AusDoCC presents….

Connections 2015

The Inaugural Australian Conference for disorders of the corpus callosum

Brisbane
March 21-22
2015

Official Program

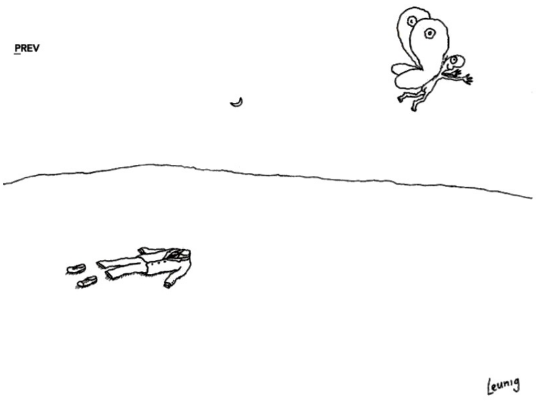
ausDoCC
australian disorders of the corpus callosum

The University Of Queensland
Australia

QBI
Queensland Brain Institute

Conference housekeeping

1. Please wear your lanyard and name tags at all times. They are your entry into sessions
2. Dinner on Saturday evening will be by ticket entry only. Tickets will be provided when registering
3. We encourage everyone to be seated ready to begin sessions on time
4. When asking questions please make them short so that we can get through as many people as possible
5. If you are in the large room for an elective please sit close to the front near the speaker
6. Please be patient if there are any glitches. This is a major 'first' for all of us
7. We hope you join in the evening entertainment. No pressure. Just fun. There will be disco lights.
8. Enjoy the conference and we hope it leaves you with wonderful memories, new friends and new knowledge.



Welcome…

to all conference participants and guests.

Hello and welcome to the inaugural Australian Disorders of the Corpus Callosum (ausDoCC) conference, the first of many to come. Some of you have traveled long distances to be here and I'm sure the trip will be well worth it.

Over the next 2 days we will have the privilege of hearing from professionals from across the globe as well as from Australia. Most importantly we will have the opportunity to talk to people who understand.

There will be opportunities to ask questions and you are encouraged to ask your questions. Our scientific advisor, Professor Linda Richards and her team from the Queensland Brain Institute will be in attendance for the 2 days and happy to talk to everyone.

I sincerely hope that you enjoy your weekend and that you leave knowing you are not alone.

Tanya Smith
President, ausDoCC

The ausDoCC Committee welcomes you all to the auspicious, first disorders of the corpus callosum conference in Australia. The committee has worked tirelessly to put together what we hope will be a fabulous weekend of learning, support, friendship and new beginnings. We hope you will gather information, participate in discussions and make valuable connections with other families.

We have arranged the program to include lectures, group discussions and panel presentations as well as an informal chatroom. There is also a specific parallel program for adults, 18 and over, who have a disorder of the corpus callosum. To keep you free to concentrate and enjoy the sessions the kids are catered for in Kids Club where they will have a wonderful 2 days and we have a fun filled disco/karaoke event for Saturday night one of our committee stepping up as DJ. We are all in for a surprise as this is a hidden talent we weren't aware of.

Remember you are not alone and we hope that you have a weekend where you will find understanding, support, unity, friendship and comfort in our growing ausDoCC community. We hope you will continue to support ausDoCC by becoming or continuing to be full members so that we fulfil our vision of advocating, uniting and supporting.

We are so thrilled you were all able to come and we hope you have a wonderful conference.

AusDoCC Committee

Tanya Smith (president)
Rebecca Walter (treasurer)
Abbie Kinniburgh

Maree Maxfield (secretary)
Linda Franklin
Michael Shanahan
Janis Baric

Kristina Coburn (vice president)
Sarah Hancock
Niki Harrison

ausDoCC Committee 2015

Tanya Smith
ausDoCC president

Tanya is a mum of 2. Her son Kody has partial agenesis of the corpus callosum. Tanya currently lives in Western Australia, and has an extensive background in a number of roles including 20 years experience in building and surveying on the Gold coast and volunteering her time for a not for profit charities supporting families with special needs locally. She looks forward to seeing Ausdocc continue to prosper

Kristina Coburn

ausDoCC Vice President

Kristina is a mum of 3 boys. Connor and Kyle both share a birthday, 8 years apart and have agenesis of the corpus callosum. Hamish is her middle son and has just started high school. Kristina also lives in WA. Kristina felt very isolated on the journey of ACC and developed the first Australian Facebook group a couple of years ago. Kristina works very hard supporting families throughout Australia loved ones with ACC.

Rebecca Walter

ausDoCC Treasurer

Rebecca is a mum of 3 and her son Joshua has agenesis of the corpus callosum which was diagnosed late in her pregnancy. Rebecca lives in Adelaide and has a background in childcare and volunteering on her kids' school committees. She is currently studying a Bachelor of Accounting and she is very passionate about supporting those with ACC.

Janis Baric Committee member

Janis is Nana to 2 children with ACC. She lives in WA and is a great support to her daughter Kristina and family. She joined ausDoCC to help be the voice of grandparents and to connect with other grandparents in a similar situation.

