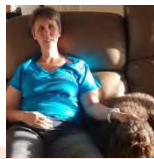
**Dr. Morenikeji (Keji) Komaiya** graduated from University College Hospital, Ibadan Nigeria in 1998 and started General Practice in 2001. She moved to Australia in 2006 from the UK. Due to her great interest in Quality Improvement, she has also been working with AGPAL (Australia GP Accreditation provider) as a GP surveyor since 2011 and QIP (Quality Innovation Performance) in 2013. Her interests include preventive medicine, mental health, travel clinic, chronic disease management, and weight loss programs. Dr Keji will speak about her experiences with ACC in addition to workshopping strategies for those who have received a diagnosis.



**Pieta Shakes** stepped into the role of Grants Officer in 2018 hoping to help raise the needed funds for AusDoCC to reach the next goals of support and advocacy. Pieta is a mental health nurse who facilitates child development, research methods, mental health promotion and mental health & illness units at Deakin University. A current PhD candidate exploring the experience of receiving a prenatal diagnosis of a disorder of the corpus callosum, Pieta is motivated by lived experience and the awesome little human that calls her "Ma." Pieta will facilitate the Medical Management and the Autism/Education elective.



It wasn't until she was 18 that **Anna Uther** was diagnosed with complete ACC. As far as she was aware, she was the only adult in the country with this disorder, until 2015, when she found AusDoCC. She is now a voice for the adults with a DCC on the Committee and will present on her lived experiences as an adult with a DCC. Anna will relate some of her experiences as an adult with ACC in a Sunday elective.



**Dr Ellen Elizabeth MacKinnon**  
Qualifications  
Bachelor of Medicine / Bachelor of Surgery University of Western Australia Australia 2004  
FRACP Australia 2016  
Occupation Paediatrician



**Samantha Connor** is a disability and human rights activist, wheelchair user, writer and self-proclaimed social media assassin. She has held a number of prominent positions in the disability sector including Vice President of People with Disability Australia and as a member of the expert group on NDIS workforce and sector capacity. Samantha has a passion for disability rights and is a cofounder of social media group NDIS Grassroots Discussion, a peer support group with 46,000 members. She has a strong background in systemic advocacy in the areas of disability and disadvantage and is currently the Convenor of Yellow Sub, a disability rights organisation. Samantha will enlighten us on the NDIS.



**The E Team**  
Meet Gabi, Molly, Pauline, Amy, Kerri and Penny. Affectionately called 'Em's Entourage,' this team of amazing individuals provides the care Emily needs, to not only survive but thrive, in a world where having a brain malformation is a tough gig. Lead by Gabi, Emily's sister and carer, these women flesh out what it means to help Emily to dream and make those dreams a reality. Each is a talented professional in her own right and as a team they combine their skills with compassion and insight. Meet Em's Entourage in the NDIS elective



## Sunday Presenters

**Shannen Stanes** is a Physiotherapist who works at Therapy Focus, a Not-for-Profit Organisation that works with kids and adults with disabilities all over WA. Shannen's experience with corpus aliosum disorders is working with two clients with ACC (Agenesis of the Corpus Callosum) for the last 3-4 years. The information provided during Shannen's presentation will be related to her experiences of working with these boys.



**Tahlia Wilson** is an Occupational Therapist who also works at Therapy Focus, a Not-for-Profit Organisation that works with kids and adults with disabilities all over WA. Tahlia's experience with disorders of the corpus callosum is also working with the same clients with ACC for the past year. Information provided will be related to her experiences of working with these boys.



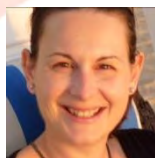
**Claire Deans** currently teaches at Westminster Education Support Centre in the northern suburbs of Perth. The centre caters for students with disabilities including ACC, Autism, CP and Down's Syndrome. It shares a campus with a mainstream school which provides opportunities for integration and inclusion. Originally from the UK, Claire has taught in a range of settings in Perth, Queensland and London. Claire is presenting from an education perspective in the Autism elective.



