



rare voices
A U S T R A L I A[®]



Annual Report 2025

Rare Voices Australia

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

Contents

03	About Rare Voices Australia
04	Chair Report
06	Chief Executive Officer Report
09	Rare Voices Australia Board, Company Secretary and Staff
12	Rare Voices Australia Round Table of Companies
13	Monitoring the Collaborative Implementation of the National Strategic Action Plan for Rare Diseases
21	Rare Voices Australia's Impact in the 2024/25 Financial Period
22	Rare Disease Advocacy and Policy
27	Progressing the Australian Government's National Strategic Action Plan for Rare Diseases
29	Rare Voices Australia Education
31	Rare Voices Australia and Research
37	Rare Voices Australia Ambassador Program
38	Rare Voices Australia's Events
39	Rare Disease Day Federal Parliamentary Event
43	2024 National Rare Disease Summit
45	2025 Rare Disease Disability Network Showcase
46	Rare Voices Australia's Communications
49	Committee/Advisory Group Participation
51	Rare Voices Australia Speaking Engagements
52	Acknowledgements
56	Financials
81	Appendix 1: Most Significant Change Story Summaries
83	Appendix 2: Key Learnings from the Most Significant Change Methodology Work

About Rare Voices Australia

Rare Voices Australia (RVA) was established in 2012 as the unified voice for Australians living with a rare disease. Over the last 13 years, RVA has 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 in the rare disease sector, including Australians living with a rare disease, governments, peak bodies, researchers, clinicians and industry. We advocate for the best outcomes for Australians living with a rare disease.

Nearly all the estimated 2 million Australians living with a rare disease experience long-term impacts daily – impacts that meet the Australian Government's definition of a disability.^{1,2} The disability impacts of living with a rare disease often aren't recognised by policymakers.

Our Vision

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

Our Mission

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

Chair Report

Dr Tarun Weeramanthri AM

I was pleased to accept the role as RVA Chair in November 2024. As Chief Health Officer in Western Australia (WA) from 2008 to 2018, I oversaw the Office of Population Health Genomics, and the development of WA's first Rare Diseases Strategic Framework (2015-2018). Throughout this time and in the years since, I have developed a strong appreciation of the importance of consumer, carer and civil society organisations in rare disease advocacy, and encouraged colleagues, both nationally and internationally, to see rare diseases as an important public health issue.

Rare Voices Australia Board of Directors

RVA's Board, comprising dedicated volunteers, oversees the organisation's strategic purpose and direction. More than half of RVA's Board has lived experience or a personal connection to rare disease. Strong governance is essential for not-for-profit organisations – particularly an organisation like RVA that continues to grow and evolve – as it ensures accountability, transparency, and alignment with the organisation's vision and mission. The RVA Board meets every two months, and a public version of RVA's Strategic Plan 2024-2027 is available at [RVA's website](#).³

The 2024/2025 financial period saw several new board members appointed. Each Director brings with them experience and expertise that enhances the board's combined skills and, in many cases, lived experience ensures RVA remains personally connected to its mission and vision. I thank all current board members for your time and dedication. Special thanks to former Chair, Dr Carol Wicking, who resigned from the board in November 2024, and handed over RVA in great shape, strong in strategy and operations, with healthy finances! I also thank former board members, Prof Eric Morand and Kate Henderson for your contribution to RVA and wish you all the best.

Rare Voices Australia Scientific and Medical Advisory Committee

RVA's Scientific and Medical Advisory Committee (SMAC) provides the organisation with medical and clinical perspectives, guidelines and information. I'd like to thank the Chair, Prof Adam Jaffé, and all members of RVA's SMAC for your valued contributions. You help the board and staff ensure that the organisation's efforts are grounded in the latest scientific evidence and medical best practices.

The Importance of a United Voice in Rare Disease

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. The interest and participation in RVA-led initiatives, including the RVA Partner Forum for RVA Partner groups/organisations, the Rare Disease Disability Network and the Australian Rare Disease Research Network is encouraging and appreciated. Thank you to all stakeholders who partner with RVA in some way. We especially thank our RVA Partner groups/organisations for their support of RVA and their communities. The Action Plan's collaborative development and ongoing implementation prove that we can achieve much more together as a sector than any stakeholder or individual group can in isolation.

I was delighted to meet so many stakeholders at the 2025 Rare Disease Day Federal Parliamentary Event in March. Upon accepting the role of RVA Chair, two of my key goals were to listen to people living with a rare disease and encourage innovative rare disease policy. As an organisation, RVA's key aims include improving healthcare access and closing the gap between research and better outcomes and experiences for patients and carers.

The Value of a Trusted, Credible National Peak Body

RVA was established in 2012 as the unified voice for Australians living with a rare disease. Since, thanks to strategic advocacy spanning over a decade, RVA has gained status as the national peak body for Australians living with a rare disease. Importantly, the organisation's reach and influence continue to grow as you will read via various stakeholder perspectives throughout this Annual Report thanks to the Most Significant Change methodology work conducted throughout 2024/25. See page 13 for more information.

Policymakers have repeatedly communicated their preference to easily engage with the rare disease sector through a credible and informed national peak body with a strong understanding of policy, systems and the sector. As RVA continues to grow and expand, we remain committed to the fundamentals that stakeholders have come to rely on the organisation to provide:

- Policy leadership and systemic advocacy
- Building the capacity of consumer-led rare disease groups/organisations
- Effectively partnering with all key stakeholders, including rare disease groups/organisations, researchers, clinicians, industry and governments

This collaborative approach is critical in continuing to raise the profile and awareness of rare diseases in Australia, in addition to driving systemic, innovative change in government policy.

Chief Executive Officer Report

Nicole Millis

The Australian Government's [National Strategic Action Plan for Rare Diseases](#) (the Action Plan) is the first nationally coordinated effort to address rare disease in Australia. An Australian Government policy framework, as a sector, we have seen the Action Plan's potential to influence and drive policy outcomes for the estimated two million Australians living with a rare disease since its launch in 2020. Nearly all of the estimated two million Australians impacted by rare disease experience long-term impacts daily – impacts that meet the Australian Government's definition of a disability.^{1,2}

RVA's work is non-disease specific and is based on the commonalities of rare diseases. Our advocacy focuses on rare disease policy, processes and systems. We provide a strong, common voice and advocate for all rare disease communities. One of RVA's key strategic roles involves the organisation continuing to build on its existing sustainability, reputation and influence to enable the 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.

As the national peak body for Australians living with a rare disease, RVA led the collaborative development of the Action Plan and as noted above, is now leading its collaborative implementation. Alongside the rare disease sector, RVA continued to progress several activities across all three pillars of the Action Plan throughout the 2024/25 financial year.

The three Action Plan Pillars are:

1. Awareness and Education
2. Care and Support
3. Research and Data

Monitoring the collaborative implementation of the Action Plan is vital to understanding how the Action Plan is driving meaningful change across the rare disease sector. You will read more about RVA's approach to measuring the Action Plan's collaborative implementation through the Most Significant Change methodology later in this Annual Report.

Ensuring rare disease policy remains a priority for governments and that the Action Plan's implementation garners bipartisan support remain key to better outcomes for Australians living with a rare disease. Thank you to the Co-Chairs of the Parliamentary Friends of Rare Diseases in the 47th Parliament for their ongoing support of Australians living with a rare disease and the sector, Dr Mike Freeland MP (Member for Macarthur), Senator Wendy Askew (Senator for Tasmania) and Dr Monique Ryan MP (Member for Kooyong). We look forward to continuing to work with the former Co-Chairs and other rare disease political champions moving forward.

Rare Voices Australia Ambassador Program

'Person-centred' is a foundation principle of the Action Plan and is key to RVA's work. RVA first introduced the RVA Ambassador Program (the Ambassador Program) in 2022 to celebrate 10 years of rare disease advocacy. The Ambassador Program provides people living with a rare disease and those with professional experience of working with rare diseases with the opportunity to share their experiences with the broader rare disease sector.

To continue promoting diversity and showcasing the breadth of rare diseases and people's unique stories, RVA refreshed the Ambassador Program in 2025 through an expression of interest process. In May 2025, RVA was excited to announce our ambassadors for the 2025-27 Ambassador Program. See page 37 for more information.

We thank all ambassadors – both our current and inaugural ambassadors – for participating in the Ambassador 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 2024/25 financial year, in both permanent and casual roles, in response to RVA's organisational growth and the increased breadth of activities undertaken. RVA's staffing increase was supported, in part, through several Commonwealth Department of Health, Disability and Ageing grants as part of investment in response to the Action Plan. You can read about these grants in more detail throughout the Annual Report.

Rare Disease Disability Advocacy

In recognition of the ongoing disability impacts on Australians living with a rare disease, RVA dedicated significant additional resource to broader rare disease disability advocacy this financial year. We are also leading the Rare Disease Disability Project (the Project) and proudly delivering projects for the [Peer Support and Capacity Building grant](#) for the National Disability Insurance Scheme (NDIS). This exciting, first-of-its kind 2-year Project will conclude in December 2026. You can read more about the Project on page 26.

Research

In line with the Action Plan's Research and Data Pillar, RVA supports the need for high quality collaborative research that is person-centred and positively impacts Australians living with a rare disease. RVA welcomes genuine partnerships with groups planning or undertaking research that addresses core principles outlined in the Action Plan. Thank you to RVA's SMAC for their ongoing guidance and support in this area.

In addition to advocating for rare disease research more broadly, several exciting, RVA-led rare disease research initiatives took place throughout the 2024/25 financial period. [Australia's Top 10 Rare Disease Research Priorities](#) were launched, aiming to identify and prioritise the 10 most important unanswered research questions for the future of rare disease research in Australia. This work was led by RVA and The Kids Research Institute Australia (formerly the Telethon Kids Institute). Meanwhile, our [Research Partnerships Program](#) continues going from strength-to-strength and the Australian Rare Disease Research Network – facilitated by RVA and Co-Chaired by SMAC members, Clin/Prof Gareth Baynam, Dr (Elizabeth) Emma Palmer and Dr Lisa Ewans – was launched. Additionally, several students have now taken part in our Higher Degree Researcher placement program. RVA is proud to support student placements to promote the awareness and education of rare diseases among early to mid-career researchers. Read more about RVA's research and data advocacy on page 31.

As you will read throughout the Annual Report, the rare disease sector continues to gain momentum with key decision and policymakers. We thank all stakeholders for their support of RVA and invaluable contributions as we continue leading the collaborative implementation of the Action Plan.

Rare Voices Australia Board, Company Secretary and Staff

Rare Voices Australia Board

The RVA Board comprises dedicated Directors, with more than half having lived experience or a personal connection to rare disease. The RVA Board meets every two months, and oversees RVA's strategic direction and purpose.

Directors in office from 1 July 2024 to 30 June 2025:

- **Dr Tarun Weeramanthri AM** (appointed Chair on 14 November 2024)
- **Dr Carol Wicking** (Chair until 14 November 2024)
- **Andrew Carter** (Deputy Chair until 14 November 2024)
- **Joanna Betteridge**
- **Andre Carvalho** (appointed to the board on 21 August 2024)
- **Kate Henderson** (resigned from the board on 21 February 2025)
- **Roxane Marcelle-Shaw** (appointed to the board on 21 August 2024)
- **Prof Eric Morand** (resigned from the board on 14 November 2024)
- **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 RVA's staffing team has lived experience or a personal connection to rare disease.

