CONSUMER

Tayla Richardson

LIVED EXPERIENCE: Disability & Rare Disease

Tayla has lived experience of Congenital Myasthenic Syndrome – a rare disorder that had a gradual onset from 17 years old, and now at 28 years old causes her full body paralysis for 1-3 hours multiple times a day, in addition to symptoms affecting her digestion, communication, vision, respiration and muscle control. Tayla is passionate to improve the care and diagnosis for others with rare diseases after enduring a complex, process-of-elimination diagnostic journey spanning 9 years. Throughout her experiences in healthcare, Tayla has developed robust self-advocacy skills and a comprehensive knowledge of the health system that enables her to critically analyse the opportunities to improve person-centred care, patient experience and outcomes. Her care has been in consultation with geneticists as well as encountering many specialist departments, which has sparked her interest in being involved as a consumer lead in multidisciplinary research. Tayla is an NDIS participant, and supports her siblings who are NDIS participants, so has a thorough understanding of navigating the system from different perspectives. As a disability advocate and engaging writer, Tayla is finding a renewed sense of purpose, service and care for others again, using her lived experience, whilst balancing her health needs.

ACHIEVEMENTS AND EXPERIENCE:

- Completed 3 years of a Bachelor of Nursing and Midwifery degree with Monash University
- Written self portrait piece of 'woman with a disability' displayed in 'FEM-affinity' exhibition online for Bunjil Place
- Previous work as a medical receptionist for outpatient OBGYN clinic
- Danced in various styles as a teenager completing many exams and performances, including in the Disneyland parade

KEY INFORMATION

Place of Birth: Townsville, Queensland, Australia
Current location: Melbourne, Victoria, Australia
Age: 28 years old
Language/s: English only
LGBTQIA+: No
NDIS Participant: Yes
Diagnoses: Congenital Myasthenic Syndrome (CMS) - Rare genetic neuromuscular disorder
Healthcare Access: Primary Health Care, Allied Health, Secondary care, Tertiary Care, Mental Health, Community services.

LINKS

- 'Embracing Equilibrium' piece for 'FEM-affinity' online exhibition - Bunjil Place

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TO BOOK TAYLA, CONTACT ADMIN@CHAMPIONHEALTHAGENCY.COM