

12 May 2021

Federal Budget 2021-22 and Australians living with a rare disease

On Tuesday 11 May 2021, Treasurer Josh Frydenberg announced the Morrison Government's 2021-22 Federal Budget.

As the 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); Senator the Hon Richard Colbeck (Minister for Senior Australians and Aged Care Services); the Hon Mark Coulton MP (Minister for Regional Health, Regional Communications and Local Government); and the Hon David Coleman MP (Assistant Minister to the Prime Minister for Mental Health and Suicide Prevention). The session was facilitated by Dr Brendan Murphy, Secretary of the Department of Health.

Below, RVA has highlighted areas of the Federal Budget 2021-22 that we believe are most relevant to Australians living with a rare disease and the rare disease sector. RVA is encouraged by the below Budget inclusions and remains committed to working with the Government to highlight the need to progress implementation of the [National Strategic Action Plan for Rare Diseases](#) (the Action Plan). We will continue to advocate in ways that are most likely to be effective and in a manner that is solutions focused.

Medical Research Future Fund (MRFF)

RVA welcomes the Government's ongoing commitment to the Medical Research Future Fund (MRFF), which is projected to reach \$650 million in funding in 2022–23 and beyond. In total, \$85 million will be dedicated to new program rounds that open on 12 May 2021 including \$70 million for the 2021 Clinical Trials Activity, Rare Cancer, Rare Diseases and Unmet Need program. Over the next four years, \$3.6 billion will also be invested into the National Health and Medical Research Council (NHMRC).

Additionally, the Government has dedicated \$4.4 million over four years to facilitate a staged implementation of mitochondrial donation in research and clinical settings in Australia. This will enable the introduction of a new assisted reproductive technology aimed at preventing children being born with severe, life threatening mitochondrial disease. In line with the Action Plan, RVA supports the Government's ongoing review of health technology policy in step with advancements in health technology. We also acknowledge RVA Partner, Mito Foundation, for their advocacy for the Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021 which paves the way for legalising mitochondrial donation in Australia.

Increased access to pre-implantation genetic diagnosis

The 2021-22 Budget commits \$95.9 million for five new Medicare Benefits Schedule (MBS) items for pre-implantation genetic diagnosis (PGD) of embryos for specific genetic or chromosomal abnormalities prior to implantation and pregnancy.

RVA welcomes this announcement in line with the Action Plan's call for increased reproductive confidence. Currently, access to PGD is limited to those able to pay privately. This funding also addresses one of the foundation principles of the Action Plan, 'equity of access', as the cost of PGD testing is quite prohibitive for many families.

RVA is seeking additional detail regarding this announcement from Minister Hunt's office and has been informed that eligibility to access subsidised PDG testing will be determined by a clinical geneticist and will relate to:

- A person's risk of having a child with a genetic and/or chromosomal disorder; and
- No curative treatment for the disorder being available for which there is severe limitation on quality of life despite contemporary treatment.

Eligibility is not disorder specific but will include conditions such as Duchenne muscular dystrophy (DMD), Huntington's disease (HD), Fragile X and cystic fibrosis.

The extension of telehealth and mental health support

The Morrison Government is extending its COVID-19 health measures by investing \$204.6 million to extend telehealth arrangements until 31 December 2021. Additionally, it will invest \$2.3 billion into the National Mental Health and Suicide Prevention Plan with the aim to deliver structural reform to Australians to ensure they have the support needed. This includes \$111.2 million in digital services, including the creation of a single digital platform under Head to Health that will provide online professional counselling, peer support, clinical support and referrals.

RVA is encouraged by the Government's commitment to telehealth and mental health support. The Action Plan calls for the integration of mental health, and social and emotional wellbeing, into rare disease care and support. It also calls for the increased utilisation of digital health, including telehealth, which will increase equity of access to services for people living with a rare disease.

Commitment to streamlining Health Technology Assessment (HTA) processes

The Morrison Government has stated that it will continue to work with the medicines and technology sector to continue streamlining and deregulating processes to apply for reimbursement of new products and services. This commitment comes with a \$36 million investment into the Health Products Portal, a new one stop shop for applying electronically to the Pharmaceutical Benefits Advisory Committee (PBAC), Medical Services Advisory Committee (MSAC) and Prostheses List for reimbursement of medicines, medical and diagnostic services and medical devices. The Government contends that the Health Products Portal will speed up access to new therapies for Australian patients.

The Action Plan calls for timely and equitable access to new and emerging health technologies. Streamlining processes in this way would contribute somewhat to this.

Priority populations

The 2021-22 delivers more than \$781.1 million to prioritise Aboriginal and Torres Strait Islander health and ageing outcomes. The Government states that this investment will contribute to priority reforms and health targets set out in the new National Agreement on Closing the Gap.

Aboriginal and Torres Strait Islanders are one of the priority populations of the Action Plan. While Aboriginal and Torres Strait Islander people are not necessarily at greater risk of rare diseases, several factors increase the potential impact of rare diseases on this cohort.

The 2021–22 Budget also continues reforms under the Stronger Rural Health Strategy to ensure equity of access for all Australians, with \$123 million to strengthen the rural health workforce and improve services in regional Australia. 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.

Regards,



Nicole Millis,
Chief Executive Officer, Rare Voices Australia