

Summary of Health Consumer Organisations supported by Medicines Australia Member Companies

Company: *Amgen Australia*
 For the period: *1 Jan-31 Dec 2021*

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
Patient Voice Initiative Incorporated	<p>Patient Voice Initiative (PVI) is a collaboration between patients (or health consumers), researchers and industry working towards improving the patient voice in the Australian health system.</p> <p>This sponsorship to support PVI was directed towards:</p> <ul style="list-style-type: none"> •Further development of the PVI consumer online toolkit •Supporting the Patient Engagement and Knowledge through Efficient Resource Search (SPEAKERS) program •Stakeholder training and engagement initiatives 	\$12,000
Rare Cancers Australia	<p>Rare Cancers Australia's (RCA) purpose is to improve the lives and health outcomes of Australians living with rare and less common cancers. Their National Oncology Alliance (NOA) was formed in 2018 to engage the broad cancer community to develop recommendations and/or policies that address the needs of those impacted by cancer.</p> <p>This sponsorship supported the NOA's 2021 initiatives, which included:</p> <ul style="list-style-type: none"> •CanForum Putting the spotlight on what needs to change to have a fully patient-centred approach to the health system •Production of a report: Realising the roles and rights of patients in cancer care and decision-making frameworks Including recommendations substantiated by evidence gathered from patients and their families. •Preparation of the cancer patient participation charter Providing a pathway for all members of the cancer community and government to publicly commit to recognising and respecting the rights and roles of patients in cancer care •NOA interactive website build Keeping information accessible for the alliance of stakeholders 	\$35,000

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Healthy Bones Australia	<p>Healthy Bones Australia (HBA), formerly Osteoporosis Australia, is a national non-for-profit organisation and the leading consumer body working to improve bone health across Australia. HBA is focused on increasing community and health professional awareness of the disease and advocating to reduce the impact of osteoporosis nationally.</p> <p>This sponsorship supported HBA with two large-scale programs:</p> <ul style="list-style-type: none"> •Know Your Bones (KYB) – an online bone health self-assessment tool that provides individuals with a report explaining their level of risk and personalised recommendations that can be discussed with a healthcare professional. In 2021, the KYB website was upgraded and optimised before a national media campaign sought to increase consumer awareness of osteoporosis and drive referrals to the site. The KYB campaign also featured new initiatives to support healthcare professional awareness of osteoporosis, including an accredited GP education module, distribution of electronic direct-mail material/ resources and editorial in select trade media publications. •National Strategic Action Plan (NSAP) for Osteoporosis – The 2019 NSAP is a document that sets out priorities, objectives, and actions for addressing Australia's growing challenge of osteoporosis. In 2021, HBA embarked on policy-focussed, parliamentary engagement program to help drive commitment to the NSAP, and maintain momentum behind its implementation in 2022 and beyond. 	\$200,000
Myeloma Australia	<p>Myeloma Australia (MA) is the only Australian myeloma specific not-for-profit organisation. Their mission is to support, educate, inform, empower and bring hope to people who are living with myeloma, and their loved ones. They also raise community awareness and understanding of myeloma; educate health professionals involved in the care and treatment of those living with myeloma; advocate for improved patient access to the latest treatments at affordable prices; and facilitate myeloma research in Australia.</p> <p>This sponsorship supported MA's myeloma nurse program that provides services and support for patients in rural, remote, and regional areas of Australia.</p> <p>The funds ensure myeloma nurses are able to offer information and assistance to patients before, during and after their treatment, helping to create a more equitable patient experience across the country.</p>	\$50,000