RVA staff in employment from 1 July 2024 to 30 June 2025:

Permanent Staff

- **Nicole Millis**, Chief Executive Officer
- **Jess Brooklyn**, Education Project Officer
- **Sarah Cannata**, Communications Manager
- **Dr Amanda Choo**, Resources and Information Officer (now RARE Portal Manager)
- **Amanda Dickey**, Disability Project Officer
- **Malcolm Fung**, Finance and Compliance Manager
- **Louise Healy**, Education and Advocacy Manager
- **Dr Falak Helwani**, Research and Evaluation Manager
- **Anne Hunter**, Executive Assistant to the Chief Executive Officer and Operations Manager
- **Fiona Lawton**, Disability Advocacy Manager
- **Evelyn Loh**, Communications and Information Officer
- **Manuel Perez**, Web Developer

Casual Staff

- **Jo Campbell**
- **Freya French**
- **Lucinda Walker**

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 is chaired by Teresa Pilbeam. Its objective is to assist the RVA Board to carry out its responsibilities, which include adopting the appropriate policies, systems, and processes to achieve desired outcomes.

Rare Voices Australia Scientific and Medical Advisory Committee

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

SMAC members from 1 July 2024 to 30 June 2025:

- Prof Adam Jaffé (Chair)
- Clin/Prof Gareth Baynam
- Dr Kaustuv Bhattacharya
- Dr Lisa Ewans
- Prof Lynn Gillam AM
- A/Prof Paul Lacaze
- Dr Kristen Nowak
- Dr (Elizabeth) Emma Palmer
- Prof John Rasko
- Ann Single
- Dr Jane Tiller

Rare Voices Australia Round Table of Companies

RVA engages with various rare disease stakeholders through different partnership models. We interact with the pharmaceutical industry as a key stakeholder in the rare disease sector through the Round Table of Companies (RTC).

The RTC is a group of pharmaceutical companies with a common interest in rare diseases and orphan drug development. RTC members provide financial support to RVA, and all member company logos are listed on [RVA's website](#). RVA facilitates the RTC in line with our [Working With Industry Policy](#). RTC members nominate up to three representatives with expertise in patient advocacy; market access for treatments and reimbursement; and government relations to attend quarterly workshops.

Quarterly Workshops

RTC members are invited to participate in quarterly workshops that provide opportunities for RVA and industry representatives to:

- Interact about topics relevant to the rare disease sector
- Exchange views with RVA as 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
- Hear from guest speakers

The quarterly workshops aim to discuss the development and availability of treatments and health services in Australia. They also assist in building relationships in a collaborative atmosphere that facilitates person-centred discussion about rare diseases.

Discussion topics for 2024/25 included:

- Health Technology Assessment Review (HTA Review)
- The HTA Consumer Evidence and Engagement Unit role and how it supports rare disease consumers to engage with HTA
- Pharmaceutical Benefits Advisory Committee (PBAC) plain language summaries for Agenda items
- Life Saving Drugs Program (LSDP) regarding the HTA Review and the movement of therapies from the LSDP to the PBAC
- Gaps and strengths of state health systems in relation to access to rare disease therapies
- Potential implications of the current geopolitical environment, including most favoured nation policy on rare disease therapies for Australian patients
- Delays in post PBAC recommendation processes to support timely access for patients
- Burden of rare disease for Australian patients
- Rare Disease Centres of Expertise advocacy

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

Stewardship of the Action Plan is a key focus area of RVA's Strategic Plan for 2025-2027.³

Monitoring the collaborative implementation of the Action Plan is vital to understanding how the Action Plan is driving meaningful change across the rare disease sector.

Understanding Impact Across the Rare Disease Sector Using the Most Significant Change Methodology

Measuring the systemic and human impact of the Action Plan requires more than counting and categorising activities. To address this challenge, in 2024, RVA staff engaged in training for the Most Significant Change (MSC) methodology. The framework was then adopted by the organisation as a measurement tool.

The [MSC methodology](#) is a validated and flexible, person-centred evaluation framework that, through guided storytelling and independent review, captures the most significant changes from the perspectives of individuals and communities.⁴ We thank everyone who so generously shared their stories and participated in the MSC work.

The MSC process involved the collection and summarising of stories from a wide range of stakeholders. The most significant of these stories were then identified through a story selection panel.

Emerging Themes: What We Heard

RVA collected stories from a diverse range of stakeholders reflecting Action Plan implementation progress. Several themes emerged across all stories: how collaboration has deepened with people and organisations working together in new ways; how policy conversations now include rare diseases more often; and how lived experience is increasingly recognised as essential in shaping decisions. Many described growing networks of support, better access to reliable rare disease information, diagnosis, treatment and care, and a stronger sense of community belonging.

Stories were then allocated into five 'domains of change' for the story selection panels: Knowledge and Capacity Building; Equity and Access; System and Policy Influence; Collaboration and Innovation; and Empowerment and Participation. Stories were also anonymised and conflicts of interest accounted for.

While the stories were diverse, they pointed to a common thread – change is happening because stakeholders are working together.

For summaries of all MSC stories collected, please see Appendix 1 on page 81.

Stories of Most Significant Change

The second phase of the MSC process involved selecting stories of most significant change under each domain of change. Panels worked together to reach consensus on which story or stories represented the most significant change for the rare disease sector. The six stories chosen as representing the most significant change are below.

Change Domain: Knowledge and Capacity Building

1

Linking Knowledge, Improving Care: The Power of a Multidisciplinary Rare Disease Network

This story was told by Professor Adam Jaffé. He is a professor of paediatrics at the University of New South Wales, a specialist respiratory physician and head of paediatrics and child health at Sydney Children's Hospitals Network.

Professor Jaffé actively contributes his clinical, academic and advocacy experience to advancing care and networks for children living with rare diseases in Australia. He is also Chair of RVA's SMAC.

The most significant change has been the formation of a national and internationally connected multidisciplinary network for families affected by a rare lung disease – Children's Interstitial Lung Disease – Australia and New Zealand (CHILD-RANZ). This network, which began as a grassroots community of practice, now conducts monthly multidisciplinary team meetings involving clinicians from across Australia, New Zealand, the United States and Malaysia. It has directly led to life-changing diagnoses and treatments, giving families access to a local physician connected to a readily accessible network of knowledge and expertise to support their care. The network has also strengthened Australia's research capacity, influenced international guidelines, and led to the establishment of an internationally recognised registry.

Before this change, families were isolated, and clinical expertise was siloed. Children would be referred from as far as Perth, not through a national system, but through international colleagues who recognised Professor Jaffé's expertise.

Selection panellists chose this story for its broad local and international reach and its multi-faceted, multi-stakeholder impact across families, clinicians and researchers. It was also selected for its replicability and potential to drive sustainable systemic change.

Change Domain: Equity and Access

2

From Exclusion to Equity: Securing Fair Access to Life-Changing Therapies

This story was shared by RVA Partner, the Myasthenia Alliance Australia (MAA), the Australian peak body representing everyone with an interest in the conditions associated with Myasthenia Gravis (MG). The MAA is a partnership of all eligible state associations and operates to enhance the lived experience for people with these conditions. MG is a chronic autoimmune condition that disrupts communication between nerves and muscles, leading to weakness and fatigue.

The most significant change for our community since 2020, is the MAA's successful advocacy for equitable access to a therapy for MG*. Through this work, the MAA built capacity and knowledge in HTA. This has enabled our organisation to be meaningfully involved in HTA and given us the confidence and expertise to contribute to broader policy advocacy for more equitable access to health technologies.

Before 2020, treatment options for people living with MG were extremely limited. Although one effective therapy was available on the Pharmaceutical Benefits Scheme (PBS) for more common conditions, it was not accessible to those with MG, leaving many to either pay significant out-of-pocket costs or go without.

Selection panellists chose this story because the change extends beyond the immediate issue, giving the community the confidence and capability for ongoing, policy-informed systemic advocacy.

*Update from the MAA: In April 2025, following sustained advocacy and input from the MAA and the MG community, the Pharmaceutical Benefits Advisory Committee recommended that all four available MG treatments be listed on the PBS.

Change Domain: System and Policy Influence

3

Building Credibility and Influence: How the Action Plan Transformed the Rare Disease Sector

This story was told by Nicole Millis. Nicole is the Chief Executive Officer at RVA and has been part of the rare disease community for many years, both professionally and personally. Nicole was directly involved in development of the Action Plan.

The most significant change has been the Action Plan, which has provided a unifying framework and language that shifted the sector from desperation to constructive, solutions-focused conversations. Through the Action Plan, rare disease communities, often isolated and marginalised, now feel heard and part of a collective movement with influence. The Action Plan gave RVA and the sector credibility, visibility and confidence. It provided a constructive framework for advocacy, which enabled the sector to move from highlighting problems and gaining sympathy to a common and consistent language, which supported understanding and created a solutions-focused space that is less overwhelming and more helpful to policymakers. The result is greater trust and stronger relationships.

“What I think the Action Plan gives us is a way to have difficult conversations that wasn’t there before. It provides a framework and words that are less emotive and easier to hear, [that are] strengths-based, and more hopeful.”

Before the Action Plan, advocacy was fragmented, overwhelming and emotionally charged, with people sharing difficult problems all at once. While this was authentic, it was likely simplistic—there was a belief that if people understood how bad it was then things would get fixed. The Action Plan showed the sector that “we had to have our hand in the solutions.”

Selection panellists chose this story for its broad, systemic and sector-wide policy impact. They noted its tangible outcomes, including changes in the language used to describe rare disease community experiences and identity, particularly in advocacy and government discussions.

Change Domain: Collaboration and Innovation

Two separate stories were selected for this change domain. One represents the most significant change for collaboration and the other for innovation.

Stronger Together: Collaboration Elevates a Rare Voice

4

This story was told by Kris Pierce. Kris is the co-founder and director of RVA Partner, SCN2A Australia, a rare disease organisation run by parent volunteers, which began in 2017 and has recently become a registered charity. Kris also has lived experience in rare disease and works in several advisory roles across the rare disease sector.

Working together and focusing on the collective benefits we can achieve across the rare disease space has been the most significant shift for me. Our collaborative approach has supported our work across all areas from healthcare and health system navigation, through to our involvement in research.

We are a small organisation representing a rare disease that affects around 40 families in Australia, with direct connections to just over half of them. Despite our small size and our focus on one rare disease, what we realised along the way is how similar our challenges are to those across other rare disease communities. This has led us to work more collaboratively with similar rare disease groups, including a larger organisation, which represents a more common diagnosis – one that is also a primary symptom for many in our rare disease community.

Linking with a larger organisation representing a common condition, has really elevated the voice of our rare disease community. It has enabled us to reach a broader audience and leverage more funding and resources to progress change for our rare community.

One example of the difference our organisation has made is our success in advocating for compassionate treatment at a hospital for a precision medicine (not gene therapy) for one of our community members. It took six months of advocating to the hospital to take on the risk of treating a child with a life-threatening rare condition, and I truly believe it would not have been approved without the collaborative relationships we had built as an organisation, or the groundswell of awareness created by the Action Plan.

