

Australian Conference Connections 2017



Australian Government
Department of Human Services

Official Program
Melbourne
May 6-7

Disorders of the Corpus Callosum

ausDoCC
australian disorders of the corpus callosum



House Keeping

- Please wear your lanyard and name tags at all times. They are your entry into sessions.
- AusDoCC Committee members are easily identified by their orange and black shirts. AusDoCC volunteers will have aqua shirts. All shirts have the AusDoCC logo.
- We encourage everyone to be seated ready to begin sessions on time
- Please enjoy the free fitness program going up and down the stairs. There is only one lift and it's not very big.
- The dinner is pre-booked and will be held in the Orbit Room, on the ground floor on Saturday night. This will be a fun night with a free Rock Trivia Quiz hosted by Purple Soup and a photobooth. Although this is not a fundraiser there may be a few raffles on the go.
- During the day, there is a chill-out, quiet room on the ground floor for anyone who is experiencing sensory overload. Please be mindful of others if using the room. Children need to be supervised by an adult.
- We have some great trade tables that we hope you will support.
- There will also be a silent auction, raffles and AusDoCC merchandise for sale during the weekend
- Please be patient if there are any glitches.
- Have a fabulous conference. We hope you leave with wonderful memories, new friends, new knowledge and great inspiration.



Bruce Fleming

Your conference host (Master of Ceremonies), “Be Inspired” session facilitator and all round good (looking) guy, Bruce Fleming is honoured to be part of the 2017 AusDoCC conference!

With a diverse background in senior management, business consultancy and leadership training in both the public service and private sector, his passion, talents and energy is focused on making a difference in people’s lives – Giving everyone the opportunity to gain:

- Access to freedom from the past,
- Insights that transform our experience of the present
- Inspiration to create infinite new possibilities for themselves and their lives!

As a qualified vocational trainer, accredited de Bono Institute facilitator, experienced life coach and professional business mentor, Bruce lives life through his core values of: Joy, Love, Integrity, Courage and Compassion. He has been aptly, variously and collectively described as: “Irreverent, funny and engaging! “A profoundly powerful, confronting and positive force of nature!” and “A unique and completely crazy individual!”

In the “Be Inspired” Session, we’ll get clarity about what inspiration means. What it might sound, look and feel like! What holds us all back! And, most importantly, how we can all NOW make a difference in our communities!

Welcome

Hey Everyone,

Welcome to our second conference, Connections 2017. It's been a mammoth task putting this event together. Over the next two days I'm sure we will learn a lot, not only from the professionals but also from each other. We will share stories, have a laugh and even shed a tear or two. It is a rare opportunity to have this many knowledgeable people together at the same time.

I want to encourage you all to ask as many questions as you can and remember there is no such thing as a stupid question. The professionals will be around for the whole time so don't be shy, feel free to introduce yourself and have a chat. Most importantly, have great time over the next two days. This is a wonderful chance to form friendships with people with whom we share a common connection. Everyone's journey may be different but is also similar, so let's all join hands and cross this bridge together!

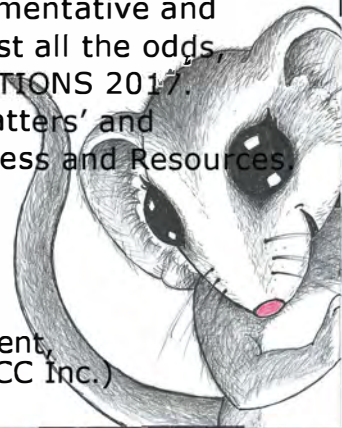
Kristina Coburn
(President)

Roll up, roll up, roll up.

There are many words to describe us, the AusdoCC committee... amazing, erratic, unpredictable, passionate, dedicated and even, fierce but I think the one that sums us up best is 'courage.' We are all courageous in our tireless dedication to raise the profile of corpus callosum disorders in Australia. The ubiquitous rollercoaster cliché of extreme ups and downs embraces all that we do. It can be applied to all our situations, from when we are in the depths of despair to raising us to elation-filled ecstatic highs. And yes, we have plenty of both. We are like family. We fight. We laugh. We cry. We toil endlessly. We learn quickly. We are jealous, protective, argumentative and all so different but we have pulled together, against all the odds, to bring you the greatest show on earth, CONNECTIONS 2017. We hope you leave, exhilarated, knowing 'ACC Matters' and ready to ROAR for Recognition, Opportunities, Access and Resources. Roll up for the ride of your life!

Maree Maxfield
(Secretary)

on behalf of the 2016/2017 Committee of management,
Australian Disorders of the Corpus Callosum (AusDoCC Inc.)



AusDoCC Committee 2017



Kristina Coburn - President

Kristina (Tina) is from Perth, Western Australia and the mother of three wonderful young men Connor, Hamish and Kyle. Connor (born 1998) and Kyle (born 2006) both have agenesis of the corpus callosum and coincidentally they also share a birthday. Tina, her husband, Alan and the boys all get on really well and have amazing family dynamics. Kristina's great sense of humour keeps them and AusDoCC, on track. After a lonely journey though the ACC world with Connor, when Kyle was diagnosed Tina felt the need to connect with as many families as possible, hence starting the original Facebook group. She is the current president of AusDoCC and is hoping to build on the foundation of the support group that currently exists.



Maree Maxfield - Secretary

Maree is mother to Abbie Kinniburgh (pACC) and is AusDoCC's secretary. She has been an executive committee member since its inception. She has a passion for spreading the message, to families and professionals, that ACC Matters and should be respected as a primary condition affecting 1:4000 Australians, many of whom have not had the validation they deserve. Maree is studying a Masters of Public Health at Melbourne Uni to help navigate the health system and learn how best to advocate for change and recognition for DCC. She used to farm and play a lot of sport and music but has got a bit creaky in the joints these days so plays the 'desk chair' and 'computer' instead.



