

Summary of Health Consumer Organisations supported by Medicines Australia Member Companies

For the period: 1 January 2020 - 31 December 2020

Company: Shire Australia Pty Ltd

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
Fabry Australia Incorporated	Funding to support Fabry Australia's Fabry Patient Educational virtual meeting and printing of their Factsheet booklet "Understanding Fabry Disease" and other educational materials for Fabry patients.	\$25,000
Gaucher Association of Australia & New Zealand	Funding to support Gaucher Association of Australia & New Zealand in the areas of: - Mask and media costs related to International Gaucher Day; - 2021 Melbourne meeting and a joint Gaucher and Fabry meeting at the ICIEM 2021 Conference; - Educational initiatives and resources - Lexi's Brave Bunny; and - Cancellation fees related to flight bookings for the European Working Group meeting.	\$10,000
Rare Voices Australia	Funding to support Rare Voices Australia's National Rare Disease Summit 2021. The Summit will bring together all stakeholders, with the focus to build on the Priorities and Actions of the National Strategic Action Plan for Rare Diseases.	\$20,000
Rare Voices Australia	Funding to support Rare Voices Australia's 2020 Mentorship and Education Project in the areas of travel and accommodation costs only and the development of printed Action Plan implementation one-page summaries for specific stakeholders. This project includes the RVA Speakers Program: Engaging with the Action Plan and Advocacy Mentorship for RVA Partner organisations.	\$10,000
Fabry Australia Incorporated	Funding to support Fabry Australia's Be Rare. Be YOU. Tattoo campaign through the purchase and use of Be Rare. Be YOU. tattoos.	\$1,000
The Immune Deficiency Foundation Australia Ltd (IDFA)	Funding to support The Immune Deficiency Foundation Australia Ltd (IDFA) in the areas of: - Weekly online support group program and webinar series for members, carers and healthcare professionals; - Establishment of an online platform to deliver member support; and - Production of resources to support online member support initiatives.	\$10,000
Rare Voices Australia	Funding to support Rare Voices Australia's Rare Disease Day Parliamentary Events 2020 which aim to highlight the challenges of rare diseases, opportunities for improvement and to raise the profile and awareness of rare disease.	\$8,000
The Immune Deficiency Foundation Australia Ltd (IDFA)	Funding to support The Immune Deficiency Foundation Australia Ltd's (IDFA) development and printing of educational patient resources for raising awareness of the signs and symptoms of primary and secondary immune deficiencies and their management and for the update and rebuild of the IDFA website.	\$20,000
HAE Australasia Ltd	Funding to support HAE Australasia Ltd's Patient Survey in the areas of: - Software and data analysis; and - Patient Meet Ups for patients and their carers in the areas of travel, accommodation, venue hire, catering and educational resources.	\$13,500
Parenteral Nutrition Down Under Inc.	Funding to support Parenteral Nutrition Down Under Inc.'s publication and printing costs of resources for their Home Parenteral Nutrition members.	\$5,000