



rare voices
AUSTRALIA®

ANNUAL REPORT 2024

Rare Voices Australia

Driving the best outcomes for
Australians living with a rare disease.



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ABOUT RARE VOICES AUSTRALIA

Rare Voices Australia (RVA) was established in 2012 as the unified voice for Australians living with a rare disease and has since gained status as 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.

RVA's work is non-disease specific and is based on the commonalities of rare disease. Our advocacy focuses on rare disease policy, processes and systems. We advocate for all rare disease communities.

Our person-centred focus sees us working with key stakeholders, including 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

In collaboration with the rare disease sector, RVA continued progressing several activities across all three pillars (Awareness and Education; Care and Support; and Research and Data) of the National Strategic Action Plan for Rare Diseases (the Action Plan) throughout the 2023/24 financial year.

The Action Plan is the first nationally coordinated effort to address rare disease in Australia. As an Australian Government policy framework, the Action Plan has the potential to influence and drive policy outcomes relevant to the estimated two million Australians living with a rare disease.

Rare Voices Australia's role as the national peak body for Australians living with a rare disease

RVA was established in 2012 as the unified voice for Australians living with a rare disease and has since gained status as the national peak body for Australians living with a rare disease.

Our work is non-disease specific and is based on the commonalities of rare diseases. RVA's advocacy focuses on rare disease policy, processes and systems. We provide a strong, common voice and advocate for all rare disease communities.

Stakeholders look to RVA to:

- Provide policy leadership and systemic advocacy
- Build the capacity of consumer-led rare disease groups/organisations
- Effectively partner with all key stakeholders, including rare disease groups/organisations, researchers, clinicians, industry and governments

This approach is critical to continuing to raise the profile and awareness of rare diseases in Australia, in addition to driving systemic change in government policy. RVA led the collaborative development of the Action Plan and since its launch in 2020, has undertaken stewardship of the Action Plan, which included releasing a [2023 Status Report: Implementing the National Strategic Action Plan for Rare Diseases \(the Status Report\)](#). RVA's name is associated with the Action Plan, which is an endorsement of RVA's role as a peak body and is reflective of the strong relationship with governments, the rare disease sector and community. The Status Report is intended to support all stakeholders to review, reflect on, and refine their approaches to support the most accessible, effective and efficient path to implementation of sustainable systemic change across all Action Plan pillars, priorities, actions and implementation steps.

RVA is proud of our role in ensuring rare disease policy remains a priority for governments and that implementation of the Action Plan garners multipartisan support. Thank you to the Parliamentary Friends of Rare Diseases for their ongoing support of Australians living with a rare disease and the rare disease sector. We look forward to continuing to work with Co-Chairs Dr Mike Freelander MP (Member for Macarthur), Senator Wendy Askew (Senator for Tasmania) and Dr Monique Ryan MP (Member for Kooyong). As we look ahead to a Federal Election year, RVA will continue focusing on strengthening existing relationships and building multipartisan support to ensure the best outcomes for Australians living with a rare disease.

RVA also continues working with the Parliamentary Friends of People with Rare and Undiagnosed Diseases in Western Australia (WA), Co-Chaired by the Hon Matthew Swinbourn MLC, Hon Donna Faragher MLC and Hon Stephen Pratt MLC. We are grateful for your support. Additionally, RVA continues to partner with the Western Australian Department of Health on projects to progress the implementation of key aspects of the Action Plan in WA. We hope to work on similar projects with other state and territory governments in the future.

One of RVA's key strategic roles involves the organisation continuing to build on its existing sustainability, reputation and influence to enable RVA's successful leadership of the collaborative implementation of the Action Plan. This in turn ensures tangible and practical outcomes for Australians living with a rare disease, now and in the future.

Rare Voices Australia Ambassador Program

'Person-centred' is a foundation principle of the Action Plan and is key to RVA's work. Established in 2022 to coincide with the organisation's 10th anniversary and to highlight the importance of lived experience, RVA's Ambassador Program continued in 2023/24.

RVA welcomed a new ambassador, Ryan Brown, in August 2023. We thank our ambassadors for participating in this program and for your fantastic contributions. At RVA, we never underestimate how challenging, yet effective sharing personal stories can be.

Organisational Growth and Sustainability

Several new staff members joined our team during the 2023/24 financial year in response to RVA's organisational growth and the increased breadth of activities undertaken.

RVA's staffing increase has been supported in part through Commonwealth Department of Health and Aged Care grants as part of investment in response to the Action Plan. This grant funding is assisting RVA in continuing to lead the collaborative development of the [Rare Awareness Rare Education \(RARE\) Portal](#). Meanwhile, the University of New South Wales-led [Rare Disease Awareness, Education, Support and Training \(RAREST\)](#) Project which focused on rare disease awareness, education, support and training concluded on 30 June 2024. You can access the suite of RAREST Project deliverables via [RVA's website](#).

Additionally, as the lead consortia member of The Navigator Project, RVA was excited to share the first progress update since the project commenced in July 2023. Read the full progress update on [RVA's website](#).

The objectives of The Navigator Project are to:

-  Support people living with rare and complex diseases, their families and carers
-  Support people to improve their health literacy and engage with the health system
-  Link people with existing health services and/or professionals to access specialised or targeted support to manage complex care needs
-  Target telehealth nurse-led support for people with rare and complex conditions, where there is limited information on their condition or access to services, where they are in situations of acute need, or where they are unable to self-manage their condition
-  Increase the potential for system improvement as the data collection and evaluation components of The Navigator Project will generate evidence to guide future government investment for service navigation

The Navigator Project involves implementing two models of patient navigation support and collecting data from a third model of telehealth services delivered through three consumer-led rare and complex disease organisations. RVA's [RARE Helpline](#) has been operating since July 2023. As of October 2024, the RARE Helpline team have responded to queries about more than 120 different rare diseases and an estimated 9% of calls have been made by people without a diagnosis.

RVA would like to acknowledge our consortia partners, the Sydney Children's Hospitals Network, the Perth Children's Hospital, and our data sharing partners, Crohn's Colitis Australia, Mito Foundation and Tuberous Sclerosis Australia for their ongoing dedication to this important work.

Amid several National Disability Insurance Scheme (NDIS) legislative changes, RVA invested in an increase of disability staffing throughout the last financial year. RVA will continue to engage in advocacy to the National Disability Insurance Agency, the Minister for the NDIS and other key stakeholders.

Research

RVA's role in identifying evidence gaps and proactively partnering with researchers and other experts to address unmet areas of need continued throughout the 2023/24 financial year. In line with the Research and Data Pillar of the Action Plan, RVA supports the need for high-quality collaborative research of all types that positively impacts the lives of Australians living with a rare disease. Thank you to RVA's Scientific and Medical Advisory Committee (SMAC) for their ongoing guidance and support in this area.

In July 2023, RVA and Monash University published [*Recommendations for a National Approach to Rare Disease Data: Findings from an Audit of Australian Rare Disease Registries*](#). The report includes the findings from the Australian Rare Disease Registry Audit project. Additionally, RVA has embarked on a [Rare Disease Research Priority Setting Project](#) with The Kids Research Institute Australia (formerly Telethon Kids Institute). This project aims to identify and prioritise the 10 most important unanswered research questions for the future of rare disease research in Australia. The project is taking place over the next 12 months, and we look forward to reporting the findings to the rare disease sector in 2025.

Rare Voices Australia's Scientific and Medical Advisory Committee

RVA's SMAC provides the organisation with medical and clinical perspectives, guidelines and information. SMAC Chair, Professor Adam Jaffé, continues to lead SMAC's engagement in several exciting research projects and activities. Throughout the 2023/24 period, RVA was pleased to welcome several new SMAC members, including Prof Lynn Gillam AM, Dr Jane Tiller and Ann Single. We look forward to working with you all moving forward. RVA sincerely thanks our SMAC members who so willingly share their time and expertise with RVA.

Rare Voices Australia's Board of Directors

RVA's national Board of Directors continues to mature thanks to a diverse range of expertise and lived experience. Each Director brings with them experience and expertise that enhances the RVA Board's combined skills and in many cases, lived experience to ensure RVA remains personally connected to our mission and vision. RVA's high-calibre board oversees the organisation's strategic purpose and direction and comprises dedicated and passionate volunteers.

There were several changes to RVA's Board of Directors over the 2023/24 financial period. Kane Blackman and Robert Hendriks formally resigned as of 13 December 2023. Having been on the board since 2016, Robert was the longest serving board member and has helped to steer the organisation through a broad range of circumstances as RVA has grown, matured and evolved. Meanwhile, Kane joined the RVA Board in 2018, just as RVA commenced the collaborative development of the Action Plan and was appointed Deputy Chair in December 2019. Kane was also the driving force for the establishment of the inaugural Parliamentary Friends of People with Rare and Undiagnosed Diseases in WA. RVA thanks you both for your valuable contributions and wishes you all the best.

