

2023 Rare Voices Australia Rare Disease Day Parliamentary Event
Ensuring Equity for Australians Living With a Rare Disease
Speech Delivered by Nicole Millis, 8 March 2023

Hello everyone.

I'd like to acknowledge the traditional owners of this land, the Ngunnawal people, and pay my respects to their Elders—past, present and emerging.

As I look out, it is wonderful to see so many familiar faces. It is also wonderful to see so many new people I look forward to meeting today. For those who don't know me, I am Nicole Millis, the Chief Executive Officer of Rare Voices Australia. Like many in the rare disease sector, I wear multiple hats and am also the mother of 21-year-old Sean who is an actor and a singer—and who lives with a rare disease.

Rare Voices Australia, or RVA, is the national peak body for Australians living with a rare disease. RVA provides collaborative leadership for the development and implementation of rare disease policy as well as health, disability and other systems that work for people living with a rare disease.

RVA is dedicated to working with all key stakeholders to drive the best outcomes for Australians living with a rare disease. Stakeholders include people living with a rare disease; advocates; rare disease clinicians and researchers; governments; and the pharmaceutical industry. At our core, RVA is very much person-centred. More than half of our Board of Directors have lived experience or a personal connection to rare disease. More than three quarters of our staff team have lived experience or a personal connection to rare disease. Members of our RVA Board, Scientific and Medical Advisory Committee (SMAC) and staff are here today. I am privileged and humbled to lead such a high-calibre and amazing team.

Our RVA Ambassadors are an important part of the RVA team. Some of our ambassadors are also here and today, we've heard from Renae. Thank you to Renae for speaking today. It is never simple to share your story so publicly, but it is so powerful—especially at this—our Rare Disease Day event.

Rare Disease Day is an international initiative held on the last day of February each year. Locally, Rare Disease Day is an opportunity to advance equity to raise awareness and inform policymakers on the issues faced by the Australian rare disease community, in an effort to achieve meaningful change. Every year RVA holds an event at Parliament House as close as possible to Rare Disease Day. Parliamentary Events provide stakeholders, including people living with a rare disease, with the opportunity to meet and speak with Parliamentarians to further highlight the impact of rare diseases. I encourage all of you to connect with each other here today. Share your stories. Listen to others' experiences. Learn from each other. Together we can come up with the best solutions.

Thank you to Minister Butler, the Minister for Health and Aged Care. It is wonderful to have your support of the rare disease sector at this event and ongoing.

Thank you to the Member for Macarthur, Dr Mike Freeland, Chair of the Standing Committee on Health, Aged Care and Sport and Co-Chair of the Parliamentary Friends of Rare Diseases alongside Senator Wendy Askew and the Member for Kooyong, Dr Monique Ryan. You have always been a political champion for the rare disease sector.

Today's event is an opportunity to strengthen the link between personal stories and policy. This is so critical in rare disease. Effective rare disease policy absolutely transforms people's lives. The key foundational and credible rare disease policy document in this country is the [National Strategic Action Plan for Rare Diseases](#) (the Action Plan). Launched in 2020 by the Australian Government with bipartisan support, the Action Plan is Australia's first nationally coordinated effort to address rare diseases and aims to deliver the best possible health and wellbeing outcomes for Australians living with a rare disease. The Action Plan was collaboratively developed by the whole rare disease sector. Similarly, the whole rare disease sector has progressed its implementation.

As the national peak body, RVA led an Action Plan implementation activity scan to track the sector's collective efforts ahead of the National Rare Disease Summit in November last year. The aim was to start mapping what is being done, what has been achieved, and importantly, to highlight gaps. Of course, this work will be ongoing. We have summary documents available that includes QR codes for extra information about the activity scan and some other updates on key work. [Download the activity scan summary.](#)

Rare Awareness Rare Education (RARE) Portal

RVA is leading the collaborative development of the RARE Portal for rare diseases. The RARE Portal is one of the key deliverables of the Australian Government's Action Plan.

The RARE Portal:

- Is a digital library of verified rare disease information, services and resources
- Is customised for the Australian context
- Caters for all stakeholders in the rare disease sector and the general public
- Is a living website that is responsive to feedback and new knowledge
- Highlights strengths and gaps across the rare disease sector, which can inform policy and service development

Today, we are soft launching the site. More content and rare disease pages will be added over time. It is important that we allow sufficient time for content to be codesigned with the community. [Download the RARE Portal flyer.](#)

National Strategy for Australia's Rare Metabolic Diseases Workforce

In 2022, RVA published the [Rare Metabolic Workforce White Paper: Towards a Strengthened Rare Disease Workforce for Australia](#) (the White Paper).

White Paper Findings

- Australians living with a rare metabolic disease have high levels of unmet need, and the care they receive depends on their postcode
- Critical workforce shortages are preventing best practice care for these patients
- Insufficient resources in specialist metabolic services are preventing access to innovative new treatments and clinical trials

The White Paper, together with sector consultation, informed the development of the [National Strategy for Australia's Rare Metabolic Disease Workforce](#) (the Strategy).

The Strategy is an evidence-based, expert-backed framework of goals, recommendations and priority actions that address current high levels of unmet need through a nationally consistent and sustainable workforce.

Implementing this Strategy is the responsibility of all stakeholders, including governments, hospital administrators, healthcare providers, specialist physician groups and policymakers across states and territories, and at a national level.

The Strategy's goals for a recognised, connected, consistent, sustainable and innovative rare metabolic disease workforce, should be further leveraged to respond to broader rare disease workforce challenges in Australia.

Lastly, I would like to acknowledge how personally honoured I am to be speaking in Parliament House today on International Women's Day (IWD). Our RVA Partner organisations, rare disease consumer-led organisations/support groups, are predominantly led by women. These consumer-led rare disease organisations play a key role in raising awareness and providing person-centred information and peer support. These organisations are vital to the rare disease sector and often fill the gaps in the system; not just in terms of awareness and education, but also care and support and increasingly, in the research sphere. However, we know these organisations are under resourced, are largely reliant on volunteers and often have a limited ability to raise funds, posing a risk to their long-term sustainability. RVA encourages the Government to provide more sustainable and appropriate funding models to better support and resource this critical part of the sector.

Now, it is my pleasure to introduce the Shadow Minister for Health and Aged Care, Senator the Hon Anne Ruston. The Senator is also the Shadow Minister for Sport; the Manager of Opposition Business in the Senate; and a member of the Parliamentary Friends of Medicine.