

30 October 2019

## 2020-21 ACT Budget Consultation

Rare Voices Australia (RVA) is pleased to provide this submission to the 2020-21 ACT Budget Consultation. RVA is Australia's peak organisation for rare disease, advocating for Australians living with rare disease. While individual diseases may be rare, an estimated 2 million Australians live with rare disease. RVA provides a strong, common voice to advocate for policy and systems that work for people living with rare disease. RVA is currently leading work on the collaborative development of the National Strategic Action Plan for Rare Diseases (the Action Plan) to achieve our vision of the best possible health and wellbeing outcomes for Australians living with rare disease.

As part of this work, RVA calls for investment into rare disease centres of excellence that would include and further develop existing specialist rare disease services such as research groups, clinics and organisations. In this way, RVA also supports the call from Capital Region Muscular Dystrophy (MD) for investment into neuromuscular clinics.

Development of the Action Plan included an extensive consultation process involving all key stakeholders in rare disease in Australia. Throughout this consultation process, stakeholders consistently raised the need for rare disease centres of excellence. Currently, rare disease clinics and research institutes with a focus on rare disease are significantly under-resourced, and often work in isolation. To achieve real progress, existing strengths must be built upon to formalise a network of centres of excellence that is appropriate and accessible for all Australians.

In rare disease, there is a real need to prioritise the systematic building of knowledge, evidence and expertise. Time is critical and there is an urgent need for the expansion of rare disease expertise and the further development of evidence-based rare disease care. Systems must actively respond to existing evidence gaps, while processes that will build knowledge and evidence both quickly and sustainably must be prioritised. Clearer pathways through health and other systems are a necessity.

Centres of excellence may be comprised of research groups or institutes, clinics, hospitals and rare disease organisations. This builds on existing strengths in the sector, increasing its sustainability in the long-term. Further investment would respond to existing critical funding gaps and build workforce capacity, ensure person-centred collaboration and co-design, while allowing for specialisation and reducing duplication.

Great complexity and unmet need in rare disease can be overwhelming. However, with effective rare disease policy and investment, we can reduce the disempowering uncertainty of rare disease.

Yours sincerely,



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