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Lung Foundation Australia	<p>Lung Foundation Australia (LFA) is the only charity and peak body of its kind in Australia that funds life-changing research and delivers support services that give hope to people living with lung disease or lung cancer.</p> <p>This sponsorship supported LFA to continue their lung cancer advocacy and lung cancer nurse programs, including:</p> <ul style="list-style-type: none"> • Making lung cancer a fair fight: A Blueprint for Reform - a report designed to raise awareness about the burden of lung cancer in Australia and the challenges faced by consumers. The report outlines feasible and pragmatic recommendations that will lead to better outcomes for people living with lung cancer. • A nurse-led, telephone-based intervention to support people living with lung cancer, their families, and carers. The service aims to address the shortage of specialist lung cancer nurses and help people living with lung cancer manage the symptoms and side effects associated with the disease and its treatment. 	\$50,000
Prostate Cancer Foundation of Australia	<p>Prostate Cancer Foundation of Australia (PCFA) is a broad-based community organisation and the peak national body for prostate cancer in Australia. They are dedicated to reducing the impact of prostate cancer on Australian men, their partners, and families.</p> <p>This sponsorship supported PCFA with the establishment of Australia's first Prostate Cancer Consumer Advocacy Forum (PCCAF). The PCCAF will significantly strengthen consumer participation across the continuum of prostate cancer care in Australia.</p> <p>It aims to raise the patient voice at the policy table, advocate for increased education and awareness, and support the increased availability of existing and new medicines to all patients who need them.</p>	\$40,500

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National Heart Foundation of Australia	<p>For over 60 years, the National Heart Foundation of Australia (NHFA) has been the trusted peak body, working to improve heart disease prevention, detection, and support for all Australians.</p> <p>This sponsorship supported the NHFA to help improve the identification and management of high cholesterol through:</p> <ul style="list-style-type: none"> •A national roundtable of leading experts across the sector exploring the management of high cholesterol in Australia, and assessing opportunities to improve lipid management in the contexts of primary prevention, secondary prevention and familial hypercholesterolaemia. •Development of an up-to-date resource for clinicians, covering guidance around the management of high cholesterol including strategies for up-titration, initiating new therapies, and addressing non-adherence. 	\$85,000
Australasian Leukaemia & Lymphoma Group	<p>The Australasian Leukaemia & Lymphoma Group (ALLG) is the only not-for-profit collaborative clinical research group in Australia and New Zealand designing and conducting clinical trials in all blood cancers such as leukaemia, lymphoma, myeloma as well as other blood disorders.</p> <p>The ALLG has also created a registry detailing the clinical pathways of patients suffering from blood cancer. The National Blood Cancer Registry (NBCR) was designed to give real world data linking demographic, cancer cytogenetic, clinical and treatment outcome information and offers a longitudinal clinical pathway for each participating patient.</p> <p>This sponsorship supported the operation of an ALLG registry-driven Minimal Residual Disease (MRD) project: MRDrive-ALL. This included:</p> <ul style="list-style-type: none"> •Coordination of the collection, processing, data entry and sample management of MRD samples for the patients registered to MRDrive-ALL •Testing at a central laboratory •Development and set up of the project including ethics submissions and patient management •Ongoing trial management between January 2022 and December 2024 	\$216,151

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McGrath Foundation	<p>The McGrath Foundation is a registered charity which aims to provide Australian families experiencing breast cancer with access to the specialist care and support by breast care nurses. The Foundation aims to achieve this by using donations it receives from fundraising activities to provide financial support to health care organisations, so that McGrath breast care nurses can be placed in communities in need across Australia. The Foundation also aims to increase breast health understanding among people of all ages.</p> <p>This sponsorship specifically supported metastatic breast cancer nurses in the health care system for people living with advanced breast cancer and was designed to help the McGrath Foundation understand and address the needs of this group of patients.</p>	\$35,000
Healthy Bones Australia	<p>Healthy Bones Australia (HBA), formerly Osteoporosis Australia, is a national non-for-profit organisation and the leading consumer body working to improve bone health across Australia. HBA is focused on increasing community and health professional awareness of the disease and advocating to reduce the impact of osteoporosis nationally.</p> <p>This sponsorship supported the development of a special report for World Osteoporosis Day (WOD) 2021. The Know Your Bones Community Risk Report is an important national tool to highlight the issue of bone health in Australia, the main risk factors for osteoporosis and under-diagnosis. The report was disseminated to key stakeholders, community groups, policy makers and health care professionals.</p>	\$15,000
Total		\$738,651