



Celebrating 10 years of rare disease advocacy
that influences policy and transforms lives

ANNUAL REPORT

Year ended 30 June 2022

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ABOUT RARE VOICES AUSTRALIA

Rare Voices Australia (RVA) is the national peak body for Australians living with a rare disease. RVA provides a strong, unified voice to advocate for policy as well as health, disability and other systems that work for people living with a rare disease.

Our person-centred focus sees us working with all key stakeholders, including people living with a rare disease, governments, key peak bodies, researchers, clinicians and industry. We advocate for the best outcomes for Australians living with a rare disease.

RVA'S VISION

RVA is dedicated to working with all key stakeholders to drive the best outcomes for Australians living with a rare disease.

RVA'S MISSION

RVA provides collaborative leadership for the development and implementation of rare disease policy in Australia.

CHAIR AND CHIEF EXECUTIVE OFFICER REPORT

RVA provided collaborative leadership for the development and implementation of rare disease policy in Australia throughout the 2021/2022 financial year.

Our primary focus was leading the collaborative implementation of the National Strategic Action Plan for Rare Diseases (the Action Plan), despite the obstacles that arose as a result of more than two years of COVID-19 restrictions.

In 2022, RVA celebrated 10 years of rare disease advocacy that has been highly successful in influencing government policy, which in turn, has been instrumental in transforming lives. At RVA, we know policy is vital to achieving equitable, transparent and consistent systemic change to drive the best outcomes for Australians living with a rare disease.

RVA is proud of our role in ensuring rare disease policy remains a priority for governments, despite a changeover in the Federal Government in May 2022 and the ongoing uncertainty of the COVID-19 pandemic. The Parliamentary Friends of Australians Living with Rare Diseases (Parliamentary Friends) continued to lead political support for the rare disease sector throughout the 2021/22 financial period. RVA would like to acknowledge the support of its Parliamentary Friends Co-Chair during the 46th Parliament, Trent Zimmerman. Additionally, we welcome and look forward to working with the Co-Chairs of the Parliamentary Friends in the 47th Parliament, Dr Mike Freeland MP, Senator Wendy Askew and Dr Monique Ryan MP. Additionally, RVA continued working with the Parliamentary Friends of People with Rare and Undiagnosed Diseases in Western Australia, which is Chaired by the Hon Matthew Swinbourn MLC, Hon Donna Faragher MLC and Hon Stephen Pratt MLC. RVA highly values working with such strategic and influential non-partisan groups.

As RVA's profile as the national peak body for Australians living with a rare disease continues to grow, how we work, engage and collaborate has become even more integral to the organisation's longevity and ongoing success.

We consistently live out our values in how we work

- We are person-centred
- We actively build and maintain partnerships
- We aim for a unified voice
- We work for equity of access and participation
- We equip and empower
- We are solutions and results oriented
- We are credible
- We adopt a systemic focus

While systemic advocacy and policy are central to our work, RVA also continued to provide advisory expertise, contribute to research partnerships and provide mentorship and education to RVA Partners (individual rare disease groups).

RVA Ambassador Program

Adopting a person-centred approach is key to RVA's work and is a foundation principle of the Action Plan. In 2022, RVA launched an Ambassador Program to coincide with the organisation's 10th anniversary and to highlight the importance of lived experience. Thank you to our RVA Ambassadors for participating in this program and for sharing their moving and courageous personal stories.

Organisational Growth

Two new staff members joined RVA's team during the 2021/2022 financial year. Malcolm Fung joined RVA as Operations and Compliance Manager and we welcomed Dr Amanda Choo as our Resources and Information Officer. These positions were created in response to RVA's organisational growth and an increased workload for the [Rare Awareness Rare Education \(RARE\) Portal](#) – a multipurpose website with rare diseases information and resources customised for the Australian context.

The RVA Board has been particularly grateful to have the additional resource and expertise provided by Malcolm Fung as we have been able to make great strides in bringing our organisational policies and procedures up to date. Malcolm, in collaboration with our Finance and Risk Committee (FaR Committee) Chair Viswanathan (Vishy) Narayanaswamy, has also made a very significant contribution to our developing risk management program.

RVA's significant staffing increase was supported in part through Commonwealth Department of Health grants as part of the initial investment in response to the Action Plan. With this grant funding, RVA continued leading the collaborative development of the RARE Portal. RVA also continued our work as a consortia partner of the university-led [Rare Disease Awareness, Education, Support and Training \(RArEST\) Project](#) which focuses on rare disease awareness, education, support and training. Additionally, RVA is pleased to partner with the Western Australian Department of Health on projects to progress the implementation of key aspects of the Action Plan in Western Australia. We hope to work on similar projects with other State and Territory Governments in the next few years.

RVA Scientific and Medical Advisory Committee

RVA's Scientific and Medical Advisory Committee (SMAC) provides the organisation with medical and clinical perspectives, guidelines and information. In 2022, we welcomed three new SMAC members, including Dr (Elizabeth) Emma Palmer (Clinical Geneticist, Sydney Children's Hospitals Network; University Lecturer, University of New South Wales); Professor John Rasko (Head of Department, Cell & Molecular Therapies, Royal Prince Alfred Hospital); and Yarlalu Thomas (Medical Student, University of Western Australia).

Our SMAC Chair, Professor Adam Jaffé, has led the way in SMAC engaging in some exciting work in the next year on setting priorities for rare disease research. Thank you to our SMAC members who so willingly share their time and expertise with RVA.

RVA Board

RVA's national Board continues to grow and mature with a range of expertise and lived experience around our virtual RVA Board table. Director, Raymond Saich OAM, stepped down in February 2022 after 6 years. The RVA Board wishes to extend our thanks and appreciation for Raymond's many contributions, including time as Co-Chair of the Board and Chair of the FaR Committee. We thank Raymond for his commitment, support and contribution to RVA over the last 6 years. In April 2022, RVA welcomed three new RVA Board Directors, Andrew Carter, Kate Henderson and Teresa Pilbeam (filling casual vacancies until formally elected at this year's annual general meeting). Each new Director has brought with them areas of expertise to enhance the RVA Board's skills and in most cases, lived experience to ensure we remain strongly personally connected to our Mission and Vision.

Strong governance has been vital to RVA's growth and our work towards achieving the best outcomes for Australians living with a rare disease. Each RVA Director is committed to achieving our organisational outcomes and to looking for areas of future value that RVA can add in achieving our goals.

Meanwhile, the RVA Board continued its focus on longer-term strategic planning throughout the 2021/2022 financial year. The collaborative implementation of the Action Plan continued despite the looming uncertainty of COVID-19. The dedication of the rare disease sector to work together to achieve the best health and wellbeing outcomes for Australians living with a rare disease is exciting for RVA staff and the RVA Board and we travel that journey with all of our stakeholders and partners.

Contribution of RVA Partners and Other Stakeholders

The RVA Board and staff are grateful for the interest, time, energy and support provided by all of our RVA Partner organisations and other key stakeholders in working together to achieve RVA's Vision to drive the best outcomes for all Australians living with a rare disease.

As the recent 2022 National Rare Disease Summit highlighted, these collaborations are electric and energising and we look forward to the next 10 years of rare disease advocacy that influences policy and transforms lives.

BOARD MEMBERS, COMPANY SECRETARY AND STAFF

RVA Board

The RVA Board comprises dedicated Directors, many with lived experience of rare disease. The RVA Board meets regularly and oversees RVA's strategic direction and purpose.

Directors in office from 1 July 2021 to 30 June 2022:

Joanna Betteridge (Chair)

Kane Blackman (Deputy Chair)

Andrew Carter – casual vacancy, April 2022

Kate Henderson – casual vacancy, April 2022

Robert Hendriks

Prof Eric Morand

Vishy Narayanaswamy

Teresa Pilbeam – casual vacancy, April 2022

Raymond Saich OAM – resigned February 2022

Dr Carol Wicking



Company Secretary

Liyi Chang

Company Secretary, RVA

Chartered Company Secretary, Institute of Chartered Secretaries and Administrators

(UK) Member, Australian Institute of Company Directors

Associate Member, Governance Institute of Australia

Chief Executive Officer and RVA Staff

RVA staff in employment during the year 1 July 2021 to 30 June 2022:

Nicole Millis (Chief Executive Officer)

Sarah Cannata

Amanda Choo – joined March 2022

Freya French – joined November 2021

Malcolm Fung – joined November 2021

Louise Healy

Falak Helwani

Anne Hunter

BOARD COMMITTEES

The RVA Board has two subcommittees, the Finance and Risk Committee (FaR Committee) and the Nominations Committee. The FaR Committee is Chaired by Vishy Narayanaswamy and is appointed to provide advice to the RVA Board on budget setting, financial and operational risk management and monitoring financial performance. The second subcommittee is the Nominations Committee, which was Chaired by Kane Blackman until December 2021, and then by Dr Carol Wicking from January 2022. The Nominations Committee supports and advises the RVA Board on the nomination policies and processes of the Chief Executive Officer, the board and its Directors.

RVA Scientific and Medical Advisory Committee

RVA's Scientific and Medical Advisory Committee (SMAC) provides the organisation with medical and clinical perspectives, guidelines and information as needed.

[SMAC Terms of Reference \(PDF\)](#)

Prof Adam Jaffé (Chair)
Clin/Prof Gareth Baynam
Dr Kaustuv Bhattacharya
Prof Alan Bittles – resigned December 2021
Dr Lisa Ewans
Dr Paul Lacaze
Dr Kristen Nowak
Dr (Elizabeth) Emma Palmer – joined January 2022
Dr Lemuel Pelentsov – resigned December 2021
Prof John Rasko
Prof Jeff Szer
Yarlalu Thomas – joined January 2022
Dr Carol Wicking
Prof Yvonne Zuryski

RVA ROUND TABLE OF COMPANIES

The RVA Round Table of Companies (the RTC) is a group of pharmaceutical companies with a common interest in rare diseases and orphan drug development.