Selection panellists chose this story because it demonstrates how connecting rare disease communities with larger common disease groups can drive change for one family and set the precedent and momentum for broader change. This story demonstrated the impact of collaboration.

From Doubt to Discovery: Clinical Trials Arrive for Our Community

5

This story was told by Meagan Cross. Meagan is a founding member and the current Chief Executive Officer of RVA Partner, the Foundation for Angelman Syndrome Therapeutics (FAST) – a research-focused rare disease charity organisation, which began in 2010.

The most significant change for our community is the initiation of clinical trials overseas for our rare disease in 2020 and then the move to make these available in Australia. It took 10 years to see these new treatments coming into the clinic. While in the medical world this is fast, for families it was a slow process, and many lost hope at times. As of today, Australia is the only country in the world running four clinical trials for our rare disease.

Despite advances in research, before 2020, there was still uncertainty around whether there would ever be a treatment for our rare disease. Even before we started the organisation in 2010, there was a belief that the condition our organisation represents may never be treatable. But we knew there was research being done. We had no idea who it would benefit and if adults would benefit at all, but we also knew our rare disease wasn't degenerative and we knew there was a genetic cause. So, we worked hard to change the way people thought about the potential for a treatment.

Selection panellists chose this story for its holistic impact from lived experience to innovation. This story demonstrated the impact of innovation.

Change Domain: Empowerment and Participation

Strengthening Unity and Recognition: The Impact of the Action Plan

6

This story was told by Sarah Cannata. Sarah is RVA's Communications Manager and has been working in the rare disease sector for over 6 years. Sarah was directly involved in development of the Action Plan.

"For me, it's hands down that the Action Plan has been the most significant change. People [the rare disease sector] see the Action Plan as their Action Plan, which it is... they helped to build and collaboratively develop the Action Plan. This created a sense of ownership over the Action Plan across the sector, and it has always been pitched as a document created "by the rare disease sector, for the rare disease sector." Framing the Action Plan as a collective sector achievement is at the core of its success."

Before 2020, rare disease advocacy and messaging was "a lot more disorganised and disjointed. Many different voices, and it was quite overwhelming. Post Action Plan launch, people are using the Action Plan... this has made messaging a little bit more consistent across the board."

The Action Plan has given rare disease advocates a clear and strategic framework and has united and simplified the sector's advocacy.

Selection panellists chose this story because it demonstrates the broad reach, awareness and overarching change for the sector given the Action Plan's applicability to all rare disease stakeholders.

How Rare Voices Australia and the Action Plan Have Helped to Drive Change

Stakeholders who shared their stories were also asked how, if at all, RVA and the Action Plan have contributed to the changes they're seeing. Based on people's responses, the combined impact of RVA and the Action Plan has been transformative in uniting the sector under a national voice, legitimising rare diseases as a national priority, and driving coordinated, systemic and sustainable change.

Accelerating Change: What the Sector Has Learned and Where to Next

Implementation of the Action Plan is the shared responsibility of the entire rare disease sector. Meaningful progress across all areas of the Action Plan is underway. A clear message emerged across every story shared through the MSC process: the time is now. For a full list of practical recommendations that the rare disease sector can use as a springboard to close gaps and accelerate systemic change at scale, see Appendix 2 on page 83.

Moving forward, RVA will apply the key learnings and core principles from the MSC methodology to embed a streamlined and sustainable approach for the ongoing monitoring of sector progress – not only to understand what is changing and why, but also to identify gaps.

**Rare Voices Australia's
Impact in the 2024/25
Financial Period**

Rare Disease Advocacy and Policy

“RVA has strengthened a sense of community across the rare disease sector making organisations like ours feel like we are not alone in our advocacy.”

RVA Partner (rare disease group/organisation representative)

“RVA has been the single most influential force in rare disease advocacy in Australia.”

Clinician/Researcher

“RVA played a key role in ensuring advocacy is solutions-oriented. RVA has an excellent reputation as very reasonable, practical and focused and this is very helpful – it is worth a lot. People underestimate the importance of personal relationships, even in federal politics. If you can trust someone, you are more inclined to take their call and take steps to help.”

Politician

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

RVA provides collaborative leadership for the development and implementation of rare disease policy in Australia. This involves liaising with all governments in Australia to influence policy and improve the services impacting people living with a rare disease. RVA’s systemic focus sees us working with all key stakeholders in the rare disease sector, including people living with a rare disease, clinicians, researchers, governments, peak bodies and industry.

RVA’s political advocacy is relationship-based, with multipartisan relationships continuing to be cultivated, developed and protected since the organisation was founded in 2012. Policymakers have repeatedly communicated their preference to easily engage with the rare disease sector through a credible and informed national peak body such as RVA, with a strong understanding of policy, systems and the sector.

Throughout the 2024/25 financial period, RVA continued advocating for the best outcomes for the estimated two million Australians living with a rare disease, nearly all of whom experience long-term impacts daily – impacts that meet the Australian Government’s definition of a disability.^{1,2} As a result, RVA has dedicated significant resource into broader rare disease disability advocacy in the last financial year. The Australian Government subsequently awarded RVA with the 2-year NDIS Peer Support and Capacity Building grant in November 2024.

To achieve the best outcomes in rare disease, it's important to engage with multiple stakeholders to drive systemic change and advocate with a unified voice that is representative of the sector. Given 2025 was a Federal Election year, enabling politicians to gain a better understanding and awareness of rare diseases was more important than ever.

RVA formally collaborates with stakeholders in several ways. We engage with:

- Over 100 RVA Partners (rare disease groups/organisations) that represent their communities and Australians living with a rare disease
- Researchers through Research Partnerships and the newly created Australian Rare Disease Research Network
- A range of other stakeholders through Project Partnerships
- Industry through the Round Table of Companies

RVA's work is strengthened by the extensive rare disease and professional expertise among the RVA Board, SMAC and staffing team. RVA continues to be highly sought after by stakeholders for our rare disease policy and consumer expertise. Additionally, personnel have professional expertise in social work, psychology, research, disability, sociology, operations/compliance, web design and communications. This expertise has helped the organisation to continually expand the breadth of its work considerably since its inception.

The ongoing collaborative implementation of the Action Plan continued to be RVA's focus throughout the 2024/25 financial year. RVA led the collaborative development of the Action Plan throughout late 2018 and 2019 and is now leading its collaborative implementation.

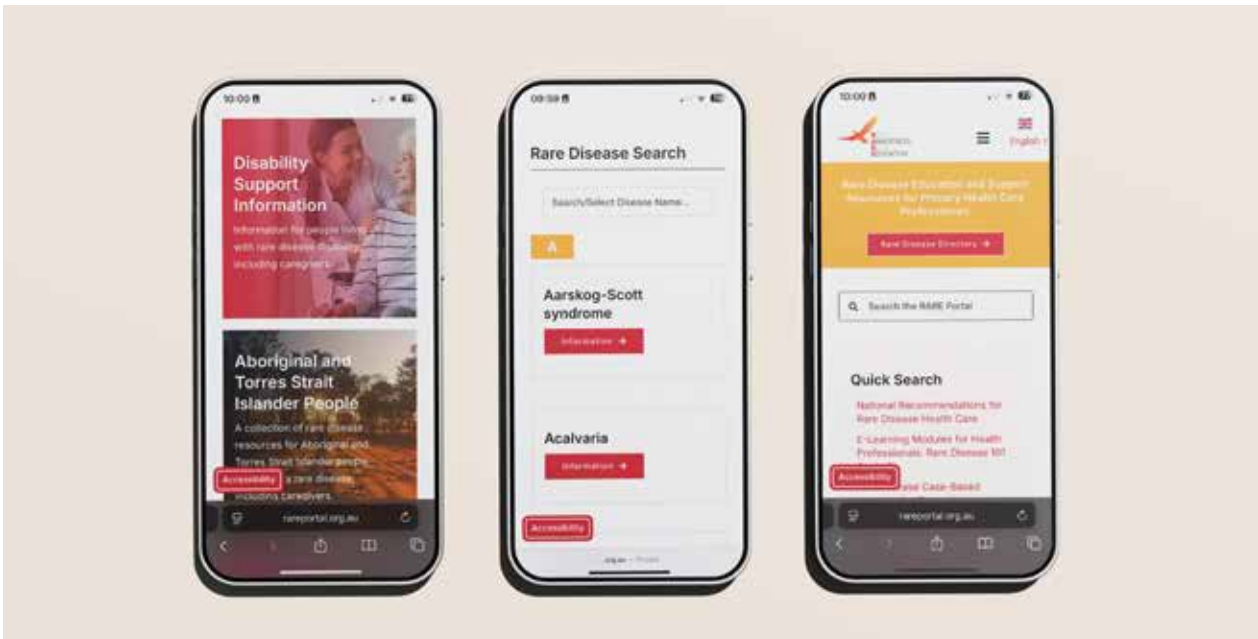
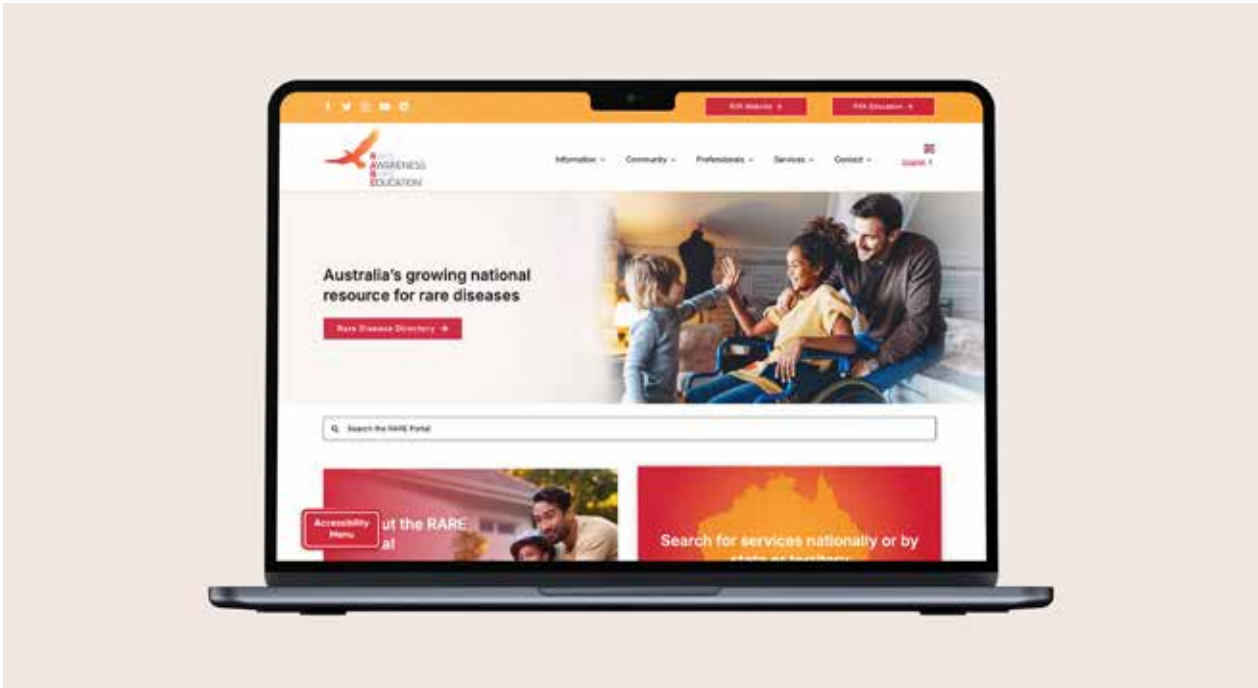
In January 2025, RVA lodged our 2025/26 Pre-Budget Submission (the Submission) to the Treasurer of Australia. The Submission consisted of three asks:

1. Investment into Rare Disease Centres of Expertise (CoE), which are identified in the Action Plan. CoE are critical to addressing gaps and providing better rare disease care.
2. A commitment to developing an Office for Rare Diseases within the Commonwealth Government.
3. Peak body funding for RVA.

