

Summary of Health Consumer Organisations supported by Medicines Australia Member Companies

Company: Alexion Pharmaceuticals Australasia  
 For the period: 1 Jan - 31 Dec 2023

Name of Health Consumer Organisation	Description of and/or purpose of support	Nature of support (monetary value or equivalent) or description of non-financial support
Childhood Dementia Initiative	Sponsorship funding of a symposium that brings together 150 clinicians, researchers, patient advocates caregivers and industry members to focus on current research and sharing of expertise across multiple rare neuro-degenerative disorders that impact children. The funding supports a program of international speakers, keynotes, panel discussions, workshops and networking opportunities that aims to improve the diagnosis, therapeutic developments and clinical care of rare childhood dementias.	\$ 15,000.00
Genetic Support Network Victoria	This funding is being used to conduct and promote the findings of a research exercise that is looking into the evidence gap that exists in understanding and documenting the lived experience and expectations of the genetic, undiagnosed and rare disease community. The lack of a comprehensive evidence base contributes to inequity. The study will identify gaps and priorities in healthcare, wellbeing and social supports and a report, calling for action, will be released to coincide with Rare Disease Day 2024.	\$ 30,000.00
Myasthenia Alliance Australia (MAA)	The MAA requested funding from Alexion to support its third national conference to be held in Sydney in October 2023. Featuring neurologists, researchers and allied health professionals, the MAA held an educational conference for people living with myasthenia gravis (MG) that travelled from across Australia to hear from presenters that shared their experiences and knowledge to help shape research, registry engagement and emerging treatment and healthcare management in MG.	\$ 5,000.00
Children's Tumour Foundation (CTF)	Alexion sponsored the CTF's neurofibromatosis (NF) Clinical Education Symposium which is an event exclusively for healthcare professionals, clinical specialists, scientists and allied healthcare practitioners who have an interest or are working in the field of neurofibromatosis. The event featured an international keynote speaker who shared information on global research and new treatment paradigms. Held in person on 28 July 2023, the event was also live streamed for virtual participants.	\$ 25,000.00
Maddie Rievoldt's Vision (MRV)	MRV gathered the leading scientists, clinicians and allied health practitioners and presented the latest research findings on bone marrow failure syndromes. International speakers from Sao Paulo and the USA along with a group of local speakers presented with a welcome event followed by 1.5 days of scientific presentations on October 13-15 2023 at the Victorian Comprehensive Cancer Centre.	\$ 7,500.00
Children's Tumour Foundation (CTF)	Provide funding to the Children's Tumour Foundation to support the development of a study and report into the burden of neurofibromatosis (NF) on the Australian economy and community. The project aims to highlight the impact of this condition on children, families, adult patients and caregivers who suffer from a range of life limiting symptoms and challenges that are poorly understood and addressed due to the lack of evidence and data that accurately measures and enables meaningful conversations that drive systemic change. The outputs will inform advocacy, support and action that can be used by the CTF, clinicians, government, philanthropists, and its industry partners to help meet the needs of the NF community.	\$ 70,000.00
Sydney Children's Hospital	The Sydney Children's Hospital Genetic Metabolic Disorder Services (GMDS) launched an awareness event on Rare Disease Day 2023 "Care for Rare" to recognise the work of the GMDS and support the 1000 patients that have over 150 different rare genetic diseases. Alexion funding helped the SCHF highlight the work of their kid's services dedicated to rare diseases.	\$ 5,000.00
Australian Amyloidosis Network (AAN)	Funding supported the AAN to host a series of travelling lectures with international and national amyloidosis expert speakers, with the intention of promoting diseases awareness and updating patient and health professional groups of the latest in amyloid research, therapeutics, clinical trials and supportive care. Workshops were held in Melbourne, Sydney, Brisbane, Adelaide and Perth. Each Workshop includes Health Professional Educational Lectures and Patient, Carer and Family Educational Lectures with a Q&A session with our speakers after each lecture.	\$ 22,000.00

Patient Voice Initiative (PVI)	The Patient Voice Initiative (PVI) is a patient-chair led multi-stakeholder initiative which works to promote and support valuing the patient voice in health policy, especially health technology assessment. The Annual Meeting of HTAi (Health Technology Assessment international) was held in Adelaide, South Australia from 24-28 June 2023. PVI sought funding to support education of patient advocates around the current HTA reform program in Australia by facilitating patient group representatives attendance at the HTAi Annual Meeting that covered meeting registration, accommodation, and travel to Adelaide. The Annual Meeting had numerous plenaries, workshops, panels, presentations, and posters discussing patient involvement in HTA.	\$ 8,000.00
Rare Voices Australia (RVA)	This funding enabled Rare Voices Australia to host a parliamentary event to coincide with Rare Disease Day 2023 which gives RVA the opportunity to highlight their role as the peak body for Australians living with a rare diseases and demonstrates their ability to bring together the rare disease sector to raise the profile of rare disease among Federal members of Parliament which is vital to progressing the implementation of the National Strategic Action Plan for Rare Diseases	\$ 10,000.00
Rare Voices Australia (RVA)	RVA established the industry Roundtable to set-up a forum that cultivates effective and transparent working relationships and open communication between RVA and industry. The RTC is a group of industries that share a common interest in rare diseases and orphan drug development. RTC membership is an opportunity for companies to support RVA's work as the national peak body for Australians living with a rare disease and enables open dialogue with RVA, rare disease patient communities, clinicians and government stakeholders and provides an effective channel to support the implementation of National Rare Disease Action Plan	\$ 20,000.00
Children's Tumour Foundation (CTF)	Fundraising and staff registration for Conquer NF in Colour, a fun run organised at locations in Sydney, Brisbane and Melbourne throughout November 2023. The event aims to raise awareness of neurofibromatosis (NF).	\$5,167.28 (which comprises \$4,405 fundraising and \$762.28 event registration fee for employees)