Niki Harrison - Vice President

Niki loves to enjoy life and holiday with her family. She works in real estate and has been on the committee since the beginning she is now vice president of AusDoCC. Her youngest daughter Abby has a DCC. She is married to Steve and they have 2 other children Brodie and Tahlia. In ausdoCC I look after memberships, meet ups and anything else that I'm needed for. 'I am part of the committee to raise awareness for the disorder so that new parents don't get the same advise that we received when we had Abby. "Just wait and see how it will affect her as we don't know"!!



Linda Franklin - Vice President

Linda Franklin is mum to a few, fulltime aunty to a couple and nanna to two. She works as a disability support worker. Linda's youngest son, Gordon, who was born with a disorder of the corpus callosum, enjoys dancing and swimming lessons every week. He has been in mainstream school for 4 years and has just started in a support unit. Gordon also has epilepsy. Linda joined the AusdoCC committee in the beginning and in the last election became a co-vice president with Niki Harrison. Linda enjoys meeting new families and often meets other families in NSW.



Maja Palacios - Treasurer/Design Officer

Maja is currently AusDoCC's treasurer and lives in Perth with her husband, Andrew and two daughters, Eva (9) and Andie (7). Andie was diagnosed prenatally with complete ACC and after birth she was found to have myriad of medical issues and an undiagnosed syndrome. Andie attended intensive early intervention programs and sees over 12 specialist medical teams. Before discovering the AusDoCC Facebook group in 2013 the family had a very isolated and unknown journey. Maja, who has a background in science, wants to contribute to raising awareness about AusDoCC and help to bridge the obvious gaps in the system. She is a motivated person with an artistic flair and a family background in photography and graphic design. While pregnant with Eva, Andrew and Maja started their own company where Maja has managed the accounts successfully for 10 years.



Abbie Kinniburgh - Adult Liaison Officer

Abbie was born in 1990 and diagnosed with partial agenesis of the corpus callosum (pACC) at age two. Abbie has completed primary and secondary school and TAFE courses. She is now studying a Bachelor of Social Work at Victoria University. Abbie has many daily challenges due to her DCC and other health conditions but gets lots of support and has much resilience. Abbie lives with her mother and her mini foxie dog, Scout, in Melbourne. Scout is Abbie's closest friend. Through working with AusDoCC, Abbie wants to spread the word about this condition in Australia. She also aims to find and support adults like herself, living with this rare condition.

AusDoCC Committee 2017



Michael Shanahan - Research Officer

Michael is an AusDoCC committee member with ACC. Michael is passionate about ACC research and is the Research Officer for AusDoCC. Michael has volunteered in several research studies at QBI, is studying a Masters of Nursing focusing his thesis on ACC, and is working on an online video series and a book on ACC as some long term AusDoCC projects. Michael is a Registered Nurse working in palliative, oncology and chronic pain management in-patient settings in a private hospital on the Sunshine Coast in Queensland, with postgraduate qualifications and a background in residential dementia care. Michael is engaged to Simone and they are planning to get married by Elvis in Las Vegas, unless we haven't got that kind of technology by 2019, it will probably just be some guy in a costume.



Tanya Smith - Newsletter Officer

Tanya is a mum to 2. Ellie is 13 and Kody is 11. She is currently living the northern rivers region of NSW. Tanya and both children are part of the research through QBI and it was recently discovered they all have the DCC gene which causes mirror movement and ACC. Only one child, Kody, has P-ACC although all 3 have a mirror movement. Tanya is past president of AusDoCC and is a current general committee member. AusDoCC has always been an important part of Tanya's family and the friendships made are very important to her and to Kody.



Melissa Bowden - Grants Officer

Melissa is a working mother to two children, a five year old boy and a three year old girl. Her son was diagnosed with partial ACC at 15 months. Melissa and her husband, Chris, were frustrated by the lack of knowledge and information about disorders of the corpus callosum, and their underlying causes. After attending the inaugural AusDoCC conference. In 2015, Melissa was amazed at the quality of speakers, the professionalism of the conference and the fact that it had been organised from the AusDoCC volunteers who were also predominantly carers of children or young adults with corpus callosum disorders. She welcomed the opportunity to join the AusDoCC committee for 2015/16. Originally hailing from Australia, but living in New Zealand for 7 years, Melissa hopes that her involvement with AusDoCC can also benefit New Zealand individuals and families affected by corpus callosum disorders.



Anna Uther - Adult Liaison

Anna lives in Sydney and was born with complete ACC. She was diagnosed in early adulthood and grew up with several siblings. Anna completed nursing qualifications at Avondale College of Higher Education and has worked in nursing. She has a passion for dogs and dogs' sports and is a volunteer obedience and agility instructor with local dog training clubs, as well being as a competitor in dog agility events. This has provided a vast opportunity for friendships and new skills. Anna joins the committee to enhance the voice of adults with DCC and has been enthusiastic about being involved with fundraising and connecting other DCC adults. She was excited to find other adults with a DCC and is keen to make connections and help build a supportive adult community.



John Jonker - Sponsor Registry Officer

We welcome new committee member, John Jonker. John lives with his partner, Anna, who has complete agenesis of the corpus callosum (ACC). John is a groundsman who looks after a sporting complex for a local council.

His interests include dog sports where he instructs in both agility and obedience at his dog clubs.


John is interested in learning more about ACC as well as helping people with similar conditions to Anna in their daily life needs.



Rebecca Walter - Treasurer till April 2017

Rebecca is Mum to 3 amazing kids, Joshua, Thomas and Maddison. Josh was diagnosed with complete ACC at 37 weeks gestation. Josh has just completed year 12 and successfully carried out a year long, school research project on DCC. Rebecca's journey with Josh has been very isolating like many others affected by a DCC and Rebecca has always been determined to help others connect and raise awareness of a disorder that seems hidden from the rest of the world. She and her family struggled to cope with a diagnosis that nobody knew about or seemed to have or understand. A whiz with figures, Rebecca has carried AusDoCC between two major conferences as treasurer. She enjoys working with numbers and has masterfully kept the AusDoCC budget in check to produce a well supported organisation with a strong foundation..