Strong governance has been vital to RVA's continued growth during the 2023/24 financial year and our work towards achieving the best outcomes for Australians living with a rare disease. The RVA Board has continued its focus on longer-term strategic planning, and we acknowledge the time and commitment our directors dedicate to RVA. A public version of RVA's Strategic Plan 2024-2027 is available to download via [RVA's website](#).

Contribution of Key Stakeholders in the Rare Disease Sector

RVA's work sees us effectively collaborating and partnering with all key stakeholders in the rare disease sector. For the best outcomes in rare disease, we need to engage multiple stakeholders, drive systemic change and advocate with a unified voice that is representative of the sector.

Thank you to our RVA Partner groups/organisations for your ongoing support of RVA and contribution to achieving the Action Plan's vision: *The best possible health and wellbeing outcomes for Australians living with a rare disease*. Additionally, RVA thanks our Board of Directors, SMAC and the RVA Round Table of Companies (industry). Your support and input are invaluable. We also thank the Members of Parliament and other policy and decision makers for their support of RVA and the rare disease sector.

RVA appreciates and values the diverse range of stakeholders that contribute their expertise, time and energy toward driving the best outcomes for Australians living with a rare disease. Your ongoing dedication continues to inspire and drive RVA's team.

IMPACT SNAPSHOT

RVA uses several metrics to measure organisational impact and identify existing gaps. We acknowledge that measuring organisational impact is potentially complex in the not-for-profit sector and continue to explore more fit for purpose models.

RVA has developed and implemented a tailored approach to metrics best suited to RVA. We routinely collect and analyse data relevant to each Action Plan Pillar; monitor progress and review it on a yearly basis; and make select data available to stakeholders. Throughout the 2023/24 financial year, RVA adopted the Most Significant Change Methodology, utilising aspects of storytelling that are most relevant to the rare disease context.

Below is a snapshot of organisational impact achieved during the 2023/24 period. We would like to acknowledge the generosity of corporates, businesses and individuals RVA largely relies on to support and fund the programs, projects and services we provide.

Rare Voices Australia Stakeholder Survey

Ahead of RVA's annual Strategy Review session in July 2024, RVA conducted a Stakeholder Survey where we asked all rare disease stakeholders for their input. Respondents were asked what they value most about RVA's role as the national peak body for Australians living with a rare disease. Respondents were also asked to rank past and current RVA activities related to the three Action Plan Pillars.

The survey was open for seven weeks and generated input from all stakeholders. A word cloud of what stakeholder's value about partnering with RVA is pictured below.



Monitoring Collaborative Implementation of the Action Plan: The Most Significant Change Methodology

The Most Significant Change Methodology was identified by RVA as a suitable tool for assessing the collaborative implementation of the Action Plan and understanding the broader impact of activities, outputs and outcomes across the rare disease sector. It has enabled RVA to collect a broad range of stories containing meaningful insights – from the power of a rare disease consumer group to the importance of funding for research; the power of a diagnosis or treatment; the importance of progressing Rare Disease Centres of Expertise; and the value of a central source of truth for Australians living with a rare disease – the Rare Awareness Rare Education (RARE) Portal.

As this work has progressed, the importance of working together as a sector to build on existing knowledge, reduce duplication, maximise current resourcing and identify gaps in the ongoing implementation of the Action Plan has consistently been highlighted.

Results from the stakeholder survey and Most Significant Change Methodology stories highlight the importance of RVA's role as the national peak body and how several key projects being collaboratively led and undertaken by RVA alongside others are working towards the best outcomes for Australians living with a rare disease.

Rare Voices Australia's Role as the National Peak Body for Australians Living with a Rare Disease

A selection of responses to the question, "What do you value most about RVA's peak body advocacy?"

"We value the recognition of RVA by government and the rare disease clinical sector as the go to voice to represent rare disease patient advocacy and appreciate the efforts to provide a clear, unified voice that advocates for policy across health, disability, and other systems to make change for those living with rare diseases..."

"The breadth of work and ability to take a systems-level coordinating approach across the health ecosystem. Continued bipartisan government engagement and broad stakeholder engagement."

Ongoing Collaborative Implementation of the National Strategic Action Plan for Rare Diseases

"The Action Plan makes people feel seen. It makes them feel like they are part of something bigger."

"... We value RVA's efforts to progress activities identified in the Action Plan including the development of the RARE Portal, the National Recommendations for Rare Disease Health Care, [the] RArEST Project and the mentorship and education provided to RVA patient group partners to build their capability and capacity to advocate for their needs."

"The Action Plan is 'a road map. A commonsense path for us to follow'. Everything we need to do sits neatly underneath the 3 Pillars. While we had many of the things in the Action Plan already in mind for our rare disease community, it validated our approach, and it continues to guide our efforts."

Implementation of the National Strategic Action Plan for Rare Diseases and Research

As Action Plan implementation continues to progress, the need to collect and measure rare disease-related data in a systemic, sustainable way to build on existing work underway in the sector is becoming more important.

While certain projects are underway to progress this work (see page 25 for more information about the Rare Disease Research Priority Setting Partnership Project), there is a vast amount of opportunity and scope for expansion in this space.

"Researchers value and leverage the Action Plan as the Australian Government's policy position on rare disease. They use it to guide the development of research objectives that will convince reviewers that their work is worth doing and worth funding. The Action Plan brings researchers back to the reason for their work. Many of my colleagues use the Action Plan, citing in grants and publications."

"The Action Plan enabled bipartisan recognition of rare disease, and this led to research funding specifically for rare disease clinical trials."

"I use the Action Plan to inform my grant applications and as stimulus for developing research questions."

Rare Awareness Rare Education (RARE) Portal

The RARE Portal is a key deliverable of the Action Plan and is a living website in ongoing development, with new information added regularly. RVA is leading the collaborative development of the RARE Portal, which houses the RARE Helpline. Read more about the RARE Portal on page 20.

“The most significant change for me is the development of the RARE Portal and the opportunity and platform it gave to our rare disease organisation to co-develop evidence-based information about our rare disease in the Australian context.”

“Now with this Australian Government funded, evidence-based resource I have an opportunity to influence what Australia says and correct the narrative... It can be dynamic and responsive to emerging research and we only have to update it in one place for all Australians. It is a single source of truth for our community...”

“The RARE Portal legitimised national information for our rare disease, and it allows us to showcase our resources to the broader rare disease community who may be able to benefit from our work.”

The public version of RVA's Strategic Plan 2024–2027 details how RVA will continue advocating for the best outcomes for Australians living with a rare disease. [Download RVA's Strategic Plan 2024–2027 \(PDF\)](#).

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 quarterly and oversees RVA's strategic direction and purpose. More than half of RVA's Board has lived experience or a personal connection to rare disease.

Directors in office from 1 July 2023 to 30 June 2024:

Dr Carol Wicking
(Chair)

Andrew Carter
(Deputy Chair)

Joanna Betteridge

Kane Blackman
(until 13 December 2023)

Kate Henderson

Robert Hendriks
(until 13 December 2023)

Prof Eric Morand

Viswanathan (Vishy) Narayanaswamy

Teresa Pilbeam

Company Secretary

Liyi Chang
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 Staff

More than three quarters of our staff have lived experience or a personal connection to rare disease.

RVA staff in employment during the year 1 July 2023 to 30 June 2024:

Nicole Millis
Chief Executive Officer

Jess Brooklyn
Education Project Officer

Sarah Cannata
Communications Manager

Dr Amanda Choo
Resources and Information Officer

Malcolm Fung
Finances and Compliance Manager

Louise Healy
Education and Advocacy Manager

Dr Falak Helwani
Research and Evaluation Manager

Isabelle Hixon
Project Officer – Mental Health & Wellbeing

Anne Hunter
Executive Assistant to the Chief Executive Officer,
Operations Manager

Fiona Lawton
Disability Advocacy Manager

Evelyn Loh
Communications and Information Officer

Manuel Perez
Web Developer

BOARD COMMITTEES

The RVA Board has two subcommittees, the Finance and Risk Committee (the FaR Committee) and the Nomination, People and Culture Committee (the NPC Committee). The FaR Committee is Chaired by Vishy Narayanaswamy and provides advice to the RVA Board on budget setting, financial and operational risk management and monitoring financial performance. The NPC Committee was Chaired by Dr Carol Wicking until she was appointed Chair of the RVA Board in January 2023. Since, the NPC Committee has been Chaired by Kate Henderson. The NPC Committee's objective is to assist the RVA Board to carry out its responsibilities, which include employing the appropriate policies, systems, and processes to achieve the desired outcomes

RVA SCIENTIFIC AND MEDICAL ADVISORY COMMITTEE

SMAC provides the organisation with medical and scientific perspectives, guidelines and information as needed. View the SMAC [Terms of Reference \(PDF\) on RVA's website](#).

