

**26 October 2022**

## **Rare Voices Australia Statement: Budget October 2022-23**

On Tuesday, 25 October 2022 the Hon Dr Jim Chalmers MP (Treasurer of Australia), announced the Albanese Government's October 2022-23 Federal Budget. In a media release, the Hon Mark Butler MP, Minister for Health and Aged Care, stated, "This is a Budget for the health of every Australian."

As the national peak body for Australians living with a rare disease, Rare Voices Australia (RVA) attended the Department of Health and Aged Care's Portfolio Briefing Webinar Presentation and Q&A with Minister Butler; the Hon Anika Wells MP (Minister for Aged Care, Minister for Sport); the Hon Ged Kearney MP (Assistant Minister for Health and Aged Care); the Hon Emma McBride MP (Assistant Minister for Mental Health and Suicide Prevention, Assistant Minister for Rural and Regional Health); and Senator the Hon Malarndirri McCarthy (Assistant Minister for Indigenous Australians, Assistant Minister for Indigenous Health). The session was facilitated by Prof Brendan Murphy AC, Secretary of the Department of Health and Aged Care.

Below, RVA has highlighted some 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 our ongoing work with the Government to progress the systemic implementation of the [National Strategic Action Plan for Rare Diseases](#) (the Action Plan).

### **Newborn Bloodspot Screening**

RVA welcomes the Government's commitment to people living with a rare disease with its investment into Australia's Newborn Bloodspot Screening (NBS) programs. The Action Plan highlights the need to address urgent funding gaps associated with the effective implementation and sustained success of NBS (see Implementation steps 2.2.2.2. and 2.3.2.3.). The Budget states that Australia's NBS programs will be restored to world-leading status through \$39 million in funding to increase the number and consistency of conditions screened across the country. During the Q&A session, Minister Butler said this was an "exciting commitment" and reiterated the need to ensure access to NBS is "universal across Australia." RVA will continue working with the Government regarding the rollout of this funding.

### **Rare Disease Telehealth Nurse Program**

It's pleasing to see an additional \$3 million over 3 years from 2022-2023 dedicated to supporting people living with a rare disease to better navigate the health system through telehealth nurses via the Rare Disease Telehealth Nurse Program. In line with Implementation step 2.1.1.1 of the Action Plan, RVA will continue working with the Government to establish standards for care and support that are integrated and incorporate clear pathways throughout all systems. The Action Plan also calls for the increased utilisation of digital health, including telehealth services.

### **National Disability Insurance Scheme**

RVA welcomes the Government's focus on the National Disability Insurance Scheme (NDIS) in the October 2022-23 Budget. Several initiatives are included in the Budget, including the announcement of an independent NDIS Review led by a panel of experts and people with disability to create a roadmap for improving the NDIS, rebuilding community trust and ensuring the NDIS' sustainability.

RVA will participate in the NDIS Review as the national peak body for Australians living with a rare disease. We also welcome the \$5.8 million Alternative Dispute Resolution Pilot to achieve fairer, faster and better outcomes for NDIS participants. This includes an additional \$6.6 million for participants to access advocacy and legal assistance.

### **Mental Health**

Living with a rare disease does not only impact a person's physical health; it impacts every facet of their life, including their mental health. In recognition of the ongoing and growing need for mental health and suicide prevention supports and services, the Government is investing \$114 million across several initiatives. This includes \$26.2 million to fund a new national network of perinatal mental health and wellbeing centres and \$19.8 million to strengthen women's health during and after pregnancy, including providing support for families bereaved by stillbirth.

### **Strengthening First Nations Health**

Aboriginal and Torres Strait Islander people are one of the priority populations identified in 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 Aboriginal and Torres Strait Islander people. RVA welcomes the Australian Government's intent to accelerate its efforts in closing the gap in health and wellbeing outcomes for First Nations peoples. This includes \$22.5 million to build a dedicated Birthing on Country Centre of Excellence at Waminda in Nowra, New South Wales. The Birthing Centre will provide culturally safe care and wrap around support services for First Nations families during pregnancy, birth and beyond.

### **Life Saving Drugs Program**

The Life Saving Drugs Program (LSDP) covers the cost of specific essential medicines to treat people living with a rare disease. The October 2022-23 includes the listing of avalglugosidase alfa (Nexviazyme®) on the Life Saving Drugs Program (LSDP) (\$11 million save over 4 years from 2022–2023).