SATURDAY					Shaded sessions for adults with DCC only		
ROOMS ->	TIMES	HORIZON	VISTA	PANORAMA	ASPECT (Adults)	GYM	
	8.00 - 9.00	REGISTRATION OPENS -CHECK IN (ground floor) RECEIVE ID LANYARD/ NAME TAG. PROGRAM & DELEGATE BAG (main conference Level 4) KIDS' CLUBS CHECK-IN BEGINS AT 8.15 a.m. on ground floor					
SESSION 1	9.00-9.30 9.30-11.00 (120 mins)	<ul style="list-style-type: none"> WELCOME to country - Bruce Fleming (MC) AusDoCC President's welcome - Kristina Coburn Federal Member for Gellibrand - Honorable Tim Watts MP, KEYNOTE SPEAKERS- 5 Questions <ul style="list-style-type: none"> Prof. Linda Richards, Prof. Warren Brown Dr. Lynn Paul Prof. Elliott Sherr 				9.00 WELCOME (Skyline) 9.30. Access (Workshop) Adults with DCC Facilitator - Margie Slater <ul style="list-style-type: none"> Education - Anthony Gartner Employment - Sofie Sneddon NDIS - Melo Kalemkeridis 	
Break	11.00-11.30	Morning tea break					
SESSION 2	11.30-12.45 (75 mins)	Mums <ul style="list-style-type: none"> Moira Rayner Kristina Coburn 	Dads <ul style="list-style-type: none"> Purple Soup 	Professionals - Raising the DCC profile (Workshop) <ul style="list-style-type: none"> Education - Anthony Gartner Research - Linda Richards Therapy - Myff Adkins Complex needs -Jennifer Cook Paediatrics - (TBC) 	Psychosocial and cognitive impacts of living with DCC <ul style="list-style-type: none"> Dr. Lynn Paul Prof. Warren Brown A/Prof. Mark Walterfang 	Friends and family <ul style="list-style-type: none"> Elizabeth Courtney - Sibling of an adult with a DCC 	
Lunch	12.45-1.45	Lunch break					
SESSION 3	1.45-3.00 (75 mins)	Autism & DCC <ul style="list-style-type: none"> Prof. Elliott Sherr AMAZE - Fiona Sharkie Yellow Ladybugs - Penny Robinson 	Therapy options #1. <ul style="list-style-type: none"> Physiotherapy - Myff Adkin Horticulture - Steve Wells Animal Assist - Melanie Jones Complex Care - Jennifer Cook 	NDIS <ul style="list-style-type: none"> Carers Victoria - Kerry Golding Mark Wyburn Pieta Shakes 	Compassionate Therapy <ul style="list-style-type: none"> Penny Jacobsen Mary Robson Leanne Sutton 	INTERVIEWS (Adults - off campus)	
Break	3.00-3.20	Afternoon tea break					
SESSION 4	3.20-4.35 (75 mins)	Genetics & DCC <ul style="list-style-type: none"> Dr. George McGillivray Keri Pereira Kate Pope (panel) 	Imaging of DCC & other associated brain abnormalities <ul style="list-style-type: none"> A/Prof. Simone Mandelstam 	Education options. <ul style="list-style-type: none"> Kathryn Arbuckle Anthony Gartner Sarah Hancock Bryar Kerridge 	Best Practices Document. (Workshop) Pre birth to aged. AusDoCC Committe Members (Adults off campus)	INTERVIEWS (Adults - off campus)	
	4.35p.m.	End of Day Program					
Evening	6 p.m.	EVENING PROGRAM - Dinner + Rock Trivia Quiz, family fun with Purple Soup (included with registration). Photo Booth. Presentations.					

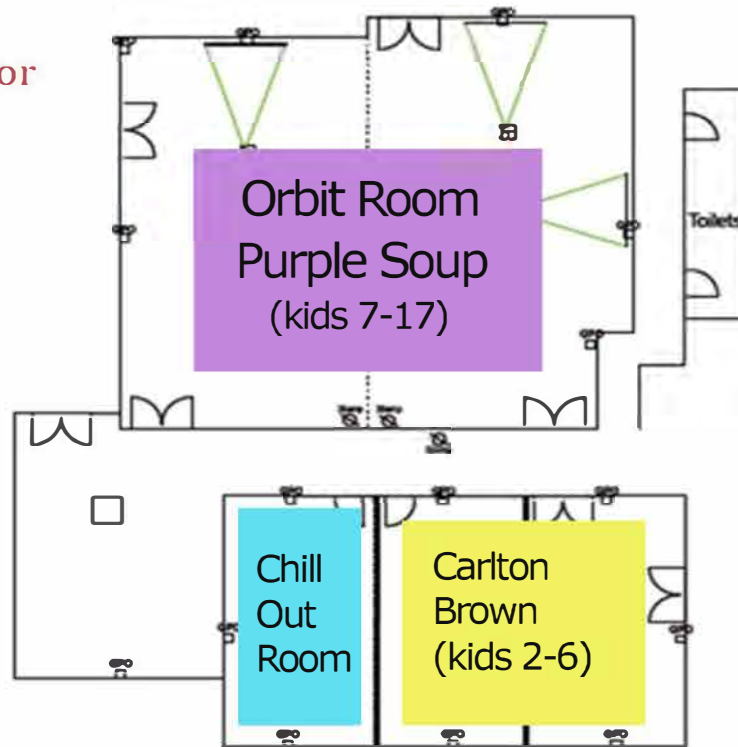
SUNDAY					Shaded Sessions for adults with DCC only	
ROOMS->	TIMES	HORIZON	VISTA	PANORAMA	ASPECT - Adults	THE GYM
SESSION 5	9.00-10.15 (75 mins)	KEYNOTE SPEAKERS - 5 questions MC - Bruce Fleming <ul style="list-style-type: none"> • Assoc. Prof. Rick Leventer • Assoc. Prof. Simone Mandelstam • Dr. George McGillivray • Assoc. Prof. Mark Walterfang 		Trade table holders demonstrations	Keeping well and active - <ul style="list-style-type: none"> • Karen Gatt AusDoCC adults with DCC - planning for the future <ul style="list-style-type: none"> • Maree Maxfield 	SIBLINGS ≥13 Lynn Paul (30 mins)
Break	10.15-10.45	Morning tea break				
SESSION 6	10.45-12.00 75 (mins)	Social Cognition & Personality <ul style="list-style-type: none"> • Dr. Lynn Paul 	Epilepsy & DCC <ul style="list-style-type: none"> •Prof. Ingrid Scheffer •A/Prof Rick Leventer •Linda Franklin 	Relax & Unwind <ul style="list-style-type: none"> •Carers Australia, (Victoria)- Tania Daniels 	Science & Medicine - ask the experts <ul style="list-style-type: none"> •Prof. Elliott Sherr •Dr George McGillivray •A/Prof. Simone Mandelstam •A/Prof. Mark Walterfang 	INTERVIEWS
Lunch	12.00-1.00	Lunch break				
SESSION 7	1.00-2.15 75 (mins)	Callosal basics and cognitive functions of DCC <ul style="list-style-type: none"> • Prof. Warren Brown 	Therapies options #2 <ul style="list-style-type: none"> •HANDLE. Mary Robson, Penny Jacobsen •Occupational. Zoe Planck •Music/Movement. Ebony Birch Hangar •Speech. Catriona Tynan & Rebecca Gillogly 	Ask the Adults with DCC - Presenters: <ul style="list-style-type: none"> • Emily Johnson • Bill Courtney • Michael Shanahan • PLUS • other adults with a DCC on panel 	Caring for Yourself - tips and services. <ul style="list-style-type: none"> • Carers Victoria - Tania Daniels 	INTERVIEWS
Break	2.15-2.45	Afternoon tea break				
SESSION 8	2.45-3.30 3.30-4.00 (75 mins)	What are the IRC ⁵ and the Australian Brain Alliance? <ul style="list-style-type: none"> • Prof. Linda Richards <ul style="list-style-type: none"> • Where to from here? Bruce Fleming 		Complex Needs Management <ul style="list-style-type: none"> - Dr Monica Cooper 	Courage & Inspiration <ul style="list-style-type: none"> • Bruce Fleming Where to from here - Reflect & speculate <ul style="list-style-type: none"> • Prof. Linda Richards 	
Close	4.00-4.30	<ul style="list-style-type: none"> • Conference Slideshow & Close 				