SMAC members from 1 July 2023 to 30 June 2024:

Prof Adam Jaffé (Chair)

Clin/Prof Gareth Baynam

Dr Kaustuv Bhattacharya

Dr Lisa Ewans

Prof Lynn Gillam AM
(joined in March 2024)

A/Prof Paul Lacaze

Dr Kristen Nowak

Dr (Elizabeth) Emma Palmer

Prof John Rasko

Ann Single
(joined in May 2024)

Dr Jane Tiller
(joined in May 2024)

RARE VOICES AUSTRALIA 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 main website](http://www.rarevoices.org.au) (www.rarevoices.org.au). RVA facilitates the RTC in line with our [Working With Industry Policy](#), holding quarterly meetings. The primary way RVA interacts with the pharmaceutical industry as a key stakeholder is through the RVA Round Table of Companies.

RTC members nominate up to three representatives with expertise in patient advocacy; market access for treatments and reimbursement; and government relations. The quarterly workshops aim to discuss the development and availability of treatments and health services in Australia. The workshops also assist in building relationships within the rare disease community in a collaborative atmosphere that facilitates person-centred discussion about rare diseases.

The workshops provide opportunities for RVA and industry representatives to:

- Interact about topics relevant to the rare disease sector
- Exchange views with the national peak body for Australians living with a rare disease
- Develop partnerships/collaborations and timely reports, surveys and analysis relevant to rare diseases from various sources

Discussion topics for 2023/24 included:

- Early diagnosis of rare disease in Australia (guest presentation by Dr (Elizabeth) Emma Palmer)
- Australia's Newborn Bloodspot Screening program
- Action Plan Evaluation Methodology
- The Department of Health and Aged Care's refresh of the National Strategic Framework for Chronic Conditions
- 2024 Rare Disease Day Parliamentary Event
- 2024 National Rare Disease Summit
- Health Technology Assessment (HTA) Policy and Methods Review
- State-based rare disease advocacy
- Interface with Medicines Australia Rare Disease Industry Working Group

OUR WORK

2023/24

RARE DISEASE ADVOCACY AND POLICY DEVELOPMENT

Influencing policy and driving systemic advocacy remains central to RVA's work as the national peak body for Australians living with a rare disease.

Founded in 2012, RVA has spent over a decade actively building and maintaining partnerships with key rare disease stakeholders. RVA's political advocacy continues to be relationship-based, with multipartisan relationships continuing to be cultivated, developed and protected throughout the 2023/24 financial year. This is especially crucial heading into a Federal Election year.

Policymakers have repeatedly communicated their preference 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, systems and the sector. For the best outcomes in rare disease, we need to engage multiple stakeholders, drive systemic change and advocate with a unified voice that is representative of the sector.

RVA formally collaborates with and strengthens over 100 RVA Partner groups/organisations. We also partner with other key stakeholders in several ways, including through the RVA Round Table of Companies (industry), Research Partnerships and Project Partnerships. RVA's systemic focus sees us working with all key rare disease stakeholders, including people living with a rare disease, clinicians, researchers, governments, key peak bodies and industry.

RVA's work is strengthened by the extensive rare disease and professional expertise among the RVA Board, SMAC and staff. Over the course of the 2023/24 period, RVA continued to be highly sought after by stakeholders for our rare disease policy and consumer expertise. RVA personnel have professional expertise in social work, psychology, research, sociology, operations/compliance, web design and communications. This breadth of experience has been crucial to the organisation's evolution and to engaging in more targeted rare disease disability advocacy, and rare disease research and HTA advocacy, while also progressing key initiatives such as The Navigator Project and the RArEST Project.

The ongoing collaborative implementation of the Action Plan continued to be the focus of RVA's work throughout 2023/24. RVA led the collaborative development of the Action Plan throughout late 2018 and 2019 and is now leading its collaborative implementation. *Developed by the rare disease sector, for the rare disease sector*, the Action Plan provides a framework and policy direction from which the entire rare disease sector can advocate on issues.

Throughout 2023/24, RVA's advocacy increasingly focused on Rare Disease Centres of Expertise (CoE) as a key implementation mechanism of the Action Plan. CoE are critical to addressing gaps and providing better rare disease care.

Ahead of the 2024–2025 Federal Budget, RVA lodged a Pre-Budget Submission that aligned with the priorities, actions and implementation steps outlined in the Action Plan to accelerate its collaborative implementation. The Submission included a call for funding of CoE through a competitive workforce grant to develop and accelerate models of expert rare disease care. CoE and a sustainable workforce are critical to addressing gaps in rare disease care.

While we are disappointed that this priority for the rare disease sector did not receive funding in the 2024–2025 Federal Budget, RVA will continue working with all Australian governments to advocate for the best outcomes for the estimated two million Australians living with a rare disease

Submissions and Political Advocacy Undertaken Throughout 2023/24

- National consultation to improve alignment and coordination between the Medical Research Future Fund and the National Health and Medical Research Council's (NHMRC) Medical Research Endowment Account
- Australian Health Practitioner Regulation Agency (AHPRA) draft Interprofessional Collaborative Practice Statement of Intent
- Health Technology Assessment Policy and Methods Review – Consultation 1
- National Statement on Ethical Conduct in Human Research
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Response to Recommendations
- Health Technology Assessment Policy and Methods Review – Consultation 2
- Interprofessional Collaborative Practice Statement of Intent public consultation
- Joint Standing Committee on the National Disability Insurance Scheme: NDIS Participant Experience in Rural, Regional and Remote Australia
- 2024–2025 Pre-Budget Submission
- Community Affairs Legislation Committee Inquiry on the NDIS Amendment – (Getting the NDIS Back on Track No.1) Bill 2024 (May 2024)
- Australian Commission on Safety and Quality in Health Care's National One Stop Shop and the National Clinical Trials Front Door Proposal
- Australian Commission on Safety and Quality in Health Care's National One Stop Shop single national Site-Specific Assessment (SSA) minimum core element
- NDIS Provider and Worker Registration Taskforce
- NHMRC Statement on Consumer and Community Involvement in Health and Medical Research public consultation
- Recommendations for a National Approach to Rare Disease Data: Findings from an Audit of Australian Rare Disease Registries
- National Strategic Framework for Chronic Conditions refresh

- Use of Genetic Testing Results in Life Insurance Underwriting
- Improving alignment and coordination between the Medical Research Future Fund and Medical Research Endowment Account
- Proposed Interprofessional Collaborative Practice Statement of Intent public consultation (PDF)
- Section 4 of the National Statement on Ethical Conduct in Human Research
- Chronic Conditions Framework Refresh
- Special Commission Inquiry into Healthcare Funding
- Treasury Consultation on the Use of Genetic Testing Results in Life Insurance Underwriting
- Review of the Medical Research Future Fund, Genomics Health Futures Mission
- Research Australia Survey on Consumer Remuneration
- Draft World Health Organization Principles for human genome access, use, and sharing
- Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research

The Navigator Project

RVA is the lead consortium partner on The Navigator Project, which was awarded funding of up to \$2.48 million by the Department of Health and Aged Care to support Australians living with a rare disease to navigate the health system, including via the assistance of telehealth nurses. This activity is scheduled to run over three years from mid-2023.

The Navigator Project involves implementing two models of patient navigation support and collecting data from a third model of telehealth services delivered through three consumer-led rare and complex disease organisations.

Telehealth Services

1. The RARE Helpline is a national, non-disease specific telehealth service that aims to provide timely access to information and answer key questions from people living with a rare and/or complex disease. The RARE Helpline is staffed by RVA personnel, including those with qualifications/training in psychology, social work and Mental Health First Aid (MHFA) through MHFA Australia.
2. Telehealth Nurse Service Navigation Trial Sites: Two discrete non-disease specific services, attached to the clinical genetic services of the Sydney Children's Hospitals Network (the Rare Kids Navigator Project) and Perth Children's Hospital (Rare Care Centre Navigator Project). The telehealth nurses provide intensive care coordination and, in some instances, case management.
3. Three consumer-led rare and complex disease organisations providing telehealth nurse services: Crohn's and Colitis Australia, Mito Foundation, Tuberous Sclerosis Australia.

Data from each of these models will facilitate an evaluation of the impact and benefit to individuals, families, carers, the health system, and the overall cost-effectiveness and sustainability of each model.