Maree Maxfield Secretary

Maree is a mum of 2. Abbie, her daughter, has partial agenesis of the corpus callosum and an absent pituitary gland. Maree currently lives in Seaholme but lived in East Gippsland for a number of years. Maree has a strong passion in supporting families affected by ACC as she has walked a very lonely journey in the 1990s in having her daughter's ACC ignored. She has also worked very hard supporting her daughter Abbie to achieve the very best she can. Maree has a background as an educator, being a school principal for a number of years and is currently studying a Masters of Public Health.

Niki Harrison
Finance committee

Niki is a mum of 3 and Abby, her youngest, has hypoplasia of the corpus callosum. Niki lives in Cranbourne, Victoria. She has a background in real estate, fundraising for her kids' schools and serving on school committees for a number of years. She also volunteers for a local charity supporting mums and babies in need. She felt very lonely at the beginning of her journey with Abby and has enjoyed supporting other families whose children have ACC.

Sarah Hancock

Research and education committee

Sarah is a mum of 2, her son Ashton has hypoplasia of the corpus callosum. Sarah lives in Lang Lang, Victoria. She has a background in nursing, working as a registered nurse in Melbourne. She is also currently studying her Masters of teaching to become a primary teacher. She enjoys supporting families affected by ACC and organising social get togethers for local families.

Linda Franklin

Membership committee

Linda is a mum of 3 and also has her 3 nieces living with her (a total of 6 kids), her youngest son Gordy has partial agenesis of the corpus callosum. Linda lives in Sydney and is very involved in organising social gatherings to support new members of Ausdocc.

Michael Shanahan

Committee member

Michael has agenesis of the corpus callosum and was diagnosed as a teenager. He lives in Brisbane and currently works as a nurse, but is also studying mechanical engineering. He hopes to help in supporting adults affected by ACC throughout Australia and improve the awareness of this condition

Abbie Kinniburgh

Committee member

Abbie has partial agenesis of the corpus callosum and an absent pituitary gland. She has been an asset to ausDoCC in assisting newly diagnosed adults who have the condition and giving parents an understanding of what it is like to live with ACC. She lives with her mum and dog, Scout, in Seaholme and is currently studying a Bachelor of Arts.

ausDoCC Connections 2015 program

Time	Session	Room*1
	Saturday March 21 2015	
8am	**Registration -** See the ausDoCC team for your name tag & welcome pack	**F**
9:00am	**Opening** Guest MP (TBC)	**SS**
9:10am	**Welcome - Becoming ausDoCC** Tanya Smith	
9:30am	**Cutting edge DCC research and links to autism** Professor Elliott Sherr	
10:00am	**DCC Perspectives as a scientist and parent of young adult with a DCC** Professor Roberto Lent	
10:30am	**Questions from the audience.**	
	Chatroom open - unfacilitated discussion space	**M**
9:00am	***Adults with DCC** - **Main program***	**SS**
10:45am	Morning tea	**F**
11:15am	**AGE GROUP SESSIONS - ELECTIVES. Parents, carers, friends, family, therapists, clinicians, researchers welcome.**	
	1. Babies and preschoolers Sarah Hancock, Pieta Harris	**SS**
	2. Primary schoolers and pre-teens Linda Franklin & Kristina Coburn	**B**
	3. Teens/adults/siblings Ron, Anne, Elizabeth Courtney, Mary O'Callaghan, Tahlia Harrison, Rebecca Walter	**M**
11:15am	***4. Adults with DCC - Welcome*** *Maree Maxfield & QBI (10 mins)* ***Social situations and society*** *Dr Lynn K Paul (50 mins)*	**NS**
12:15pm	lunch	**F**
1:15pm	**Sourcing the code - genetics explained** Professor Tania Attié Bitach Dr George McGillivray **Exploring imaging in DCC** Professor Fernanda Tovar Moll Dr Simone Mandelstam	**SS**
2:30pm	**Questions from the audience**	
	Chatroom open - unfacilitated discussion space	**M**
1:15pm	***Adults with DCC - Social activity. Off campus.*** ***Ten Pin Bowling, Cafe Club*** *Maree Maxfield, Kristina Coburn*	**CBD**
2:45pm	afternoon tea	**F**

***1. KEY. ROOMS:** SS-Sth Stradbroke. NS-Nth Stradbroke. B-Bribie. M-Moreton F-Foyer

ausDoCC Connections 2015 program

Time	Session	Room*1
3:15pm	**DISCUSSION AND INFORMATION ELECTIVES**	
	1. Aids and Apps - making life easier Tanya Smith, David Ingerson, Shane Williams, Jennifer Poppe	**SS**
	2. Mums and other female carers Niki Harrison	**B**
	3. Just blokes Steve Harrison	**M**
	4. Teens with DCC - (for teens with a DCC only) (30 mins) **My sibling has a DCC - (for teen siblings only)** (30 mins) Dr Lynn K Paul	**NS**
	5. Adults with DCC - Social activity. Off campus.Ten Pin Bowling, Cafe Club *ausDoCC*	**CBD**
4:30pm	**Close of main program Day 1.**	
6:00pm	**Dinner** Buffet dinner **Evening entertainment - AusDoCC Rocks disco & karaoke** DJ Niki.	**SS**
	Notes Day 1	