AusDoCC Kids Club

The AusDoCC Kids Club will be held on the ground floor.

Floor Plans

Ground Floor



Providers

Charlton Brown nannies, Hannah and Jazmin along with volunteer Rachael are providing a fun themed program for children aged 3-6yrs old in Boardroom 2. Purple Soup staff, Tim and his team along with 6 volunteers will be entertaining the children aged 7-17 yrs old in the Realm and Scope Rooms.

Directions

Clearly label all of your child's belongings.

Please have your phones on vibrate in the event that the Kids Club staff need to contact you. The staff are fully qualified, however should they experience behavioural issues with your child, you will be called to the club room.

Should children require nappy changes parents will be called to assist their child.

An area within child care rooms will be partitioned off so parents can change their child comfortably.

**Parents need to be at the hotel and the conference to use this service.

Should parents leave the conference for sightseeing, shopping or any other purposes, they will be asked to collect their child prior to leaving the conference.

Adult Program

Aussie adults with a Disorder of the Corpus Callosum (DCC):

Slowly but surely growing Our group started out as one adult with a DCC. Isolated, misunderstood and often having her needs ignored for 20 years, she travelled to America to eventually find help, support and understanding at an ACC conference. Meeting all these people so much like her for a whole weekend in America was a whole new world of comfort, confidence and connection. Coming back from America she discovered the newly emerging support organisation in Australia, for disorders of the corpus callosum, that is now AusDoCC. There was an opportunity after this experience to attempt to connect with others in Australia and initiate something that many others like her were wanting and needing.

Over the last 3-4 years we have built up a scattered but linking group of about 40-50 Aussie adults with a DCC, something for us all to be proud of. That was rarity itself and it is such a rare, misunderstood condition. Through AusDoCC, we are slowly but surely building up our identity and connection as the 'Aussie adults with a DCC' group. Through the two conferences so far, some meet ups in different states and representation of three of us on the AusDoCC committee, we are becoming a group that can share experiences, support and assist each other with a connection that no relation, friend or partner can really do (Except maybe our non verbal, non judgemental, always loyal pets). We connect because our brains do not connect.

Abbie Kinniburgh

(Adult Liason Officer)



Adults with a DCC session information

Session	Session description
SATURDAY- Session.1	Welcome to AusDoCC Connections conference 2017! Adults then go to Our Space in the Aspect Room... People experienced or working in the areas of tertiary education, employment and the NDIS will speak to us. They work with people with extra needs. They will speak about themselves and their workplace. They will also speak about academic support, legal/conflict resolution support, disclosure of and explanation of having a DCC and NDIS info, hints and tips. They will then answer questions from our group and have a casual discussion with us.
SATURDAY- Session.2	Researchers will speak about their involvement in ACC related to psychosocial aspects and their main areas of interest. Topics include anxiety, social skills and any past or present research. They will then have a casual discussion with us and answer questions from our group.
SATURDAY- Session.3	As a group of adults with a DCC, we will travel out in taxis with some volunteers to support us and go to Docklands to have some lunch and do an activity that is enjoyable, work free and laid back. It will be relaxed, accommodating and flexible. Do not stress! =)
SATURDAY- Evening SUNDAY- Session.5	Relax, connect and have fun at dinner and a quiz to finish off the first day. Karen Gatt will speak to us about health and wellbeing including healthy eating, exercise, motivation and dealing with different needs in these areas. She will also speak about herself and her background in this area and working with people with extra needs. She will then have a casual discussion with us and answer some questions. Then... As a group of adults with a DCC with an aim to stay connected, stay informed and build our identity, we will spend some time building on what we would like to achieve and do in the near and far future, with facilitation. What are our priorities?
SUNDAY- Session.6	Researchers will speak about their involvement with DCC research and science. They will speak of specific area they are interested in such as Autism and brain imaging in relation to ACC. They will then have a casual discussion with us and answer some questions.
SUNDAY- Session.7	Adults with a DCC will be invited to participate in a panel for other conference attendees to ask questions of us and share our experiences. A few adults with a DCC will give a short presentation about themselves and their experiences of living with a DCC.
SUNDAY- Session.8	It can be hard leaving an event with people who understand and relate and returning to the wider community. We will discuss this and some strategies that may help this. Linda Richards & her team will come and have a chat to us about science and research in Australia
SUNDAY- Closing	Slideshow and close of Connections conference 2017.