RTC members provide financial support to RVA, and all member company logos are listed on RVA's website (www.rarevoices.org.au). RVA facilitates the RTC in line with our [Working With Industry Policy](#), holding quarterly meetings/workshops.

RTC members nominate up to three representatives with expertise in patient advocacy, market access for treatments and reimbursement, and government relations. Due to COVID-19, the quarterly meetings during the 2021/22 financial year were held via Zoom. These meetings aim to discuss the development and availability of treatments and health services in Australia. They also assist in building relationships within the rare disease community in a collaborative atmosphere that facilitates discussion about rare diseases. The meetings provide opportunities for RVA and industry representatives to:

- Interact on topics relevant to the rare disease sector
- Exchange views with leaders of the rare disease community
- Develop partnerships and collaborations and timely reports, surveys and analysis relevant to the field of rare diseases from different sources

Discussion topics for 2022 included:

- RVA updates on activities and key achievements for each quarter
- 2022 Rare Disease Day
- 2022 National Rare Disease Summit
- Action Plan implementation updates and provision of a document to track RVA activity and initiatives against the Action Plan
- Newborn bloodspot screening advocacy updates
- Rare Disease Industry Working Group updates
- *The New Frontier – Delivering better health for all Australians* report priorities for RVA and priorities for industry
- HTA Submission Summary Pilot Project
- Proposed RVA Education on Rare Disease Therapy – development, registration and reimbursement in Australia

Submissions:

- Joint Standing Committee on the National Disability Insurance Scheme (NDIS) consultation
- PBAC discount rate consultation
- Australian Commission on Safety and Quality in Health Care's National One Stop Shop and National Clinical Trials Front Door proposal
- TGA consultation regarding the adoption of EMA Scientific Guidelines for Registry Based Studies

RVA political advocacy update:

- Fit-for-purpose assessment processes for rare disease therapies
- Rare disease workforce
- Rare disease research
- National Disability Insurance Agency (NDIA) response to rare disease candidates
- Newborn bloodspot screening
- Repurposing of medicines on the Pharmaceutical Benefits Scheme (PBS) for common conditions
- Medical Services Advisory Committee (MSAC) application process

RVA Round Table of Companies

Alexion Pharmaceuticals Australasia
Amicus Therapeutics
Biogen Idec Australia Pty Ltd
BioMarin Pharmaceutical Australia Pty Ltd
CSL Behring Ltd
Ipsen Pty Ltd
Kyowa Kirin Australia Pty Ltd
Menarini Australia Pty Ltd
Pfizer Australia Pty Ltd
PTC Therapeutics Australia Pty Ltd
Recordati Rare Diseases Group
Roche Products Pty Limited
Sanofi Genzyme Australia
Swedish Orphan Biovitrim Pty Ltd (SOBI)
Takeda Australia Pty Ltd
UCB Australia Pty Ltd
Vertex Pharmaceuticals Australia Pty Ltd
Vifor Phama Pty Ltd

OUR WORK 2021–2022

RARE DISEASE ADVOCACY AND POLICY DEVELOPMENT

Influencing policy and systemic advocacy continue to be central to RVA's work. RVA formally collaborates with and helps to strengthen our 97 RVA Partner organisations. We also work effectively with all rare disease stakeholders, including people living with a rare disease, clinicians, researchers, governments, key peak bodies and industry.

RVA's political advocacy is relationship based. These bipartisan relationships have continued to be developed, fostered and protected during the 2021/2022 financial year. RVA's role as a credible and informed peak body continued to grow during this period. When engaging with RVA, politicians frequently state the importance of being able to easily engage with the rare disease sector via a credible and informed national peak body such as RVA with a strong understanding of policy and the sector.

In 2018 and 2019, RVA led the collaborative development of the Australian Government's Action Plan, which was launched by the Minister for Health with strong bipartisan support in February 2020. The Action Plan is the first nationally coordinated effort to address rare diseases in Australia. Since its launch, RVA has been leading the Action Plan's collaborative implementation. The Action Plan provides a framework and policy direction from which the entire rare disease sector can advocate on issues. As such, it informs RVA's advocacy and is powerful for systemic advocacy. Developed by the rare disease sector, for the rare disease sector, the Action Plan has authenticity, credibility and consensus. As the Action Plan is a Government policy framework, it encourages alignment with subsequent Government policy.

Newborn Bloodspot Screening

Ahead of the Federal Election in May 2022, RVA was excited to welcome the Australian Labor Party's (ALP) commitment, if elected, to invest in consistent and equitable newborn bloodspot screening (NBS). The ALP forming a majority government presented the rare disease sector with a timely opportunity to revisit the challenges and gaps with NBS that RVA has been raising with Commonwealth and State Governments over the last two years. On 16 June 2022, RVA hosted [*The Changing Face of Newborn Bloodspot Screening – A Rare Disease Sector Forum*](#). The forum brought together RVA Partner organisations, NBS clinical and research experts, NBS policy experts and industry to discuss the importance of a consistent and equitable program, the role of national leadership, how the NBS program is changing and what these changes mean for the rare disease sector. RVA welcomed the Australian Government's launch of the Public Consultation Paper on the Newborn Bloodspot Screening Expansion (the Consultation Paper). We are encouraged by the Government's consultation with stakeholders and will be responding to the Consultation Paper as the national peak body for Australians living with a rare disease. RVA looks forward to continuing this work with all Governments and other key stakeholders.

National Medicines Policy Review

The National Medicines Policy (NMP) Review was commissioned by the Australian Government in recognition of the substantial changes to the health landscape since the policy was published in 2000. An Expert Advisory Committee was established to lead the Review of the NMP for the Department of Health. Finalisation of the NMP Review was extended until after the Federal Election in May 2022. RVA has contributed to the NMP Review to date in several ways, including:

- [Lodging a Submission](#) to the initial consultation in October 2021
- Participating in a one-on-one interview as the national peak body with the NMP Review's Expert Advisory Committee
- [Submitting a response](#) to the draft NMP in March 2022
- [Lodging a Submission](#) to the final draft NMP in September 2022

National Disability Insurance Scheme

During the 2021/22 financial year, progress was made on several key systemic issues. RVA continued its advocacy to the National Disability Insurance Agency (NDIA) and the office of the Minister for the National Disability Insurance Scheme (NDIS). The NDIA Codesign and Engagement team has committed to regular meetings with RVA as the national peak body for Australians living with a rare disease. The Codesign and Engagement team will work with RVA and link us with other policy level decision makers at the NDIA. RVA will act as a conduit between the NDIA and the rare disease sector and will continue to highlight priorities and challenges for Australians living with a rare disease accessing the NDIS. In doing so, RVA will continue liaising with our RVA Partner organisations in addition to aligning with the Action Plan and the report, [Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases](#).

National Rare Disease Workforce Strategy

In February 2022, RVA launched the [Rare Metabolic Disease Workforce White Paper: Towards a Strengthened Rare Disease Workforce for Australia](#) (the White Paper). This pilot project, focusing on the workforce challenges of the rare metabolic disease workforce, is an initial step to progress the development of a national rare disease workforce strategy. It specifically addresses Priority 3.1 of the Action Plan, 'Develop a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics'. Since the launch of the White Paper, RVA has engaged with several rare disease group leaders, members of government, state health departments and professional medical bodies in one-on-one meetings and forums to discuss the best way forward. These discussions have informed the development of the *National Strategy for Australia's Rare Metabolic Disease Workforce*.

Rare Disease Registry Audit

The Rare Disease Registry Audit, led by Monash University registry experts, Professor Susannah Ahern and Dr Rasa Ruseckaite, progressed the work outlined in the Action Plan (see Implementation 3.1.4.1). RVA oversaw this critical work in recognition of the importance of rare disease registries (RDRs), which is also acknowledged in the Action Plan. The objectives of this project were to highlight the 'current state of play' of RDRs in Australia. Other areas addressed through consultation with existing Australian RDRs included barriers and enablers to setting up sustainable RDRs, perceptions about the future potential for RDRs to improve clinical outcomes and ideas for the way forward. Publications based on the [RDR audit research findings](#) are in development and will be published in 2023.

Health Technology Assessment Policy and Methods Review

In September 2021, the Australian Government agreed to support an independent review of Health Technology Assessment (HTA) current policy and methods used by the Pharmaceutical Benefits Advisory Committee (PBAC) to assess new medicines for listing on the Pharmaceutical Benefits Scheme (PBS), contemporary research and relevant methodologies and purchasing practices used by comparable international jurisdictions. RVA looks forward to participating in the HTA Policy and Methods Review as the national peak body for Australians living with a rare disease.

MENTORSHIP & EDUCATION PROGRAM

During the 2021/22 financial year, RVA built on the success of its Mentorship & Education Program, which focused on implementation of the Action Plan and building the advocacy capacity of the rare disease sector. (Action 2.1.4, 'Develop the capacity of rare disease organisations to represent and advocate for people living with a rare disease and their families'.) The Mentorship & Education Program also includes education to the broader rare disease sector and has become core to RVA, leveraging from the Action Plan.

To 30 June 2022, RVA provided a total of 166 instances of customised mentorship and strategy support to 63 RVA Partner organisations and other stakeholders. Mentoring has covered a broad range of areas, including clinical trials and the role of rare disease organisations, policy and systemic advocacy, health technology assessment (HTA), awareness and education strategies, developing a Scientific and Medical Advisory Committee, Medicines Australia's Code of Conduct Guidelines, working with researchers, applying for funding, input into submissions, the Medicare Benefits Schedule (MBS) Review and political advocacy.