***1. KEY. ROOMS:** SS-Sth Stradbroke. NS-Nth Stradbroke. B-Bribie. M-Moreton F-Foyer

ausDoCC Connections 2015 program

Time	Session	Room*1
	Sunday March 22 2015	
8:30am	**Registration -** See the ausDoCC team for your name tag & welcome pack	**F**
9:00am	**DCC in Australia. Where to from here?** Professor Linda Richards	**SS**
9:30am	**Cognitive & social processing skills** Dr Lynn K Paul	
10:15am	**Questions from the audience**	
10:30am	**NDIS update** Fiona Anderson	
	Chatroom open - unfacilitated discussion space	**M**
9:00am	***Adults with DCC - DCC in Australia. Where to from here? (main program)*** *Professor Linda Richards.*	**SS**
9:30am	***Self directed discussion workshop - Topic drawn from conference*** *(60mins)* *ausDoCC (if needed)*	**NS**
10:45am	morning tea	**F**
11:15am	**DISCUSSION AND INFORMATION ELECTIVES**	
	1. NDIS information QandA discussion Fiona Anderson	**SS**
	2. **Education - negotiating learning and schools** Fiona Hart**,** Sarah Hancock, Maree Maxfield, Tanya Smith	**M**
	3. Connecting parts to whole - a holistic approach Mary Robson & Penny Jacobsen	**B**
	Adults with DCC - Research at QBI. DCC discoveries in the lab. *Professor Linda Richards & QBI team*	**NS**
12:15pm	lunch	**F**
1:15pm	**DISCUSSION AND INFORMATION ELECTIVES**	
	1. Which therapy is right for my child? Linda Franklin, Mary Robson, Penny Jacobsen, Nina Delzoppo, Julie Harrison, Amy Cooper	**SS**
	2. Communication for non verbal/hearing impaired children Associate Professor Dimity Dornan AO, Tanya Smith	**B**
	3. Top 10 Tips - where to go for support Kristina Coburn	**M**
1:15pm	***Adults with DCC - Looking ahead. Planning session.*** *Maree Maxfield & Sarah Hancock*	**NS**
2:15pm	afternoon tea	

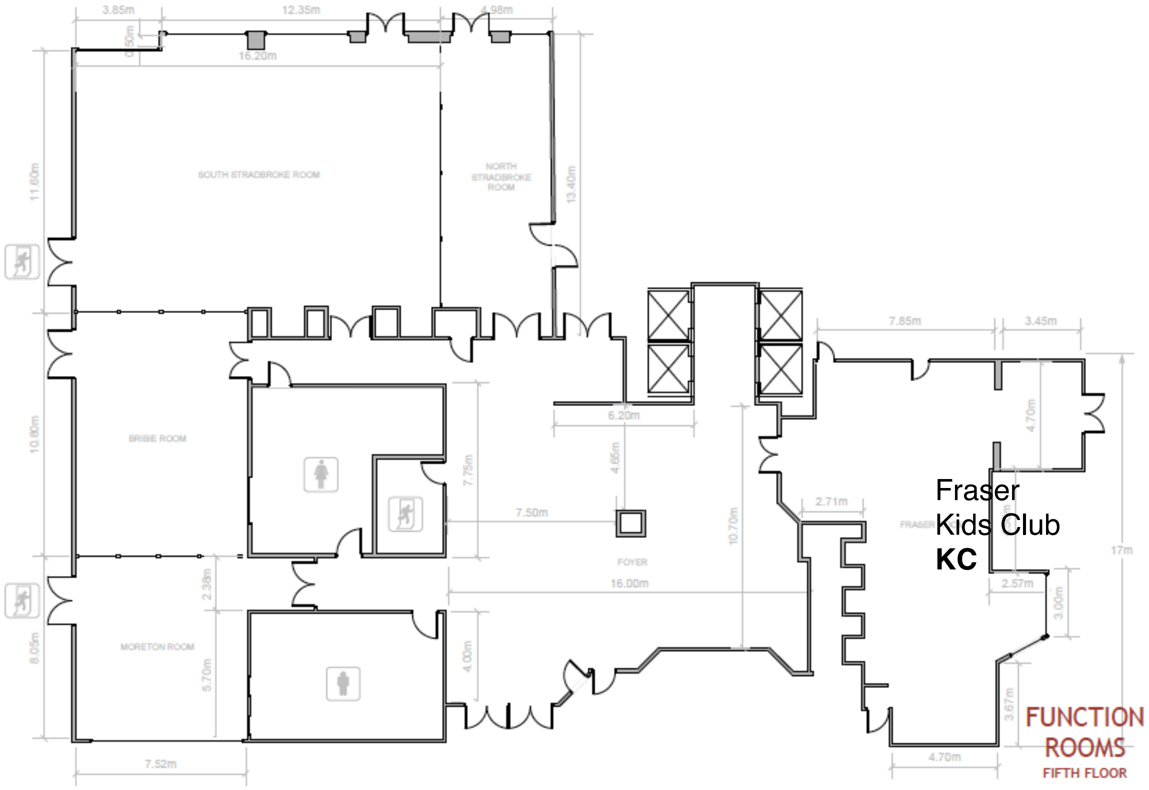
***1. KEY. ROOMS:** SS-Sth Stradbroke. NS-Nth Stradbroke. B-Bribie. M-Moreton F-Foyer