Adults with a DCC sessions facilitated by Margie Slater

Keynote Speakers



Prof. Warren Brown, M.D., Ph. D.

Warren S. Brown is Professor of Psychology and Director of the Lee Travis Research Institute at the Fuller Graduate School of Psychology. He is a research neuropsychologist/neuroscientist who has coauthored over 80 scientific publications. He has an interest in the cognitive and psychosocial impact of ACC in older children and adults, and the impact of childhood hemispherectomy on adult cognitive and social functioning. He has studied callosal function in dyslexia, ADHD, multiple sclerosis, and Alzheimer's disease and has researched brain wave changes associated with aging and dementia, language comprehension, dialysis treatment for kidney disease, and attention deficits in schizophrenia. Most recently, Brown and colleagues from other institutions have researched the psychology and neuroscience of exemplars of the virtues of compassion and generosity. He is also co-author or co-editor of 4 books on neuroscience and philosophy/religion.



Dr Lynn Paul, BA, MA, PhD

Dr Paul is a senior research scientist at Caltech, where she directs a research program studying brain-structure, cognition and social processing in ACC. She also continues her collaborative work describing the cognitive and behavioural profile of individuals with ACC as associate research professor at Fuller Graduate School of Psychology. Dr Paul was a co-founder of AusDoCC's sister organisation in the USA, NODCC. She co-authored "ACC and Me," a children's book about a boy with ACC. Dr Paul's interests include understanding the role cortical connectivity plays in development of higher-order social cognition, social processing and brain structure in high functioning adults with autism and individuals with congenital bilateral amygdala lesions. She is Director of the Psychological Assessment for Research Laboratory at Caltech and principle investigator for the Psychological Assessment Core of the Conte Center for Social Decision Making. Dr Paul maintains a clinical psychology practice (LK Paul and Associates) treating adult psychotherapy clients and undertaking neuropsychological assessments on individuals with ACC.



Prof. Linda Richards

Linda J. Richards, PhD, FAA, FAHMS is a Professor of Neuroscience and Deputy Director of the Queensland Brain Institute 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 President of the Australasian Neuroscience Society and co-chair of the Australian Brain Alliance. Professor Richards is head of the brain development and disorders laboratory at QBI and is a leading expert on the formation of the corpus callosum and is scientific advisor and patron for AusDoCC. In 2015 she co-founded an International Consortium for the Corpus Callosum and Cerebral Connectivity with colleagues from Australia, USA, France and Brazil, bringing together clinicians and scientists working to identify the causes of developmental brain disorders and how best to provide support and care for affected individuals and their families.



Prof. Elliot Sherr

Professor Elliott Sherr, M.D., Ph. D. Dr Sherr is a professor in neurology and paediatrics at the Institute of Human Genetics at UCSF and co-directs the Comprehensive Center for Brain Development at UCSF. He directs the Brain Development Research Program, which studies the genetics and biology of autism and epilepsy. His lab studies how brain function is altered in the most common known genetic cause of autism. Dr Sherr studies the genetics of disorders of callosal development, having identified a number of genes that link callosal development to autism. Dr Sherr is also a member of a large epilepsy genetics consortium leading a team seeking to understand the genetic causes of severe childhood epilepsies. Dr Sherr was the 2006 recipient of the Philip R. Dodge Young Investigator Award from the Child Neurology Society. He is a child neurologist and cares for children with neurodevelopmental disorders, including autism, intellectual disability and epilepsy.



Prof Ingrid Scheffer

Laureate Professor Ingrid Scheffer is a physician-scientist whose work as a paediatric neurologist and epileptologist has led the field of epilepsy genetics over 25 years, in collaboration with Professor Samuel Berkovic and molecular geneticists. Her work has resulted in identification of the first epilepsy gene and subsequently many more genes. She has described many novel epilepsy syndromes and refines genotype-phenotype correlation. Ingrid's major interests lie in the genetics of the epilepsies, epilepsy syndromology and translational research. She has research projects in genetics of speech disorders, autism and intellectual disability. Ingrid led the first major reclassification of the epilepsies in two decades as Chair of the International League Against Epilepsy Commission for Classification and Terminology. Awards include American Epilepsy Society Clinical Research Recognition Award, 2013 GSK Award for Research Excellence, ILAE Ambassador for Epilepsy Award, 2013 Emil Becker Prize for child neurology and Asia-Pacific L'Oréal-UNESCO Women in Science Laureate for 2012. She is a Fellow of the Australian Academy of Science and Vice-President of Australian Academy of Health and Medical Sciences. She was co-recipient of 2014 Prime Minister's Prize for Science and received the Order of Australia in 2014.

Keynote Speakers



A/Prof Richard Leventer

Dr Leventer is a consultant paediatric neurologist at the Royal Children's Hospital and a group leader of neuroscience research within the clinical sciences theme of the Murdoch Children's Research Institute (MCRI). He was awarded his PhD on the topic of brain malformations in 2007, which included research, commenced whilst doing a neurogenetics fellowship in the Brain Malformation Program at the University of Chicago. Dr Leventer is director of the RCH/MCRI Brain Malformation Program and Clinic, which is the referral centre for children with brain malformations from Australia and New Zealand. He is a chief investigator on the Accelerated Gene Identification Program within the MCRI Bruce Lefroy Centre. He conducts collaborative research on brain malformations with local, national and international colleagues including active projects on ACC with genetics, basic science and neuropsychology colleagues. Dr Leventer is the Australian representative on an international consortium studying white matter disorders. Dr Leventer was president of the Australia and New Zealand Child Neurology Society from 2002 –2007.