This work has helped to build the advocacy capacity of rare disease groups to effectively respond to their specific advocacy needs. Support is available to all RVA Partner organisations as well as emerging rare disease organisations and provides mentorship and strategy regarding community and stakeholder engagement, policy and government relations. This work also includes a formal program consisting of social media promotion and facilitated peer-to-peer networking with rare disease organisation leaders through RVA's closed Facebook group for RVA Partner organisations.

A significant focus of the Mentorship & Education Program is providing tailored support for HTA, research and clinical trials and rare disease organisation governance. Additionally, [RVA's Online Education Portal](#) was launched in December 2021 with the intent to provide free and restricted resources available to stakeholders on a 24/7 basis.

Customised Education Sessions

RVA has provided customised education sessions on request to several RVA Partner organisations throughout 2021/22. These sessions were designed to meet the specific needs of the relevant rare disease community and build capacity across a range of areas aligned with the pillars of the Action Plan.

Topics covered in 2021/22:

- Developing An Advocacy Strategy
- Reimbursement Processes in Australia
- The Action Plan
- Tips for Making a Consumer Comment to the Pharmaceutical Benefits Advisory Committee (PBAC)
- Rare Disease Workforce Advocacy
- National Newborn Bloodspot Screening Program

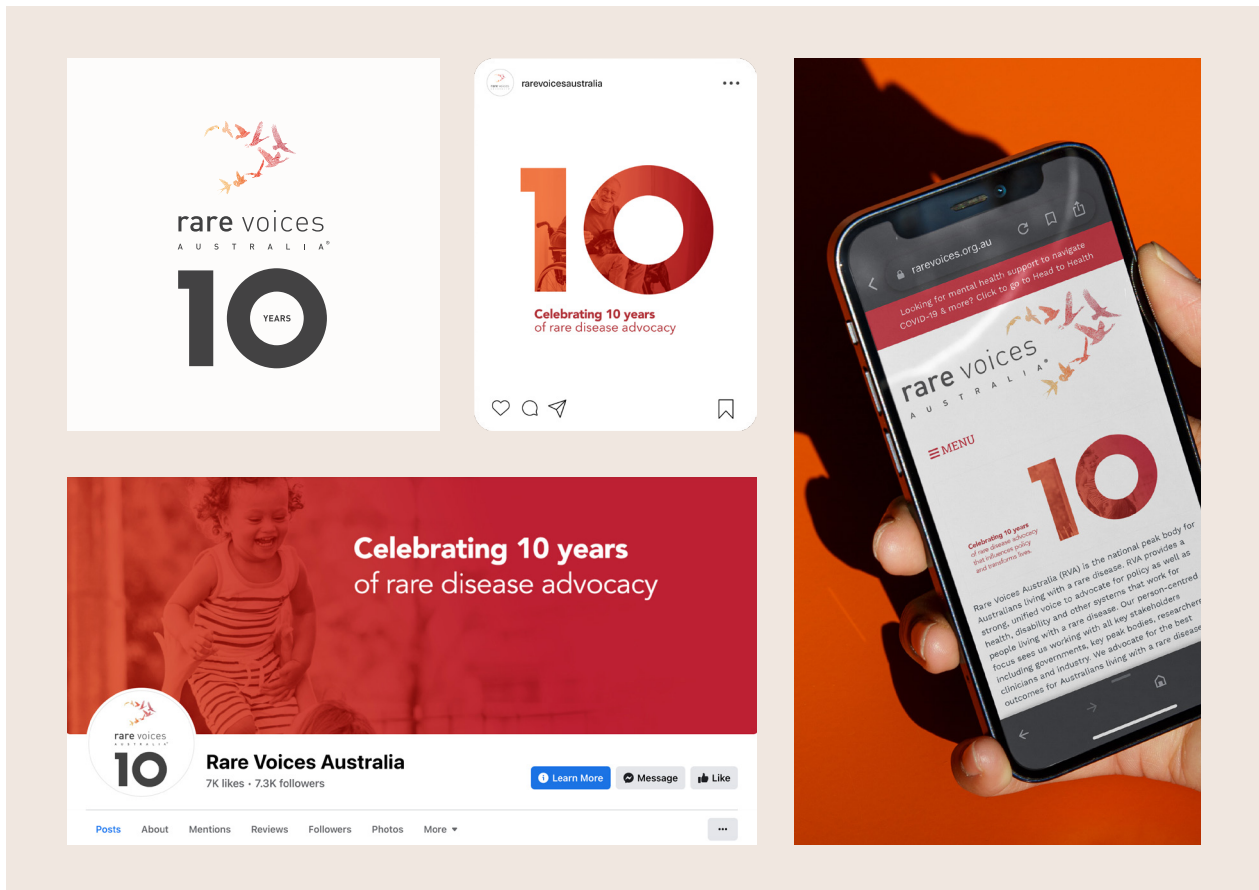
RVA Partner Organisations

The number of RVA Partner organisations continues to grow. We have partnered with 97 rare disease organisations during the 2021/22 financial year. RVA has provided support and guidance to several emerging rare disease organisations. RVA Partners have actively informed the development of several key policy submissions and have collaborated with RVA on important advocacy priorities, including drug repurposing and newborn bloodspot screening. Like the Mentorship & Education Program, this work continues to build the capacity of rare disease organisations, as outlined in the Action Plan (Action 2.1.4).

EVENTS

10 Year Anniversary

In 2022, RVA celebrated 10 years of rare disease advocacy that influences policy and transforms lives. Thank you to everyone who contributed to RVA's work over the last decade. From former RVA Board Directors and Scientific and Medical Advisory Committee members to RVA Partners, former staff and all stakeholders, we acknowledge your ongoing support. While much work still needs to be done to achieve the best outcomes for Australians living with a rare disease, we are incredibly proud of RVA's work and achievements to date.



Ambassador Program

RVA's 10th Anniversary Ambassador Program (the Ambassador Program) was launched in 2022 to mark the organisation's 10th year. The overarching theme of the Ambassador Program is, Illuminating People Living with a Rare Disease. RVA was thrilled to welcome our first official RVA Ambassadors and thank them for being involved in this new initiative. Each ambassador brings their own unique lived experience of rare disease.

RVA Ambassadors:

Katie Alexander
Andrew Bannister
Lachy Beckett
Ebony Callaghan
Nathan Charles
Tim Fulton
Tammie Rees
Beck Webber
Renae Wood



Annual Parliamentary Event

In December 2021, RVA made the strategic decision to postpone our annual Parliamentary Event until after the Federal election in May 2022 due to the lack of sitting days and the ongoing impact of COVID-19. RVA typically organises a Parliamentary Event for Rare Disease Day (the last day of February annually). This decision enabled RVA to raise awareness of rare diseases among new Parliamentarians post-election and gave us the opportunity to reiterate the importance of rare disease policy. Most importantly, we highlighted the experiences of the estimated two million Australians living with a rare disease to a new Minister for Health and Aged Care.

Virtual National Rare Disease Summit

RVA's first-ever Virtual National Rare Disease Summit (the Virtual Summit) took place on 12 November 2021. The Virtual Summit brought together key stakeholders in the rare disease sector, including people living with a rare disease, governments, key peak bodies, researchers, clinicians and industry. The theme was, *A person-centred approach to implementing the National Strategic Action Plan for Rare Diseases*. Person-centred is one of the Action Plan's foundation principles and shaped the Virtual Summit. People living with a rare disease opened the event and shared their voice throughout.

RVA thanks Greg Hunt (the former Minister for Health and Aged Care), for opening the Virtual Summit, as well as the Hon Mark Butler MP (Shadow Minister for Health and Ageing in the 46th Federal Parliament) who delivered speeches. We also thank Dr Mike Freeland MP (Co-Chair, Parliamentary Friends of Australians Living with Rare Diseases; Deputy Chair, Standing Committee on Health, Aged Care and Sport in the 46th Federal Parliament) and Trent Zimmerman (Co-Chair, Parliamentary Friends of Australians Living with Rare Diseases; Chair, Standing Committee on Health, Aged Care and Sport in the 46th Federal Parliament) who joined the *Emerging Therapies and Their Potential to Revolutionise Care for People Living with a Rare Disease* panel discussion and answered questions from attendees.

The Virtual Summit featured a diverse range of speakers to reflect various stakeholder expertise. Over 140 people nationwide registered to attend the Virtual Summit with each session stimulating much discussion that further informed implementation of the Action Plan.

Rare Disease Day

Rare Disease Day is marked on the last day of February annually. Facilitated by EURORDIS – Rare Diseases Europe, Rare Disease Day is the globally-coordinated movement for rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. RVA is the national alliance representing Australia for Rare Disease Day. We work with the other participating national alliances on annual campaign planning and have been appointed to the Rare Disease Day Steering Committee, which takes a longer-term view of the campaign.

RVA ONLINE EDUCATION PORTAL

RVA's Online Education Portal was launched in December 2021 to complement the workshops, webinars and customised mentoring support provided to RVA Partner organisations. Available 24/7, the site contains a number of free and restricted resources that will be added to over time.

Courses:

- RVA Education: The Changing Face of Newborn Bloodspot Screening – A Rare Disease Sector Forum
- RVA Education: How to Illuminate Landmarks to Celebrate Awareness Days
- RVA Education: Australia's Rare Disease Landscape
- RVA Education: Amplifying Advocacy Using the National Strategic Action Plan for Rare Diseases

RAREST PROJECT

The Rare Disease Awareness, Education, Support and Training (RArEST) Project is a collaboration between RVA, the University of New South Wales, the University of Western Australia and Macquarie University. The RArEST Project was awarded \$1.9 million in funding from the Australian Government and will develop and deliver rare disease awareness resources, education, support and training.

The RArEST Project comprises three streams:

Stream 1: Support for individuals, including mental health and wellbeing resources

Stream 2: Health professional education, support and training

Stream 3: Adopting a co-design approach to awareness and education for systemic improvement in rare disease care and support

This work is being guided by a Stakeholder Reference Group, which was appointed in 2022 and consists of people living with a rare disease representing the breadth of rare diseases and communities.