Alignment with Existing Work Being Undertaken on the Rare Awareness Rare Education (RARE) Portal

The RARE Helpline complements work already being undertaken on the [Rare Awareness Rare Education \(RARE\) Portal](#) for rare diseases. The RARE Portal is a key deliverable of the Action Plan and is a living website in ongoing development, with new information added regularly. RVA is leading the collaborative development of the RARE Portal.

The RARE Portal contains current, reliable and straightforward information and resources for all rare disease stakeholders customised for the Australian context. More information and resources will continue to be added to the site in time. 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.

The RARE Portal consultation process is ongoing. We thank those who have contributed to the RARE Portal to date, especially our RVA Partner groups/organisations who are codeveloping individual rare disease pages with the RARE Portal team.

The Navigator Project Interim Evaluation Findings: January to April 2024

In August 2024, RVA released interim evaluation findings spanning from January to April 2024. The interim findings are based solely on data from consumer-led organisation-based telehealth services and the RARE Helpline. It is important to note these findings are based on limited available data, and strong conclusions cannot be made at this early stage.

From January to April 2024, a total of 155 people contacted the telehealth services. Almost 60% of service users were individuals living with a rare or complex disease, 40% were family members or carers and the remainder were health professionals. Interestingly, most RARE Helpline service users are diagnosed with a rare disease for which there is no known Australian support group. [Read the interim findings in full on RVA's website.](#)

The Rare Disease Awareness, Education, Support and Training (RArEST) Project

The RArEST Project concluded on 30 June 2024 and was a collaboration between RVA, the University of New South Wales, the University of Western Australia and Macquarie University to deliver rare disease awareness resources, education, support and training. While there is still more to do, the RArEST Project team is proud of what's been achieved through this Australian Government-funded initiative.



All RArEST Project resources were developed in consultation with people living with a rare disease and other experts. Thank you to the RArEST Project Stakeholder Reference Group, the Australian Rare Disease Organisations Community of Practice (ARDOCoP) and the Stream 2 Working Group for your time, effort, enthusiasm and invaluable input. View all the RArEST Project deliverables on [RVA's website](#).

RArEST Project Learnings

A key learning from the RArEST Project is the power of authentic multi-stakeholder co-design. To provide stakeholders with an easy-to-follow snapshot of RArEST Project learnings and deliverables, a suite of one-pagers was developed.

[Overall RArEST Project learnings](#)

[Stream 1 learnings and deliverables](#)

[Stream 2 learnings and deliverables](#)

[Stream 3 learnings and deliverables](#)

PROGRESSING THE AUSTRALIAN GOVERNMENT'S NATIONAL STRATEGIC ACTION PLAN FOR RARE DISEASES

Progressing the Awareness and Education Pillar

In partnership with a range of stakeholders, RVA is leading work on progressing implementation of the Awareness and Education Pillar. Key projects and examples include the ongoing development of the [Rare Awareness Rare Education \(RARE\) Portal](#); [RVA's Online Education Portal](#); and our Mentorship and Education Program which focuses on building the advocacy capacity of rare disease groups/organisations.

Progressing the Care and Support Pillar

In partnership with a range of stakeholders, RVA is leading work on progressing implementation of the Care and Support Pillar. Key projects and examples include The Navigator Project; the RArEST Project (which concluded on 30 June 2024); the RARE Portal; NBS advocacy; the Refreshed National Medicines Policy; ongoing health technology assessment advocacy; and disability advocacy.

Progressing the Research and Data Pillar

In partnership with a range of stakeholders, RVA is leading work on progressing implementation of the Research and Data Pillar. Key projects and examples include measuring implementation of the Action Plan; the RARE Portal; RVA's Research and Project Partnerships; progressing work on guidelines for Australian CoE; and [Recommendations for a National Approach to Rare Disease Data](#).

MENTORSHIP AND EDUCATION PROGRAM

RVA's Mentorship and Education Program (the Program) focuses on building the advocacy capacity of rare disease groups/organisations.

Action 2.1.4 of the Action Plan is to "Develop the capacity of rare disease organisations to represent and advocate for people living with a rare disease and their families." The Program also provides education to the broader rare disease sector and has become a core RVA activity, aligning with key priorities, actions and implementation steps in the Action Plan. During the 2023/24 financial year, RVA continued our Mentorship and Education Program, despite reduced funding.

To 30 June 2024, RVA provided a total of 96 instances of customised mentorship and strategy support to RVA Partner groups/organisations and other stakeholders. Mentoring covered a broad range of topics, including NBS; rare disease disability advocacy; clinical trials and the role of rare disease groups/organisations; policy and systemic advocacy; the HTA Policy and Methods Review; understanding regulatory and reimbursement processes for access to health technologies in Australia; developing a Scientific and Medical Advisory Committee; working with researchers; applying for funding; submissions; and political advocacy. The Program helps to build the capacity of rare disease groups/organisations to effectively respond to their community's specific advocacy needs. Support is available to all RVA Partner groups/organisations and provides mentorship and strategy guidance for community and stakeholder engagement, policy and government relations. This work also includes a formal program consisting of social media promotion and facilitates peer-to-peer networking with rare disease groups/organisation leaders through the newly introduced RVA Partner Forums and RVA's closed Facebook group for RVA Partner group/organisations. In 2024, the Rare Disease Partner forum was launched to provide a format for leveraging the shared learnings and expertise of the rare disease sector.

Customised Education Sessions

RVA has provided customised education sessions on request to several RVA Partner groups/organisations throughout 2023/24. 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 Action Plan Pillars (Awareness and Education; Care and Support; and Research and Data).

Topics covered in 2023/24:

- Access to Rare Disease Therapies in Australia – From Clinical Trials to Reimbursement
- Rare Disease Advocacy in Australia
- Making a Consumer Comment to the Pharmaceutical Benefits Advisory Committee
- Rare Disease and Mental Health
- Providing Person-centred Care for People Living with a Rare Disease (Medical Student Education)

Additionally, RVA continues to partner with the Western Australian Department of Health on projects to progress the implementation of key aspects of the Action Plan in WA. Two Mental Health and Rare Disease fact sheets, customised for WA, were developed throughout the 2023/24 financial period.

[Mental Health and Rare Disease fact sheet for consumers](#)

[Mental Health and Rare Disease fact sheet for health professionals](#)

RVA hopes to work on similar projects with other state and territory governments in the future.

RVA Partner Groups/Organisations

The number of RVA Partner groups/organisations remains steady. We partnered with over 100 rare disease groups/organisations throughout the 2023/24 financial year. RVA has also provided support and guidance to several emerging rare disease groups/organisations. RVA Partners have actively informed the development of several key policy submissions and have collaborated with RVA on important advocacy priorities, including the HTA Policy and Methods Review and rare disease disability advocacy. This work continues to build the capacity of rare disease groups/organisations, as outlined in the Action Plan (Action 2.1.4).

RVA also formally partners with individuals living with a rare disease (including family and carers), researchers, clinicians and other care professionals.

RVA's Online Education Portal

To complement the workshops, webinars and customised mentoring support provided to RVA Partner groups/organisations, RVA launched our [Online Education Portal](#) in December 2021. Since its launch, RVA has continued adding content, with both free and restricted resources available on a 24/7 basis to all rare disease stakeholders.

New and updated modules were added to the [Funding Rare Disease Organisations](#) resource throughout the 2023/24 financial period. Additionally, the following webinars targeted at health and community professionals were published to explain the development of resources for priority populations:

- [Developing the Rare Disease Resource Collections for Priority Populations](#)
- [Developing the Rare Disease Resources for the Aboriginal and Torres Strait Islander Community](#)
- [Developing the Rare Disease Resources for the Multicultural Community](#)
- [Developing the Rare Disease Resources for the Regional, Rural, and Remote Community](#)

RARE VOICES AUSTRALIA AND RESEARCH

The main objective of RVA's involvement in research is to encourage and advocate for a person-centred approach to rare disease research that is aligned with the Action Plan.

RVA's ongoing commitment to research and our strong track record and relationships with researchers and health and medical research funding bodies add credibility to our work.

Rare Voices Australia Research Activities

- RVA Research Partnerships Program (2020 to present)
- Regular in-kind support – disseminating/promoting opportunities to be involved in research, advisory roles and mentorship roles
- Advocacy to health and medical research funders for increased investment in rare disease research
- Higher Degree Researcher placement program

Rare Disease Research Advocacy

RVA plays an active role in educating researchers and funding bodies about the important role of rare disease policy in the planning, execution and implementation of rare disease research. RVA has close relationships with members of the Health and Medical Research Office. Throughout the 2023/24 financial year, we have had several invitations to contribute to consultations on the review of existing funding initiatives and share learnings around best practice in involving community organisations and peak bodies in research. See the 'Submissions and Political Advocacy Undertaken Throughout 2023/24' section for a list of research advocacy-related consultations that RVA contributed to.

