



Monday 25 March 2024

PHANZ Leaders at Rare Disorders Whitepaper Launch

March has been marked as Rare Disorders Month, shining a light on the unique challenges and needs of individuals and families living with rare disorders across Aotearoa. In a significant move to address these challenges, members of the Public Health Association of New Zealand (PHANZ) Council attended the launch of a pivotal whitepaper by Rare Disorders NZ.



The event, held at Parliament on the eve of Rare Disorders Month on 28 February, was not just a ceremony but a crucial step forward in advocating for better support and policies for those affected by rare disorders. Co-President Nari Faiers and Chairperson of the Asian Caucus, Nivedita Sharma Vij, represented PHANZ, showcasing their dedication to health equity and the well-being of all New Zealanders.

Rare Disorders NZ's whitepaper is a product of comprehensive surveys and reflects the real voices and experiences of whānau living with rare disorders. The document, born from the biennial Voice of Rare Disorders surveys, fills a significant gap in our health system's data, shedding light on the impact of rare disorders on individuals' lives. It highlights the areas in need and the barriers preventing people from accessing the care necessary for a quality life.

The launch event aimed not only to present these findings but also to underscore the necessity for equitable policymaking and the development of a Rare Disorders Strategy focused on effecting meaningful change. The gathering was graced with mihimihi and welcome from Hon Peeni Henare, with Hon Matt Doocey, Associate Minister for Mental Health, officially launching the whitepaper. The keynote address was delivered by Dr Gareth Baynam, Medical Director of the Rare Care Centre and Clinical Centre of Expertise for Rare and Undiagnosed Diseases in Western Australia.

Distinguished guests included Ministers Dr Shane Reti, David Seymour, Diana Sarafati - Director of Health, and Selah Hart, DCE Public & Population Health at Te Aka Whai Ora, alongside Todd Stevenson, CEO of Medicine NZ, and esteemed members of the Rare Disorders collective.

Reflecting on the event, Nari Faiers expressed, "We congratulate Rare Disorders NZ for their work in ensuring whānau and community voice contributes to policy and strategy development." This event signifies a collective stride towards inclusivity, understanding, and support for those living with rare disorders under the banner #glowupandshowup #invisibleDisabilities #NoOneLeftBehind.