Thank you, Minister Butler.

Thank you to Mike [Dr Mike Freelander MP] and Monique [Dr Monique Ryan] for your words and ongoing support of the rare disease sector. A little bit later, we will also hear from the other Co-Chair of the Parliamentary Friends of Rare Diseases, Senator Wendy Askew, the Senator for Tasmania.

I'm Nicole, the Chief Executive Officer of Rare Voices Australia (RVA). I'm privileged to lead the RVA team, many of whom are here today, including our RVA Chair Dr Carol Wicking and Directors, Professor Eric Morand and Teresa Pilbeam; some of our staff; and members from our Scientific and Medical Advisory Committee, Chaired by Professor Adam Jaffé.

It is fantastic to see so many people here. Thank you all for coming. This event reflects all the different rare disease stakeholders: people living with a rare disease; advocates; RVA Partner groups/organisations; clinicians; researchers; government; Department of Health staff; and parliamentarians. All of you are part of the rare disease sector. Thank you for participating in Rare Disease Day.

Today's theme is *Progress Beyond Policy*. Thanks to all of you and indeed, the whole rare disease sector, Australia has a strong person-centred policy framework, the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan). Thank you to everyone for embracing the Action Plan and running with it. We see the pillars, principles, priorities and actions constantly referenced in policy consultations and submissions, resource development, research grants. The 'what?' we need to do and 'why?' Thank you all for ensuring the Action Plan is a priority.

Today, we're highlighting another part of the Action Plan. On page 47, there is a section titled 'Implementation Mechanisms'. This is the 'how?' section of the Action Plan. The things that will enable, embed and progress implementation. Implementation mechanisms describe things such as the Rare Awareness Rare Education (RARE) Portal and the Centre for Precision Medicine and Rare Disease, recommended by the *New Frontier Report* and accepted in principle by government. This section also includes legislation. Currently, the rare disease sector is calling on parliamentarians to legislate against genetic discrimination by the insurance industry.

When we talk about implementation mechanisms, it's not always about building new structures or new things but just as much about reframing and re-organising how we respond to rare disease in a more consistent, systematic and sustainable way; now and in the future.

Today, we are focusing on two key implementation mechanisms:

- The National Recommendations for Rare Disease Health Care, which have now been endorsed by 9 colleges/institutions and recognised by the Royal Australian College of General Practitioners; and
- The need for Rare Disease Centres of Expertise

Later, we will hear from RVA's Research and Evaluation Manager, Dr Falak Helwani, who will share her personal story and the need for Centres of Expertise. Centres of Expertise (also known as Centres of Excellence) represent international best practice rare disease care. Previous work undertaken by RVA on the rare metabolic workforce also highlighted the need for Centres of Expertise to provide a more sustainable and integrated and person-centred model of care.

There are criteria for Centres of Expertise but, to me, if I strip everything right back, the real value is that they bring together wisdom and expertise. Clinical expertise and wisdom; research expertise and wisdom; and expertise and wisdom from people living with rare diseases. Centres of Expertise enable this wisdom and expertise to continuously grow and build.