These three requests align with the priorities, actions and implementation steps outlined in the Action Plan. Importantly, they would significantly accelerate its collaborative implementation, while also addressing gaps in workforce and systems capacity.

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.³

Rare Awareness Rare Education (RARE) Portal



“[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.”

RVA Partner (rare disease group/organisation representative)

Work on the [Rare Awareness Rare Education \(RARE\) Portal](#) progressed steadily throughout the 2024/25 financial period. Throughout this period, work on a website refresh was prioritised with a focus on enhancing user experience and accessibility. Thank you to all stakeholders, particularly our RVA Partner group/organisation leaders, for their willingness to work with RVA to continue developing the RARE Portal, Australia's growing national resource for rare diseases. Stakeholder input into the RARE Portal is invaluable and was central to informing the website refresh.

The “provision of an accessible multi-purpose digital repository of information and resources for rare diseases, including available care and support services” is a key deliverable of the Action Plan. The RARE Portal is a living website in ongoing development, with new information added regularly. It contains verified rare disease information and resources, customised for the Australian context. RVA has adopted an extensive multi-stakeholder approach in the collaborative development of the RARE Portal. RVA continues to work on accelerating RARE Portal development while ensuring this robust and extensive consultation process remains central to the site's ongoing development.

The RARE Portal is increasingly being recognised and used by key rare disease stakeholders, including people living with a rare disease, governments, general practitioners, other healthcare professionals, researchers, peak bodies, industry, the National Disability Insurance Agency and others.

The Navigator Project

“That is so helpful... You totally made my day! I have been struggling with what to do/feeling at a loss in the system and knowing how to navigate it.”

RARE Helpline caller

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 in 2023 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 finish on 30 June 2026. 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:** 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. Additionally, the RARE Helpline complements work already being undertaken on the RARE Portal.
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:** Crohn’s and Colitis Australia, and RVA Partners, Mito Foundation and Tuberous Sclerosis Australia, have been providing telehealth nurse services.

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

Rare Disease Disability Project

“Thank you, it is such an honour and blessing to be a part of this powerful group.”

Stakeholder Reference Group member

“Thank you so much RVA and everyone else – great session and conversations. Look forward to the next one.”

Rare Disease Disability Network member

“So grateful to have been on that call - really helped me after a few busy days ”

Rare Disease Disability Virtual Kitchen Table Peer Support Session attendee

RVA is leading the Rare Disease Disability Project (the Project) and is proudly delivering projects for the [Peer Support and Capacity Building grant](#) for the National Disability Insurance Scheme (NDIS). This exciting, first-of-its kind 2-year Project will conclude in December 2026. The Project is being guided by a Stakeholder Reference Group (SRG) comprising people with lived experience of rare disease disability and diverse representation from priority populations (Aboriginal and Torres Strait Islander people; culturally and linguistically diverse communities; people living in regional, rural and remote areas; and other groups).

Key Components of the Rare Disease Disability Project

- The SRG
- The Rare Disease Disability Network consisting of 35 actively engaged RVA Partner groups/organisations
- Rare Disease Disability Virtual Kitchen Table Peer Support Sessions
- A nationally co-designed Rare Disease Disability Toolkit

Read the latest updates for the Project on [RVA's website](#).

Broader Rare Disease Disability Advocacy

In recognition of the ongoing disability impacts on Australians living with a rare disease, in addition to leading the Project, RVA has also dedicated significant resource and focus on broader rare disease disability advocacy throughout the 2024/25 financial year.

Read RVA's disability-related submissions that focus on broader rare disease disability advocacy at [RVA's website](#).

Progressing the Australian Government's National Strategic Action Plan for Rare Diseases

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 Portal; RVA's online education website, which complements our mentorship and education activities; and engaging in the global annual Rare Disease Day campaign.

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 Rare Disease Disability Project; broader rare disease disability advocacy; and ongoing HTA advocacy and reform.

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 Rare Disease Centres of Expertise; Australia's Top 10 Rare Disease Research Priorities; and facilitating the Australian Rare Disease Research Network.

Submissions and Political Advocacy Undertaken Throughout 2024/25

- 2025/26 Pre-Budget Submission
- Australia's Top 10 Rare Disease Research Priorities
- Communique: Long-Term Strategic Guidance of Australia's Digital Health and Health Data Infrastructure
- Community Affairs Legislation Committee Inquiry on the NDIS Amendment – (Getting the NDIS Back on Track No. 1) Bill 2024
- Consultation on Proposed Changes to NDIS Act (Bill No.2) – Quality and Safeguarding Amendments – NDIS Quality and Safeguards Commission
- Department of Social Services Consultation – NDIS Supports Rules
- Department of Social Services National Carer Strategy Consultation
- Draft Lists of NDIS Supports – Department of Social Services
- Foundational Supports (General Supports) – Department of Social Services
- Genetic Discrimination in Life Insurance Treasury Consultation Collective Response
- Guidelines for Community Involvement in Genomic Research
- Joint Standing Committee on the NDIS: NDIS Participant Experience in Rural, Regional and Remote Australia
- Metabolic Medicine Developments
- National Health Genomics Policy Framework and Implementation Plan 2026-2030 – Consultation Draft
- National Carer Strategy Consultation – Department of Social Services
- National Health and Medical Research Strategy
- National Statement on Ethical Conduct in Human Research 2025
- NDIS Neurodegenerative, Palliative Care and Rare Diseases Advisory Group
- NDIS Pricing and Funding Arrangements
- NDIS Provider and Worker Registration Taskforce
- Registration of NDIS Participants Who Self-Direct Their Supports – NDIS Quality and Safeguards Commission
- Response to the Draft National Carer Strategy – Department of Social Services
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Response to Recommendations
- Tasmanian Government 20-Year Preventative Health Strategy Consultation

Rare Voices Australia Education

“[RVA] have developed so much around education for rare disease patients.”

Rare disease stakeholder

A key part of RVA’s role as the national peak body for Australians living with a rare disease is education.

Building the advocacy capacity of rare disease groups/organisations continues to be a focus, alongside education to the broader rare disease sector. All education activities align with the key priorities, actions and implementation steps in the Action Plan, particularly Action 2.1.4, “Develop the capacity of rare disease organisations to represent and advocate for people living with a rare disease and their families.”

RVA 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. RVA provides mentorship and strategy guidance for community and stakeholder engagement, policy and government relations.

Throughout the 2024/25 financial period, RVA provided a total of 88 instances of customised mentorship and strategy support to RVA Partner groups/organisations and other stakeholders. Mentoring covered a broad range of topics, including policy, systemic advocacy, rare disease disability advocacy, access to treatment, HTA, governance, NBS, applying for funding, submissions, working with researchers and more.

RVA Partner groups/organisations are encouraged to leverage RVA’s channels through social media promotion and RVA Partner Forums as well as RVA’s closed Facebook group for representatives, which both facilitate peer-to-peer networking.

Customised Education Sessions

RVA provided customised education sessions on request to 6 RVA Partner groups/organisations throughout the 2024/25 financial period. These sessions are 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.

Topics covered in the 2024/25 financial period:

- Rare disease advocacy
- Strategy development
- HTA Review and rare disease
- Development of priority population resources
- Clinical trials and rare diseases
- Mental health resources for people living with a rare disease

RVA Partner Groups/Organisations

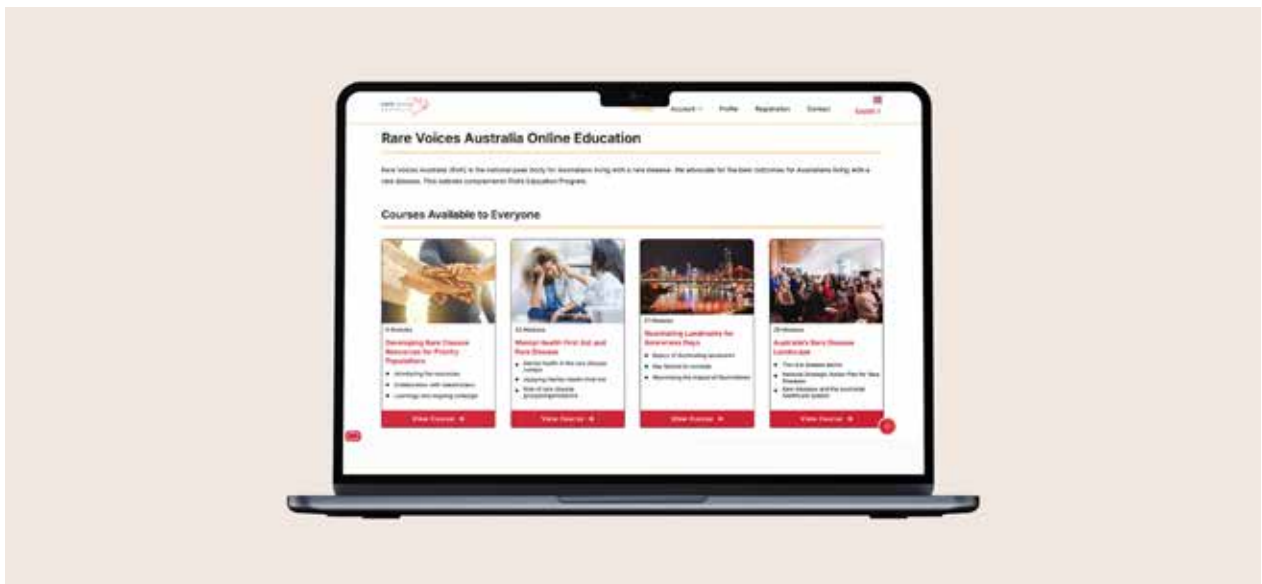
Throughout the 2024/25 financial period, RVA partnered with over 100 rare disease groups/organisations. The number of RVA Partner groups/organisations remains steady.

RVA education continues to build the capacity of rare disease groups/organisations, as outlined in the Action Plan (Action 2.1.4). RVA also provides support and guidance to several emerging rare disease groups/organisations. Additionally, we formally partner with individuals living with a rare disease (including family and carers), researchers, clinicians and other care professionals.

RVA Partner Forums

RVA Partner Forums continued throughout the 2024/25 financial period. These meetings were launched in 2024 to provide a format for leveraging the shared learnings and expertise of rare disease group/organisation representatives. Held virtually and open to up to two representatives from each RVA Partner group/organisation, the forums are well attended and are designed to create a safe space for leaders to interact and learn from each other.

