rare voices
AUSTRALIA

4 April 2019

Federal Budget 2019-20 and Rare Disease

On Tuesday evening, Treasurer Josh Frydenberg announced the Morrison Government's 2019-20 Federal Budget. As a peak body, Rare Voices Australia (RVA) attended the Department of Health 2019-20 Federal Budget Briefing in Canberra. In the lead-up to and beyond the election (reports indicate that an announcement is imminent), RVA will continue to work with all Parliamentarians including the Government, the Opposition and Independents, to address unmet rare disease policy needs within but also beyond the Health Portfolio (eg. the National Disability Insurance Scheme). RVA will continue our critical stakeholder consultation and development of the National Strategic Action Plan for Rare Diseases. We are also working with The McKell Institute on Rare Disease and Access to Services, drafting a White Paper that will also inform part of the Action Plan (the online survey closes on 12 April, click here to participate).

Below, RVA has highlighted excerpts from the Federal 2019-20 Budget that we view as particularly positive for rare disease.

Guaranteeing Medicare - strengthening primary care

The National Strategic Action Plan for Rare Diseases was included under the 'strengthening primary care' heading. Rare disease being classified under primary care by the Government is promising and a clear sign of progress.

Improving access to medicines: Life Saving Drugs Program

In his speech, Minister Greg Hunt said that access to medicines is central to his role as Health Minister. Last week, we congratulated RVA Partner, Batten Disease Support & Research Association Australia (BDSRA), on its effective advocacy towards the announcement that Brineura, the first treatment for Batten disease, will be funded through the Life Saving Drugs Program (LSDP). Brineura will be listed on the LSDP from 1 May, 2019.

Additionally, a new brand of Nitsinone and a new strength of the originator brand, will be available from 1 May, 2019 to treat hereditary Tyrosinaemia Type 1. This particular patient community has strong leadership from RVA Partner, the Metabolic Dietary Disorders Association (MDDA).

Investing in Health and Medical Research

The Budget revealed a 10-year investment plan for funding of the Medical Research Future Fund (MRFF) of nearly $5 billion. Four key themes underpin the plan: patients, researchers, translation and missions. $614 million will go towards clinical trials for rare cancers, rare diseases and unmet needs.

Through our submission to the MRFF priorities, RVA had previously called for MRFF investment into rare disease registries and encouraged funding for Data Infrastructure, expected to fund registries, biobanks and data linkage. This Program provides $10 million a year from 2020-21, and applications for funding are expected to be called for soon.

RVA remains committed to advocating strategically and effectively on behalf of the rare disease community. Feel free to forward this message onto others who may be interested.

Yours sincerely,

Nicole Millis,
Chief Executive Officer - Rare Voices Australia