22q

Foundation Australia
& New Zealand

Program Schedule
25th November 2023
Perth Children's Hospital

Welcome to our 22q family meeting and conference! Since its establishment in 1994, our foundation has proudly served as the world's first support group for 22q11.2 Deletion Syndrome (formerly VCFS). More recently, we've extended our support to include those affected by 22q Duplication Syndrome. Notably, our foundation operates entirely through the efforts of our dedicated volunteers who bring passion to every aspect of our mission. We want to say a special thank-you to Kelly Grant for being one of our WA local representatives. Kelly, as many of you know organised this years 22q at the Zoo, Perth and has helped raise funds to bring this conference to you.

While the bulk of our income stems from donations generously given by affected families and friends, it's noteworthy that we've allocated support through the provision of 10 x $1000 travel grants for attendees of this meeting. This initiative was made possible by securing a grant from the Federal Government's Department of Social Services.

Attending days like today can often be overwhelming. We encourage you to take breaks when needed, participate in discussions and reach out and establish new connections.

Please note that the professionals here today cannot answer specific medical questions relating to your children or yourselves. Information provided is for educational purposes only.

9:00AM Registration
9:30AM Maria Kamper - President 22q Foundation Australia and New Zealand
9:35AM Welcome - Dr Natasha Moseley (22q Clinic PCH)
9:45AM 22q Overview - Associate Professor Honey Heussler
(22q Clinic QCH)
10:15AM General Paediatrics - What to look for, assessments etc
Dr Vinita Prasad (22q Clinic QCH)
10:40AM Morning Tea
11:00AM Lived experience plus education and schooling – Rhi Sugars,
The Atypical Educator
12:00PM Anxiety, Mental Wellbeing - Associate Professor Linda Campbell
(22q Minded Clinic)
12:40PM Q & A
12:45PM Immunology - Dr Natasha Moseley (22q Clinic PCH)
1:05PM ENT - Dr Hayley Herbert (22q Clinic PCH)
1:20PM Q & A
1:30PM Lunch and Breakout
People with 22q Facilitated (Dr Laura Roche) discussion
Care4Parents (Dr Campbell) an open discussion
2:50PM Transition to Adult services - Dr Rachel Collins
(Transition Services PCH)
3:10PM Social Skills – Dr Laura Roche PhD
3:30PM Speech & Language considerations - Dr David Gillett &
Corina Gill *CPSP (PCH)
4:00PM Genetic Counseling - Stephanie Broley (PCH)
4:20PM Q & A
4:45PM Close

Meet Our Speakers

Maria Kamper - President 22q Foundation Australia & New Zealand
Maria Kamper is a mother of three, two of whom have rare diseases. Maria is a disability advocate, a national and international presenter, who is dedicated and passionate about raising awareness and supporting people affected by 22q. Maria has been on the committee of the 22q Foundation Australia and New Zealand since 2006 and has been President sicne 2009.

Dr Natasha Moseley
Dr Moseley is a country girl at heart, growing up 'down south' in Albany. She completed her medical training through the University of Western Australia and has worked in Paediatrics at PMH/PCH since 2012. Natasha has completed dual training in Clinical Immunology and General Paediatrics and works across the Immunology and General Paediatric departments at Perth Children's Hospital as well as in private practice at Hollywood Medical Centre in Nedlands. Natasha leads the Primary Immunodeficiency Service at PCH and is the clinical lead in establishing newborn screening for Severe Combined Immune Deficiency (SCID) in Western Australia in 2023. Dr Moseley and Dr Rachel Collins have worked together to establish the 22q11 clinic at PCH, with the inaugural clinic running serendipitously on none-other than 22-11 - 22... 22q day itself!

Associate Professor Honey Heussler
A/Prof Honey Heussler is a Developmental and Behavioural Paediatrician with dual Sleep Physician qualification. She is an Associate Professor with the University of Queensland and is Director of Developmental Paediatrics and Medical Director, Child Development Services as well as clinical responsibility in Behavioural and Sleep clinics with Children's Health Queensland.

Dr Vinita Prasad,
Vinita is a Developmental and Behavioural Paediatrician with a dual qualification in General Paediatrics. Vinita has done her community child health and general paediatrics training at the Mater Children's Hospital and the Queensland Children's Hospital and is a fellow of the Royal Australasian College of Physicians. She has a special interest in rare neurodevelopmental disorders and is the lead clinician in the 22q, Angelman and Rett syndrome clinics at Queensland Children's Hospital.