RVA Online Education



[RVA's online education](#) complements the workshops, webinars and customised mentoring support provided to RVA Partner groups/organisations. In 2025, the online education website was refreshed to make the site easier to navigate and more accessible. As part of this process, several dated courses were archived. The online education website contains courses exclusively available to RVA Partners and courses available to everyone. RVA will continue adding content moving forward. The PDF resource, *A Guide for Rare Disease Organisation Leaders in Australia*, is in the process of being digitised for the website.

Rare Voices Australia and Research

“RVA’s general advocacy and their work bringing together the Action Plan and highlighting the commonalities in rare disease have helped researchers and funders change their attitudes around the importance of rare disease research and its far-reaching benefits.”

Researcher

RVA advocates for a person-centred approach to rare disease research that is aligned with the Action Plan. Our ongoing commitment to research, strong track record and relationships with researchers and health and medical research funding bodies adds credibility to our work.

RVA engages with Australian rare disease researchers through our SMAC, our Research Partnerships Program (2020 to present) and the Australian Rare Disease Research Network (ARDRN), which was launched in July 2025. Facilitated and chaired by RVA and SMAC members, Clin/Prof Gareth Baynam, Dr (Elizabeth) Emma Palmer and Dr Lisa Ewans, the ARDRN aims to broaden RVA’s reach, bringing together a community of rare disease researchers across Australia. The ARDRN offers rare disease researchers a platform to connect and stay informed about the changing rare disease policy landscape, RVA’s advocacy priorities, and to align with the Action Plan.

Rare Disease Research Advocacy

As the national peak body for Australians living with a rare disease, RVA plays a key 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 strong relationships with members of the Health and Medical Research Office and was appointed to the National Strategy Technical Reference Group for the [National Health and Medical Research Strategy](#) (the National Strategy) in July 2025. The Technical Reference Group supports the next phase of development of the National Strategy. The group will comprise representatives from selected organisations across the health and medical research sector. RVA’s appointment to the Technical Reference Group will ensure Australians living with a rare disease continue to be represented as work on the finalisation of the National Strategy continues.

RVA’s health and medical research advocacy and connections extend beyond Australia. RVA has a growing presence in the European Rare Disease Research Alliance (ERDERA), working together with members of RVA’s SMAC to set up Australia’s ERDERA National Mirror Group.

Higher Degree Researcher Placement Program

RVA is proud to support student placements to promote awareness and education of rare diseases among early to mid-career researchers. RVA recognises the importance of engaging with researchers early in their careers to embed a foundational culture of community engagement in health and medical research.

In February 2024, RVA onboarded University of Technology Sydney (UTS) Master of Genetic Counselling student, Dr Catherine Kennedy to conduct a scoping review as part of her course. Dr Kennedy's scoping review aimed to identify examples of evaluated and effective models, enablers and tools of care coordination that could be leveraged or adapted for Australians living with a rare disease. This project was driven by a known gap in care coordination for Australians living with a rare disease, strengthened through evidence from The Navigator Project and specifically, the RARE Helpline. The results of Dr Kennedy's scoping review provided useful examples, which can be leveraged in RVA's advocacy for Rare Disease Centres of Expertise.

In 2024, RVA commenced a higher degree researcher (HDR) placement program, as part of the Australian Government's [Research Training Program industry internships](#) – an initiative designed to provide HDR students with practical, industry-based experience and strengthen pathways for research-trained graduates into non-academic careers. RVA hosted Lucinda Walker, a second year PhD student from the Institute for Molecular Biosciences at the University of Queensland, from August-November 2024. During her time with RVA, Lucinda was involved in developing [RARE Portal](#) content using her scientific and research skills, participated in consultations, and presented a talk about her placement experience at the 2024 National Rare Disease Summit. In June 2025, RVA began discussions with the Institute for Molecular Biosciences to onboard a new higher degree research student, Angela Khin Oo Lwin, for a 3-month placement beginning August 2025.

The positive impact of RVA's HDR placement program is already evident. RVA's first HDR student, Lucinda Walker, not only became an RVA volunteer contributing to the [RARE Portal](#) but has since joined RVA in a paid role.

Other research activities RVA engages in:

- Advocacy to health and medical research funders for increased investment in rare disease research
- Submissions to health and medical research advocacy-related consultations
- Invite-only workshops to inform research-related government or peak body driven activities. For example, the National One Stop Shop; development of the National Health and Medical Research Strategy; and Research Australia's workshop group on the Long-term Strategic Guidance of Australia's Digital Health and Health Data Infrastructure

- Public workshops that inform research-related government or peak body driven activities. For example, the Australian Research Data Commons workshop on the Data Integration Framework
- Regular in-kind support – disseminating/promoting opportunities to be involved in research, advisory roles and mentorship roles

Rare Voices Australia-Led Research Projects

Australia's Top 10 Rare Disease Research Priorities

In 2025, The Kids Research Institute Australia (formerly the Telethon Kids Institute) and RVA published [Australia's Top 10 Rare Disease Research Priorities \(the Top 10\)](#).

The report presents the outcomes of the Rare Disease Research Priority Setting Partnership project, which adopted a modified James Lind Alliance research approach. The aim of this work was to establish Australia's Top 10 Rare Disease Research Priorities based on what matters most to people living with a rare disease, including their parents, carers, health professionals, and other rare disease community representatives. The findings from this work helps to inform RVA's advocacy to health and medical research funders and researchers. In the inaugural meeting, members of the Australian Rare Disease Research Network also recognised the Top 10 as a valuable tool for guiding future research agendas, informing funding applications and aligning with international efforts.

This work responds to a key priority under the Research and Data Pillar in the 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.

Research Partnerships

Across the 2024/25 financial year, there have been 18 requests for RVA research partnerships. 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 as 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 communicate duplication. Due to increased demand and to maximise RVA's support of our research partners, RVA began accepting new Research Partnership Proposals during set periods in 2025.

Project Partnerships

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 2025

Research Project Name	Key Investigators	Institution/Affiliation
Diagnosis4All: Co-designing Equitable and Sustainable Solutions to Reduce the Diagnostic Odyssey to MRFF 2024 Genomics Health Futures Grant Opportunity	Dr (Elizabeth) Emma Palmer, Dr Lisa Ewans, Kris Pierce, A/Prof Natalie Taylor, Krista Rescei, Dr Alan Mar, Prof Daniel McArthur, Prof Claire Wakefeild, Bronwyn Terril, Dr A/Prof Owen Siggs, A/Prof Jodie Ingles	University of New South Wales
Establishment of horizon scanning of new medical and health technologies in Australia	A/Prof Orin Chisholm, Nicoletta Conway	University of Sydney
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

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 Braithwaite	Macquarie University
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

Research Project Name	Key Investigators	Institution/Affiliation
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
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
Rare Disease Flagship Study: Preferences for Genomics Testing	Dr Simon Fifer, Maya Joshi	Community and Patient Preference Research (CaPPRe)
Rare Care Centre*	Clin/Prof Gareth Baynam	Perth Children's Hospital

*Project partnerships

Rare Voices Australia Ambassador Program

RVA first introduced the RVA Ambassador Program in 2022 to celebrate 10 years of rare disease advocacy.

To continue promoting diversity and showcasing the breadth of rare diseases and people’s unique stories, RVA refreshed the program in 2025 through an expression of interest process.

Rare Voices Australia 2025-27 Ambassadors



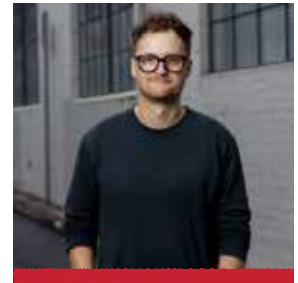
Andrew Bannister
Honorary Ambassador



Natasha Ball



Diane Cass



Archie Dowell



Lucy Evans



Lauren Geatches



Ryan Zilioli

Thank you to our inaugural ambassadors, listed below, for their invaluable contributions from 2023 to 31 December 2024:

- Katie Alexander
- Lachy Beckett
- Ryan Brown
- Ebony Callaghan
- Nathan Charles
- Tim Fulton
- Tammie Rees
- Beck Webber
- Renae Wood

Rare Voices Australia's Events

Rare Disease Day Federal Parliamentary Event

Rare Disease Day

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

A globally coordinated movement, Rare Disease Day works towards equity in social opportunity, healthcare, and access to diagnosis for people living with a rare disease.

RVA typically organises a Federal Parliamentary Event to mark Rare Disease Day.

As the national peak body for Australians living with a rare disease, RVA is the national alliance representing Australia in annual Rare Disease Day preparations. We are also on the Rare Disease Day Steering Committee, which takes a longer-term strategic view of the campaign.



[Rare Disease Day 2025 Video](#)

The official 2025 Rare Disease Day video showcased people living with a range of rare diseases from all around the world, including inaugural RVA Ambassador, Tammie Rees, and her daughter Ava who lives with Maple Syrup Urine Disease, a rare metabolic disease. Tammie and Ava were also featured in the official campaign promotional material for 2025.

Global Chain of Lights and Landmark Illuminations in Australia

The Global Chain of Lights is a key Rare Disease Day initiative, with the global community uniting to illuminate landmarks in support of people living with a rare disease. RVA thank the small group of volunteers who coordinated organising illuminations in Australia in 2025 with support from RVA as needed.



Federal Parliamentary Event

“RVA has provided forums such as [the] Summit and Parliamentary [Event] where patient groups can learn from each other, increase knowledge and capacity, and have their experiences validated – these are invaluable.”

RVA Partner (rare disease group/organisation representative)

Parliamentary Events are important as they enable stakeholders to meet and speak with parliamentarians to further highlight rare diseases. RVA’s 2025 Parliamentary Event was held on 11 February due to the limited Federal Parliament Sitting Calendar.

Despite how busy the week was in Canberra given 2025 was a Federal Election year, the event was one of RVA’s most well attended gatherings. Over 100 guests joined RVA, including people living with a rare disease; parliamentarians; departmental staff; peak bodies;

researchers; clinicians; and industry. This is testament to the momentum gained by the rare disease sector in recent years.

Read the highlights and see more photos on [RVA's website](#).



Acknowledgements

RVA thanks the following parliamentarians who spoke at the Parliamentary Event:

- Hon Mark Butler MP, Minister for Health and Aged Care in the 47th Parliament
- Senator the Hon Anne Ruston, Shadow Minister for Health and Aged Care in the 47th Parliament
- Dr Mike Freeland MP, Co-Chair of the Parliamentary Friends of Australians Living with Rare Diseases and Member for Macarthur in the 47th Parliament
- Dr Monique Ryan, Co-Chair of the Parliamentary Friends of Australians Living with Rare Diseases and Member for Kooyong in the 47th Parliament
- Senator Wendy Askew, Co-Chair of the Parliamentary Friends of Australians Living with Rare Diseases and Senator for Tasmania in the 47th Parliament

We also thank our other speakers:

- Dr Tarun Weeramanthri AM, RVA's Chair
- Fiona Lawton, RVA's Disability Advocacy Manager

Additionally, special thanks to our RVA Partners (rare disease group/organisation leaders), the RVA Board, our SMAC members and staff who joined us for the Parliamentary Event.