Rare Voices Australia Led Research Projects

Rare Disease Research Priority Setting Partnership Project

In January 2024, RVA engaged The Kids Research Institute Australia (formerly Telethon Kids Institute) to conduct a rare disease priority setting partnership. This project aims to identify and prioritise the ten most important unanswered research questions, as identified by people living with a rare disease and the professionals who care for and represent them, for the future of rare disease research in Australia.

This Rare Disease Priority Setting Partnership project directly responds to a key priority under Pillar 3, Research and Data, in the Australian Government's Action Plan:

Priority 3.2: Develop a national research strategy for rare diseases to foster, support and drive all types of research for rare diseases, contributing to agreed priorities and systematically addressing gaps.

A public report will be available in 2025. The findings from this work will inform RVA's advocacy to health and medical research funders and researchers.

Research and Project Partnerships

Across the 2023/24 financial year, there have been eight requests for RVA research partnerships, and all are awaiting outcomes of their applications at the time of writing. RVA is a highly sought-after partner for 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 groups/organisations. RVA's Research Partnerships program gives RVA a broad knowledge of the types of rare disease research funded across Australia and the ability to identify and point out duplication.

To manage capacity and growing demands, RVA has continued to refine our [Research Partnership Guidelines](#) and application process to ensure we have an active and meaningful role in research that is appropriately recognised, and aligns with RVA's research priorities and the Action Plan. Researchers are required to fill in an online application form to apply for an RVA Research Partnership. RVA also has a process for engaging in [non-academic project partnerships](#).

RVA partners with researchers and contributes actively to research in a variety of ways, both in-kind and budgeted.

RVA contributes actively to research partnerships in the following ways:

- Reviewing and contributing to journal articles
- Consulting on grant applications
- Participating in advisory groups and steering committees
- Reviewing documents, including materials for recruitment and consent
- Providing letters of support for grant applications
- Disseminating survey/recruitment materials

Active/Funded Rare Voices Australia Research/Project Partnerships as of 30 June 2024

Research Project Name	Key Investigators	Institution/Affiliation
The missing heritability of human disease: discovery to implementation	A/Prof Gina Ravenscroft	University of Western Australia
Development of a generalizable evaluation framework for high upfront-cost gene therapies: clinical, financial, ethico-legal and cultural considerations	Prof Kirsten Howard	University of Sydney
A national long-read genome sequencing program to improve rare disease diagnosis	Dr Ira Deveson	Garvan Institute of Medical Research
Embedding genomics in primary care: using implementation science to design a robust national approach	Prof Jeffrey Braithwait	Macquarie University
Genie! A web-based AI platform supporting site preparedness for rAAV gene therapy	Prof John Rasko	Royal Prince Alfred Hospital
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 Gecz	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
gEnomics4newborns: Integrating ethics and equity with effectiveness and economics for genomic newborn screening	A/Prof Sarah Norris	University of Sydney
Ethical governance for clinical and genomic data	Prof Ainsley Newson	University of Sydney
Newborn screening model using integrated multi-omics in South Australia (NewbornsInSA)	A/Prof Karin Kassahn	South Australia Pathology
Rare Care Centre*	Clin/Prof Gareth Baynam	Perth Children's Hospital

*Project partnerships

Research Project Name	Key Investigators	Institution/Affiliation
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	Murdoch Children's Research Institute
Australian Undiagnosed Disease Network	Dr Tiong Tan, Prof John Christodoulou	Murdoch Children's Research Institute
Australian Functional Genomics Network	Dr Tessa Mattiske	Murdoch Children's Research Institute
RAREST Project	Dr (Elizabeth) Emma Palmer, Prof Adam Jaffé, Prof Michelle Farrar, Clin/Prof Gareth Baynam, Prof Yvonne Zurynski, Nicole Millis, Louise Healy	RVA, University of New South Wales, University of Western Australia, Macquarie University
NurtureNextGen: Co-design of a digital tool to support families of children with genetic neurodevelopmental conditions to receive balanced prognostic information	Dr Erin Turbitt, Prof David Amore, Prof Allison McEwan	University of Technology Sydney
Rare Disease Flagship Study: Preferences for Genomics Testing	Dr Simon Fifer, Maya Joshi	Community and Patient Preference Research (CaPPRe)

*Project partnerships

RARE VOICES AUSTRALIA AMBASSADOR PROGRAM

RVA's Ambassador Program (the Ambassador Program) was launched in 2022 to celebrate the organisation's 10th anniversary.

The overarching theme of the Ambassador Program is *Illuminating People Living with a Rare Disease*. Due to its overwhelming success, the Ambassador Program continued beyond 2022 with each ambassador bringing their own unique lived experience of rare disease.



RVA Ambassadors throughout the 2023/24 financial period:



Katie
Alexander*



Andrew
Bannister



Lachy
Beckett



Ryan
Brown



Ebony
Callaghan



Tim
Fulton



Tammie
Rees



Beck
Webber



Renae
Wood

To highlight the diversity of Australians living with a rare disease, RVA will seek new ambassadors in 2025 through an expression of interest process. We thank our outgoing ambassadors for their efforts and for so generously volunteering their time, effort and energy since being appointed.

*Image credits: Alison Wynd, 2019, News Corporation

RVA EVENTS

RARE DISEASE DAY

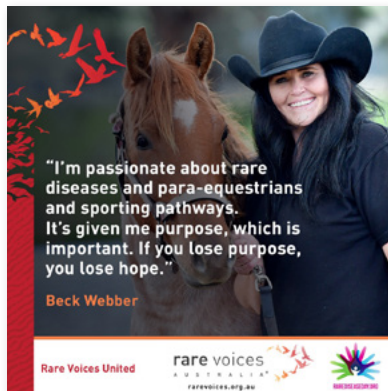
Rare Disease Day is marked on the last day of February annually around the world.

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 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.

Rare Voices United

In 2024, RVA launched the Rare Voices United social media campaign ahead of Rare Disease Day, which illuminates people living with a rare disease on the last day of February annually and beyond via our RVA Ambassadors. RVA promoted the campaign ahead of Rare Disease Day and throughout 2024, including at the 2024 National Rare Disease Summit. We thank EURORDIS for the Communications Support Programme funding RVA received to develop Rare Voices United. The Communications Support Programme was made possible by a dedicated grant from Fondation IPSEN under the aegis of Fondation de France.





RARE DISEASE DAY FEDERAL PARLIAMENTARY EVENTS

RVA typically organises a Parliamentary Event for Rare Disease Day (marked on the last day of February annually).

Parliamentary Events are an opportunity for the rare disease sector to continue fostering strong relationships with all political parties. Co-Chaired by Dr Mike Freeland MP (Member for Macarthur); Dr Monique Ryan (Member for Kooyong); and Senator Wendy Askew (Senator for Tasmania), the Parliamentary Friends of Australians Living with Rare Diseases (the Parliamentary Friends) aims to provide a non-partisan forum for parliamentarians to meet and interact with intended stakeholder groups on matters relating to rare diseases. We thank the Co-Chairs of the Parliamentary Friends for their continued support of RVA and the rare disease sector. Read more about Parliamentary Events on [RVA's website](#).

2024 Rare Disease Day Parliamentary Event – 29 February 2024: 'Progress Beyond Policy'

RVA's largest-ever 2024 Rare Disease Day Parliamentary Event was marked on the rarest day of the year (29 February). Hosted by the Parliamentary Friends, the event theme was *Progress Beyond Policy*. Attendees heard about the importance of Rare Disease CoE and Australia's first [National Recommendations for Rare Disease Health Care](#) (the Recommendations) were launched. A RAREST Project deliverable, the Recommendations were written to help health professionals provide quality care for people living with a rare disease.

Acknowledgements

Thank you to the following Members of Parliament who spoke at RVA's 2024 Parliamentary Event and who continue to show their support for the estimated two million Australians living with a rare disease:

- The Hon Mark Butler MP, Minister for Health and Aged Care
- Senator Anne Ruston, Shadow Minister for Health and Aged Care
- Dr Monique Ryan, Co-Chair, Parliamentary Friends of Rare Diseases and Member for Kooyong
- Dr Mike Freeland MP, Co-Chair, Parliamentary Friends of Rare Diseases and Member for Macarthur
- Senator Wendy Askew, Co-Chair, Parliamentary Friends of Rare Diseases and Senator for Tasmania

We also thank our other speakers:

- Dr (Elizabeth) Emma Palmer, senior clinical lecturer at University of New South Wales, Sydney, and leading co-author of the Recommendations
- Dr Falak Helwani, Research and Evaluation Manager, RVA

Additionally, special thanks to the RVA Board of Directors, our SMAC members and RVA Ambassadors who joined us on Rare Disease Day.