A/Prof Simone Mandelstam

Dr Simone Mandelstam is an associate Professor at the University of Melbourne department of Paediatrics and Radiology. She has worked on a number of projects for the Florey Institute of Neuroscience and Mental Health, involving advanced MRI techniques for further classification and delineation of congenital brain malformations and research into epilepsy imaging in children. Simone is based at the Royal Children's Hospital as a senior specialist paediatric and epilepsy radiologist in the Department of Medical Imaging and has extensive experience with the variety of presentations of corpus callosum disorders and associated brain abnormalities. Simone is a keynote speaker at the Connections 2017 family conference and is also holding some private free appointments as part of the conference



Dr George McGillivray

George McGillivray is a **Medical Geneticist from Melbourne**, Australia. His expertise includes counselling parents about genetic conditions diagnosed during pregnancy and after birth, with a special interest in genetic conditions that affect the structure of the brain, including ACC. Together with Prof Leventer, George has run a neurogenetics clinic for children with brain malformations at the Royal Children's Hospital for 15 years, the only such clinic in Australia. George and Obstetrician colleagues at The Mercy Hospital recently started a Fetal Neurology clinic to better assess babies with neurological problems. His clinical research includes the study of babies and children as part of gene discovery projects at The Murdoch Children's Research Institute seeking to identify new genes causing rare conditions. George has contributed to publications on prenatal diagnosis, medical ethics, gene discovery and neurogenetics. He is an author of current guidelines on genetic testing for the Australasian College of Obstetricians and Gynaecologists and the International Society of Ultrasound in Obstetrics and Gynaecology.



Dr Monica Cooper

Monica Cooper is a General Paediatrician working in the Department of Neurodevelopment and Disability and for the Complex Care Service at the Royal Children's Hospital in Melbourne. Monica works with medically fragile children and with children who have physical and intellectual disabilities. Monica's work focuses on issues that impact on a child and their family, including tone management, continence, nutrition, mood and sleep. Monica has a particular interest in cerebral palsy and the aetiology of cerebral palsy. Monica is currently undertaking a PhD focusing on the Epilepsies in Cerebral Palsy. Monica has presented her research findings at national and international conferences. Monica also teaches paediatric trainees and medical students. The rest of her time is spent with her family, reading or drinking too many cups of tea.



A/Prof Mark Walterfang

A/Prof Walterfang has been a consultant neuropsychiatrist at the Statewide Neuropsychiatry Unit at the Royal Melbourne Hospital for more than 15 years, and is involved in the inpatient and outpatient management of neuropsychiatric disorders. He completed his PhD in 2011 examining the relationship of the structure of the corpus callosum to major psychiatric illness. His PhD was awarded both the University of Melbourne's Chancellor's Prize and the Faculty of Medicine's Dean's Prize. Additionally, he holds academic appointments at the Department of Psychiatry, University of Melbourne, and the Florey Institute of Neuroscience and Mental Health. Research on computational neuroimaging analysis in psychiatric and neurodegenerative disorders, has produced in excess of 100 Medline-indexed publications. He has an active interest in rare disorders, including callosal agenesis, and rare neurometabolic disorders and became AusDoCC advisor for adults with DCC in 2016.

Session Notes

HORIZON	VISTA	PANORAMA
SATURDAY		
1	<p>Welcome and opening Keynote speakers - 5 questions Introduction to Professors Linda Richards, Warren Brown, Elliott Sherr & Dr Lynn Paul. Each speaker will answer the same 5 questions relating to themselves and their work, as well as offering snippets of advice to fellow professionals and families affected by DCC.</p>	
2	<p>Mums Moira Rayner leads a session for mums who have a child or adult with a DCC Kristina Coburn will offer some practical resources for support</p>	<p>Dads Dads will be treated to a unique opportunity to develop their skills in Icecreamology with Purple Soup.</p> <p>Professionals Raising the DCC profile (Workshop) A discussion on how we can find champions to help advocate & raise the profile of DCC to let educational and health professionals understand that 'ACC Matters.'</p> <p>Education - Anthony Gartner Research - Linda Richards Therapy - Myff Adkins Complex needs -Jennifer Cook Paediatrics - (TBC)</p> <p>**NB**IN THE GYM Elizabeth Courtney will talk about life as a sibling of a child/adult with a DCC and facilitate discussion. The positives and challenges.</p>
3	<p>Autism & DCC Prof Elliott Sherr will share his decades of expertise as a paediatric neurologist and pre-eminent world scientist and clinician advising and supporting families and children who have DCC & autism Fiona Sharkie explains the goals of Amaze including respect to all people on the autism spectrum, offering meaningful societal opportunities to participate and contribute as well as to improve attitudes and behaviours towards people on the autism spectrum. An adult on the spectrum, Penny Robinson will relate her experiences as ambassador to Yellow Ladybugs</p>	<p>Therapy Options #1 Physiotherapy. Assisting in early intervention and the long-term development of the child Horticulture. How VegTrug can assist people of all ages and abilities enjoy the benefits of improved physical, mental & social health Animal Assist. A neurobiological perspective on the impact of animals to enhance the counselling process. Complex Care. Multi modal therapies offering structured support for those with DCC and chronic illness</p>
4	<p>Genetics & DCC Dr George McGillivray will explain some of the related effects of genetics on DCC Keri Pereira introduces us to the Genetic Support Group Victoria (GSNV), a NFP offering support to enable individuals and other support groups to flourish George, Keri and Kate Pope will answer questions, as a panel, related to DCC and genetics</p>	<p>Imaging of DCC & other associated brain abnormalities A/P Simone Mandelstam MRI is the most important imaging modality for the diagnosis of callosal disorders and associated brain malformations. This talk will cover the basics of how MRI works and explain best practice for the imaging of children. Important radiological terminology will be discussed using MRI examples.</p>
		<p>NDIS Carer and Community Educator, Kerry Golding, will provide insight for Carers, particularly shedding light on the diverse aspects of care. Mark Wyburn's 12-year-old son has been an NDIS participant in one of the first trial sites since 2014 and will discuss his family's preparation and experience with the NDIS process through self-management. Pieta Shakes shares her knowledge and experience of rolling into the NDIS in November 2016 with a plan in place that adequately covers her daughter's therapy and support needs.</p>
		<p>Strategic Planning - Best Practices for DCC. (Workshop) Pre-birth to aged. AusDoCC Committee Members will share their perspectives on what we feel are best practices for health professionals managing someone with a DCC. We would love input from other parents'/professional' for perspectives on our expectations and ideas for improving knowledge and management of DCCs.</p>



ACC Matters!

