

Summary of Patient Organisations supported by Medicines Australia Member Companies

Company: Alexion Pharmaceuticals Australasia
For the period: 1 January - 31 December 2025
Total PO Sponsorship: \$127,500.00

Name of Patient Organisation	Description of and/or purpose of support	Nature of support (monetary value or equivalent) or description of non-financial support
MS (Multiple Sclerosis) Australia	Support for patients with rare neuro myelitis optica spectrum disorder to attend the community forums (NMOSD Patient Community Forum) during the Progress in MS Research Conference.	\$2,000
MS (Multiple Sclerosis) Australia	Support towards MS Australia's biennial Progress in MS Research Conference. The conference is Australia's leading event exploring innovative research into the causes, prevention, improved treatments and ultimately a cure for multiple sclerosis (MS). The conference is designed to promote the exchange of scientific thought, advance research on MS and related diseases in Australia, and to provide research updates to the MS community.	\$15,000
Genetic Alliance Australia (GAA)	Financial support towards the Genetic Alliance Australia Annual Forum and Showcase featuring Shared Strengths for Rare Futures. The funding went towards convening the event which highlighted the need for equitable care models in rare care, showcased examples of innovation and collaboration and facilitated cross-disciplinary networking.	\$5,000
PNH Support Association Australia (PNHSAA)	PNH Support Association of Australia is the only organisation dedicated to Australians with Paroxysmal Nocturnal Haemoglobinuria (PNH). Funding assisted with convening the first National Members Meeting since 2020 and allowed patients diagnosed with Paroxysmal Nocturnal Haemoglobinuria to share lived experiences and to obtain information about the current treatments.	\$10,000
Children's Tumour Foundation (CTF)	Financial support towards the 2025 Australian NF (neurofibromatosis) Clinical Symposium which showcased both Australian and international speakers, stimulates new collaborations, demonstrates progress and fuels new ideas to conquer NF. It was also an opportunity for health professionals and researchers to come together, in person and virtually, to network and discuss the latest in medical management, treatment and research into neurofibromatosis in Australia and around the globe.	\$25,000

Name of Patient Organisation	Description of and/or purpose of support	Nature of support (monetary value or equivalent) or description of non-financial support
Neurological Alliance Australia (NAA)	Funding to enable the provision of travel grants to enable smaller, voluntary, NAA member organisations to attend NAA's workshops a National Action Plan for Neurological and Neuromuscular Conditions, and/or the launch event at Parliament House.	\$10,000
Myasthenia Gravis Foundation America	Funding as part of the MGFA scholarship program in support of young investigators from Australia and members of the Australian Patient Association to attend the MGFA International Conference.	\$15,000
Genetic Support Network Victoria	Funding support towards Genetic Support Network of Victoria's annual Rare Disease Day event on International Rare Disease Day. The event showcased unique perspectives across the sector focussed on experience/specialist areas and reflecting on the last 25 years – the promise at the turn of the century and how we are placed at delivering that promise. This will include patient experience and expectations, patient support groups, clinical care, the health/genomic workforce, therapy development and access, mental health support and the genomics/scientific landscape.	\$1,500
Rare Voices Australia (RVA)	Grant for Rare Voices Australia's 2025 Sector Development and Education Program to progress the aims of the Action Plan that are focused on developing the capacity of rare disease groups/organisations to represent and advocate for people living with a rare disease and their families and equipping and encouraging frontline health professionals to consider, investigate and refer for a potential rare disease diagnosis.	\$15,000
Rare Voices Australia (RVA)	Membership of the RVA Round Table of Companies (RTC) - a forum that cultivates effective and transparent working relationships and open communication between RVA and the industry. RVA is dedicated to working with key stakeholders to drive the best outcomes for Australians living with a rare disease. Membership would permit member companies 3 representatives to attend 4 quarterly RVA RTC meetings per year.	\$20,000
Patient Voice Initiative	Funding towards the Patient Voice Initiative's 2025 initiatives in improving health technology assessment (HTA) for and with patients requires capacity development and thought leadership. 2025's activities are specifically designed to progress the preferences expressed by patient communities during the HTA Policy and Methods Review (2022-2024).	\$9,000