**GSNV Mental Health Working Group Member Biographies - 2021**

**Nikki Dean:**

Professionally I am a Clinical Nurse Educator with over 15 years’ experience in Cancer Nursing and I hold postgraduate qualifications in Cancer and Palliative Care Nursing. Through my experience as a Cancer Nurse, I have clinical experience with mental health and supportive care screening, assessment, referrals and support. Personally, I am a mum of a 4-year-old boy diagnosed with a rare genetic syndrome, 15q24microdeletion syndrome. His diagnosis came after identifying health and developmental concerns in his first year of life. We regularly access therapy to support my son with his development and as a family live with the impact of his microdeletion on his health and development.  Myself and members of my family have also had our own experiences with mental health challenges. My son and my families experience motivate me to contribute to this important work group.

**Alice Cronin:**

Alice has qualifications in health science, public health and education. Most recently, Alice has worked as a Public Health Teacher in tertiary education and as Health Promotion Officer in a community health setting. She has a range of experience with non-profit organisations both locally and overseas, and has worked with various communities. SHe is currently working as the Health Promotions Officer for TASCA.

**Lisa Forster:**

Lisa holds a BSc (Hons) degree in biomedical science, with experience as a research scientist in the field of genetics. Lisa also holds a Diploma in Anatomy, Physiology and Massage along with a Certificate in Psychology and a Diploma in Herbal Studies. She has worked in the New Zealand health industry for over 10 years. The range of her experience covers assessing and facilitating care packages for older people, employment and education support in the mental health area and leading a team offering crisis respite for youth. Lisa was also part of the Be Leadership graduates in 2014. She is wholeheartedly committed to offering effective support to others in their time of need.

**Bianca Comfort:**

Bianca is a Psychologist (Clinical Registrar) who works in a private practice in Croydon, VIC. She works predominantly with clients experiencing chronic illness and/or chronic pain and sees a number of clients with rare and genetic conditions. Bianca has both a professional and personal interest in rare and genetic conditions, having lived experience with hEDS and other rare conditions. Bianca is active in support networks for psychologists, acting as the Secretary for the Rehabilitation Psychology for Injury, Chronic Illness and Pain Interest Group as well as Chair of the APS Outer East Melbourne Branch. Bianca is also currently undertaking research with Psychology Honors students into experiences of invalidation (by family, friends, and treaters) of people with chronic illnesses. Bianca hopes to raise awareness of the psychological stressors and mental health conditions experienced by people with rare or genetic conditions and hopes to increase access to psychological support for this population.

**Monica Ferrie:**

I’m inspired by potential and possibility, for individuals, teams and communities. My work is targeted to discover, facilitate and achieve them both in a number of capacities.I am the GSNV Chief Executive in a part time capacity which allows me to also be the Director of Bold and Brave Consulting and Toilet Training Educators, Treasurer of the Balibo House Trust, Honorary Fellow of Melbourne University and Board Director of the Asia Pacific Alliance of Rare Diseases. Experience in senior leadership roles in Government, Education, the private sector, international projects, education including a Master of Business Administration and a commitment to community provide a foundation for making a difference across a range of sectors.My work has allowed me to develop many skills over the years and I continue to utilise these and build more:Business Mentoring, Strategic Planning, Facilitation and Training, Leadership, Learning, Decision Making and Problem Solving.

**Nick Brobson:**

As a 2020 Bachelor of Psychological Science Graduate, and someone who has witnessed how rare diseases impact people’s everyday metal health, I believe I would be able to offer useful input in how we can help improve the quality of life of persons living with genetic, undiagnosed, and rare conditions.

I am also a carer and close family member of three women living with Ehlers Danlos Syndrome. I have been involved with the Ehlers Danlos Syndrome Australia National Support Group Melbourne and have also grown up with an older brother with Autism. I completed my degree with James Cook University where I studied subjects which covered aspects of rare diseases and how they impact everyday life. I am now completing a graduate certificate in counselling with Deakin. As a martial arts instructor, I’ve had the opportunity to teach and interact with a range of people living with medical and mental health conditions. I have offered support and guidance to them and understand that each person will have different needs and that no journey, nor experience, will be the same. I have 5 years of customer service experience working at Woolworths, where I have developed strong verbal communication and people skills and am highly regarded by my managers and customers.

I am motivated to change the stigmas relating to mental health to enable the GUaRD communities to access fair treatment. I believe this is a key issue which needs to be addressed immediately. With the many difficult changes 2020 has brought, I recognise easy access to mental health resources is crucial, now, more than ever, and I believe I could provide innovative solutions to the current restrictions

**Heather Renton:**

Heather is the Chief Executive Officer and Founder of Syndromes Without a Name (SWAN) Australia. SWAN provides information and support to families caring for a child with an undiagnosed or rare genetic condition. Heather is the mother of two children, one of whom has a rare genetic condition called FOXP1 Syndrome. Heather is a consumer representative on a number of different advisory groups and committees and is a passionate health and disability advocate.