Session Notes

	HORIZON	VISTA	PANORAMA
5	<p>Keynote speakers - 5 questions Introduction to Associate Professors Rick Leventer, Simone Mandelstam, Mark Walterfang and Dr George McGillivray. Each speaker will answer the same 5 questions relating to themselves and their work, as well as offering snippets of advice to fellow professionals and families affected by DCC.</p>		<p>Trade table holders demonstrations. Trade table holders will demonstrate any relevant products and aspects of goods related to DCC</p>
6	<p>Social cognition & personality. Human beings tend to presume that behavior, attitudes, and emotions are a direct result of an individual's personality. In this session, Dr Lynn Paul will discuss ways that 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 DCC.</p>	<p>Epilepsy & DCC Prof Ingrid Scheffer. Epilepsy is often associated with malformations of brain development including DCC. The first new classification of seizure types and epilepsies in almost 30 years will be presented with examples and discussion of epilepsy syndromes which help physicians to select optimal anti-epileptic therapy. A/Prof. Rick Leventer. Clinical and research progress and practices in paediatric epilepsy and DCC Linda Franklin. Sharing the story as Mum to 9yo Gordon with ACC and epilepsy</p>	<p>Relax & Unwind Tania Daniels. Have you forgotten how to relax? Try out some simple, enjoyable techniques to unwind and recharge that are easy to fit into a busy life.</p>
7	<p>Callosal basics & cognitive functions of DCC Dr Warren Brown begins this session with a description of the corpus callosum, the nature of agenesis of the corpus callosum (ACC), and research issues in studying callosal agenesis. Next will be a survey of 20 years of research in Dr. Brown's lab on the cognitive impact of ACC in areas such as motor coordination of the two hands, general intelligence, memory, and problem-solving. Finally, a basic model of the cognitive outcome of ACC will be discussed.</p>	<p>Therapy Options #2 HANDLE. A personalised, professional, practical approach to overall development, learning and lifestyle changes that simply make everything work remarkably better for people to help all family members realise their full potential. Occupational. The role of a Paediatric OT, and how can they help a child with a DCC including a case study overview of a client with ACC Music/Movement. Therapeutic use of music enables connections between the brain's hemispheres. Discover how it enhances language development, communication, well-being and overall cognitive development. Speech. Providing access to Augmentative and Alternative Communication (AAC) for individuals with complex communication needs. Implementation of a school-wide initiative to provide all students with complex communication needs access to comprehensive AAC systems resulting in improvements in all student behaviours and skills.</p>	<p>Caring for Yourself (PANORAMA ROOM)Tania Daniels – Carers Victoria Carers often say it's impossible to find time to look after themselves. This workshop discusses the benefits, barriers and strategies to help you care for yourself. This session will focus on the carer perspective, exploring why self-care is important, what stops us caring for ourselves and some of the beliefs that may influence our actions. It will also look at how Carers can 're-frame' these beliefs and identify strategies to help look after themselves." ***** **NB** In the ASPECT ROOM Adults with a DCC, Emily Johnson, Bill Courtney and Michael Shanahan will give insights into the successes and challenges of their lived experiences as adults with a DCC. After this they and other adults with DCC, will form a panel and answer questions from the audience.</p>
8	<p>What are the IRC⁵ and the Australian Brain Alliance? Scientific research can help provide an understanding of the causes of corpus callosum malformations in people. Given the variability of corpus callosum malformations, we want to understand the changes in brain structures, genes and cognitive abilities of affected people. This is being made possible through the work of the IRC5. In this talk, Prof. Linda Richards will provide information about the IRC5 as well as the Australian Brain Initiative, a new program to focus government spending on neuroscience research for the benefit of all Australians.</p>		<p>Complex Needs Management Dr Monica Cooper "The care needs of a family and their child with a neuro-disability". I will present the perspective of the General Paediatrician. I will discuss some of the key communication and management aspects that evolve as the family and child navigate through the medical system.</p>
9	<p>Roll up. Roll up. Roll up... The ride is almost over. Don't miss the Grand Finale. Our amazing photographer/videographers, Dave Marama & Rachel Thomson, will treat you to the wonderful collection of photos gathered during the conference. Look out for yourselves, your kids, your presenters and your new friends, as we revisit the many moments of CONNECTIONS 2017.</p>		

Various Presenters



Anthony Gartner is social worker who manages AccessAbility Services at Swinburne University in Hawthorn, Melbourne. He has a keen interest in the factors that contribute to success for people who live with disability and a commitment to inclusive strategies to ensure people living with disability have the best chance possible.



Myffanwy is an experienced Paediatric Physiotherapist who found her niche in Paediatrics and subsequently in neurodevelopmental therapy. She established Physiotots in 2002 as a Paediatric Physiotherapy service for children of all ages. Paediatrics is her passion and she is dedicated to treating and promoting children in reaching their maximal functional potential.



Professionally Bryar is an experienced primary educator working in mainstream settings. Personally she's a mother of three primary aged daughters, one of whom has ACC. She brings together her knowledge and skills as a teacher and her passion and care as a parent who wants the very best for her child.



Penny is a Lecturer at Monash University. She's an Ambassador and speaker in the Speaker's Agency of The I CAN Network, Ambassador of Yellow Ladybugs and a Volunteer of Aspergers Victoria as Twitter queen for guest speaker events. She was diagnosed with Aspergers at 14 (in Year 9).



Emily 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.



Being Mumma to a gorgeous 5yo girl with complete ACC and autism spectrum disorder, Pieta's days of working as a mental health nurse have passed and now her days are spent homeschooling, going on adventures, navigating playdates and consuming too much coffee. Nights are filled with the beginnings of a higher degree by research of ASD and psychopathology comorbidity and a little too much Facebook.