The RArEST Project is a key initiative in progressing implementation of the Action Plan as it addresses several of the key priorities, actions and implementation steps identified across the Awareness and Education and Care and Support Pillars. Initiatives include [Rare Disease Project ECHO®](#) (a community of clinical learning practice to increase awareness of rare diseases and provide health professionals with multidisciplinary peer learning and evidence-based, clinically informed expert support to deliver contemporary best practice health care nationally), Rare Disease 101 Australia (e-learning modules for health professionals devised in collaboration with Medics4RareDiseases) and Mental Health First Aid Training for RVA Partner organisations.

RARE PORTAL

The Rare Awareness Rare Education (RARE Portal) is one of the key deliverables of the Action Plan. RVA continued leading the collaborative development of the RARE Portal for rare diseases during the 2021/22 financial year. The site will contain current, reliable and straightforward information and resources for all rare disease stakeholders. The RARE Portal's key points of difference are that it's customised for the Australian context, and its development is informed by a robust, extensive multi-stakeholder consultation process, led by RVA. Development of the RARE Portal has been funded by the Australian Government. The RARE Portal seeks to highlight the gaps and strengths across the rare disease sector to guide the way forward for evidence-based policy and strong Australian-based research and innovation into all rare diseases. RVA thanks everyone who has contributed to the development of the RARE Portal to date, and we look forward to continuing this important work with the sector. We especially thank RVA Partner organisation leaders who have shown so much enthusiasm about the RARE Portal and a genuine willingness to work with RVA towards the best outcomes for Australians living with a rare disease.

RVA RESEARCH AND PROJECT PARTNERSHIPS

Across the 2021/22 financial year, the number and scope of RVA research and project partnerships have grown exponentially. RVA has become a highly sought-after partner on grant applications and pilot projects. The rare disease sector is increasingly recognising and valuing RVA as a credible source of rare disease policy and health systems information, and a vital link to a growing number of rare disease organisations. RVA has continued to refine our [Guidelines for Research Partnerships](#) to ensure we have an active and meaningful role in research partnerships that is appropriately recognised. Also, in response to new requests from the sector, we now have a process for engaging in [non-academic project partnerships](#).

RVA has partnered with researchers in a variety of ways, including reviewing and contributing to journal articles; consulting on grant applications; agreeing to participate in advisory and steering committees; providing letters of support; dissemination of surveys and interview opportunities for rare disease researchers both in Australia and abroad; and other in-kind contributions.

In June 2022, Nicole Millis published a peer-reviewed article in the Journal of Inherited Metabolic Diseases, entitled *View from the inside: Patient advocacy in guiding policy development for metabolic disorders*. This opportunity followed Nicole's invitation to speak at the annual meeting for the Human Genetics Society of Australasia in late 2021.

Reference: Millis N. *View from the inside: Patient advocacy in guiding policy development for metabolic disorders*. *J. Inherit. Metab. Dis.* 2022;45(5):866–71.

Available from: <https://doi.org/10.1002/jimd.12532>

Active/funded RVA research/project partnerships as of 30 June 2022

Research Project Name	Key Investigators	Institution/Affiliation
Pathways to Benefit for Indigenous Australians in Genomic Medicine	Prof Alex Brown	South Australian Health and Medical Research Institute
PERSYST: Pathogenic Evaluation of Recalcitrant Variants by SYStematic Transactivation	Prof Jozef Gecs, Dr Lachlan Jolly	University of Adelaide
Assessing benefits of extended genomic newborn screening trialled on 100,000 infants from Generation Victoria	A/Prof David Godler	Murdoch Children's Research Institute (MCRI)
gEnomics4newborns: Integrating Ethics and Equity with Effectiveness and Economics for genomic newborn screening	A/Prof Sarah Norris, Prof Ainsley Newson, Jo Watson, Prof Michelle Farrar	University of Sydney (USYD)
Ethical governance for clinical and genomic data	Prof Ainsley Newson, Prof Alex Brown, Azure Hermes	USYD
Newborn screening model using integrated multi-omics in South Australia (NewbornsInSA)	A/Prof Karin Kassahn, Dr Drago Bratkovic, Prof Hamish Scott, A/Prof Chris Barnett, Dr Enzo Ranieri	South Australia Pathology
Rare Care Centre*	Clin/Prof Gareth Baynam, Sue Baker, Paula Fievez	Perth Children's Hospital
A Phase 2A/2B placebo-controlled randomised clinical trial to test the ability of triheptanoin to protect primary airway epithelial cells obtained from patients with ataxia-telangiectasia against death induced by glucose deprivation	Prof David Coman	The University of Queensland
KidGen Clinics, Education, Data and Research (KidGen CEDAR): Improving Care and Outcomes of Australians with Genetic Kidney Disease	Prof Andrew Mallett, Lauren Hill	MCRI
Australian Undiagnosed Disease Network	Dr Tiong Tan, Prof John Christodoulou	MCRI

Research Project Name	Key Investigators	Institution/Affiliation
Australian Functional Genomics Network	Dr Tessa Mattiske	MCRI
Neurotherapeutics BRAIN AID – Benefits, Risks and Alternatives: Information to Augment Informed Decision Making	Prof Michelle Farrar, Dr (Elizabeth) Emma Palmer	University of NSW (UNSW) and Sydney Children’s Hospital Network (SCHN)
Australian Clinical Trials Alliance Working Group for Early Trial Approval Models	Prof Nic Zeps, Dr Fiona Nemeh, Michael Mihatsch	Australia Clinical Trials Alliance (ACTA)
HeSANDA Initiative	Dr Fiona Nemeh	ACTA/Australian Research Data Commons (ARDC)/Health Studies Australian National Data Asset (HeSANDA)
Rare Awareness, Education, Support and Training (RAREST) Project	Dr (Elizabeth) Emma Palmer, Prof Adam Jaffe, Prof Michelle Farrar, Prof Gareth Baynam, Prof Yvonne Zurynski, Nicole Millis, Louise Healy	RVA, UNSW, University of Western Australia, Macquarie University
Missed opportunities in clinical practice: Tools to enhance healthcare providers’ awareness and diagnosis of rare diseases in Australia	Dr Jane Desborough, Prof Matthew Cook, Tergel Namsrai, A/Prof Katrina Anderson	Australian National University
National Survey on Community Inclusion	Kayleen Lenzo, Sylvana Mahmic	Plumtree Children’s Services
Rare Barometer – Global Survey on Diagnosis	Hlawulani Mkhabela, Andrea Osvoll, Sandra Coubier	EURORDIS/Rare Diseases International
The insurance and genetics moratorium (A-GLIMMER) study	Jane Tiller, A/Prof Paul Lacaze	Monash University

*Project partnerships

For confidentiality, RVA partnerships that are still under review by granting bodies have not been included in this table.

COMMUNICATIONS

RVA Website

RVA's website (www.rarevoices.org.au) continues to gain traction as a central source of information for Australians living with a rare disease and stakeholders in the rare disease sector. The site will continue to be refined to continue enhancing the user experience, while retaining a person-centred focus and serving all key stakeholders in the rare disease sector. In the 2021/22 financial year, RVA's website was visited by 30,000 users who engaged in over 41,000 sessions. RVA also manages the Rare Disease Day Australia website. In the 2021/22 financial year, the Rare Disease Day Australia website was visited by 3,800 users who engaged in over 4,800 sessions.



Social Media

Social media continues to be another important touchpoint. RVA's Facebook, Twitter, LinkedIn, Instagram and YouTube channels continued to grow steadily and organically in the 2021/22 financial year. Below is a follower breakdown according to each platform as of 30 June 2022:

- **Facebook:** 7,281 followers
- **Twitter:** 2,814 followers
- **Instagram:** 1,248 followers
- **LinkedIn:** 805 followers

RVA's YouTube channel houses 50 videos.

RVA also moderates a closed Facebook group where RVA Partner organisation leaders are given the opportunity to connect, engage and share leadership/management strategies that are relevant to the sector. Additionally, the Rare Disease Day Australia Facebook page had 5,095 followers as of 30 June 2022.