Parliamentary Friends of Australians Living with Rare Diseases

The 2025 Federal Election on 3 May meant the Parliamentary Event was the final gathering of the Parliamentary Friends of Australians Living with Rare Diseases in the 47th Parliament. All Parliamentary Friendship Groups need to be reestablished after every Federal Election.

Thank you to the Co-Chairs in the 47th Parliament – Dr Freeland, Dr Ryan and Senator Askew – for their ongoing support of Australians living with a rare disease and RVA.

2024 National Rare Disease Summit

RVA hosts the biennial National Rare Disease Summit (the Summit), a key event in the Australian rare disease calendar.

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 aligned with achieving the best outcomes for Australians living with a rare disease. The next Summit is scheduled for 2026.

The 2024 National Rare Disease Summit was held on 15 and 16 November in Brisbane. The 2024 theme was Progress Beyond Policy. Implementation of the Action Plan requires ongoing collaboration and support from the entire rare disease sector to achieve its vision: The best possible health and wellbeing outcomes for Australians living with a rare disease. The Summit provided the rare disease sector with a fantastic opportunity to progress the collaborative implementation of the Action Plan, while maintaining a person-centred approach.



RVA thanks the diverse range of speakers who shared their expertise and perspectives at the 2024 Summit, particularly former RVA Ambassador Ryan Brown who shared his personal story. Special thanks to our other inaugural RVA Ambassadors who also joined us. Additionally, we thank Senator Askew who joined us in person and spoke on behalf of the Parliamentary Friends of Australians Living with Rare Diseases in the 47th Parliament.

RVA also thanks Minister Butler and Senator Ruston who were unable to join us but provided recorded messages.



What Attendees Said About the 2024 National Rare Disease Summit

"Thank you for a wonderful day yesterday and congratulations on a fantastic event."

RVA Partner (rare disease group/organisation representative)

"... two brilliant days at the National Rare Disease Summit in Brisbane, coordinated by the incredible Rare Voices Australia, with so many passionate contributions from the whole sector, patient groups, government, clinicians, researchers, industry. The meeting was a stark reminder that so much of the care and progress for people with rare diseases comes from ridiculously dedicated people who push no matter what, including fighting against inflexible and outdated systems."

Clinician/Researcher

"Felt so honoured to be on a panel and it has already been so beneficial to us so thank you again so very much for the opportunity. Enjoy some downtime after what was a brilliant few days."

RVA Partner (rare disease group/organisation representative)

"A short note to congratulate you and your team on hosting a wonderful conference in Brisbane. My first Rare Voices Australia conference, but not my last. I learned so much about rare diseases, the research and collaboration that's going on and the patient and persistent advocacy."

Industry

2025 Rare Disease Disability Network Showcase

RVA hosted an end-of-year in-person Rare Disease Disability Network Showcase on 2 December 2025 in Brisbane, ahead of the International Day of People with Disability on 3 December.

The RDDN Showcase brought together leaders from rare disease groups/organisations and other invited sector stakeholders for the first time in person. RVA thanks everyone who attended and spoke at the inaugural event, which showcased:

- Several initial resources that form a nationally co-designed Rare Disease Disability Toolkit
- Projects undertaken by RVA Partners as part of Grant Round 1 of the Rare Disease Disability Project (the Project)

Learn more about the Project via [RVA's website](#).

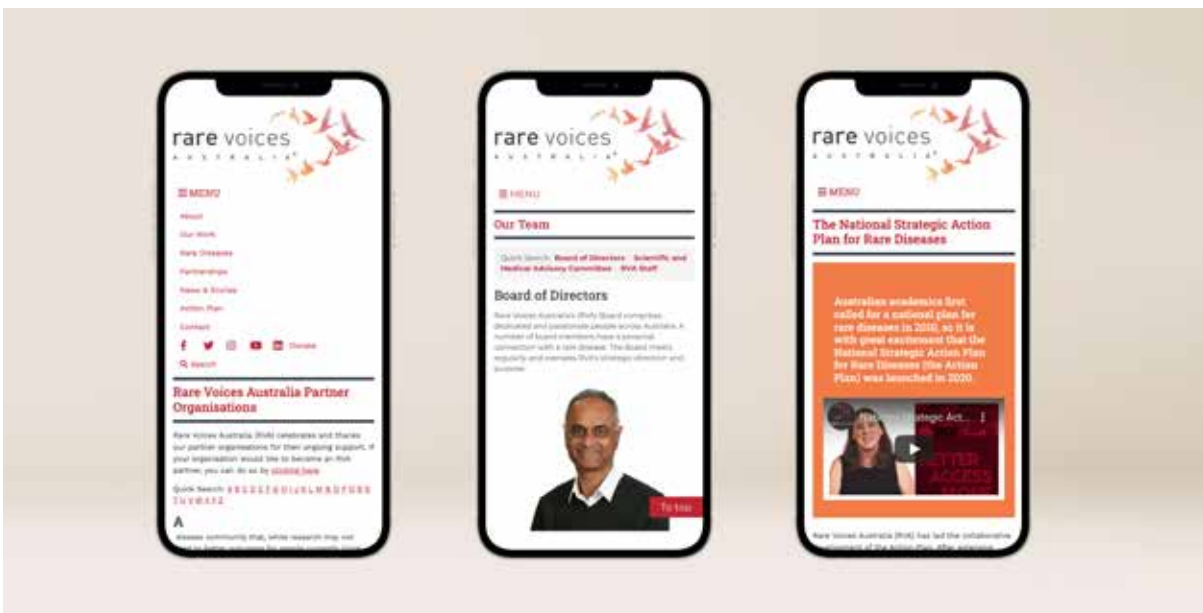
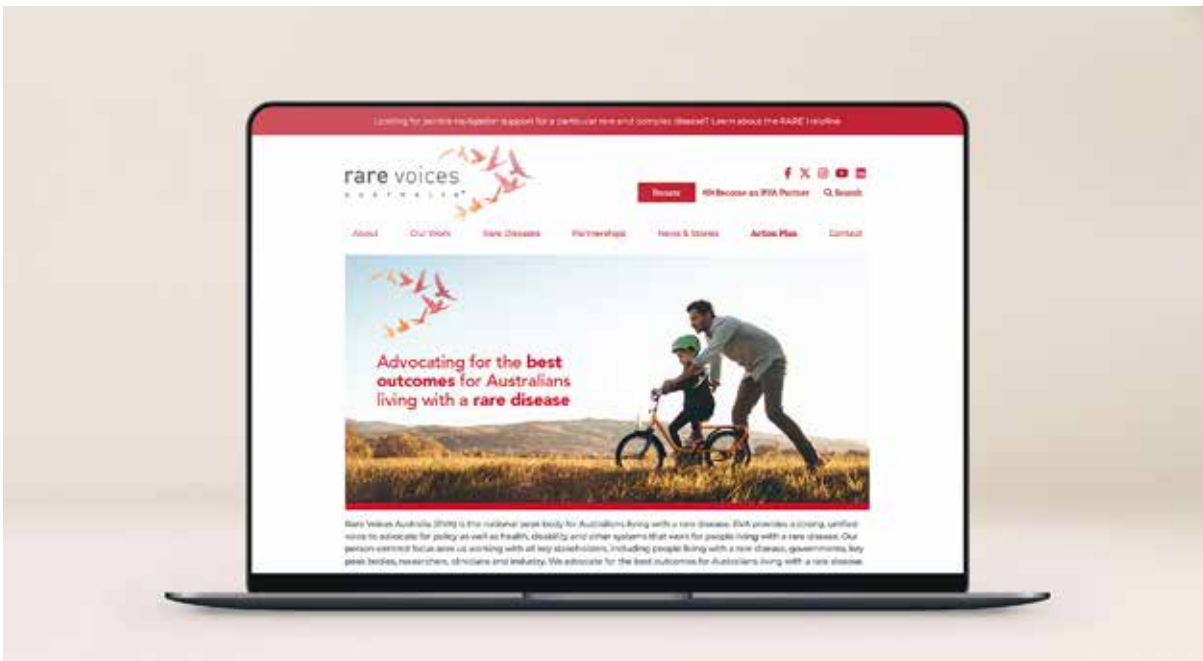


Rare Voices Australia's Communications

Channels

Main Website





[RVA's main website](#) continued to be a key source of information throughout the 2024/25 financial period for Australians living with a rare disease with 49,000 active users. A focus throughout this period was to enhance user experience and accessibility needs. RVA will be rebuilding our main website in 2026 to further enhance user experience, accessibility and better link to the [RARE Portal](#) and [RVA's online education site](#).



Social Media

RVA's social media presence continued to grow steadily throughout the 2024/25 financial period. Social media is another important touchpoint for RVA to reach a wide range of rare disease stakeholders. All RVA's reach across social media is organic.

Below is a follower breakdown by platform at the time of writing:

			
Facebook	Instagram	Linkedin	X
11,946 followers	2,182 followers	2,182 followers	2,847 followers

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 relevant to the sector.

Monthly eNewsletter

The number of subscribers to RVA's monthly eNewsletter continues to grow. The database consists of all rare disease stakeholders and each edition includes:

- A personal story of the month written by an Australian living with a rare disease
- An editorial written by RVA's Chief Executive Officer
- The latest [RARE Portal](#) updates
- Articles with links to the Action Plan
- A snapshot of what RVA has been working on
- Rare Disease Disability Project News
- Information about the RARE Helpline
- RVA Partner group/organisation news
- Other information relevant to rare diseases both in Australia and globally
- The course of the month for the [online education website](#)

Relevant content from the eNewsletter is cross promoted via RVA's social media channels. An archive of recent newsletters spanning the last 12 months is available on [RVA's website](#).

Rare Awareness Rare Education (RARE) Portal eNewsletter

RVA distributes a mid and end-of-year [RARE Portal](#) eNewsletter update. Relevant content is also cross promoted via RVA's social media channels.

The mid-year update in 2025 focused on the RARE Portal refresh and requested feedback from stakeholders. The RARE Portal eNewsletter database continues to grow steadily. You can view the RARE Portal eNewsletter archive spanning the last 12 months on the [RARE Portal Editorial Team page](#).

Media

As the national peak body for Australians living with a rare disease, the Australian media continues to reach out to RVA for commentary regarding rare disease-related issues. RVA adopts a considered, person-centred media approach to enable thoughtful, strategic communication that contributes to achieving the best outcomes for Australians living with a rare disease. Wherever possible, RVA facilitates connections between media and our RVA Partner groups/organisations in instances when they are best placed to provide commentary to media. We also provide mentorship to RVA Partner groups/organisations regarding engaging with the media as needed.

