Summary of Patient Organisations supported by Medicines Australia Member Companies

Company:	*Alexion Pharmaceuticals Australasia*
For the period:	*1 January - 31 December 2024*
Total support:	*$97,000*

Name of Patient Organisation	Description of and/or purpose of support	Nature of support (monetary value or equivalent) or description of non-financial support
Rare Voices Australia (RVA)	Funding to support a 2-day National Rare Disease Summit inviting rare disease support organisations, people living with rare disease, governments, key peak bodies, clinicians, researchers and industry to facilitate broader stakeholder engagement to progress critical issues in the National Strategic Action Plan.	$23,000.00
Rare Voices Australia (RVA)	Industry Roundtable Membership provides the opportunity to support RVA's work as the national peak body for Australians living with a rare disease. This work includes policy advocacy, leadership of the National Strategic Action plan for rare diseases, building key relationships with other peak bodies and participation in advisory panels, including research steering committees, white paper development, advisory board and consumer co-design activities.	$20,000.00
Patient Voice Initiative (PVI)	Funding provided enables PVI to deliver their 2024 scope of work which includes the expansion of their Patient Voice Hub, the HTA Champions Program, support consumer voice input to HTA submissions, patient evidence capacity building program, consumer conversations with the Department of Health and act as thought leaders in HTA reform.	$9,000.00

Neurological Alliance Australia (NAA)	Monetary support to help the NAA host a one day Summit at Parliament House, Canberra inviting Ministers, Shadow Ministers, Parliamentary allied associates, key departmental and government representatives to hear from people with lived experience of neurological conditions. The Summit provided a focal point for the establishment of a funded National Action Plan for neurological conditions.	$15,000.00
Children's Tumour Foundation	The funding supported the national launch and external outreach campaign to share the findings in the Neurofibromatosis (NF) Health and Social Impact Study report to build awareness of the unmet needs of the NF community and generate advocacy and goodwill to address policy reform and systemic change. Activities included a launch event in Parliament House, printing of 100 copies of the report, a digital promotion campaign, production of infographics and digital assets and a social media campaign.	$15,000.00
Children's Tumour Foundation	In partnership with the Children's Tumour Foundation Medical Advisory Panel, the funding was used to develop an independently hosted workshop event that allowed NF experts, government and healthcare experts and representatives from the NF community to progress the recommendations from the NF Health and Social Impact report, and outline the gaps and solutions to consistent care provision for people living with NF in Australia.	$15,000.00