Rhi Sugars
Born with 22q11 Duplication Syndrome, Rhi Sugars is an Autistic – ADHDer who is passionate about inclusion and celebrating and sharing her Neurodivergent world. With a professional background in early childhood education, Rhi has spent the past 17 years watching her fellow colleagues seek out inclusion support but often being left without the support they're searching for. As a mother of two children, one with 22q Deletion and one with 22q Duplication, Rhi has experienced the frustration and concern of having to leave her children in the care of, or be taught by educators lacking in inclusion and Neurodiversity knowledge.

Associate Professor Linda Campbell
Linda is a Clinical Psychologist and Associate Professor at the University of Newcastle in Australia. Linda has more than 20 years of research and clinical experience working with people, across the lifespan, who have been diagnosed with 22q11.2 deletion syndrome, their families and broader support network. Linda's research spans from brain imaging to cognition to mental health to the lived experiences of young people and families and has resulted in many scientific articles. In Linda's clinical work, she enjoys helping clients learn more about themselves, to be more present and self-compassionate using strength-based and affirming approaches to engage meaningfully in life. Linda is also passionate about education that helps families and individuals better understand the 22q11.2 deletion syndrome that also equips them with the knowledge and tools to advocate for themselves effectively. Linda's research, clinical work, and education trainings are interconnected, each informing and enhancing the other to create a comprehensive and impactful approach.

Dr Hayley Herbert
Since doing the subspecialty Fellowship in ENT in 2015 Hayley has continued to work as an ENT surgeon at Perth Children's Hospital. She has been Head of Department since 2018 and is a senior member of the Complex Airway Team and Cleft Palate team at PCH. She has also subspecialised in Laryngology. Hayley has been active in Research and is a University of Western Australia Senior Lecturer. She loves looking after her complex paediatric patients.

Dr Rachel Collins
Rachel is originally from Northern Ireland she has worked in Paediatrics at PMH/PCH since 2008. Dr Collins is a Consultant General Paediatrician and Consultant in Hospital In The Home. Dr Collins and Dr Natasha Moseley established the 22Q11 clinic at PCH together in 2023. Dr Collins is also Clinical Lead of the CAHS Transition service. She is Director of Paediatric Education at Perth Children's Hospital, a Senior Lecturer in Paediatrics at University of Western Australia and Medical Director of the AMA Youth Friendly Doctor and Dr YES programs. Dr Collins has a number of special interests and has completed research and developed collaborations in these areas including Youth Health and supporting families with complex chronic diseases. Her number one job she is being mum to three kids.

Dr Laura Roche
Laura advocates a strengths-based approach to learning for children and youth with neurodevelopmental disorders. Her work is focused on improving the way young people with disorders such as 22q and autism communicate with others and navigate their world, starting with acknowledging their existing abilities, understanding their needs, and working in close collaboration with their families to implement evidence-based interventions.

Corina Gill BSc (Speech & Hearing), CPSP
Corina graduated from Curtin University in Perth, Western Australia in 1991, and has worked on the Perth Children's Hospital Cleft Lip and Palate and Craniofacial Teams since 1997, alongside a dedicated multidisciplinary team including: Orthodontists, Paedodontists, and Plastic, Oral, Craniofacial and Maxillofacial surgeons. Corina has extensive experience in paediatric speech pathology and holds advanced credentials in velopharyngeal dysfunction through the lifespan (including nasendoscopic and videofluoroscopic assessment); paediatric dysphagia (feeding and swallowing difficulties); ENT management; and hearing implant habilitation.
Corina is passionate about: providing client centred, evidence-based practice; safety and quality; and educating colleagues and students to achieve the best outcomes for the children and families that I service.

Dr David Gillett
David is a Specialist Plastic Surgeon and a Craniomaxillofacial Surgeon. David specialises in caring for children and adults with cleft, lip and palate and other craniofacial problems. David is a founding member of the Australian New Zealand Society of Craniomaxillofacial Surgeons and was the President of the Australasian Cleft Lip and Palate Association from 2005 until 2018.

Dr Stephanie Broley
Stephanie is the senior genetic counsellor in the Genetic Paediatric Service of WA, working both clinically in paediatrics and the Rare Care Centre. She is also involved with multidisciplinary services within PCH including the 22q11 clinic. Stephanie has over 20 years of experience in multiple specialty areas working at The Children's Hospital at Westmead and Genetic Services WA with special interests in communication about genetic conditions and uncertainty counselling interventions as well as co-development of innovative services and pathways to meet the needs of individuals and families living with rare diseases.