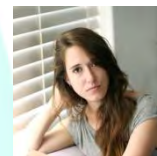
**Louise Sheehy** Most of Louise's career has been involved in the not for profit sector. Louise has been working with teenagers and adults on the Autism Spectrum, since 2011, developing services based on a strengths based approach to increase equality of opportunity. Louise has been interested in rights and education since her role as an educational policy worker in Ireland in 2000. She is passionate about ensuring that individuals on the autism spectrum are actively involved in planning, delivery and development of services. Louise will present in the Autism elective.



**Dr. Tania Bianco** is a licensed Clinical Neuropsychologist, Clinical Psychologist and Educational and Developmental Psychologist. She completed both her Doctor of Psychology (Clinical and Clinical Neuropsychology) and her Master of Psychology (Applied Developmental) through the University of Western Australia. Dr. Bianco is a member of the Australian Psychological Society and the WA Branch of the College of Clinical Neuropsychologists. Dr. Bianco established a private practice during 2013 and also currently acts as the Senior Neuropsychologist on the Paediatric Team at the Neurosciences Unit (Department of Health, WA), where she has worked for 17 years. Her primary area of interest and specialisation is the comprehensive assessments of children and adolescents with neurological and learning challenges. Liaison with a broad range of medical, educational, allied health, justice and external funding providers is prioritised to inform and establish effective home, educational and community management for the clients involved in her care. Tania will present in the Autism elective.



**Ana Palacios** is a contemporary artist whose work spans practices of research, traditional craft and storytelling through objects. After receiving an autism diagnosis as an adult, Ana realised her art practices were a positive adaptation to the challenges of being neurodiverse. Ana soon began working as a visual arts facilitator for Autism West, where she combined her passions of working with young people and exploring creative research. Her role has expanded to include the Youth Empowerment Research Project with the Youth Advisory Council, which recognises the lived experience of participants and neurodiverse staff as a valuable resource in the development of Autism West's programs and community. Ana is attending as key facilitator for the Adult's with ACC group and will present in the Autism electives.



**Jenny Lee-Kelsall** is the mother of Logan (10) and Angel (6). After testing beginning at 28 weeks of pregnancy, Jenny learnt that Angel had ACC, something that Jenny and most medical staff hadn't heard of. The family's lives changed in a matter of minutes. Emotions of feeling sad, frightened, and isolated abounded. Jenny Lee-Kelsall wants to give others the hope that she never had and talk about her family's journey. Jenny has worked for Child Protection WA for the past 14 years. Working with medical professionals has supported Jenny to link Angel with services. However, she also acknowledges the struggles that many families have in reaching out for support and therapy. Jenny will speak about her experiences in the therapy elective.



**Sophie Minuta** is an Occupational Therapist and works in a community setting at WizeTherapy to support and promote development, achievement and participation for children, adolescents and young adults. Sophie works in a transdisciplinary therapy team to support families and children to achieve their goals by providing a comprehensive service that is tailored specifically to the unique and individual needs of the child and their family. Sophie will present in the therapy elective.





# Adults with DCC

As we welcome back old friends and make new ones, this conference promises to build the skills, knowledge and friendships of the growing group of Australian adults with DCC. Ana Palacios will facilitate the group with assistance from Maree Maxfield and a line-up of experienced professionals.

This 'adults only' program is a rare opportunity to get together and hang out with other like-minded adults. Nothing compares with that. Adults with a DCC will have a safe and confidential space to discuss concerns, issues and successes, while also enjoying many other activities with all the other Connections 2019 attendees.

On Sunday, the adults will generously share their experiences and insights with other conference attendees. Don't miss the opportunity to hear from some of our adults as they share with presentations and a panel to answer your questions.

## Here's a rundown on what to expect.

### FRIDAY MAY 10

- 2-5pm Find your bunkroom, choose your bed, make it up and unpack.  
5.30pm Be seated in the dining room for the welcome & important information. Then we have dinner and **evening options** - African Drumming, chatting, a quiet sensory space and games.