Facebook
7,281 followers



Twitter
2,814 followers



Instagram
1,248 followers



LinkedIn
805 followers



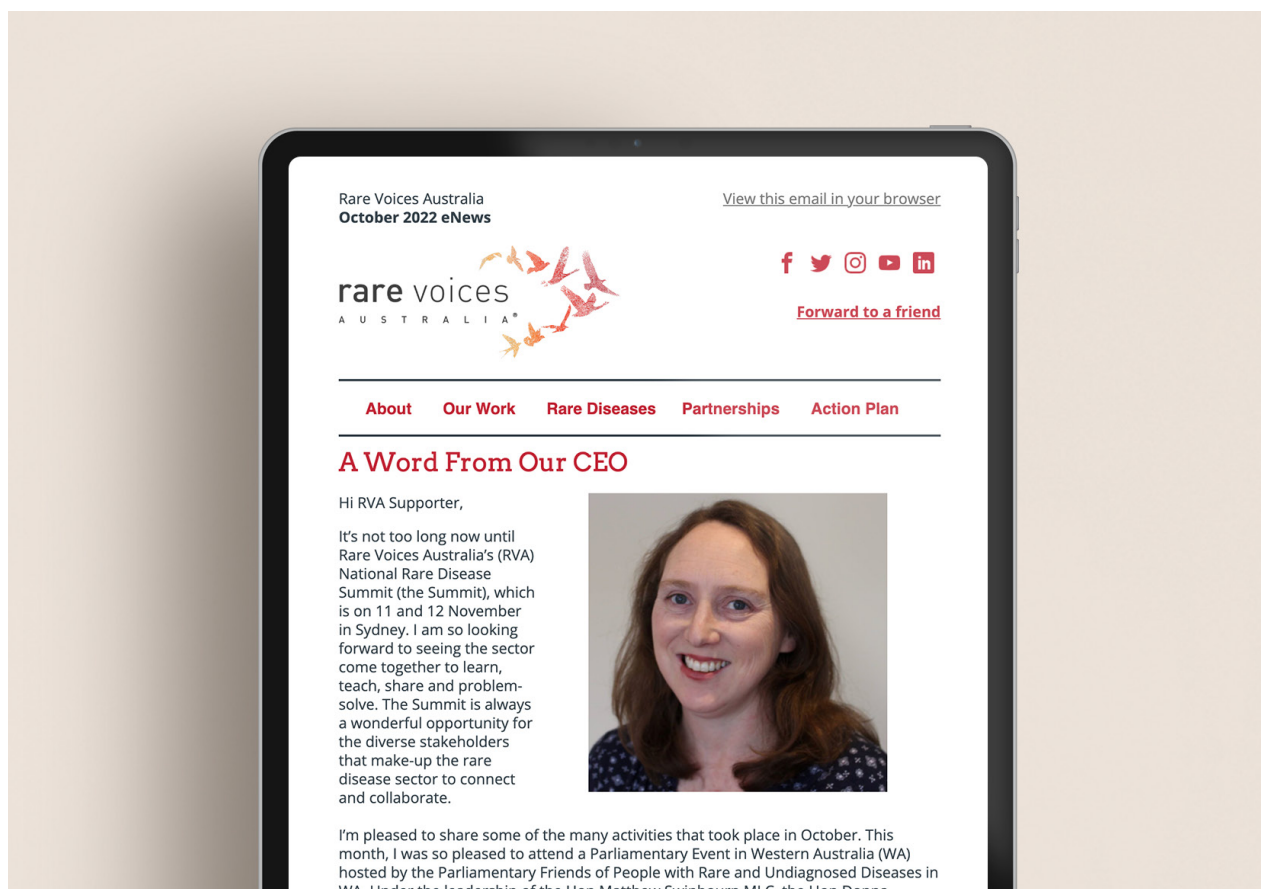
YouTube
50 videos

Monthly eNewsletter

RVA's monthly eNewsletter is distributed to a steadily growing database consisting of all key rare disease stakeholders. Each edition features:

- A personal story written by an individual living with a rare disease
- An editorial written by RVA's Chief Executive Officer highlighting RVA's work and relevant updates
- Articles with links to Action Plan implementation
- A snapshot of what RVA has been working on during the month
- News from RVA Partner organisations
- Other information relevant to rare diseases both in Australia and globally

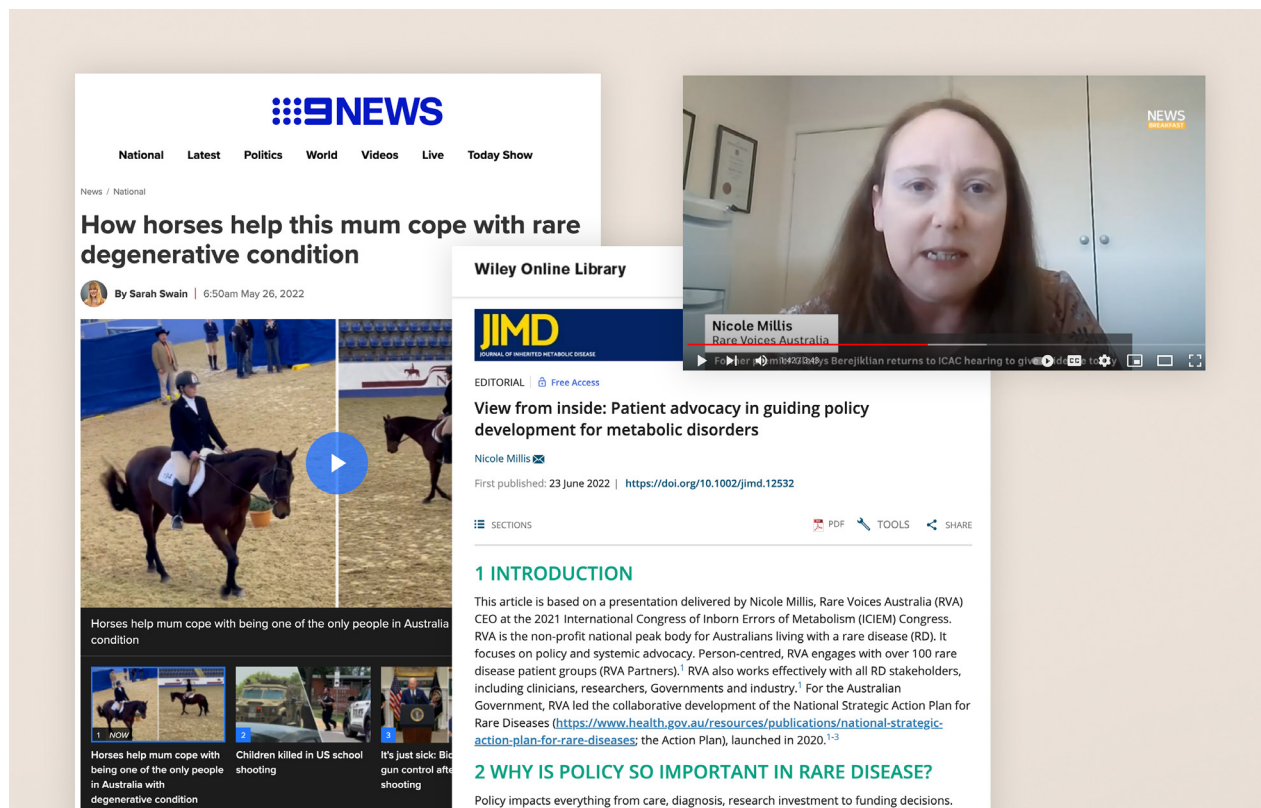
The monthly eNewsletter is one of RVA's key communication tools and an archive is published on RVA's website. Relevant content from the eNewsletter is cross promoted via RVA's social media channels.



Media

As RVA's profile continued to build as the national peak body for Australians living with a rare disease over the 2021/22 financial year, media increasingly sought RVA's expertise. RVA continued to strengthen its existing relationships with journalists and media covering relevant beats in health, politics, disability and other areas. Media coverage is typically featured on RVA's website and is cross promoted on our social media channels. In the 2021/22 financial year, RVA was featured in the following media outlets:

- ABC (online)
- ABC News Breakfast (TV)
- Journal of Inherited Metabolic Disease (online)
- MedNews (online)
- Nine News (online)



COMMITTEE/ADVISORY GROUPS PARTICIPATION

RVA have provided input on the following advisory panels/consultations in 2021/22:

- Australian Undiagnosed Disease Network (UDN-Aus) – Murdoch Children’s Research Institute
- GeneEQUAL – NSW Department of Health
- Gene Therapy Advisory Committee (NSW)
- Cell and Gene Therapy Whitepaper Scorecard – EvoHealth
- University of New South Wales RNA Institute End User Advisory Group
- Clinical Trials Roundtable – Australian Clinical Trials Alliance
- National One Stop and National Clinical Trials Front Door Project
- Partnered on 9 Medical Research Future Fund (MRFF)-Genomics Health Futures Mission grant applications
- Rare Diseases International Regional Round Table
- National Congenital Anomalies Advisory Group
- Rare Disease Day Outreach Committee and Steering Committee
- United Nations Resolution (video presentation)
- Rare Diseases Now (RDNow)
- University of Technology Sydney Genetic Counselling Industry Advisory Board
- International Rare Diseases Research Consortium (IRDiRC) Joint Consortium Assembly & Scientific Committee
- International Rare Diseases Research Consortium Patient Advocates Constituent Committee (IRDiRC PACC)
- Victorian Newborn Bloodspot Screening Committee
- Queensland Genomics Impact Assessment Focus Group
- Queensland Genomics Community Advisory Group
- National Congenital Anomaly Advisory (NCAAG) Group
- World Health Organization (WHO) Collaborative Global Network 4 Rare Disease Panel of Experts
- Health Direct Australia National Information Partner

Other related appointments of RVA’s Chief Executive Officer:

- Consumer Nominee on the Life Saving Drugs Program Expert Panel

RVA SPEAKING ENGAGEMENTS

Date	Event
July 2021	Cell and Gene Therapies: Rising to the Challenge Report
August 2021	Human Genetics Society of Australasia (HGSA) Conference
September 2021	Research Australia's Philanthropy Round Table
September 2021	BioSymposium: Advancements in Precision Medicine
September 2021	Australian Sickle Cell Advocacy's Inaugural Sickle Cell Disease Conference
November 2021	2021 International Congress of Inborn Errors of Metabolism (ICIM) Conference
January 2022	Idiopathic Thrombocytopenia Purpura (ITP) Australia Virtual Patient Conference 2022
February 2022	Global Rare Disease Day – World Expo in Dubai
June 2022	Myasthenia Gravis Association of Queensland (MGAQ) Awareness Meeting
June 2022	Consumers Health Forum of Australia Consumer Link Webinar
June 2022	Genetic Alliance Australia Leaders Meeting
June 2022	2022 Niemann-Pick Disease Type C (NPC) Conference – Australian NPC Disease Foundation

POLICY

- *Rare Metabolic Disease Workforce White Paper: Towards a Strengthened Rare Disease Workforce for Australia*

Submissions

- Australian Commission on Safety and Quality in Health Care's National One Stop Shop and the National Clinical Trials Front Door Proposal
- Guiding Principles: Ensuring Culturally Safe Health Genomics in Partnership with Aboriginal and Torres Strait Islander Peoples
- Interim Submission: Joint Standing Committee on the National Disability Insurance Scheme (NDIS) — Current Scheme Implementation and Forecasting for the NDIS
- National Medicines Policy Review
- Joint Standing Committee on the National Disability Insurance Scheme Parliamentary Inquiry into Independent Assessments
- Therapeutic Goods Administration Consultation: Repurposing of prescription medicines
- National Disability Insurance Agency public consultation: access and eligibility policy with independent assessments
- PBAC discount rate consultation
- TGA consultation regarding adoption of EMA Scientific Guideline for Registry Based Studies

GOVERNMENT GRANTS

There has been an increase in government grants relating to rare diseases in response to the Action Plan. RVA has worked with several strategic partners and consortia including the University of New South Wales, Macquarie University, University of Western Australia, Commonwealth Department of Health, Western Australia and WA Department of Health, to be awarded several government grants. These grants will accelerate the implementation of several key items in the Action Plan over the next three years.

