**30 March 2022**

## Budget 2022-23 and Australians Living with a Rare Disease

On Tuesday, 29 March 2022, the Hon Josh Frydenberg MP (Treasurer of Australia) announced the Morrison Government's 2022-23 Federal Budget, which included a record investment in Australia's health system with a total commitment of $537 billion over the next four years.

As the national peak body for Australians living with a rare disease, Rare Voices Australia (RVA) attended the Department of Health's Portfolio Briefing webinar presentation and Q&A with the Hon Greg Hunt MP (Minister for Health and Aged Care); the Hon Dr David Gillespie MP (Minister for Regional Health); the Hon David Coleman MP (Assistant Minister to the Prime Minister for Mental Health and Suicide Prevention); and Senator the Hon Richard Colbeck (Minister for Senior Australians and Aged Care Services). The session was facilitated by Dr Brendan Murphy, Secretary of the Department of Health.

Below, RVA has highlighted areas of the Budget we believe are most relevant to Australians living with a rare disease and the rare disease sector. While RVA is encouraged by these Budget inclusions, we remain committed to working with the Government to prioritise and progress more systemic implementation of the National Strategic Action Plan for Rare Diseases (the Action Plan). As always, RVA remains committed to advocating in ways that are most likely to be effective and in a manner that is solutions focused.

### Ongoing investment into research

RVA welcomes the Morrison Government's ongoing commitment to the National Health and Medical Research Council (NHMRC) and the Medical Research Future Fund (MRFF) over four years from 2022–23.

The NHMRC is the nation's leading expert body in health and medical research; it is responsible for developing evidence-based health advice in Australia. The Government will invest $3.7 billion in the NHMRC. In 2021, rare disease expertise was appointed to the NHMRC for the first time.

The MRFF is the Government's $20 billion research fund underpinned by a 10-year investment plan. The Government is investing $2.6 billion in the MRFF. The MRFF funds several rare disease-related grant opportunities, such as the 2021 Genomics Health Futures Mission Grant Opportunity and 2021 Rare Cancers, Rare Diseases and Unmet Need Grant Opportunity. Additionally, the MRFF funds clinical trials, and for many people living with a rare disease, participation in a clinical trial may be the only way to access treatment.

The Government also announced the Biotechnology in Australia – Strategic Plan for Health and Medicine. From a health perspective, biotechnology is creating medicines and technologies that can combat rare diseases.

### Integration of genomics into Australia's health system

RVA welcomes the Government's investment of $28.1 million to establish Genomics Australia to support the implementation of genomics as a standard of healthcare in Australia. The Morrison Government has stated that Genomics Australia will lead the integration of genomics into the nation's health system. The Action Plan highlights the importance of genomics in rare diseases, and RVA is encouraged by this Budget inclusion.

**Pre-conception (carrier) testing and screening**

Prenatal and newborn screening programs are vital in the early detection of rare diseases. The 2022-23 Federal Budget will dedicate $81.2 million to make Mackenzie's Mission for genetic carrier screening universal and permanent. Mackenzie's Mission is a research study that provides reproductive genetic carrier screening to couples across Australia. Genetic testing will be available for cystic fibrosis, spinal muscular atrophy (SMA) and fragile X syndrome to people planning a pregnancy, and their reproductive partners, from 1 November 2023. RVA has continued to advocate for screening at a systemic level and congratulates those involved in this positive outcome for these specific rare disease communities.

**Access to treatment**

Government funding for evidence-based treatments can be life-changing in rare disease. The 2022-23 Federal Budget provides new listings on the Pharmaceutical Benefits Scheme (PBS) for treating cystic fibrosis and SMA in children less than nine-months-old with type 1 SMA or pre-symptomatic patients with 1-2 copies of the SMN2 gene. RVA congratulates those involved in advocating for this fantastic outcome for the SMA and cystic fibrosis communities.

**Mental health support**

The Action Plan acknowledges that living with a rare disease does not solely impact a person's health; it impacts every facet of their life, including education, employment and mental health. Priority 2.5 of the Action Plan calls for the integration of mental health, and social and emotional wellbeing, into rare disease care and support. RVA is encouraged by the Government's ongoing commitment to mental health and its $648.6 million investment into Stage 2 of the Mental Health and Suicide Prevention Reform Plan to ensure Australians can access appropriate mental health care as needed.

**Priority populations**

RVA welcomes the Budget's focus on recognised priority populations of the rare disease sector, including Aboriginal and Torres Strait Islander peoples, people living in regional, rural and remote areas and people from culturally and linguistically diverse (CALD) backgrounds.

More than $4.6 billion will be dedicated to prioritising and improving health outcomes for Aboriginal and Torres Strait Islander people. This includes $5.9 million to support priority populations, including Aboriginal and Torres Strait Islander peoples and CALD communities, to catch up on missed health screening opportunities.

Additionally, the Government will continue to build on its 10-Year Stronger Rural Health Strategy, with an investment of $296.5 million in the 2022–23 Budget. This includes improved access to critical and life-saving diagnostic imaging in regional and rural areas and $99.3 million to build training and education opportunities in rural regions. RVA is encouraged by this investment as we know that where people live can have a significant impact on workforce supply and people's ability to access services.

**National Disability Insurance Scheme**

The 2022-23 Federal Budget will deliver a record investment of $157.8 billion into the National Disability Insurance Scheme (NDIS) over four years. While not every person living with a rare disease will have an associated disability, those who do will often require support and assistance in their daily activities. To ensure these needs can be met, systems such as the NDIS must be responsive, flexible and provide person-centred care. In line with the Action Plan (see Implementation step 2.1.2.2), RVA will continue to engage in ongoing dialogue with the National Disability Insurance Agency (NDIA) regarding a fit-for-purpose response to people living with a rare disease.

**Telehealth and digital health**

The Action Plan calls for the increased utilisation of digital health, including telehealth (see Implementation step 2.1.1.3), which will increase equity of access to services for people living with a rare disease. RVA welcomes the Government's $512 million investment to ensure telehealth remains a permanent part of Australia's health system. Additionally, the Budget includes $72 million to modernise Australia's health system.

Regards,

Nicole Millis
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Rare Voices Australia