### SATURDAY MAY 11

- 7.30am Breakfast  
8.45am Be seated in Pelican for the Official Opening, then follow Ana & Maree to Adults HQ.  
9.00am **Hello, My People:** Introductions and **Snap It Up** information  
**\*Session 1** **Let's talk about ... relationships, sexuality and how to be safe.** There will time for questions and discussions in this closed session with Natasha and the adults with a DCC. If the group chooses to divide into 2 shorter sessions, Margie Slater will lead discussion groups, addressing topics collected during 'Hello my People.'  
11.00am **Let's talk about ... Snap It Up (continued).**  
**Session 2** **Keep calm and Zumba ...** Kristie will get everyone grooving to ZUMBA. Join in any time or watch/chill. Connor can give you the heads up. He's an expert.  
1.15pm **Let's talk about ... ACC research and genetics.** Linda and Paul will explain their roles as scientists and researchers and then you can challenge them with some tricky questions.  
**Session 3**  
3.00pm **Options:** Onsite adventure activities, Art with Ana, Animal Farm, quiet sensory space, IRC<sup>5</sup>.  
5.30pm Be seated in the dining room ready for dinner and evening activities including magic, Zumba, henna tattoos, a photobooth, games, a quiet sensory space and chatting

### SUNDAY MAY 12 (Happy Mothers' Day Mums)

- 7.30am Breakfast  
9.00am **Life with a DCC:** This is a session for others to learn about adults with a DCC, firsthand, from you.  
**Session 4** Lynn Paul will explain her latest published research and then Anna, Margaret and Emily will give a presentation about themselves. This is followed by a panel of adults willing to answer questions from the audience.  
11.00am **Let's talk about ... Social situations & anxiety.** Lynn will tell you a little about herself, her psychosocial research findings and then discuss any questions and issues you may have. This is a closed session where you are able to speak in confidence. Chatham House rules.  
**\*Session 5** **Let's talk about ... the NDIS.** Disability advocate and activist Samantha Connor will tell you a little about herself and her work and lead a discussion about the successes and pitfalls of the NDIS for adults with DCC.  
1.15pm All attendees to the finale. Linda Richards will tell us about future DCC research and how we can help. Natasha will prepare us all to ease back into our lives when we get home. The formal conference will close with a slide show of the weekend.  
**Session 6**  
2.00pm **Options:** \*Informal group chat with Natasha and Lynn Paul.  
Onsite camp adventure activities, Art with Ana, quiet sensory space.  
4pm **The End.** Only 731 sleeps until Connections 2021

*\*Sessions for adults with a DCC only. Any other attendees present must be with full consensus of the group.*



The IRC<sup>5</sup> is composed of scientists and clinicians around the world with a shared mission. The mission is to discover the causes, consequences, and effective interventions for disorders of the corpus callosum (DCC) and associated disorders of cerebral connectivity.

At Connections 2019 we have 3 IRC<sup>5</sup> scientists providing us all with a wonderful opportunity to hear an overview of the latest research, current understanding and best practices for developmental malformations of the corpus callosum. IRC<sup>5</sup> members, **Professor Linda Richards (QBI, Brisbane), A/Professor Paul Lockhart (MCRI, Melbourne) and Dr Lynn Paul (Caltech, California) are global leaders in ACC research.** During the conference they will present the latest research findings on aspects of connectivity, genetics and psychosocial impacts of corpus callosum disorders.

The IRC<sup>5</sup> members meet in a different international location each year. Their inaugural meeting coincided with AusDoCC's inaugural Connections conference in Brisbane in 2015 and we have a close affinity with the group. Last year some of us attended the IRC<sup>5</sup> symposium in California preceding the NODCC conference and this year they are meeting in France. AusDoCC has been invited to attend the scientific IRC<sup>5</sup> symposium and also meet with representatives of the other key international parent support groups, to form an advisory group to the IRC<sup>5</sup>.

AusDoCC is thrilled to have 3 committee members attending - 2 executive representatives, Maree Maxfield and Kristina Coburn and Michael Shanahan representing adults with a DCC. Although AusDoCC is providing some financial assistance this year, generally AusDoCC representatives and IRC<sup>5</sup> members are fully self funded and committed to creating awareness and increasing the knowledge base around the causes and management of corpus callosum disorders.

These three presenters will also speak at a symposium for professionals on Saturday afternoon at Amazing Brains Connect, a concurrent event running alongside Connections 2019. This is great opportunity for Perth professionals.