Action 1.1.1: Develop and conduct national awareness and education activities for rare diseases.

Priority 1.2: Ensure Australians living with a rare disease have access to information and education that enables them to be active participants in their rare disease journey.

Action 1.3.2: Equip and encourage frontline health professionals to consider, investigate and refer for a potential rare disease diagnosis.

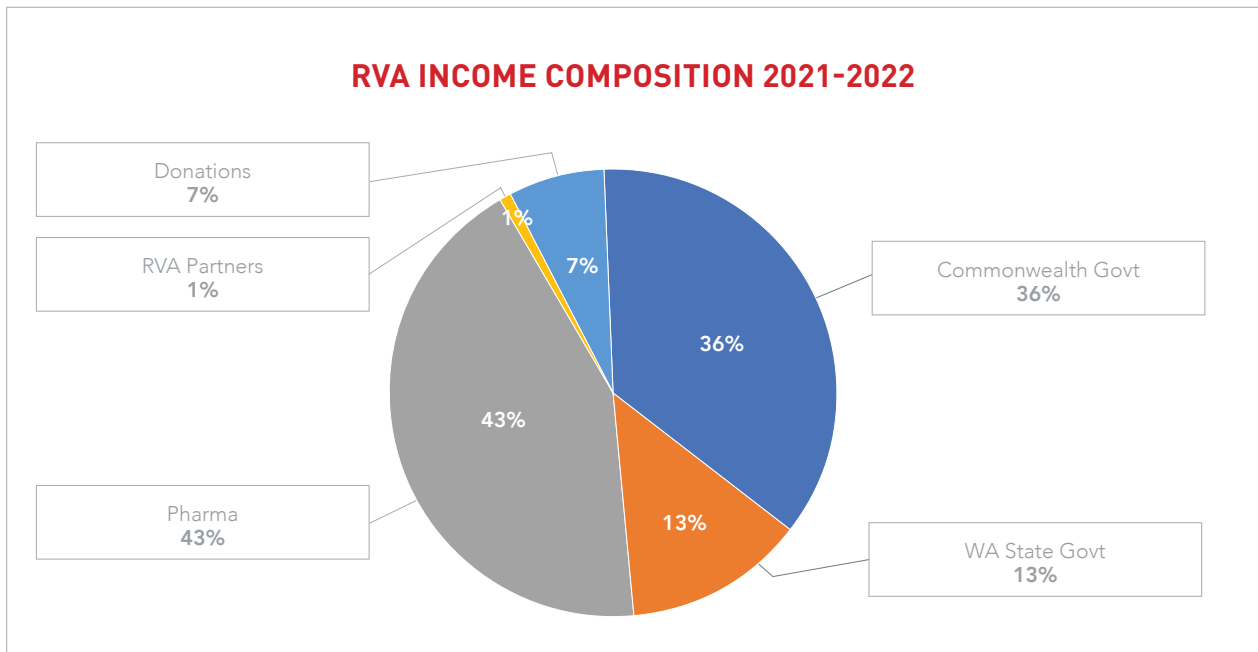
Action 2.1.2: Build a broad range of care and support services that are responsive to the changing needs of people living with a rare disease and their families.

Action 2.1.5: Embed the voice of people living with a rare disease and their families and carers throughout structures and systems that impact rare diseases.

FINANCIALS

FUNDING OF RVA

RVA actively seeks funding by direct grants and partnerships with state governments, the federal government, philanthropic organisations and from the pharmaceutical industry. RVA also receives funds from donations from the public and RVA Partner fees.



RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Annual Report
For the year ended 30 June 2022



M G ARTHUR & ASSOCIATES

Accounting • Taxation • Business Services

M G Arthur & Associates
P.O Box 8015
Norwest NSW 2153

Phone: 02 9639 4420 Fax: 02 9639 4470

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303

Annual Report for the year ended 30 June 2022

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RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Director's Report

Your directors present their report on the company for the financial year ended 30 June 2022.

Directors

The names of the directors in office at any time during, or since the end of, the year is:

ANDREW CARTER (appointed on 06 April 2022)
CAROL WICKING
ERIC MORAND
JOANNA BETTERIDGE
KANE BLACKMAN
KATE HENDERSON (appointed on 06 April 2022)
ROBERT HENDRIKS
RAYMOND SAICH (resigned on 22 February 2022)
TERESA PILBEAM (appointed on 13 April 2022)
VISWANATHAN NARAYANASWAMY

The Directors have been in office since the start of the financial year to the date of this report unless otherwise stated.

Operating Result

The profit for the company for the financial year ended 30 June 2022 amounted to \$128,707
(30 June 2021 - \$68,187)

Principal Activities

The principal activities of the company during the course of the year was affirming its position as the national peak body advocating for Australians living with a rare disease.
No significant change in the nature of these activities occurred during the year.

Significant Changes in the State of Affairs

No significant changes in the company's state of affairs occurred during the financial year.

After Balance Date Events

No matters or circumstances have arisen since the end of the financial year which significantly affected or may significantly affect the operations of the company, the results of those operations, or the state of affairs of the company in subsequent financial years.

Future Developments

The company expects to maintain the present status and level of operations and hence there are no likely extraordinary developments in the operations in future financial years.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Director's Report

Environmental Issues

The company's operations are not regulated by any significant environmental regulation under a law of the Commonwealth or of a State or Territory.

Dividends

No dividends were declared or paid since the start of the financial year. No recommendation for payment of dividends has been made.

Share Options

No options over issued shares or interests in the company were granted during or since the end of the financial year and there were no options outstanding at the date of this report.

Directors Benefits

No director has received or has become entitled to receive, during or since the financial year, a benefit because of a contract made by the company or related body corporate with a director, a firm which a director is a member or an entity in which a director has a substantial financial interest.

Indemnifying Officer or Auditor

No indemnities have been given or agreed to be given or insurance premiums paid or agreed to be paid, during or since the end of the financial year, to any person who is or has been an officer or auditor of the company.

Proceedings on Behalf of Company

No person has applied for leave of Court to bring proceedings on behalf of the company or intervene in any proceedings to which the company is a party for the purpose of taking responsibility on behalf of the company for all or any part of those proceedings. The company was not a party to any such proceedings during the year.

Auditors Independence Declaration

A copy of the auditor's independence declaration as required under section 307C of the Corporations Act 2001 has been included.

Signed in accordance with a resolution of the director:



JOANNA BETTERIDGE

Director

Dated: 14 December 2022

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Statement of Comprehensive Income
For the year ended 30 June 2022

	Note	2022 \$	2021 \$
Revenue	2	1,056,464	456,215
Other revenue	2	89,351	54,129
Depreciation		(3,584)	(1,032)
Employee benefit expenses		(570,504)	(306,775)
Other expenses		(443,020)	(134,350)
Profit before income tax		128,707	68,187
Income tax expense		-	-
Profit for the year after income tax		128,707	68,187
Other Comprehensive Income for the year		-	-
Total Comprehensive Income for the year		128,707	68,187

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Statement of Financial Position
As at 30 June 2022

	Note	2022 \$	2021 \$
Assets			
Current Assets			
Cash and cash equivalents	3	1,841,616	1,863,938
Trade and other receivables	4	44,412	797
Total Current Assets		1,886,028	1,864,735
Non-Current Assets			
Property, plant and equipment	5	8,428	2,925
Total Non-Current Assets		8,428	2,925
Total Assets		1,894,456	1,867,660
Liabilities			
Current Liabilities			
Trade and other payables	6	1,075,157	1,223,032
Provisions	7	80,242	34,277
Total Current Liabilities		1,155,399	1,257,309
Total Liabilities		1,155,399	1,257,309
Net Assets		739,058	610,351
Equity			
Retained profits		739,058	610,351
Total Equity		739,058	610,351

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Statement of Change in Equity
For the year ended 30 June 2022

	Other Reserves	Retained Earnings	Total
Balance at 1 July 2020	-	542,164	542,164
Comprehensive income			
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	68,187	68,187
Balance at 30 June 2021	-	610,351	610,351
Comprehensive income			
Profit attributable to the members	-	128,707	128,707
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	128,707	128,707
Balance at 30 June 2022	-	739,058	739,058

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Statement of Cash Flows
For the year ended 30 June 2022

	2022	2021
	\$	\$
Cash Flow From Operating Activities		
Receipts from customers	1,187,106	1,217,861
Payments to Suppliers and employees	(1,202,273)	6,918
Interest received	1,931	4,903
Cash Flow Boost	-	7,392
Net cash provided by (used in) operating activities (note 8)	<u>(13,236)</u>	<u>1,237,074</u>
Cash Flow From Investing Activities		
Payment for:		
Payments for property, plant and equipment	(9,086)	(3,959)
Net cash provided by (used in) investing activities	<u>(9,086)</u>	<u>(3,959)</u>
Cash Flow From Financing Activities		
Repayment of borrowings	-	-
Net cash provided by (used in) financing activities	<u>-</u>	<u>-</u>
Net increase (decrease) in cash held	(22,322)	1,233,115
Cash at the beginning of the year	1,863,938	630,823
Cash at the end of the year (note 3)	<u>1,841,615</u>	<u>1,863,938</u>

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements
For the year ended 30 June 2022

The financial report covers Rare Voices Australia Limited as an individual entity, incorporated and domiciled in Australia. Rare Voices Australia Limited is a company limited by guarantee.