ausDoCC Connections 2015 program

Time	Session	Room*1
2:45pm	**DISCUSSION AND INFORMATION ELECTIVES** **1. Which therapy is right for my child? (repeat)** Tanya Smith, Mary Robson, Penny Jacobsen, Nina Delzoppo, Julie Harrison, Amy Cooper, Tanya Curtis **2. Ask the adults. QandA panel - adults with DCC.** Adults with a DCC Maree Maxfield & QBI **3. Managing epilepsy and seizures** Linda Franklin, Yvette McMurtrie	SS NS B
2:45pm	***Adults with DCC - Ask the adults. QandA panel of adults with DCC.*** *Adults with DCC* *Maree Maxfield & QBI plus audience.*	NS
4:00pm	**All participants to South Stradbroke room for closing events**	
4:05pm	**Presentation to QBI** ausDoCC **Slideshow of the weekend** Josh Walter, Hamish Coburn **Wrap and close** Tanya Smith	SS
4:05pm	***Adults with DCC- presentation to QBI & slideshow.*** *(main program)*	SS
	OPTIONAL SESSIONS	
4:20pm	**Optional individual case review** Professor Linda Richards and QBI team. Dr Simone Mandelstam. Dr George McGillivray.	NS
5:00pm 5:05pm	**Special Resolution Meeting ausDoCC** ausDoCC financial members **General committee meeting ausDoCC** ausDoCC committee members	B B
	NOTES DAY 2.	

***1. KEY. ROOMS:** SS-Sth Stradbroke. NS-Nth Stradbroke. B-Bribie. M-Moreton F-Foyer

ausDoCC conference rooms - Hotel Jen



Kids Club is proudly sponsored by the ausDoCC Trivia Night organised in 2014 by our ‘fundraising queen,’ Niki Harrison.

Who, when, where?

It will operate for the duration of the day sessions for the conference on Saturday March 21 and Sunday March 22 from 8:30am to 4:30pm. An 8.30am drop off ensures all children will be settled and parents will be ready for a prompt 9am start. It will be on the 5th floor within the main conference area in the Fraser Room.

Operator of the Kids Club

Kids Club will be run by Charlton Brown, a licensed, accredited organisation. Their staff all have first aid including CPR and Asthma and anaphylactic training. All have a Blue card and appropriate working with children's check. The activities include a range of arts and crafts, board games, DVD's, Playstation, sensory play, blocks, indoor bowling and face painting. Please keep your phone on vibrate for any contact.

Meals

Meals will be provided for kids including morning tea, lunch and afternoon tea. Registered children will have dinner with their parents at the Saturday night dinner and should have a ball at the follow up entertainment.

More information

- Parents will be required to sign permission forms to allow photos taken and used during the conference.
- 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.
- Child care workers and Disability Support workers will be onsite for Kids Club. However should they experience behavioral 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.
- Parents are not required at Kids Club unless called upon by staff.

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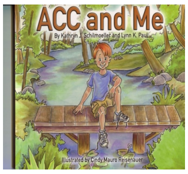

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DCC clinicians and researchers

Professor Linda Richards

Professor Richards did her undergraduate degree at Monash University and obtained her BSc (Hons) and a PhD from The University of Melbourne and The Walter and Eliza Hall Institute in the laboratory of Professor Perry Bartlett. Her thesis was on the determination of neuronal lineage in the developing spinal cord.

Linda is an Associate Professor at the Queensland Brain Institute at the University of Queensland. In addition to running her laboratory, Professor Richards is passionate about informing the public about science. In 2006 she founded the Australian Brain Bee Challenge, a program that inspires and excites high school students about science.

Professor Elliott Sherr

Elliott Sherr is a Professor in Neurology and Pediatrics and the Institute of Human Genetics at UCSF. He directs the Brain Development Research Program, a group that studies the genetics and biology autism and epilepsy (http://brain.ucsf.edu). Specific areas of interest include understanding the link between cerebral connectivity and brain function (as exemplified by agenesis of the corpus callosum) and understanding the biological underpinnings of autism. Dr Sherr is a native of California and completed his undergraduate degree in Philosophy and Biology at Stanford University. He obtained his MD and PhD at Columbia University in New York and completed his clinical training in Pediatrics and Neurology at UCSF. He lives in San Francisco with his wife (a biotechnology financial executive) and his three children.