View the photos and read the speech delivered by Nicole Millis, RVA's Chief Executive Officer, on [RVA's website](#).

Western Australia Rare Disease Day Parliamentary Event – 29 February 2024

RVA was also pleased to attend the Parliamentary Event in WA hosted by the Parliamentary Friends of People with Rare and Undiagnosed Diseases WA (the Parliamentary Friends Group). RVA acknowledges the Co-Convenors of the Parliamentary Friends Group, the Hon Matt Swinbourn MLC, the Hon Donna Faragher MLC and the Hon Stephen Pratt MLC, for their ongoing support of the rare disease community. We also thank the stakeholders who attended for their support of the rare disease community.

Inaugural Queensland Parliamentary Event – 14 November 2023

RVA organised our inaugural Queensland Parliamentary Event dedicated to people living with a rare disease on 14 November 2023. The drop-in event provided RVA Partner group/organisation leaders with the chance to interact directly with parliamentarians who stopped by to meet RVA and others representing Australians living with a rare disease. View the photos from the event on [RVA's website](#).

The Parliamentary Event provided RVA with the opportunity to advocate for the following strategic aims:

- A stronger presence in Queensland's Parliament
- Work with parliamentarians to develop an implementation plan for progressing relevant aspects of the Action Plan
- Identify the relevant division within Queensland's Department of Health responsible for progressing a strategic approach to rare diseases

Biennial National Rare Disease Summit

RVA hosts the biennial National Rare Disease Summit (the Summit). The next Summit is scheduled for 15 and 16 November 2024 in Brisbane. The Summit brings together key stakeholders in the rare disease sector, including rare disease support group/organisation leaders, people living with a rare disease, governments, key peak bodies, clinicians, researchers and the pharmaceutical industry. Each Summit has its own unique theme in line with achieving the best outcomes for Australians living with a rare disease. To date, the Summit has been held in 2015, 2018, virtually in 2021 due to COVID-19 and 2022.

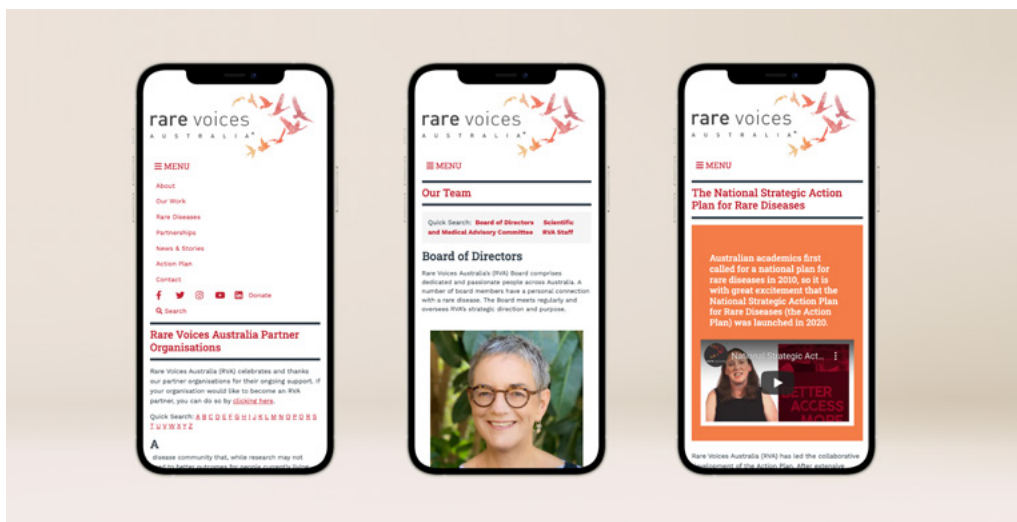
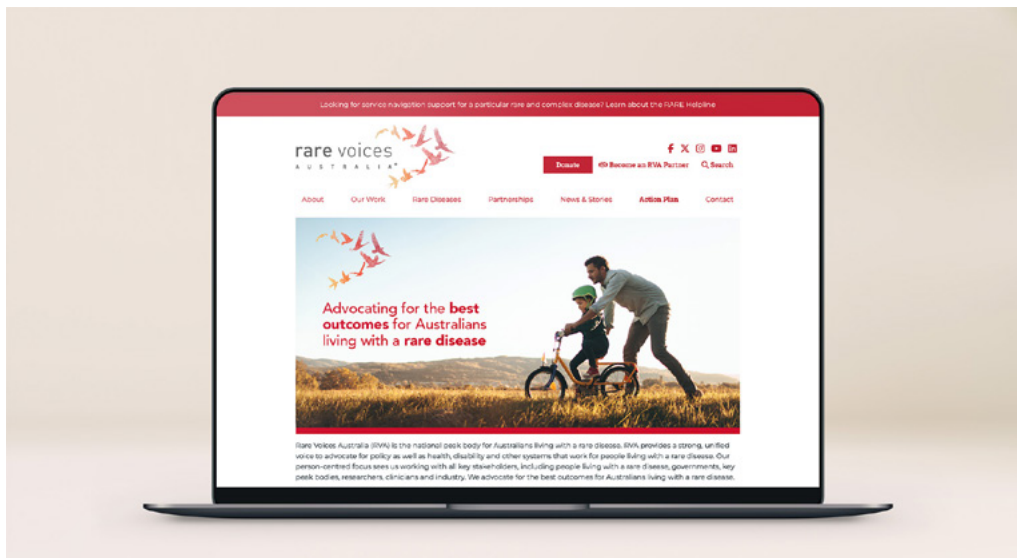
COMMUNICATIONS

COMMUNICATIONS

Rare Voices Australia Website

www.rarevoices.org.au

RVA's main website continued to gain traction throughout the 2023/24 financial year with visits from 49,000 users and 70,000 sessions. For many rare disease stakeholders, RVA's website is their introduction to other key rare disease initiatives such as the Online Education Portal and the RARE Portal, which houses the RARE Helpline. The website continues to be refined with the aim of enhancing user experience and addressing accessibility needs, while retaining a person-centred focus.



Social Media

Thanks largely to an increase in staff, RVA was able to dedicate more time and resources to social media throughout the 2023/24 financial year. RVA’s Facebook, Twitter, LinkedIn, Instagram and YouTube channels continued to grow steadily, reiterating that social media continues to be another important touchpoint for RVA to reach a variety of rare disease stakeholders.

Below is a follower breakdown by platform as of 30 June 2024

			
Facebook	X / Twitter	Instagram	LinkedIn
11,700 followers	2,935 followers	1,847 followers	1,819 followers

RVA’s YouTube channel houses 52 videos. RVA also moderates a closed Facebook group where RVA Partner group/organisation leaders are given the opportunity to connect, engage and share leadership/management strategies that are relevant to the sector.

Rare Voices Australia’s 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
- Articles with links to Action Plan implementation
- An update on the RARE Portal
- A snapshot of what RVA has been working on
- News from RVA Partner groups/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](#) of recent newsletters is published on RVA’s website. Relevant content from the eNewsletter is cross promoted via RVA’s social media channels.

Rare Awareness Rare Education (RARE) Portal eNewsletter

RVA distributes a mid and end-of-year RARE Portal eNewsletter update to showcase progress made. The eNewsletter database continues to grow steadily and RVA has been encouraged by stakeholders' interest and willingness to contribute to the RARE Portal. Read past RARE Portal eNewsletters via [RVA's website](#).

The RARE Portal eNewsletter has become another key communication tool, particularly with the launch of the RARE Helpline. Relevant content is also cross promoted via RVA's social media channels.

Media

The Australian media routinely seek out RVA's expertise as the national peak body for Australians living with a rare disease. RVA is often the first port of call for media looking to cover rare diseases broadly or specific rare diseases and throughout the 2023/24 financial year, the organisation continued to strengthen its existing relationships with journalists and media covering relevant beats in health, politics, research, disability and other areas.

Where appropriate, we connect our RVA Partner groups/organisations with media looking to run stories about individual rare diseases and provide mentorship and guidance as needed.

RVA's Rare Disease Day media strategy for 2024 focused on the launch of the National Recommendations.

