rare voices
AUSTRALIA

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Newborn Bloodspot Screening National Policy Framework

Rare Voices Australia (RVA) welcomes the announcement of the Newborn Bloodspot Screening National Policy Framework. Over the last 15 months, RVA has strongly called for the endorsement of the Framework by the Australian Health Ministers' Advisory Council (AHMAC). RVA is very pleased that this has now eventuated and particularly would like to congratulate the Newborn Bloodspot Screening Working Group, chaired by Professor Craig White. This Framework was developed from their 18 months of intense work and significant stakeholder engagement.

This is a landmark policy achievement which for the first time ensures nationally-agreed, consistent, transparent, best-practice policy to guide and strengthen newborn bloodspot screening in Australia now and in the future. RVA applauds the Framework's focus on quality and safety, as well as family-centredness. Importantly, it is transparent and driven by information and evidence.

RVA knows that the early and accurate diagnosis of rare diseases leads to better outcomes for patients, and long-term benefits to the Australian healthcare system. Early diagnosis enables the best clinical care, treatment options, access to services, support, increased reproductive confidence and participation in clinical trials (research). The expansion of newborn bloodspot screening is of vital importance to many of our RVA Partner organisations and the broader rare disease community. RVA believes that this national Framework provides much needed clarity around this decision-making process with its defined agreed criteria. It also reduces the potential of specific rare disease communities competing against each other regarding this issue and promotes a more equitable, transparent and measured response.

The Framework clearly outlines the decision-making pathway and states that a condition can be nominated by anyone. There are defined nationally-agreed criteria that enable consideration of the benefit for the target population of screening, and of whether the benefits of doing so outweigh the harms. There needs to be benefit to the baby of early diagnosis; benefit that is balanced against the harms and cost. A reliable test must be available and a satisfactory system in place to deal with testing and follow up care.

This Framework has helped to future-proof newborn screening in Australia. In the absence of this policy, Australia has not added any new disease test to the NBS in the last 15 years despite major progress in diagnostics and treatment options in that time. For the best outcomes for babies and families, it is important that screening and diagnostic programs are up to date and accessible. The Newborn Bloodspot Screening National Policy Framework is a critical factor in this. Thank you to all involved in its development, including the valuable support provided by the Office of Population Health Genomics, WA. RVA looks forward to the Framework's implementation.

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With Compliments

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