Professor Tania Attie-Bitach

Professor Tania Attié-Bitach, is a human geneticist specialising in molecular genetics of congenital malformations at Paris Descartes University. She has developed clinical and genetic research on human fetal disorders at the Imagine Institute, Necker Medical School. She has driven several projects leading to the identification of genes responsible for Meckel syndrome, related ciliopathies and other lethal disorders such as Matthew-Wood and Fowler syndromes. She currently leads a national project (ANR Cilaxal) aiming to characterise the genetic causes of isolated and syndromic causes of corpus callosum anomalies in humans.

Professor Roberto Lent

Roberto Lent is Professor of Neuroscience at the Institute of Biomedical Sciences, Federal University of Rio de Janeiro, Brazil. He also earned his MD and PhD at this University. Professor Lent has worked at the Institute of Biophysics for almost 20 years, moving to the Institute of Biomedical Sciences in 1994, where he runs the Laboratory of Neuroplasticity. He is currently the Director of the Institute.

He has conducted studies on neuroplasticity, neurodevelopment and evolution of the nervous system, employing different techniques, from cell biology to neuroimaging.

DCC clinicians and researchers

Professor Fernanda Tovar-Moll

Fernanda Tovar-Moll earned her MD degree from the Federal University of Rio de Janeiro (UFRJ), Brazil. She is currently an associate Professor at the Institute of Biomedical Sciences and director of the Bioimaging Unit for Small Animals (CENABIO) at UFRJ. Fernanda is also the scientific advisor for the D'Or Institute for Research and Education, a private not for profit research institute which she cofounded in 2009. Her main research interest using radiological techniques, is in mapping the brain circuits in humans and mice in order to better understand the pathophysiological mechanisms involved in connectivity and plasticity in the normal brain and in those with neurological disorders.

Associate Professor Simone Mandelstam

Is an associate Professor at the University of Melbourne department of Paediatrics and Radiology. She also 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.

Dr Lynn K Paul

Lynn K. Paul, PhD is a Senior Research Scientist at California Institute of Technology, where she is directing a research program studying brain-structure, cognition and social processing in Agenesis of the Corpus Callosum (AgCC). Dr Paul received a PhD in Clinical Psychology from Fuller Graduate School of Psychology and completed a post-doctoral fellowship in clinical neuropsychology from the Department of Neurology, UCLA.

Currently, she is an Associate Research Professor at Fuller Graduate School of Psychology, where she continues to collaborate with Dr Brown on research describing the AgCC profile.

In 2002, Dr Paul collaborated with other professionals and family members to found the National Organization for Disorders of the Corpus Callosum (NODCC). Dr Paul is also more broadly interested in understanding the role cortical connectivity plays in development of higher-order social cognition. In addition to research on AgCC, she collaborates with Dr Ralph Adolphs on studies of social processing and brain structure in high functioning adults with autism spectrum disorders and individuals with congenital bilateral amygdala lesions.

Dr George McGillivray

Is a clinical geneticist and paediatrician who is part of the Murdoch Children's Research institute in Melbourne and the Victorian Clinical Genetics Service. One of his main roles is the Neurogenetics Genetics Clinic at the Royal Children's Hospital Melbourne. He has a keen interest in the identification of different genes involved causing neurodevelopmental disorders.

Various Presenters

Pieta Harris has a 3 year old daughter, Matilda, who has a disorder of the corpus callosum (DCC). Pieta is passionate about gaining extensive knowledge about all areas of research, medicine and education in order to give her daughter the best start in life and to assist others. Pieta is also responsible for another wonderful new life as she was the founding president of ausDoCC and called the initial meeting in April 2012. Pieta is an energetic advocate for creating awareness of DCC and is presenting in the 'Babies and preschoolers' age-group elective.

David Ingerson is the dad of Tara and first introduced Australia to agenesis of the corpus callosum when he made a national radio program on ABC radio in 2008 about a day in his family's lives. Both he and his wife Caroline advocate strongly for improvements in disability services and to current systems. David also invented and produced the original Carers Watch for early stage dementia sufferers approximately 5 years ago and is currently finalising a new version that aims to help a much wider range of disabilities and conditions. The radio program can be heard here: http://www.abc.net.au/radionational/programs/allinthemind/a-day-in-the-life-ofmeet-the-ingersons/3271620

The QBI lab members are members of Linda Richards' research team and participate in various laboratory roles. Each is pursuing a field in the area of brain research, in particular ACC. they are the bright young minds of the future and play an extremely important role in scientific endeavours in the laboratory as well as liaising with families participating in research. They are actively involved in our family conference as participants and assistants to the ausDoCC team

Shane Williams is managing director of Arctic Heat. His knowledge of body cooling products is unsurpassed. Qualified with a Diploma of Remedial and Sports Massage his career spans decades as trainer with AFL football clubs including St Kilda and Brisbane Lions. He provides the technical expertise and leadership to ensure the continued success of Arctic Heat

Tahlia Harrison is a young carer and has a younger sister, Abby, who has agenesis of the corpus callosum. She loves her sister to the ends of the earth and has a wonderful relationship built on trust and fun. Through play and general 'sisterly love' Tahlia encourages Abby to achieve 'acrobatic' feats that seem impossible. Tahlia attends Cranbourne secondary school and is also an elite athlete.