AS a CEO Fiona leads AMAZE, the peak body in Victoria for people on the autism spectrum and their families. She brings immense experience as a CEO in government and non-government organisations to her role. Fiona has a passion to see ideas around awareness and inclusion translate to tangible opportunities for autistic people.



Rebecca is currently working as a Speech Pathologist and Allied Health Coordinator at a Special Developmental School and is passionate about increasing the awareness of the role of Speech Pathology for individuals with communication difficulties. Through active involvement within Speech Pathology Australia, she has participated projects looking at increasing awareness of Speech Pathology services within both the health and education sectors.



Jennifer's inspiration for creating the Western Health Collective is her own experience with a rare autoimmune condition. Having no clear direction dealing meant that her own research was critical to her quality of life. Jennifer saw the results of using a wholistic approach to management of chronic conditions both in herself and her patients with a goal to align the complementary therapies closer with Western medicine.



Sarah is a Registered Nurse working in adult intensive care and currently studying to become a primary school teacher. She lives in the outskirts of Melbourne where she does a great job parenting her two children. Her eldest child Ashton has a disorder of the corpus callosum and a rare genetic syndrome among other things.



Karen Gatt is Australia's favorite weight-loss mum. She changed her life by losing 67kg and understands where others are coming from. Her belief is that it only takes one step to change your life! Her brainchild, The Clothesline Diet Club, has changed so many lives for the better including her own.



Sofie comes to Disability Employment with extensive national corporate account management experience. At EPIC Assist they recognised that her skills enhanced opportunities for jobseekers facing barriers. Sofie excels in working one on one with jobseekers and employers to ensure the needs of each are addressed.



Kathryn Arbuckle is a Special Education Teacher at Nepean School. With over 20 experience with students with physical disabilities, complex learning needs and health impairments her roles have included classroom, music, dance and drama teaching. This year Kathryn has eight students in her primary class with half of them having a DCC



The original green thumb, Steve loves making the joy of gardening available to everyone. His fantastic system removes challenges relating to accessibility.

Various Presenters

	<p>Keri Pereira is a genetic counsellor and is genetic support and education coordinator at the Genetic Support Network of Victoria based at the Murdoch Children's Research Institute. The GSNV is a non-for-profit organisation offering support to individuals and families impacted by genetic conditions. Keri also is the Victorian coordinator for the Australian Genomic Health Alliance, a research project exploring the integration of genomics into the Australian healthcare system.</p>		<p>At Carers Victoria, Tania delivers programs for carers on a range of topics. She has extensive experience as an adult educator and various roles in the welfare sector. She has worked with diverse groups and individuals from a CALD and ATSI background. Tanya is passionate about education and believes in its power to transform people and lives.</p>
	<p>Kerry works with Carers Victoria providing emotional support and case management to carers who support someone with a mental health condition. Kerry's current role involves the delivery of training that promotes carer health and well-being and information on the NDIS, Kerry's educational background is in Psychology, Narrative therapy and fine art.</p>		<p>Zoe Planck, an experienced Paediatric Occupational Therapist, is one of the directors of Bright Start Therapy. She holds multiple training certificates and is the only OT in Melbourne, certified and trained in the internationally recognised intensive therapy program, "TheraSuit Method". Zoe is passionate about executing a team approach across all therapy disciplines to produce realistic and achievable therapy outcomes.</p>
	<p>Leanne has been happily married to Mark with whom she has three beautiful, healthy and happy children. Originally hailing from New Zealand, she now lives in Melbourne and is committed to her family both here and across the Tasman. Her determination and resilience has served her well as she supports her daughter who has a complete agenesis of the corpus callosum.</p>		<p>Moira Rayner is a senior lawyer with particular expertise in workplace relations and anti-discrimination law, management and policy advice and investigations, working closely with employers who embrace diversity. She chaired the Law Reform Commission in WA; was Commissioner for Equal Opportunity for Victoria; a Hearings Commissioner for the Australian Human Rights Commission and an Acting Anti-Corruption Commissioner. In 1999 she published the Women's Power Handbook with Joan Kirner. In 2017 she is a practising lawyer, conciliator, mediator and educator.</p>
	<p>As the parent Linda Franklin is well versed in the details of epilepsy. Her experience over the years has brought many challenges and a lot of insight about what it's like to be the parent of a child with a disorder of the corpus callosum.</p>		<p>Mary E. Robson Co-Director of Compassionate Therapy and Training Centre, HANDLE® Practitioner and Instructor, Board President and Asia Pacific Regional Education Director for The HANDLE Institute. Visionary, Change-maker, Giver of Compassion and Funster!</p>
	<p>Mark Wyburn lives in NSW with wife Roslyn and three children. Their youngest son Luke has partial agenesis of the corpus callosum and moderate hearing loss. Mark has been secretary of Parents of Deaf Children (PODC) parent support group. He has contributed multiple submissions to government and government committee hearings for the NDIS and hearing services, and represented parent's views in government working groups.</p>		<p>Melanie G. Jones, is a psychologist with a special interest in Animal-Assisted Therapy and is the Director of Lead The Way, offering counselling and therapy using Therapy Animals, such as dogs, cats and horses. Melanie also provides training courses for professionals. Melanie's PhD research focuses on the therapeutic benefits of working with dogs and horses, with a particular focus on the neurobiology of human-animal interactions.</p>
	<p>Penny Jacobsen Giver of Compassion, Co-creator of programs at Compassionate Therapy and Training Centre, Change-maker, Certified HANDLE® Practitioner, Creative, Dog walker, Powerlifter, Mindfulness Practitioner, Photographer, Advocate for humans, animals and the planet.</p>		<p>Melo Kalemkeridis is a Parent Facilitator at Plumtree NSW, who provide support for young children with a delay or disability. Melo is a certified trainer for Circle of Security Parenting Program and runs a fortnightly Dads Group in Inner West Sydney. Melo is a certified Life Coach and NLP practitioner.</p>



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