

Genetic Alliance Australia is a member of:

International Alliance of Patient Organisations (IAPO)
Orphanet
European Organisation of Rare Diseases (EURORDIS)
Health Consumers NSW
Rare Diseases International
NORD – National Organisation for Rare Disorders (USA)
Genetic Alliance UK, USA and SA
Unique – Understanding Chromosome Disorders (UK)
Organisation for Rare Diseases in India

Genetic Alliance is a consumer representative on:

Genetics Network Executive Committee
NSW Newborn Screening Advisory Committee
Consumer Health Forum - Voting Member
Stepping Stones Triple P (SSTP) National reference Group



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Genetic Alliance Australia

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Funded By:



Trisomy X Conference

Friday 4th May 2018

10.00 am- 4.00pm

At

Meeting Rooms 6.1 & 6.2
Level 6, Garvan Institute of Medical Research
384 Victoria Street,
Darlinghurst NSW 2010

PROGRAMME



Brought to you by



Mission Statement

"To facilitate support for those affected directly or indirectly by genetic conditions throughout Australia"

Genetic Alliance Australia (GA)

"Making the right connections since 1988"

Genetic Alliance Australia is a tax-deductible Registered Charity formed in 1988 to provide peer support and information for individuals and families affected by a rare disease (80% of which are genetic in origin). There are over 11,500 known hereditary single gene disorders and hundreds of chromosomal abnormality. In addition, many common health problems have a genetic basis. It is estimated that in the first twenty years of life, about six out of every hundred people will be affected by a disorder with a genetic basis. Genetic Alliance's database represents over 14,000 rare diseases and our contact register represents over 3000 people. Some of GA's programs are telegroup counselling, sibling workshops, peer support and information counselling, genetic seminars, support group leadership meetings, Annual BRCA1/2 information day and Genetic Awareness Week. On a number of occasions, Genetic Alliance Australia has lobbied the government on various issues. GA works alongside genetic services, allied health professionals, organisations and support groups.



NOTES:



Guest Speakers (cont.)



Amanda Miller (Bach. Education –Primary) is the founder of the Triple X / Trisomy X Support Group Australia. Amanda lives on the Sunshine Coast, Queensland with her husband, two daughters and a son. Her eldest daughter, Grace, has Trisomy X and provided her with the inspiration to begin the Support Group on the 20th September 2013 which currently supports over 115 Australian families that have Trisomy X. The support group aims to advocate for Trisomy X, to increase awareness of the condition and to primarily help others by sharing knowledge from personal experiences.

Amanda has been a Primary Teacher for over 17 years and currently teaches Year 5 at a local Catholic Prep to Year 12 school. She has a passion for teaching children how to speak the Japanese language as she was a Japanese LOTE Teacher for four years in the Blue Mountains, NSW. *“Through effort and awareness, we can reach the stars!”*



Melissa O'Brien is a nurse who has spent most of her clinics career working in paediatrics. She now works in management. Melissa and her husband John have two girls Marcella and Louisa. They recently moved from rural NSW to Canberra. Relaxation time is spent scrapbooking (badly!) with friends.



Liesl Homes has been the Community Engagement Officer at **headspace** in Bondi Junction since before it opened two years ago. Her role includes community education, speaking at schools, universities and having stalls at community events; coordinating social media; and supporting the Youth Reference Group. Prior to that, Liesl worked at the Mental Health Coordinating Council in the Learning and Development team, particularly coordinating the Aboriginal Mental Health Traineeship project. Liesl is passionate about inclusion, and having people living life to the full, whatever their mental health or physical health status might be.

PROGRAMME

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| 9:30am | Registration |
| 10:00am | Welcome – Steffani-Jade McDonagh, Executive Officer, GA
- Amanda Miller, Founder, Trisomy X Support Group |
| 10:10am | Amanda Miller, <i>What is trisomy X? An overview</i> |
| 10:20am | Small Group Activity |
| 11:00am | Liesl Homes, Headspace - |
| 11.45am | Personal Story – Jacqui Benson |
| 12.00 | LUNCH |
| 12:45pm | Personal Story – Jenna Worley |
| 1.00pm | Jenny Rollo OAM – <i>Siblings: What about me?</i> |
| 1.45pm | Lisa Battersby |
| 2.40pm | Personal Story – Melissa O'Brien |
| 3.00pm | Amanda Miller – Educational Implications |
| 3:45pm | Evaluations and Close |

Jenna Worley is 25 years old, currently living at home and working full time. She was diagnosed with 47XXX at the age of 4. She didn't discover she was hearing impaired till the age of 9.

Guest Speakers



Steffani-Jade McDonagh has over 18 years' experience in the not for profit sector, including over 15 years in senior charity management. This has covered roles in community and disability supports as well as seven years with a Carers Charity in Ireland. Her experience spans several countries including South Africa, Ireland, England and now Australia. Having led or been a senior leader in four other charities she has a wealth of experience in political lobbying, advocacy, training / higher education and business management but most critically of delivering, developing and enhancing services to clients. She

also has a decade's experience in growing charities both through fundraising and grant aid.



Jenny Rollo OAM has over 30 years' experience in the disability field as founder, and presently President, of the Cornelia de Lange Syndrome (CdLS) Association. She is a co-founder and the Australian representative of the International Federation of CdLS Support Groups which was formed in 2001.

Locally (with other parents) she has spent 12+ years from 2004 advocating, lobbying State and Federal politicians, planning, and designing a cluster accommodation model for RASAIID (Ryde Area Supported Accommodation for Intellectually Disabled). The homes opened in April 2016.

Jenny works for Genetic Alliance Australia as Projects Manager.

Her adult son, David, who has CdLS, and his two younger siblings have given Jenny the lived experience of issues facing families in similar circumstances.



Lisa Battersby is an occupational therapist and mental health clinician with over fifteen years' experience working with people whose ability to do the things they want and need to be able to do is impacted by difficulties with their thinking, behaviour and mental health.

Lisa is Director and Senior Occupational Therapist at Zeal & Co Consulting in Bondi Junction, a private practice with a small team of psychology and occupational therapy clinicians.

Lisa graduated from the University of Sydney in 2002 with a Bachelor Applied Science (Occupational Therapy) and started her career working with people with traumatic and acquired brain injuries. Lisa moved to the United Kingdom in 2004 completing a number of locum positions in neurological rehabilitation before accepting a role in a medium security psychiatric hospital where she worked until her return to Australia.



Wayne and Jacqui Benson live in the outskirts of Sydney on a hobby farm with their 2 young adult kids, one super powered Triple X teenage daughter and a number of fur and feather babies.

Wayne is a 30 plus year veteran of the NSW Police Force who holds the rank of Superintendent and is in

charge of Campbelltown City and Macquarie Fields commands. In fact later today he will be receiving the Australian Police Medal, the highest honour for a Police Officer.

Jacqui is a former NSW police officer with 20 years of service who recently finished studying a certificate in disability services and modules in Community Services . After a bout of battling illness she is looking forward to getting fit and healthy and getting on with the next adventures of her career and family life.