The Courtney Family has been very supportive of ausDoCC and have been involved in several DCC related activities. Anne Courtney and her good friend Mary O'Callaghan have written a book, "Where There's a Will, There's a Way" about Anne's son, Bill, who has agenesis of the corpus callosum. They will be presenting as parents, sister and friend of an adult with a disability.

Queensland Presenters

Associate Professor Dimity Dornan AO

Executive Director and Founder - Hear and Say

PhD UQ, HonDUniv USQ, BSpThy, FSPAA, CpSp, LSLS Cert AVT

Dimity Dornan AO is a Speech Pathologist and the Founder and Executive Director of Hear and Say, which enables deaf children to listen and speak. Hear and Say provides services for over 670 children and families. Dimity also initiated Hear and Say Research and Innovation, and Hear and Say WorldWide global professional training.

Dimity has initiated and chairs a number of other groups including the Queensland Hearing Nexus (a Queensland-based hearing research group) and Human-Bionics Interface Frontiers, linking professionals in the Human Bionics field globally.

Dimity has been named Associate Professor at two universities - the University of Queensland and Griffith University. She has also been granted a number of awards including: Member of the Order of Australia (1998); Fellow of Speech Pathology Australia (1999); Paul Harris Fellow, Rotary International (1999); Australian Medical Association Award of Distinction for Services to Medicine (1999); Ernst and Young Australian Social Entrepreneur of the Year (2005); Suncorp Queenslander of the Year (2010-2011); University of Queensland Alumnus of the Year (2011); Telstra Business Woman of the Year for Queensland (2011); Queensland Greats award (2013); Dame of Honour, Order of St John of Jerusalem (Knights Hospitaller); Officer of the Order of Australia (2014), and the Lord Mayor's Business Awards, Lifetime Achievement Award (2014).

NATIONAL DISABILITY INSURANCE SCHEME *Fiona Anderson*

National disabilityinsurance Scheme

Fiona Anderson is NDIA Queensland Assistant Director Engagement and Implementation.

Fiona is a former journalist and has worked in corporate and not for profit communications and stakeholder engagement. Fiona managed the successful grassroots campaign for the NDIS - Every Australian Counts - in Queensland, building strong connections with people with disability, their families and carers and providers. She also recently:

- Prepared a report, recommendations and video "Differently Wired, Ready to Work" demonstrating the experiences and views of people with Autism Spectrum, for the Disability Employment Services Consumer Engagement Project
- Researched and wrote AFDO's *Education Policy for Students with Disability*

Fiona has two adult children; her 19 year-old son with a disability is in his first year of university. Her family has lived the challenges of whole family social inclusion, mainstream education, balancing therapy with ordinary life, and the financial impact on families of funding essential, costly disability equipment.

Yvette McMurtrie

Yvette obtained her teaching degree in 1993 from the University of Sydney and taught in the NSW education system for 10 years. Subsequently Yvette completed her Masters of Education (Honours Stream) in Health education and Health promotion in 1997 at the University of Sydney.

Yvette has worked for Epilepsy Queensland since 2006 as a client service officer. In 2010 she was appointed as Client Services Coordinator, leading a professional team consisting of counsellors, teachers, nurses and disability support workers and has presented at Queensland Paediatric Epilepsy Training workshops and attended international conferences including the Asian & Oceanian Epilepsy Congress (2010) and International epilepsy congress (2011).
Yvette is also part way though a Masters of Science (Epilepsy Management) at Leeds Metropolitan University.

Mary Robson. I have a BS in Health Sciences from Boston University and a Teaching Credential from Dominican College. I received certification as a Practitioner and Instructor from The HANDLE Institute (THI) in 2002 where I worked side by side with the founder, Judith Bluestone, for five years. I am currently the Asia Pacific Regional Education Director for THI. I have worked with well over a thousand individuals and families in the group home, teaching, and clinical setting. I am Co-Director of Compassionate Therapy and Training Centre, which is located amidst the rainforest and wildlife on picturesque Tamborine Mountain.

I offer effective, drug free, label free, non-judgemental treatment programs to individuals with life, learning, social and sensory challenges, to improve the quality of their lives. I have the fortunate opportunity to meet and work with extraordinary individuals, with labels such as Autism, Aspergers' Syndrome, ADHD, Dyslexia, Cerebral Palsy, Learning Disorders, Bi-Polar Disorder, brain injury, and many more, and to see them grow and learn and be able to do the things they want to do in life. I also have the opportunity to train families, teachers, and professionals so that they too can offer this support to those they care about.

Jennifer Poppe is an Occupational Therapist from LifeTec, an Independent Living Centre (ILC) based in Queensland. Together with ILCs from each Australian state and the ACT, LifeTec forms part of the collective network known as Independent Living Centres Australia. Each ILC aims to provide independent, commercially unbiased, actionable information and advice about assistive technology to government, policy-makers and the broader community. LifeTec does this by providing information, education and consultation services to the public, with many of their services being free of charge.
Jennifer has worked with adults and children from a wide range of backgrounds but the majority of her experience lies with working with children and young adults and their families. She has observed the positive impact of even simple products and techniques to make a person's life easier and is passionate about spreading awareness of assistive technologies to support a person's participation in all areas of life, no matter what their ability or disability.

