



16 November 2018

Morrison Government announces support of National Rare Disease Framework

[Rare Voices Australia](#) (RVA), the national peak not-for-profit organisation advocating for the nearly 2 million Australians living with rare disease, welcomes the Morrison Government's support of a National Rare Disease Framework. The Hon. Greg Hunt MP, Minister for Health, made the announcement today as part of the official opening of RVA's biennial 2018 National Rare Disease Summit, which is taking place on 16-17 November 2018 in Melbourne.

The Morrison Government will commission RVA to work with all stakeholders to deliver the National Rare Disease Framework with \$154,000 in grant funding. The Minister acknowledged the work of Rare Voices Australia which has "made such a difference... a driving force for change."

"To ensure the most equitable, effective, efficient and coordinated approach to rare disease, Australia needs a National Rare Disease Framework consisting of six strategic priorities: diagnosis, access to treatments, data collection, coordinated care, access to services and coordinated research. RVA welcomes the Morrison Government's commitment to ensuring Australia is a leader among the APEC Rare Disease Network, in addition to bringing the nation in-line with the EU, UK and other parts of the world," said RVA's Chief Executive Officer, Nicole Millis.

"To effectively respond to the challenges of rare disease, Australia needs a health system that looks to reduce uncertainty via policy that is Fair For Rare. Effective rare disease policy transforms patients' lives and now more so than ever, we know that such policy needs to be part of a National Rare Disease Framework," said Ms Millis.

Ms Millis added: "We thank the Hon. Minister Hunt for his ongoing commitment to Australians living with a rare disease and look forward to working with the Government moving forward. In 2018, we've seen a number of landmark announcements in the rare disease space including the Life Saving Drugs Program (LSDP) Reform, \$261 million dedicated to rare cancers and rare diseases via the Medical Research Future Fund (MRFF), the announcement of a Newborn Bloodspot Screening National Policy Framework and the National Genomics Mission.

"The Morrison Government's announcement today, supporting a National Rare Disease Framework, ensures the best possible outcomes for current Government investment in rare disease. It's the only way to help guide the most effective rare disease policy now and in the future. Additionally, it helps to raise the profile of rare disease more permanently and most importantly, ensures no Australian is left behind.

"A National Rare Disease Framework will successfully build on existing Government investment in rare disease, to enhance activities already underway and continue to guide and importantly, future-proof the ongoing development of new and innovative patient-centred and effective rare disease policy."

-Ends-

For interview and photo opportunities with Ms Millis, please contact Sarah Cannata on 0472 501 237 or communications@rarevoices.com.au

Please note: the 2018 National Rare Disease Summit is an invite only event. Media is welcome to attend. To express your interest in attending, please contact Ms Cannata via the above contact details.

About Rare Voices Australia

[Rare Voices Australia](#) (RVA) is Australia's peak body for rare disease, advocating for Australians living with rare disease. We provide a strong, common voice to advocate for health policy and a healthcare system that

works for people living with rare disease. Our patient-centred focus sees RVA working with key stakeholders including patients, key peak bodies, governments, researchers, clinicians and industry to promote rare disease, diagnosis, access to treatments, data collection, coordinated care, access to services and coordinated research.