**Program timetable:**

**2pm: Arrival**

**2.30pm: Introduction – Michael Shanahan, member of AusDoCC**

**2:35pm: Development of the corpus callosum and how ACC occurs –Professor Linda Richards**

**3.30pm: Genetics of corpus callosum disorders – A/Professor Paul Lockhart**

**4.30pm: Break for 10min**

**4.40pm: Cognition and behaviour in corpus callosum disorders – Dr Lynn Paul**

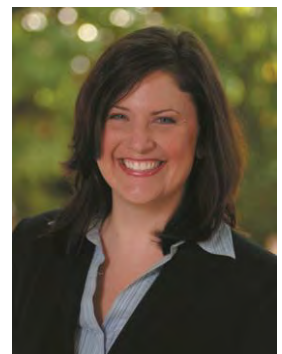
**5.40pm: General Question and answer session**



**Professor Linda Richards**  
PhD FAA FAHMS  
Deputy Director Queensland  
Brain Institute



**A/Professor Paul Lockhart**  
Murdoch Children Research  
Institute  
Genetics and Laboratory  
Research



**Dr Lynn Paul**  
Psychology Senior Research  
Scientist Caltech (USA)

## Brain Sells shop, lucky tickets and more....

Check out AusDoCC and ACC related items from our Brain Sells shop and help to support the work of AusDoCC.

100% of the profits go straight back into creating resources, holding events and supporting families.

Order can also be made at [www.ausdocc.org.au/shop](http://www.ausdocc.org.au/shop)



**Win a money tree**

**Get your lucky ticket! \$1 each or 6 for \$5**

Vouchers valued at over \$500

inc Bunnings, Coles, Woolworths and other national stores

**Winner will be announced May 12, 2019**

**Box raffles, games and lots of fun activities**

*Zippity doo dah. Helloooooooooooooo.*

*It's me Edna, the fat tailed dunnart.*

*You may have read my stories in the AusDoCC newsletter.*

*You may even have your own avatar of me because I have my own merch.*

*I am very very spesh because I have no corpus callosum just like lots of you guys. I have come to this conference to hang out with my bestest friends in the whole wide world. You will see me around having an amazing time. And guess what? I am writing a book and you can read it later this year. You might even be in it!*

*Hope you have an awesome weekend at Connections 2019.*

*love from Edna*





# Conference Sponsors



Memorial fund In memory of Brodie Harrison



Happy Boxes and bags



Anna Uther and John Jonker



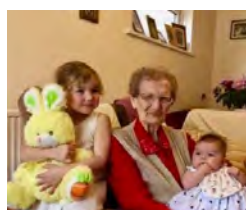
Australian Government  
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William Uther



Bill Rule



Ludford Family  
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Memorial fund In  
Memory of Dr John Uther

# Thank you to all...

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Linda Tammen  
Emily Hawkes  
Brodie Harrison  
Linda Richards  
David Randerson  
Cathey Gray  
William Uther  
Monica Dunne  
John Jonker  
Catherine Davie  
Simon Amcal Chemist  
Fiona Stuart  
Pamela Parodi  
Barry Smith  
Kerry Todero  
John Jonker

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Julie Haenow  
Nicole De-Lefontaine  
Tyler Baric

Marcia Weston  
Nikola Baric  
Helen Phillips  
Alison Dirix  
Charmaine Hutton  
Tina Cochrane

## **Presenters/Facilitators & Other**

Ana Palacios  
Andrea Johnson  
Anna Uther  
Claire Deans  
Dr Ellen MacKinnon  
Dr. Morenikeji Komaiya  
Amy Dwight  
Pauline green  
Kerri Thompson  
Molly Toner  
Katie Ormrod  
Gabi Johnson  
Emily Johnson  
Jenny lee kelsall  
Kristina Coburn  
Louise Sheehy  
Maree Maxfield  
Margie Slater  
Margret Kruitl  
Michael Shanahan  
Niki Harrison  
Pieta Harris  
Samantha Connor  
Shannen Stanes  
Tahlia Wilson  
Tania Bianco  
Tina Furse  
Lisa McNally  
Daniel Lane  
Nicola Baric  
Marcelo and Jocelyn Palacios  
Anderson Kristie and assistant  
Toby Zhang  
Rhiannon Whitney  
Aylee Affotey  
Daniel Affotey  
David Jones

AND ANY OTHERS WE  
MAY HAVE MISSED



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## AusDoCC Committee 2019



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