**Jan Mumford:**

Jan’s work with genetics and families is from the hope it offers as well as the challenges this new information gives. Jan has a varied background in large organisations in telecommunications and small business, WHS consultancy. Her work with research groups provides a community perspective, promoting the health and support needs of those affected. At the state and federal levels, Jan has worked with peak advocacy groups for improved services and provided feedback on government policy and procedures. Jan’s experience and background strengthens Genetic Alliance support for families at all stages of a diagnosis as well as a community voice at state and federal levels.

**Hollie Feller:**

Hollie works part time for the Genetic Support Network of Victoria on communications and projects within the organisation but brings with her lived experience as the parent of her son who was born with the rare genetic condition Usher syndrome. Her roles in the rare and genetic disease space started when she co-founded UsherKids Australia in 2016 and now is a Director of this growing national support network. She is a fierce advocator for early diagnosis of Usher syndrome through genetic testing, the education of clinical professionals as well as support for families around the country to share research and information about the current generation of USH kids. She divides her time between work at the Genetic Support Network of Victoria, volunteering for UsherKids Australia, Paediatric Vision Impairment Alliance Australia and is also on the Board at Genetic Cures Australia(GCA Australia), a charity she established with her husband to further accelerate Australian research and therapies for inherited retinal conditions.

**Rachel Pope- Couston:**

I graduated from the Melbourne Master of Genetic Counselling in 2014 and I am currently working as an Associate Genetic Counsellor with the Tasmanian Clinical Genetics Service. Genetic counsellors undertake an extensive certification process that I will complete this year, which will make me a Certified Genetic Counsellor. I have been a committee member and the Treasurer of the GSNV since 2013 and it has been a joy to be part of the growth and evolution of the GSNV over the past 6 years. I come from a family that all works in healthcare in one form or another and where we are all passionate about advocacy and making sure that every person is represented and respected. I came to genetic counselling a bit later in life after a number of experiences convinced me it was what I really wanted to be doing. I believe that genetics (and now genomics) has the ability to empower individuals and families, but that people often need support to access and utilise the benefits, which is why I am so pleased to be a committee member, and President of the Genetic Support Network of Victoria Committee.

**Melanie Karakaidos:**

I am the mother of an 8-year-old girl with a very rare liver disease PFIC (progressive familial intrahepatic cholestasis). I am also the President of the worldwide charity for PFIC- The PFIC Network [www.pfic.org](https://protect-au.mimecast.com/s/eJMkCL7E7xcPgwjOTqQLrn?domain=pfic.org)

I live in New South Wales but passionately advocate for all patients/ families in Australia with PFIC, a number of whom live in Victoria. Part of my role as president is to offer peer support to families and patients around the world. The one thing I have learned is that everyone's mental health suffers with a rare disease; the PFIC patient who in excruciating pain, the siblings have to cope in this family unit, the caregivers who get no sleep as the child is up all-night scratching with an excruciating unbearable internal itch all over their body. Mental health is a huge and often unnamed issue for those with a rare genetic disease.

**Julie Cini:**

Julie has a passion for advocacy, empowerment, and compassion. Her resilience to keep going after facing adversity, and to leave legacies in honour of her 2 daughters, is part of her successful career. Julie now wants to teach others how to deliver good advocacy and make a difference in their chosen field.

**Liz Robinson:**

I am the mother of an 8-Elizabeth is a parent of a now adult child living with a rare genetic condition resulting in a profound intellectual disability and complex health needs including a degenerative neurological condition.

Elizabeth has a legal and policy background and has held significant leadership roles in the community including as President of Novita. Elizabeth has been recognised formally for developing community models to better connect people with supports, including children with disabilities and their families and students facing adversity. She has been involved at a Commonwealth and State level on advising government and community bodies on matters relating to people living with disabilities and those that care for them

**Clare Stuart:**

Clare manages policy and advocacy at Mito Foundation, driving improvements to health, disability and social support for people living with mitochondrial disease. She has a Masters in Public Health, has worked in policy development with NSW Ministry of Health and spent many years as a volunteer, staff member and manager of Tuberous Sclerosis Australia.

# Clare played a key role in the establishment of Rare Voices Australia and was a member of the steering committee for the first National Strategic Action Plan for Rare Diseases. Clare's passion for improving the lives of people with genetic and rare conditions is fuelled by her experience as a sister of Lizzie, who lived with tuberous sclerosis, a profound intellectual disability, epilepsy, kidney disease and many other complex health conditions