RVA was featured in the following media outlets/newswire services in the 2023/24 financial year:

- The Medical Journal of Australia InSight+
- MedNews
- Research Australia's 'INSPIRE'
- ABC Online
- ABC Radio 'Nightlife' program
- Body+Soul
- The Guardian
- WIN News
- Rare Disease and Orphan Drugs Journal
- Cosmos Magazine
- PLOS ONE by Public Library of Science

COMMITTEE/ADVISORY GROUP PARTICIPATION

RVA has provided input on the following advisory panels/consultations in 2023/24:

- Rare Disease International's Mapping Rare Initiative Group
- National Disability Insurance Agency Stakeholder Engagement Group
- Rare Disease Day Steering Committee Group
- Highly Specialised Therapies Steering Committee (WA Department of Health) Group
- National Congenital Anomalies Advisory Group
- Medicines Australia Code of Conduct Review Group
- Rare Disease Research Priority Setting Project Advisory Group and Steering Committee Group
- GenSCAN Consortium's Ethical, Legal and Social Issues Working Group
- National Advanced Therapeutics Collaboration Steering Committee Group
- GenSCAN Policy and Economics Working Group
- GenSCAN Ethical, Legal and Social Implications Working Group
- RDNOW Consumer Engagement Committee Group
- Queensland Newborn Bloodspot Screening Stakeholder Group
- HTA Stakeholder Group
- Rare Disease Centre of Excellence Steering Committee Group
- University of Technology Sydney Genetic Counselling Industry Advisory Board Group
- Prader-Willi Syndrome Centre of Expertise Steering Committee meeting
- Genomics In General Practice Advisory Group
- Rare Diseases International: Australia and the World Health Assembly Resolution on Rare Diseases Group
- Neurodegenerative Palliative Care and Rare Diseases Working Group
- PERSYST Project Consumer Advisory Group
- EpiGNs Stakeholder Group

Other related appointments of RVA's Chief Executive Officer and Education and Advocacy Manager:

- Consumer Member for Enhanced Consumer Engagement Process Co-design Group
- Consumer Advocate Expert Advisory Group on Genomics Australia
- Life Saving Drugs Program Expert Panel – consumer nominee

RVA SPEAKING ENGAGEMENTS

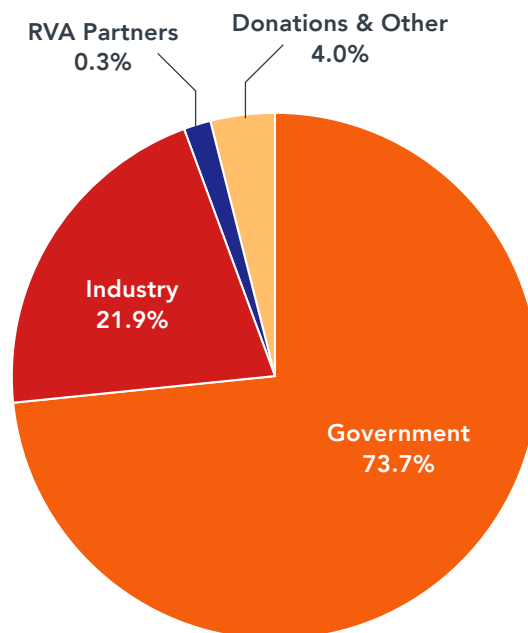
Date	Event
July 2023	RVA Education Webinar – Expanding Newborn Bloodspot Screening: Progress Made & Next Steps
July 2023	Rare Disease Project ECHO®: Rare Disease Research
August 2023	Institute for Molecular Bioscience at the University of Queensland to share RVA's work with higher degree research (HDR) students
October 2023	Inaugural Lysosomal Disease Summit
January 2024	Patient Voice Initiative and Community and Patient Preference Research (CaPPRe) Webinar: Why is patient-based evidence important?
January 2024	The Family Voices Podcast – Making an impact in the lives of children with rare diseases
March 2024	FSHD Global Research Foundation's Parliamentary Event
March 2024	Advocacy in Action patient forum
April 2024	SydCon Conference
May 2024	National Advanced Therapeutics Forum panel presenter
June 2024	MindSpot: RArEST Project mental health resources
June 2024	Australian NPC Disease Foundation's Conference
August 2024	Human Genetics Society of Australasia (HGSA) 47th Annual Scientific Meeting
September 2024	17th National Rural Health Alliance Conference

FINANCIALS

FUNDING OF RVA

RVA actively seeks funding from direct grants and partnerships with government, and from the pharmaceutical industry. RVA also receives funds from donations from the public and RVA Partner fees.

RVA Income Composition 2023-2024



RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Annual Report
For the year ended 30 June 2024



M G ARTHUR & ASSOCIATES

Accounting • Taxation • Business Services

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

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RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303

Annual Report for the year ended 30 June 2024

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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 2024.

Directors

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

ANDREW CARTER
CAROL WICKING
ERIC MORAND
JOANNA BETTERIDGE
KANE BLACKMAN (resigned on 13/12/2023)
KATE HENDERSON
ROBERT HENDRIKS (resigned on 13/12/2023)
TERESA PILBEAM
VISWANATHAN NARAYANASWAMY

The Directors have been in the 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 2024 amounted to \$547,184.
(30 June 2023 - \$152,391)

Principal Activities

The principal activities of the company during the course of the year were acting 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 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

Rare Voice Australia Ltd is a not-for-profit company and a company limited by guarantee. As such, the company does not declare any dividends.

Share Options

The constitution of Rare Voice Australia Ltd does not provide for share options. As such, no options over issued shares or interests 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:



CAROL WICKING

Director

Dated 16 October 2024

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Statement of Comprehensive Income
For the year ended 30 June 2024

	Note	2024 \$	2023 \$
Revenue	2	2,137,680	1,171,240
Other revenue	2	70,274	45,274
Depreciation		(7,478)	(4,132)
Employee benefit expenses		(876,737)	(669,752)
Other expenses		(776,555)	(390,239)
Profit before income tax		547,184	152,391
Income tax expense		-	-
Profit for the year after income tax		547,184	152,391
Other Comprehensive Income for the year		0	0
Total Comprehensive Income for the year		547,184	152,391

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 2024

	Note	2024 \$	2023 \$
Assets			
Current Assets			
Cash and cash equivalents	3	2,542,282	2,374,355
Trade and other receivables	4	1,340	22,165
Total Current Assets		2,543,622	2,396,520
Non-Current Assets			
Property, plant and equipment	5	9,314	4,296
Total Non-Current Assets		9,314	4,296
Total Assets		2,552,936	2,400,816
Liabilities			
Current Liabilities			
Trade and other payables	6	1,026,112	1,426,038
Provisions	7	88,192	83,330
Total Current Liabilities		1,114,304	1,509,368
Total Liabilities		1,114,304	1,509,368
Net Assets		1,438,632	891,448
Equity			
Retained profits		1,438,632	891,448
Total Equity		1,438,632	891,448

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 2024

	Other Reserves	Retained Earnings	Total
Balance at 1 July 2022	-	739,058	739,058
Comprehensive income			
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	152,391	152,391
Balance at 30 June 2023	-	891,448	891,448
Comprehensive income			
Profit attributable to the members	-	547,184	547,184
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	547,184	547,184
Balance at 30 June 2024	-	1,438,632	1,438,632

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 2024

	2024	2023
	\$	\$
Cash Flow From Operating Activities		
Receipts from customers	2,190,388	1,224,125
Payments to suppliers and employees	(2,048,356)	(704,917)
Interest received	38,391	13,533
Net cash provided by (used in) operating activities (note 8)	<u>180,422</u>	<u>532,741</u>
Cash Flow From Investing Activities		
Payment for:		
Payments for property, plant and equipment	(12,496)	0
Net cash provided by (used in) investing activities	<u>(12,496)</u>	<u>0</u>
Cash Flow From Financing Activities		
Repayment of borrowings	0	0
Net cash provided by (used in) financing activities	<u>0</u>	<u>0</u>
Net increase (decrease) in cash held	167,927	532,741
Cash at the beginning of the year	2,374,356	1,841,615
Cash at the end of the year (note 3)	<u>2,542,282</u>	<u>2,374,356</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 2024

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.

New or amended Accounting Standards and Interpretations adopted

The company has adopted all of the new or amended Accounting Standards and Interpretations issued by the AASB that are mandatory for the current reporting period. The adoptions of these Accounting Standards and Interpretations did not have any significant impact on the financial performance or position of the company. Any new or amended Accounting Standards or Interpretations that are not yet mandatory have not been early adopted.