Therapy and Education

Fiona Hart. I began my teaching career as a kindergarten teacher and then moved into primary teaching where I worked with hundreds of different children and families, where very few children had diagnosed disabilities. After I had my own children I went back to university to do my Special Education degree then began working as a teacher in an early intervention program for children with a variety of developmental delays. This led onto my teaching in a special school for children with physical disabilities and health impairments where I found my passion! During my time at Nepean Special School I have had the privilege of teaching three students who have Agenesis of the Corpus Callosum.

Tanya Curtis founded Fabic (Functional Assessment & Behavioural Interventions Clinic) in 2006 with a vision to support people to ‘Understand & Change’ unwanted behaviours, whilst simultaneously valuing each person’s uniqueness and individual strengths. Tanya presents behaviour specialist workshops locally, nationally & internationally, is the author of “Challenging Change, Behaviour Strategies for Life” and has developed online behaviour support programs.Tanya's professional qualifications include a Master of Behaviour Management, Master of Counselling, Bachelor of Health Science (Behaviour Management) and an Associate Diploma of Education.

Nina Delzoppo is an occupational therapist, Hippotherapist and an RDA NCAS level 1 Coach. She currently works as an occupational therapist in state schools and loves being able to make a positive difference by enabling children to access and participate in learning programs. In 2007 she completed a Bachelor of Applied Science (Equine) and worked for a number of years at the McIntyre Centre. Here she developed a passion for working with children with a disability and their families and saw the amazing outcomes equine assisted activities can have for some children. In 2013 Nina completed the Graduate Entry Masters in Occupational Therapy Studies and became a level 1 Hippotherapist in

Amy Cooper is a Registered Music Therapist currently working in Brisbane in the areas of special education and aged care. Amy studied a Bachelor of Music in vocal performance, before completing her Masters in Music Therapy at the University of Queensland. She is passionate about creating a connection through music with people across the lifespan – from young children with autism to older adults in dementia care.

Julie Harrison BPhty (Hons), Cert Hydro (Latrobe) Julie is a physiotherapist who runs a private aquatic physiotherapy practice at Hydrotherapy Brisbane treating a wide range of patients, in particular, clients with neurological conditions. Julie’s interest in paediatrics started as an undergraduate at The University of Queensland when her honours thesis was titled “A study of post rotatory nystagmus in hyperactive children with vestibular and spatial problems”.

Julie worked in private practice before working at the Cerebral Palsy League coordinating hydrotherapy. Julie lectures in hydrotherapy to undergraduate students in physiotherapy at the University of Queensland and James Cook University. A qualified swimming coach, she has developed a program to enable coaches to teach swimming to the disabled and she teaches this in special schools across Australia.

Penny Jacobsen. I survived slipping through the education system cracks. With determination and a zest for life, I focused my attention on understanding learning and the obstacles to learning and helping those experiencing more complex challenges than my own. Inspired by the individuals I worked with, I pursued training in methods to aid their efforts to communicate. I was moved to understand more about why life was challenging for them and what more I could do to empower them.

I learned of the HANDLE approach, and in 2006 become a Certified HANDLE Screener. I moved back to Australia and then went on to become a Certified HANDLE Practitioner in 2008 as Co-Director of Compassionate Therapy and Training Centre as well as engaging in activities that nurture and nourish my soul.

Session notes

Saturday 9am. KEYNOTE 1. Following the opening by a Qld member of parliament, ausDoCC president, Tanya Smith, will welcome everyone and outline ausDoCC's beginnings. Keynote speakers, Profs. Elliott Sherr and Roberto Lent, will speak on their latest research findings related to disorders of the corpus callosum (DCC). Roberto has the unique perspective of being a researcher and also a parent of a young adult with a DCC.

Current research in DCC and autism

Presented by Elliot H. Sherr, MD PhD

The focus of this session will be a discussion on the latest research being conducted (in the US) into disorders of the corpus callosum. The different types of corpus callosum conditions will be explained including agenesis/partial/hypoplasia, as well as the other brain malformations that can be present. Also mentioned will be the similarities of DCC to autism and the differences between the two conditions.

DCC from perspectives of a scientist and a parent

Presented by Prof. Roberto Lent

In the first part of the session there will be a discussion of, the concept of neuroplasticity in relation to disorders of the corpus callosum. The ability of the brain to form new connections is an amazing feat. Neuroplasticity can be helpful in overcoming the lack of connectivity between the two sides of the brain, when the corpus callosum is absent but can also cause added difficulties in functioning. The second part of the session will look at the unique perspective of being a parent of a child with a DCC and also being a research scientist.

Babies and preschoolers.

This is facilitated discussion group for anyone involved with, or interested in DCC kids in this age group. Sarah and Pieta will give short presentations of their lived experience followed by discussions from prepared topics or those arising from the group.