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES

Basis of Preparation

These general purpose financial statements have been prepared in accordance with Australian Accounting Standards and Interpretations issued by the Australian Accounting Standards Board ('AASB') and the Corporations Act 2001. The company is a not for profit entity for financial reporting purposes under Australian Accounting Standards.

Australian Accounting Standards set out accounting policies that the AASB has concluded would result in financial statements containing relevant and reliable information about transactions, events, and conditions. Compliance with Australian Accounting Standards ensures that the financial statements and notes also comply with International Financial Reporting Standards (IFRS). Material accounting policies adopted in the preparation of these financial statements are presented below and have been consistently applied unless stated otherwise.

The financial statements, except for the cash flow information, have been prepared on an accrual basis and are based on historical costs, modified, where applicable by the measurement at fair value of selected non-current assets, financial assets and financial liabilities. The amounts presented in the financial statements have been rounded to the nearest dollar.

The financial statements were authorized for issue by the directors of the company.

Accounting Policies

a. Revenue Recognition

Non-reciprocal grant revenue is recognized in profit or loss when the entity obtains control of the grant and it is probable that the economic benefits gained from the grant will flow to the entity and the amount of the grant can be measured reliably.

If conditions are attached to the grant which must be satisfied before it is eligible to receive the contribution, the recognition of the grant as revenue will be deferred until those conditions are satisfied.

When grant revenue is received whereby the entity incurs an obligation to deliver economic value directly back to the contributor, this is considered a reciprocal transaction and the grant revenue is recognized in the statement of financial position as a liability until the service has been delivered to the contributor, otherwise the grant is recognised as income on receipt.

Rare Voices Australia Limited receives non-reciprocal contributions of assets from the government and other parties for zero or a nominal value. These assets are recognized at fair value on the date of acquisition in the statement of financial position.

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements
For the year ended 30 June 2022

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

a. Revenue Recognition (continued)

Donations and bequests are recognized as revenue when received.

Revenue from the rendering of a service is recognized upon the delivery of the service to the customer.

All revenue is stated net of the amount of goods and services tax (GST).

b. Property, Plant and Equipment

Each class of property, plant and equipment is carried at cost or fair value as indicated, less, where applicable, accumulated depreciation and impairment losses.

Plant and Equipment

Plant and equipment is measured on a cost basis and are therefore carried at cost less accumulated depreciation and any accumulated impairment losses. In the event the carrying amount of plant and equipment is greater than its estimated recoverable amount, the carrying amount is written down immediately to its estimated recoverable amount and impairment losses are recognized either in the profit and loss or as a revaluation decrease if the impairment losses relate to a revalued asset. A formal assessment of the recoverable amount is made when impairment indicators are present.

Subsequent costs are included in the asset's carrying amount or recognized as a separate asset, as appropriate, only when it is probable that future economic benefits associated with the item will flow to the company and the cost of the item can be measured reliably. All other repairs and maintenance costs are recognized as expenses in the profit and loss in the financial period in which they are incurred.

Plant and equipment that have been contributed at no cost or for nominal cost are recognized at the fair value of the assets at the date it is acquired.

Depreciation

The depreciable amount of all fixed assets, including buildings and capitalized lease assets but excluding freehold land is depreciated over the asset's useful life to the entity commencing from the time the asset is available for use. Leasehold improvements are depreciated over the shorter of either the unexpired period of the lease or the estimated useful lives of the improvements.

The assets' residual values and useful lives are reviewed, and adjusted if appropriate, at the end of each reporting period.

c. Cash and Cash Equivalents

Cash and cash equivalents includes cash on hand, deposits held at call with financial institutions, other short-term, highly liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within short term borrowings in current liabilities on the statement of financial position.

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements
For the year ended 30 June 2022

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

d. Accounts Receivable and Other Debtors

Accounts receivable and other debtors includes amounts due from members as well as amounts receivable from customers for goods sold in the ordinary course of business. Receivables expected to be collected within 12 months of the end of the reporting period are classified as current assets. All other receivables are classified as non-current assets.

e. Goods and Services Tax (GST)

Revenues, expenses and assets are recognised net of the amount of associated GST, unless the GST incurred is not recoverable from the tax authority. In this case it is recognised as part of the cost of the acquisition of the asset or as part of the expense.

Receivables and payables are stated inclusive of the amount of GST receivable or payable. The net amount of GST recoverable from, or payable to, the tax authority is included in other receivables or other payables in the statement of financial position.

Cash flows are presented on a gross basis. The GST components of cash flows arising from investing or financing activities which are recoverable from, or payable to the tax authority, are presented as operating cash flows.

Commitments and contingencies are disclosed net of the amount of GST recoverable from, or payable to, the tax authority.

f. Income Tax

No provision for income tax has been raised as the entity is exempt from income tax under Division 50 of the Income Tax Assessment Act 1997.

g. Provisions

Provisions are recognised when the company has a present (legal or constructive) obligation as a result of a past event, it is probable the company will be required to settle the obligation, and a reliable estimate can be made of the amount of the obligation. The amount recognised as a provision is the best estimate of the consideration required to settle the present obligation at the reporting date, taking into account the risks and uncertainties surrounding the obligation.

If the time value of money is material, provisions are discounted using a current pre-tax rate specific to the liability. The increase in the provision resulting from the passage of time is recognised as a finance cost.

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements
For the year ended 30 June 2022

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

h. Comparative Figures

Where required by Accounting Standards comparative figures have been adjusted to confirm with changes in presentation for the current financial year.

Where an entity applies an accounting policy retrospectively, makes a retrospectively reclassifies items in its financial statements, a statement of financial position as at the beginning of the earliest comparative period must be disclosed.

i. Trade and Other Payables

These amounts represent liabilities for goods and services provided to the company prior to the end of the financial year and which are unpaid. Due to their short-term nature they are measured at amortised cost and not discounted. The amounts are unsecured and are usually paid within 30 days of recognition.

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements
For the year ended 30 June 2022

	2022 \$	2021 \$
Note 2: Revenue and Other Income		
Revenue:		
Sponsorships	894,099	257,500
Special projects	162,365	198,714
	1,056,464	456,214
Other revenue:		
Donations & memberships	87,420	40,333
Interest revenue	1,931	4,903
Other revenue		8,892
Total Revenue	1,145,815	510,342
Note 3: Cash and cash equivalents		
Bank accounts:		
WBC Cheque Account	19,286	20,797
WBC Cash Reserve Account	1,489,986	1,209,524
WBC Debit Card	1,236	1,875
Other cash items:		
Term Deposits	331,107	631,741
	1,841,616	1,863,938
Reconciliation of Cash:		
Cash at the end of the financial year as shown in the statement of cash flows is reconciled to items in the statement of financial position as follows:		
- Cash and cash at bank	1,841,616	1,863,938
	1,841,616	1,863,938
Note 4: Trade and other receivables		
Current		
Trade debtors	44,412	797
	44,412	797

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements
For the year ended 30 June 2022

	2022 \$	2021 \$
Note 5: Property, plant and equipment		
Plant and equipment:		
- At cost	18,169	18,169
- Less: Accumulated depreciation	(18,169)	(18,169)
Office equipment:		
- At cost	13,045	3,958
- Less: Accumulated depreciation	(4,617)	(1,032)
	8,428	2,925

Note 6: Trade and other payables

Current

Trade creditors	22,909	1,129
Revenue received in advance	1,012,476	1,178,750
ATO liability	2,611	36,253
GST payable	1,973	(30)
Superannuation payable	14,204	7,289
Other payroll liabilities	20,984	(358)
	1,075,157	1,223,033

Note 7: Provisions

Current

Provision for long service leave	17,152	
Provision for annual leave	63,089	34,277
	80,242	34,277

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements
For the year ended 30 June 2022

	2022 \$	2021 \$
Note 8. Reconciliation Of Cash		
Reconciliation Of Net Cash Provided By/Used In Operating Activities To Net Profit		
Profit (loss) after income tax	128,707	68,187
Non-cash flows in profit		
Depreciation	3,584	1,032
Changes in assets and liabilities:		
(Increase) decrease in trade and other receivables	(43,615)	719,813
Increase (decrease) in trade and other payables	(147,875)	434,453
Increase (decrease) in sundry provisions	45,965	13,589
Net cash provided by operating activities	(13,234)	1,237,074
(Increase) decrease in property, plant and equipment	(9,086)	(3,959)
Net cash provided by investing activities	(9,086)	(3,959)
Net increase (decrease) in cash held	(22,320)	1,233,113

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements
For the year ended 30 June 2022

Note 9. Entity Details

The registered office of the company is:
30 Darebin Street
HEIDELBERG VIC 3084

The principal place of business of the company is:
30 Darebin Street
HEIDELBERG VIC 3084

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Detailed profit and Loss Statement
For the year ended 30 June 2022

	2022 \$	2021 \$
Income		
Sponsorships	894,099	257,500
Special projects	162,365	198,714
Donations and memberships	87,420	40,333
Interest received	1,931	4,903
Other revenue		8,892
	1,145,816	510,344
Expenditure		
Accountancy, audit and legal	18,471	13,590
Consultancy	303,991	42,294
Bank fees	1,188	744
Depreciation	3,584	1,032
Meeting and conference expenses	-	2,427
Board/governance expenses	10,705	-
Project expenses	-	31,753
Office supplies	2,161	807
Telephone and internet	6,299	3,501
Travel and accommodation	9,551	4,706
Computer expenses	-	-
Insurance	7,759	4,867
Subscriptions	9,700	7,869
Summit Expenses	48,566	-
Website cost	16,127	20,716
Salaries and wages	476,920	267,749
Annual leave provision	28,812	13,590
Long service leave provision	17,152	-
Superannuation	47,620	25,436
Other expenses	8,501	1,070
	1,017,110	442,157
PROFIT / (LOSS) FROM ORDINARY ACTIVITIES BEFORE INCOME TAX	128,707	68,187

The accompanying notes form part of these financial statements.

**RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Director's Declaration**

The Board of RVA declares that the accompanying concise financial report is presented fairly in accordance with applicable Australian Accounting Standards and is consistent with the Company's 30 June 2022 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2022 and performance of the Company for the year then ended; and in the Board's opinion, there are reasonable grounds to believe that RVA will be able to pay its debts as and when they become due and payable. This statement has been made in accordance with a resolution of the Board made on 8 December 2022.



Director: Joanna Betteridge

Dated: 14 December 2022

The accompanying notes form part of these financial statements.

DN
French & French
Accounting, Tax & Advisory

D.M French & N.C French
T/As French & French
ABN: 79 472 864 011

Auditor's Independence Declaration

As lead auditor for the review of Rare Voices Australia Limited for the year ended 30 June 2022, I declare that to the best of my knowledge and belief, there have been no contraventions of any applicable code of professional conduct in relation to the review.

Signed on:



Noel French Partner of (D.M French & N.C French)

French & French

IPA#116465 -Registered Auditor for Law Society and SMSF Reg # 5732

Date: 14 December 2022

Suite 1/5-7 Littleton Street, Riverwood NSW 2210
T: +61 2 9211 6000 F: +61 2 9211 6166
E: info@travelaccounting.com.au
W: www.travelaccounting.com.au



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DN
French & French

Accounting, Tax & Advisory

D.M French & N.C French
T/As French & French
ABN: 79 472 864 011

Independent auditor's review report to the members of
Rare Voices Australia Limited ABN. 69 156 254 303

Report on the financial report

We have reviewed the accompanying financial report, being a special purpose financial report, of Rare Voices Australia Limited (the Company) which comprises the statement of financial position as at 30 June 2022, the statement of comprehensive income, statement of changes in equity and statement of cash flows for the year ended on that date, selected other explanatory notes and the directors' declaration.

Directors' responsibility for the financial report

The directors of the Company are responsible for the preparation of the financial report that gives a true and fair view in accordance with Australian Accounting Standards and the *Australian Charities and Not-for-profits Commission (ACNC) Act 2012* and for such internal control as the directors determine is necessary to enable the preparation of the financial report that gives a true and fair view and is free from material misstatement whether due to fraud or error.

Auditor's responsibility

Our responsibility is to express a conclusion on the financial report based on our review. We conducted our review in accordance with Australian Auditing Standard on Review Engagements *ASRE 2415 Review of a Financial Report – Company Limited by Guarantee, or an Entity Reporting under the ACNC Act or Other Applicable Legislation or Regulation*, in order to state whether, on the basis of the procedures described, we have become aware of any matter that makes us believe that the financial report is not in accordance with the Division 60 of the *Australian Charities and Not-for-profits Commission (ACNC) Act 2012* including giving a true and fair view of the Company's financial position as at 30 June 2021 and its performance for the year ended on that date; and complying with Australian Accounting Standards and the *Australian Charities and Not-for-profits Commission Regulations 2013*. As the auditor of Rare Voices Australia Limited, ASRE 2415 requires that we comply with the ethical requirements relevant to the review of the financial report.

A review of a financial report consists of making enquiries, primarily of persons responsible for financial and accounting matters, and applying analytical and other review procedures. A review is substantially less in scope than an audit conducted in accordance with Australian Auditing Standards and consequently does not enable us to obtain assurance that we would become aware of all significant matters that might be identified in an audit. Accordingly, we do not express an audit opinion.

Independence

In conducting our review, we have complied with the independence requirements of the *Australian Charities and Not-for-profits Commission (ACNC) Act 2012*.

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Conclusion

Based on our review, which is not an audit, we have not become aware of any matter that makes us believe that the financial report of Rare Voices Australia Limited is not in accordance with the *Australian Charities and Not-for-profits Commission (ACNC) Act 2012* including:

1. giving a true and fair view of the Company's financial position as at 30 June 2022 and of its performance for the year ended on that date;
2. complying with Australian Accounting Standards and Division 60 of the *Australian Charities and Not-for-profits Commission Regulations 2013*.

Emphasis of matter - basis of accounting and restriction on use

We draw attention to Note 1 in the financial report, which describes the basis of accounting. The financial report has been prepared for the purpose of fulfilling the directors' financial reporting responsibilities under the *Australian Charities and Not-for-profits Commission (ACNC) Act 2012*. As a result, the financial report may not be suitable for another purpose. Our report is intended solely for Rare Voices Australia Limited and its members and should not be used by parties other than Rare Voices Australia Limited and its members. Our conclusion is not modified in respect of this matter.

Signed on:



Noel French Partner of (D.M French & N.C French)

French & French

IPA#116465 -Registered Auditor for Law Society and SMSF Reg # 5732

Date: 14 December 2022

Suite 1/5-7 Littleton Street, Sydney NSW 2210

T: +61 2 9211 6000 F: +61 2 9211 6166

E: info@travelaccounting.com.au

W: www.travelaccounting.com.au



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ACKNOWLEDGEMENTS

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RVA highly values our relationships with our RVA Partner organisations. RVA Partners are rare disease groups that provide support and/or drive research for rare disease communities. They have also contributed to the collaborative development of the Action Plan and broader rare disease advocacy. RVA's collaboration with our partner organisations is critical to making a difference to the Australian rare disease sector.

2021–22 RVA Partner Organisations (97 specific rare disease organisations):

Acrodysostosis Support and Research	Fibrous Dysplasia/McCune Albright Syndrome Australia
Angelina Cask Neurological Research Foundation	FOP Australia
Angelman Syndrome Association Australia	Foundation for Angelman Syndrome Therapeutics
ausEE	Australia
Australian Addisons Disease Association	FOXG1 Research Foundation Australia
Australian Cystinosis Support Group	Fragile X Association of Australia
Australian Dysphonia Network	Friedreich Ataxia Research Association
Australian NPC Disease Foundation Inc	FSHD Global Research Foundation
Australian Pompe Association	Gaucher Association of Australia and New Zealand
Australian Sickle Cell Advocacy Inc	Genetic Alliance Australia
Batten Disease Support & Research	HAE Australasia Ltd
Brain Tumour Alliance Australia	Haemochromatosis Australia
BrAshA-T	HCU Network Australia
CHARGE Syndrome Association of Australasia	Huntington's Victoria
Charles Bonnet Syndrome Foundation	Huntington's WA (Inc)
Children's Tumour Foundation of Australia	Immune Deficiencies Foundation Australia
CMCT-OVM	ISMRD
Congenital Adrenal Hyperplasia Support Group	ITP Australia
Australia	Jack's Butterflies
Cystic Fibrosis ACT	Kennedy's Disease Downunder
Cystic Fibrosis Queensland	Kids to Adults: Chronic Illness Alliance
Daniel Ferguson Foundation	LAM Australia Research Alliance
DEBRA Australia	Leukodystrophy Australia
Duchenne Australia	Leukodystrophy Resource & Research Org
Dup15q Australia	Maddie Riewoldt's Vision
Ehlers-Danlos Syndrome Australia National Support	Mal de Debarquement Syndrome Australia
Group	Malan Syndrome Foundation
Fabry Australia	Metabolic Dietary Disorders Association
Fanconi Anaemia Support	Mito Foundation

MND Australia	Rett Syndrome Association of Australia
MPN Alliance Australia	Sanfilippo Children's Foundation
Multiple Sclerosis Australia	SATB2 Gene Foundation Australia
Muscular Dystrophy Association NSW	Save Our Sons Duchenne Foundation
Muscular Dystrophy Association of WA	Scleroderma Association of QLD
Muscular Dystrophy Foundation Ltd	SCN2A Australia
Muscular Dystrophy QLD	Sotos Syndrome Australasia
Myasthenia Alliance Australia	Spinal Muscular Atrophy Australia
Myasthenia Gravis Association QLD	Superficial Siderosis Research Alliance
Myositis Association Australia	TAMS - The Australasian Mastocytosis Society
Narcolepsy Australia	Team Telomere
Parenteral Nutrition Down Under (PNDU)	Thalassaemia and Sickle Cell Australia
PCD Australia	The Homer Hack
Peutz Jeghers Syndrome Australian Support Group	The PKU (Phenylketonuria) Association of NSW
PFIC Network	Through the Unexpected
Phelan-McDermid Syndrome Foundations Australia	Tuberous Sclerosis Australia
PNH Support Association of Australia	UsherKids Australia
Poland Syndromighties	Victorian Clinical Genetics Services
Prader-Willi Syndrome Association of Victoria	XLH Australia
PSC Support Australia Inc	
Pseudomyxoma Survivor	
Rare Find Foundation	
Reflections	

Individual Members

In 2021–2022, RVA also had 20 individual partners.

RVA AFFILIATIONS

Australian Ethical Health Alliance
 Asia Pacific Alliance of Rare Disease Organisations (APARDO)
 Child UnLimited
 Consumers Health Forum of Australia
 EURORDIS – Rare Diseases Europe
 Healthdirect Australia
 Rare Diseases International
 Research Australia



rare voices
A U S T R A L I A[®]

10
YEARS

Rare Voices Australia (RVA)

PO Box 138, Mentone, Victoria, 3194

Tel: +61 (0) 497 003 104

info@rarevoices.org.au

www.rarevoices.org.au

 @RareVoices

 @rarevoicesaustralia

 @RareVoicesAustralia

 [linkedin.com/company/rare-voices-australia](https://www.linkedin.com/company/rare-voices-australia)

 [youtube.com/channel/Rare Voices Australia](https://www.youtube.com/channel/RareVoicesAustralia)