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 recognized 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 2024

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 include 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 2024

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

d. Accounts Receivable and Other Debtors

Accounts receivable and other debtors include amounts due 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 recognized net of the amount of associated GST, unless the GST incurred is not recoverable from the tax authority. In this case it is recognized 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 recognized 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 recognized as a provision is the best estimate of the consideration required to settle the present obligation at the reporting date, considering 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 recognized 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 2024

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 amortized 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 2024

	2024 \$	2023 \$
Note 2: Revenue and other income		
Revenue:		
Sponsorships ¹	1,993,680	874,140
Special projects	144,000	297,100
	2,137,680	1,171,240
Other revenue:		
Donations and Partners	31,866	31,742
Interest revenue	38,391	13,533
Other revenue	17	0
	70,274	45,274
Note 3: Cash and cash equivalents		
Bank accounts:		
WBC cheque Account	19,960	22,795
WBC cash Reserve Account	1,493,244	2,039,264
WBC debit card	3,106	1,876
Stripe AUD	581	0
Other cash items:		
Term Deposits	1,025,391	310,421
	2,542,282	2,374,356
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	2,542,282	2,374,356
	2,542,282	2,374,356
Note 4: Trade and other receivables		
Current		
Trade debtors	1,340	22,165
	1,340	22,165

¹ This includes government/other grants, and industry round table

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 2024

	2024 \$	2023 \$
Note 5: Property, plant and equipment		
Plant and equipment:		
- At cost	20,682	18,168
- Less: accumulated depreciation	(18,286)	(18,168)
Office equipment:		
- At cost	23,028	13,045
- Less: accumulated depreciation	(16,110)	(8,749)
	9,314	4,296
Note 6: Trade and other payables		
Current		
Trade creditors	8,019	10,165
Refund to customers	0	11,000
Revenue received in advance	940,000	1,274,500
ATO liability	56,475	113,884
GST payable	(604)	1,091
Superannuation payable	22,222	15,876
Other payroll liabilities	0	(478)
	1,026,112	1,426,038
Note 7: Provisions		
Current		
Provision for annual leave	62,489	61,822
Provision for long service leave	25,703	21,508
	88,192	83,330

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 2024

	2024 \$	2023 \$
Note 8. Reconciliation of cash		
Reconciliation of net cash provided by/used in operating activities to net profit		
Profit (loss) after income tax	547,184	152,392
Non-cash flows in profit		
Depreciation	7,478	4,132
Changes in assets and liabilities:		
(Increase) decrease in trade and other receivables	20,825	22,247
Increase (decrease) in trade and other payables	(399,927)	350,882
Increase (decrease) in sundry provisions	4,862	3,088
Net cash provided by operating activities	180,422	532,741
Increase (decrease) in property, plant and equipment	(12,496)	0
Net cash provided by investing activities	(12,496)	0
Net increase (decrease) in cash held	167,926	532,741

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 2024

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 2024

	2024 \$	2023 \$
Income		
Sponsorships ²	1,993,680	874,140
Special projects	144,000	297,100
Donations and Partners	31,866	31,742
Interest received	38,391	13,533
Other revenue	17	0
	<u>2,207,954</u>	<u>1,216,514</u>
Expenditure		
Accountancy, audit and legal	27,090	17,770
Consultancy	64,705	73,357
Bank fees	1,163	1,516
Depreciation	7,478	4,132
CRM costs	4,255	5,702
Computer expenses	13,783	0
Board/governance expenses	1,988	20,904
Office supplies	3,769	3,832
Telephone and internet	9,048	9,751
Travel and accommodation	25,723	71,214
Insurance	13,353	11,932
Subscriptions	14,703	11,368
Summit expenses	36,597	116,972
Publications and resource development	112,058	0
Project partners	425,250	0
Website cost	6,583	14,847
Salaries and wages	785,712	603,644
Annual leave provision	667	-1,268
Long service leave provision	4,194	4,356
Superannuation	86,164	63,020
Other expenses	16,487	31,074
	<u>1,660,771</u>	<u>1,064,123</u>
PROFIT / (LOSS) FROM ORDINARY ACTIVITIES BEFORE INCOME TAX	<u>547,183</u>	<u>152,391</u>

² This includes government/other grants, and industry round table

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 2024 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2024 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 16 October 2024.



Director: Carol Wicking

Dated: 16 October 2024

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 2024, 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

16th October 2024



INSTITUTE OF
PUBLIC
ACCOUNTANTS*



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* Limited liability by a scheme approved under professional Standards Legislation

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 2024, 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 2024 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*.

-2-

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 2024 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

16th October 2024



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ACKNOWLEDGEMENTS

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RVA highly values our ongoing relationships with our RVA Partner groups/organisations.

RVA Partners are rare disease groups/organisations that provide support and/or drive research for specific 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 RVA Partners is critical to making a difference to the Australian rare disease sector.

2023/24 RVA Partner Groups/Organisations:

Alpha-1 Organisation Australia Inc.	Debra Australia
Angelina Cask Neurological Research Foundation	Duchenne Australia
Angelman Syndrome Association Australia	Dystonia Network of Australia Inc.
ausEE Inc.	EB Research Partnership Australia
Australian Addison's Disease Association Inc.	Fabry Australia
Australia and New Zealand Vasculitis Society	Familial Mediterranean Fever & Autoinflammatory Diseases Australia
Australian Cystinosis Support Group	Fanconi Anaemia Support Australasia (FASA)
Australian Dysphonia Network Inc.	Fibrodysplasia Ossificans Progressiva (FOP) Australia
Australian Foundation for CDKL5 Research	Fibrous Dysplasia/McCune Albright Syndrome Australia
Australian NPC Disease Foundation Inc.	Foundation for Angelman Syndrome Therapeutics Australia (FAST)
Australian Pituitary Foundation	FOXG1 Research Foundation Australia
Australian Pompe Association	Fragile X Association of Australia
Brain Tumour Alliance Australia	Friedreich Ataxia Research Association
BrAshA-T Ataxia-Telangiectasia Limited	FSHD Global Research Foundation
CHARGE Syndrome Australasia	Gaucher Association of Australia and New Zealand
Childhood Dementia Initiative	Genetic Alliance Australia
Children's Tumour Foundation	Genetic Cures for Kids (Our Moon's Mission)
Congenital Diaphragmatic Hernia (CDH) Australia	Genetic Support Network Victoria (GSNV)
Connective Tissue Disorders Network Australia (CTDNA)	HAE Australasia
Cystic Fibrosis Queensland	Haemochromatosis Australia
Cystic Fibrosis Western Australia	
Daniel Ferguson LGMD Foundation	

HCU Network Australia	Prader-Willi Syndrome Association (PWSA) Victoria
Huntington's Australia	Primary Ciliary Dyskinesia (PCD) Australia
ITP Australia	Progressive Familial Intrahepatic Cholestasis (PFIC) Network
Immune Deficiencies Foundation Australia (IDFA)	PSC Support Australia
International Advocate for Glycoprotein Diseases (ISMRD)	Pseudomyxoma Survivor
Kennedy's Disease Downunder	Pulmonary Hypertension Association Australia (PHAA)
Leukodystrophy Australia	PURA Foundation Australia
Liver Foundation	Racing for MNDi
Maddie Riewoldt's Vision	Rare Find Foundation
Malan Syndrome Foundation	Reflections
Marfan Association Queensland	Rett Syndrome Association of Australia
Metabolic Dietary Disorders Association (MDDA)	Sanfilippo Children's Foundation
Mito Foundation	SATB2 Connect
Motor Neurone Disease (MND) Australia	Save Our Sons Duchenne Foundation
Moyamoya Australia	Scleroderma Australia
MPN Alliance Australia	Scleroderma Queensland
Multiple Sclerosis (MS) Australia	Scleroderma Victoria
Muscular Dystrophy Foundation Australia	SCN2A Australia
Muscular Dystrophy New South Wales	Sotos Syndrome Australasia
Muscular Dystrophy Queensland	Spinal Muscular Atrophy Australia Inc.
Myasthenia Alliance Australia	STXBP1 Australia
Myasthenia Gravis Association of QLD Inc.	Superficial Siderosis Research Alliance (SSRA)
Myositis Association Australia	Thalassaemia and Sickle Cell Australia
Neuromuscular WA	The Australian Cystinosis Foundation
ozED - Australian Ectodermal Dysplasia Support Group	The Australasian Mastocytosis Society (TAMS)
Parenteral Nutrition Down Under (PNDU)	Through the Unexpected
PNH Support Association Australia Inc.	The Phenylketonuria Association of NSW
Prader-Willi Research Foundation of Australia	Tuberous Sclerosis Australia (TSA)
	XLH Australia

INDIVIDUAL PARTNERS

During the 2023/24 financial period, RVA had 60 individual partners.

AFFILIATIONS

Australian Ethical Health Alliance

Asia Pacific Alliance of Rare Disease Organisations (APARDO)

Child UnLimited

Consumers Health Forum of Australia

EURORDIS – Rare Diseases Europe

Genetic and Rare Diseases (GARD) Information Center

Healthdirect Australia

Health Technology Assessment International (HTAi)

Human Genetics Society of Australasia

Rare Diseases International

Research Australia



rare voices
A U S T R A L I A[®]

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📺 [youtube.com/channel/RareVoicesAustralia](https://www.youtube.com/channel/RareVoicesAustralia)