Primary schoolers and preteens

This is a facilitated discussion group for anyone involved with or interested in DCC kids in this age group. Linda and Kristina will give short presentations of their lived experience followed by led discussions from prepared topics or those arising from the group.

Teens/adults/siblings

This is facilitated discussion group for anyone involved with or interested in adults with a DCC or being a sibling. Tahlia and the Courtney family and friend Mary will talk of their lived experience followed by a question and answer session to speakers.

Saturday 1:15pm

KEYNOTE 2. Further keynote speakers will present talks on genetics and imaging, related to DCC. This will be followed by questions from the audience to a panel composed of the four presenters.

Genetics explained

Presented By Dr George McGillivray and Professor Tania Attiè-Bitach

There are around 200 genetic conditions associated with Agenesis of the Corpus Callosum. In this session the genetics of DCC will be explored. This will include an explanation of the tests available to try and diagnose the causes of DCC, and a genetics overview for parents and people with a DCC.

Imaging explained

Presented by Prof. Fernanda Tovar-Moll and Associate Professor Simone Mandelstam

Magnetic Resonance Imaging and Computed Tomography are the imaging techniques used for diagnosing a disorder of the corpus callosum. The focus of this session will be an explanation of both imaging techniques and what they can tell us about the person with A DCC. For instance what other pathways of communication lie within the brain when the corpus callosum is absent or under developed.

Aids and Apps - making life easier

Tanya will present a session describing some great iPad Apps for kids with DCC. Dave will introduce his invention of a tracking phone/watch and Jennifer will introduce the range of things on offer through Independent Living Centres.

Mums and other female carers plus Just Blokes.

These facilitated sessions are gender divided for people to discuss issues and share experiences in their roles as carers for someone with a DCC. Discussion topics will be suggested and also arise from the group.

Sunday 9am. KEYNOTE 3. Professor Linda Richards will describe her DCC research at Queensland Brain Institute and speak of exciting global plans for the future. Dr Lynn Paul will address cognitive and social processing skills that are so often a feature of our teens with DCC. Fiona Anderson will give an update of the NDIS at this point.

DCC in Australia. Where to from here?

Presented Professor Linda Richards, PhD

Rapid advances in multiple areas of neuroscience research are occurring at an unprecedented pace. This is largely due to major breakthroughs in the areas of genetics, magnetic resonance imaging, cellular and molecular neuroscience and neuropsychology. This session will provide a brief overview of the major discoveries discussed at the preceding scientific conference and discuss the exciting possibility of a major international initiative in corpus callosum research.

Cognitive and social processing skills

Presented By Lynn K Paul Sternberg PhD

Living with ACC, what is it like? This session will explore the impact this condition has on the person living with ACC and how having ACC affects the ability to think and respond in social situations. There will be a discussion on how to help and understand a person with a DCC and is targeted at individuals with a DCC and their families.

NDIS information and QandA session

As a follow up to the full session update, this will be an opportunity for people to ask questions related to more specific situations.

Education - negotiating learning and schools

Fiona, Maree, Sarah and Tanya will give short presentations of their own experiences teaching and as parents of kids with DCC in main stream and special education settings. This is general information as all school systems differ between states.

Connecting parts to a whole - a holistic approach

We are all well aware of our current reality and the challenges included in it. Many of us imagine a future reality that is easier. Our challenges often result in needing to do things in less conventional ways. In turn this often results in behaviours that others judge - further perpetuating the challenges. What lies below the surface of the iceberg that is responsible for our current reality? What explains our behaviours and challenges? How does knowledge of those things help us to utilise neuroplasticity to affect a change? What is your role in creating systems and supports that meet both your and your child's potential? This presentation explores those questions and offers a systems approach for a transformative future reality.

Which therapy is right for my child. (Repeated session)

Therapists will speak about hippotherapy, occupational, HANDLE, music and hydro therapies. Shane will be present in session 1 to introduce ice vests and other products to help deal with temperature regulation. Session 2 will be a repeat of session one but instead of Arctic Heat (Shane), Tanya will speak about behavioral therapy. Each session will have short presentations followed by QandA if time allows.

Communication for the nonverbal child

AP Dimity Dornan AO will describe her theory and practices for teaching non verbal children to communicate and speak, as well as strategies for children with hearing impairments.

Top 10 tips. Where to go for support.

Kristina will offer practical advice from the most effective national assistance bodies including Centrelink, Companion Card and Carers Australia. There will be a sheet listing these, plus some application forms available at the conference.

Ask the adults - QandA panel

This will be a question and answer session where the adults with DCC will form a panel and the audience will be able to ask questions. Often parents are very curious as to how their kids may grow up and also what things the adults may have done as children. There will be no presentations in this session.

Managing epilepsy and seizures

Yvette will present a full session relating key epilepsy information with an opportunity for questions at the end.

Slide show.

This will be a presentation of the highlights of the conference. Look out for your photo and those of your kids in Kids' Club.

** **CHATROOM- the Moreton room is available on three occasions for people to meet and discuss things informally. If you go to that room on the times noted in the program, it is just for casual discussions and there will be no facilitator. Please feel free to join others in there.**

Notes