Committee/Advisory Group Participation

RVA has provided input on the following advisory committees/consultations through the 2024/25 financial period:

- AusUDN Consumer Group
- Department of Social Services – Draft Lists of NDIS Supports
- Department of Social Services – Foundational Supports (General Supports) Consultation
- Department of Social Services – National Carer Strategy Consultation
- EpiGNs Community Advisory Group
- European Rare Disease Research Alliance Survey
- Genetics Services Western Australia Codesign Working Group
- Genomics4Newborns Stakeholder Advisory Group
- Genomics in General Practice Steering Group
- Genomics of Rare Disease Registry Advisory Committee (Garvan)
- GeneEQUAL Advisory Board
- GenSCAN ELSI Working Group
- GenSCAN Health Policy and Economics Working Group

- Independent Health and Aged Care Pricing Authority – NDIS Pricing and Funding Arrangements
- LINEAGE Study Project Advisory Committee
- McKell Institute Rare Disease Expert Advisory Group
- MRFF, Genomics Health Futures Mission Implementation Plan
- National Congenital Anomaly Advisory Group
- National Health and Medical Research Strategy Surveys
- NDIS Quality and Safeguards Commission – Consultation on Proposed Changes to NDIS Act (Bill No.2) - Quality and Safeguarding Amendments
- NDIS Quality and Safeguards Commission – Registration of NDIS Participants Who Self-Direct Their Supports
- Neurodegenerative, Palliative Care and Rare Disease Disability Advisory Group
- NurtureNextGen Community Advisory Group
- Patient Voice Initiative: Patient Organisation Meeting
- PERSYST Community Advisory Group
- Pilot Study for Involve Australia
- Prader Willi Centre of Excellence Advisory Group
- Rare Disease Awareness, Education, Support and Training (RArEST) Steering Committee (UNSW)
- RNA Institute End User Advisory Committee
- Queensland Health Disability Interface Advisory Group
- Queensland NBS Advisory Group
- RDNOW Consumer Advisory Group
- RVA Rare Disease Disability Roundtable
- UTS Genetic Counselling Industry Advisory Board

Relevant individual appointments:

- HTA Consumer Consultative Committee (RVA's Chief Executive Officer)
- HTA Review Implementation Advisory Group – consumer nominee (RVA's Chief Executive Officer)
- LSDP Expert Panel – consumer nominee (RVA's Chief Executive Officer)
- National Strategy Technical Reference Group for the National Health and Medical Research Strategy (RVA's Research and Evaluation Manager)
- NDIS Co-Design Working Group: Workforce Capability and Culture (RVA's Disability Advocacy Manager)

- NDIS Neurodegenerative, Palliative Care and Rare Diseases Advisory Group (RVA's Disability Advocacy Manager)
- PBAC Nutritional Products Working Group (RVA's Education and Advocacy Manager)
- Queensland Government Health and Disability Advisory Group (RVA's Disability Advocacy Manager)

Rare Voices Australia Speaking Engagements

- Alexion's Rare Disease Policy Roundtable with the Minister for Health and Aged Care (in the 47th Parliament), the Hon Mark Butler MP
- Alexion's Rare Disease Policy Roundtable with the Shadow Minister for Health and Aged Care (in the 47th Parliament), Senator the Hon Anne Ruston
- AstraZeneca Conference – Leading the Future of Healthcare
- Genomics Education Network 2024 – Rare Disease Education Resources for Healthcare Professionals
- HTA Consumer Consultative Committee Annual Meeting 2024 – The Evolving Influence of the Consumer Led Sector
- Human Genetics Society of Australasia Annual Scientific Meeting 2024
- National Paediatric Medicines Forum 2024 – Access to Rare Disease Therapies Advocacy
- Product Life Group Leaders Breakfast – Challenges and Opportunities on Patient Advocacy and Engagement
- Rare Disease NSW Rare Disease Day Events 2025 – What's New in Rare Disease? and Resources for Families
- Rural Health Alliance National Conference 2024 – Priority Population Rare Disease Resources
- 3rd Autoinflammatory Disease Symposium

Acknowledgements

Acknowledgements

RVA values our ongoing relationships and formal partnerships with stakeholders, including our RVA Partner groups/organisations and individual partners (individuals living with a rare disease, including families and carers, researchers, clinicians and other care professionals).

2024/25 RVA Partner Groups/Organisations:

Alpha-1 Organisation Australia	DEBRA Australia
Angelina Cask Neurological Research Foundation	Duchenne Australia
Angelman Syndrome Association Australia	Dystonia Network of Australia
ausEE Inc.	EB Research Partnership
Australian Addisons Disease Association	Fabry Australia
Australian and New Zealand Vasculitis Society	Fanconi Anaemia Support
Australian Cystinosis Support Group	FH Australia
Australian Dysphonia Network	FMF and AID Australia
Australian NPC Disease Foundation	FOP Australia
Australian Pituitary Foundation	Foundation for Angelman Syndrome Therapeutics
Australian Pompe Association	FOXG1 Research Foundation Australia
Batten Disease Support & Research	Fragile X Association of Australia
Brain Tumour Alliance Australia	Friedreich Ataxia Research Association
CDH Australia	FSHD Global Research Foundation
CHARGE Syndrome Association of Australasia	Gaucher Association of Australia and New Zealand
Childhood Dementia Initiative	Genetic Alliance Australia
Children's Tumour Foundation of Australia	Genetic Cures for Kids (Our Moon's Mission)
Connective Tissue Disorders Network Australia (CTDNA)	Genetic Support Network Victoria
Cure EB Charity Foundation	HAE Australasia Ltd
Cystic Fibrosis Queensland	Haemochromatosis Australia
Cystic Fibrosis WA	HCU Network Australia
Daniel Ferguson Foundation	Huntington's Australia

Immune Deficiencies Foundation Australia	PNH Support Association of Australia
ISMRD	Prader Willi Research Foundation
ITP Australia	Prader-willi Syndrome Association of Victoria
Jack's Butterflies	PSC Support Australia
Kennedy's Disease Downunder	Racing for MNDi
Leukodystrophy Australia	Rare Find Foundation
Maddie Riewoldt's Vision	Rett Syndrome Association of Australia
Malan Syndrome Foundation	SATB2 Gene Foundation Australia
Metabolic Dietary Disorders Association	Save Our Sons Duchenne Foundation
Mito Foundation	Scleroderma Association of Qld
MND Australia	Scleroderma Australia
MPN Alliance Australia	Sotos Syndrome Australasia
Multiple Sclerosis Australia	Spinal CSF Leak Australia
Muscular Dystrophy Australia	Spinal Muscular Atrophy Australia
Muscular Dystrophy Foundation	STXBP1 Australia
Muscular Dystrophy Qld	Superficial Siderosis Research Alliance
Muscular Dystrophy Tasmania	Syndromes Without A Name
Myasthenia Alliance Australia	Thalassaemia and Sickle Cell Australia
Myasthenia Gravis Association Qld	The Australasian Mastocytosis Society
Neuromuscular WA	The Australian Cystinosis Foundation
Parenteral Nutrition Down Under	The Homer Hack
PCD Australia	Tuberous Sclerosis Australia
PFIC Australia	VCFS 22q11 Foundation
PHA Australia	XLH Australia

Individual Partners

RVA formally partners with individuals living with a rare disease for which:

- There is no support group/organisation, or
- They are not a member of an existing support group/organisation, or
- The support group/organisation is not an RVA Partner group/organisation.

Additionally, we partner with individuals who are researchers, clinicians and other care professionals.

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

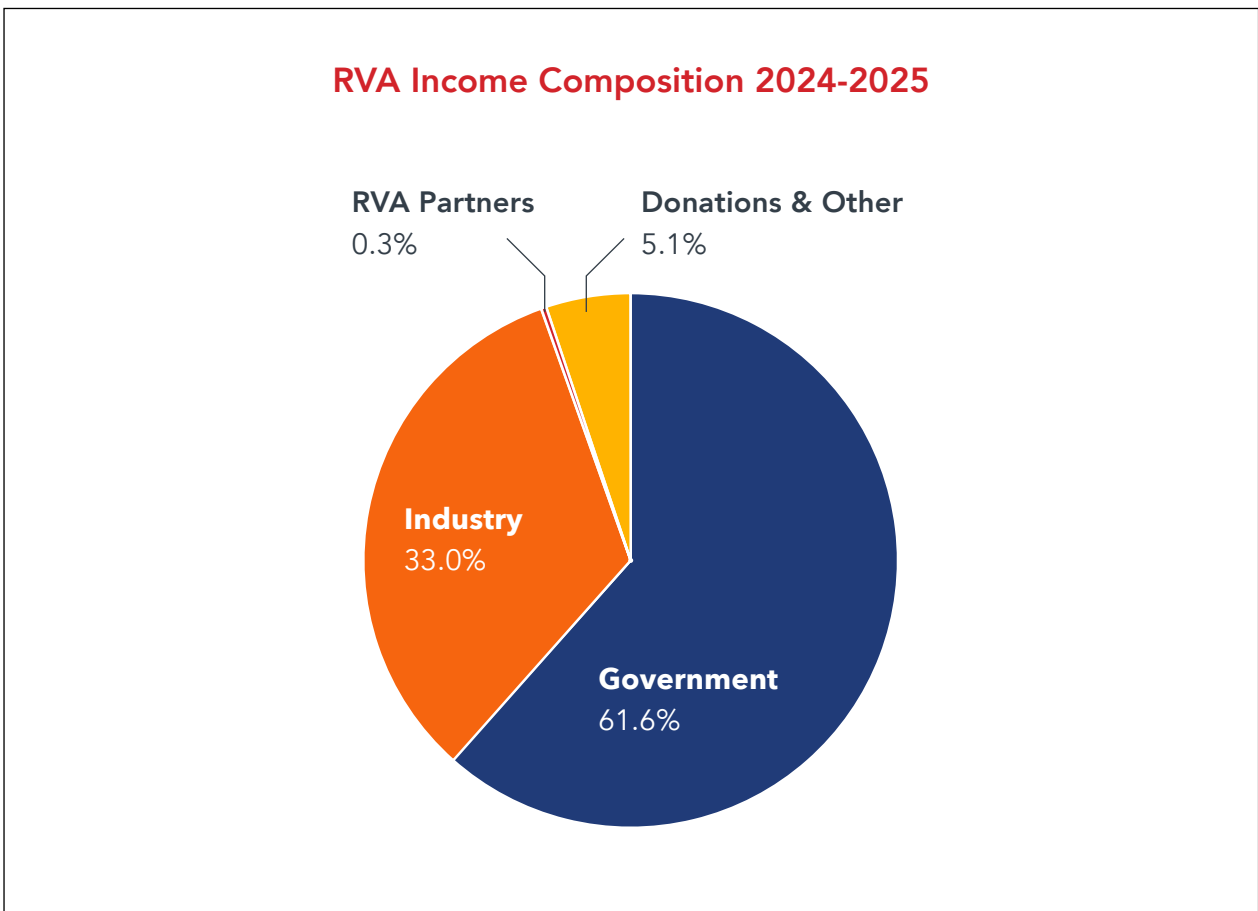
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2. Australian Bureau of Statistics. Disability, ageing and carers, Australia: Summary of findings. July 2024. Accessed on 16 October. Available from: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>
3. Rare Voices Australia. Rare Voices Australia Strategic Plan 2024-2027. 7 p. Available from: https://rarevoices.org.au/wp-content/uploads/2024/08/StrategicPlan_2024-27_PublicVersion.pdf
4. Davies, Rick. The 'Most Significant Change' (MSC) Technique: A Guide to Its Use. 2005. 105 p. Available from: https://www.researchgate.net/publication/275409002_The_'Most_Significant_Change'_MSC_Technique_A_Guide_to_Its_Use

Financials

Income of RVA

RVA receives income from direct grants and partnerships with government, and from the pharmaceutical industry. RVA also receives funds from public donations, RVA Partner fees and bank interest.



RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Annual Report
For the year ended 30 June 2025



M G ARTHUR & ASSOCIATES

Chartered Accountants | Tax and Business Advisors

PO BOX 8015 NORWEST NSW 2153
ABN 78 678 848 761

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303

Annual Report for the year ended 30 June 2025

CONTENTS

Director's Report

Statement of Comprehensive Income

Statement of Financial Position

Statement of Changes in Equity

Statement of Cash Flows

Notes to the Financial Statements

Detailed Profit & Loss Statement

Directors' Declaration

Auditor's Independence Declaration

Independent Auditor's Review Report

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 2025.

Directors

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

Andre Carvalho (effective from 21/08/2024)
Andrew Carter
Carol Wicking (resigned on 14/11/2024)
Eric Morand (resigned on 14/11/2024)
Joanna Betteridge
Kate Henderson (resigned on 21/02/2025)
Roxane Marcelle-Shaw (effective from 21/08/2024)
Tarun Weeramanthri (effective from 14/11/2024)
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 2025 amounted to \$354,651.
(30 June 2024 - \$547,184)

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.

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

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 directors.



Dr Tarun Weeramanthri AM

Director

Dated 22 October 2025

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Statement of Comprehensive Income
For the year ended 30 June 2025

	Note	2025 \$	2024 \$
Revenue	3	1,992,151	2,137,680
Other revenue	3	100,702	70,274
Depreciation		(4,674)	(7,478)
Employee benefit expenses		(1,004,346)	(876,737)
Other expenses		(729,182)	(776,555)
Profit before income tax		354,651	547,184
Income tax expense		-	-
Profit for the year after income tax		354,651	547,184
Other Comprehensive Income for the year		-	-
Total Comprehensive Income for the year		354,651	547,184

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 2025

	Note	2025 \$	2024 \$
Assets			
Current Assets			
Cash and cash equivalents	4	3,062,041	2,542,282
Trade and other receivables	5	33,962	1,340
Total Current Assets		3,096,003	2,543,622
Non-Current Assets			
Property, plant and equipment	6	32,390	9,314
Total Non-Current Assets		32,390	9,314
Total Assets		3,128,393	2,552,936
Liabilities			
Current Liabilities			
Trade and other payables	7	1,208,848	1,026,112
Provisions	8	126,262	88,192
Total Current Liabilities		1,335,110	1,114,304
Total Liabilities		1,335,110	1,114,304
Net Assets		1,793,283	1,438,632
Equity			
Retained profits		1,793,283	1,438,632
Total Equity		1,793,283	1,438,632

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 2025

	Other Reserves	Retained Earnings	Total
Balance at 1 July 2023	-	891,448	891,448
Comprehensive income			
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
Comprehensive income			
Profit attributable to the members	-	354,651	354,651
Other comprehensive income for the year	-	-	-
Total comprehensive income for the year attributable to members of the entity	-	354,651	354,651
Balance at 30 June 2025	-	1,793,283	1,793,283

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 2025

	2025	2024
	\$	\$
Cash Flow From Operating Activities		
Receipts from customers	1,983,271	2,190,388
Payments to suppliers and employees	(1,512,722)	(2,048,356)
Interest received	76,960	38,391
Net cash provided by (used in) operating activities (note 9)	<u>547,509</u>	<u>180,422</u>
Cash Flow From Investing Activities		
Payment for:		
Payments for property, plant and equipment	(27,750)	(12,496)
Net cash provided by (used in) investing activities	<u>(27,750)</u>	<u>(12,496)</u>
Cash Flow From Financing Activities		
Repayment of borrowings	-	-
Net cash provided by (used in) financing activities	-	-
Net increase (decrease) in cash held	519,759	167,927
Cash at the beginning of the year	2,542,282	2,374,356
Cash at the end of the year (note 4)	<u>3,062,041</u>	<u>2,542,282</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 2025

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.

Note 2: Summary of Significant Accounting Policies

a. Revenue & Other Income

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 2025

a. Revenue & Other Income (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).

Interest

Interest revenue is recognized using the effective interest method, which for floating rate financial assets is the rate inherent in the instrument. All revenue is stated net of the amount of goods and services tax (GST).

Other Income

Other income is recognized on an accruals basis when the Company is entitled to it.

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.

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 2025**

NOTE 2: Summary of Significant Accounting Policies (continued)

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.

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 2025**

NOTE 2: Summary of 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.

j. Employee benefits

Provision is made for the Company's liability for employee benefits, those benefits that are expected to be wholly settled within one year have been measured at the amounts expected to be paid when the liability is settled. The company's obligations for short-term employee benefits such as wages and salaries are recognized as a part of current trade and other payables in the statement of financial position.

Employee benefits expected to be settled more than one year after the end of the reporting period have been measured at the present value of the estimated future cash outflows to be made for those benefits. In determining the liability, consideration is given to employee wage increases and the probability that the employee may satisfy vesting requirements. Cashflows are discounted using market yields on high quality corporate bond rates incorporating bonds rated AAA or AA by credit agencies, with terms to maturity that match the expected timing of cashflows. Changes in the measurement of the liability are recognized in profit or loss.

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 2025

	2025 \$	2024 \$
Note 3: Revenue and other income		
Revenue:		
Grants, sponsorships and memberships	1,701,352	1,993,680
Special projects	290,799	144,000
	<u>1,992,151</u>	<u>2,137,680</u>
Other revenue:		
Donations	23,721	31,866
Interest revenue	76,959	38,391
Other revenue	22	17
	<u>100,702</u>	<u>70,274</u>
Note 4: Cash and cash equivalents		
Bank accounts:		
WBC cheque Account	57,483	19,960
WBC cash Reserve Account	1,964,266	1,493,244
WBC debit card	2,306	3,106
Stripe AUD	465	581
Other cash items:		
Term Deposits	1,037,521	1,025,391
	<u>3,062,041</u>	<u>2,542,282</u>
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	3,062,041	2,542,282
	<u>3,062,041</u>	<u>2,542,282</u>
Note 5: Trade and other receivables		
Current		
Trade debtors	33,962	1,340
	<u>33,962</u>	<u>1,340</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 2025

	2025 \$	2024 \$
Note 6: Property, plant and equipment		
Plant and equipment:		
- At cost	20,682	20,682
- Less: accumulated depreciation	(19,484)	(18,286)
Office equipment:		
- At cost	23,028	23,028
- Less: accumulated depreciation	(19,569)	(16,110)
Website Education Portal		
-At cost	15,500	-
- Less : accumulated depreciation	(17)	-
Website Rare Portal		
	12,250	-
	<u>32,390</u>	<u>9,314</u>
Note 7: Trade and other payables		
Current		
Trade creditors	16,418	8,019
Revenue received in advance	1,086,000	940,000
ATO liability	79,587	56,475
GST payable	1,618	(604)
Superannuation payable	25,225	22,222
	<u>1,208,848</u>	<u>1,026,112</u>
Note 8: Provisions		
Current		
Provision for annual leave	81,166	62,489
Provision for long service leave	45,097	25,703
	<u>126,263</u>	<u>88,192</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 2025

	2025 \$	2024 \$
Note 9. Reconciliation of cash		
Reconciliation of net cash provided by/used in operating activities to net profit		
Profit (loss) after income tax	354,651	547,184
Non-cash flows in profit		
Depreciation	4,674	7,478
Changes in assets and liabilities:		
(Increase) decrease in trade and other receivables	(32,622)	20,825
Increase (decrease) in trade and other payables	182,736	(399,927)
Increase (decrease) in sundry provisions	38,070	4,862
Net cash provided by operating activities	547,509	180,422
Increase (decrease) in property, plant and equipment	(27,750)	(12,496)
Net cash provided by investing activities	(27,750)	(12,496)
Net increase (decrease) in cash held	519,759	167,926
Note 10. Remuneration of auditors		
During the financial year, the following fees were paid or payable for services provided by DM French & NC French, the reviewer of the company:		
Audit/review services – DM French & NC French	1,200	2,400
Audit/review of the financial statements	1,200	2,400

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 2025

	2025 \$	2024 \$
Note 11. Key management personnel disclosures		
The aggregate compensation (including salaries and superannuation) made to directors and other members of key management personnel of the company is set out below:		
Key management personnel	155,687	146,809
	<u>155,687</u>	<u>146,809</u>

Note 12. 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 2025

	2025	2024
	\$	\$
Income		
Grants, sponsorships and memberships	1,701,352	1,993,680
Special projects	290,799	144,000
Donations and Partners	23,721	31,866
Interest received	76,959	38,391
Other revenue	22	17
	<u>2,092,853</u>	<u>2,207,954</u>
Expenditure		
Accountancy, audit and legal	27,370	27,090
Consultancy	1,732	64,705
Bank fees	1,242	1,163
Depreciation	4,674	7,478
CRM costs	4,449	4,255
Computer & IT expenses	28,669	13,783
Board/governance expenses	5,519	1,988
Office supplies	3,026	3,769
Telephone and internet	9,305	9,048
Travel and accommodation	19,286	25,723
Insurance	16,508	13,353
Subscriptions	13,052	14,703
Summit expenses	124,418	36,597
Publications and resource development	6,323	112,058
Project partners	455,680	425,250
Website cost	5,479	6,583
Salaries and wages	866,623	785,712
Annual leave provision	18,676	667
Long service leave provision	19,394	4,194
Superannuation	99,655	86,164
Other expenses	7,121	16,487
	<u>1,738,202</u>	<u>1,660,771</u>
PROFIT / (LOSS) FROM ORDINARY ACTIVITIES BEFORE INCOME TAX	<u>354,651</u>	<u>547,183</u>

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 2025 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2025 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 22nd October 2025.



Dr Tarun Weeramanthri AM

Director

Dated: 22 October 2025

The accompanying notes form part of these financial statements.

Auditor's Independence Declaration

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 2025, 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

22nd October 2025



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Independent Auditor's Review Report

French & French
Accounting, Tax & Advisory

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

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

Report on the financial report

We have reviewed the accompanying financial report, being a general purpose financial report, of Rare Voices Australia Limited (the Company) which comprises the statement of financial position as at 30 June 2025, 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 2025 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 a review 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 a review. 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 2025 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
22nd October 2025



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Appendices

Appendix 1: Most Significant Change Story Summaries

Knowledge and Capacity Building

- The establishment of a national rare disease charity in 2024 marked a major turning point for a group of rare diseases, providing the first formal national advocacy for this community who had relied on informal Facebook groups for support and information.
- The RARE Portal has provided a platform for co-developing evidence-based rare disease information tailored to the Australian context. Before this, there was no guidance available for adults living with the condition our organisation represents.
- The formation of a national and internationally connected multidisciplinary network of rare disease expertise for a group of rare diseases has led to life-changing diagnoses and treatments. It has enabled families to access local physicians supported by a global network of knowledge to guide their care.
- The opportunity to co-develop a page for our rare disease on the RARE Portal has led to greater recognition of our community among primary care clinicians, resulting in more timely diagnoses.

System and Policy Influence

- Growing recognition of rare disease in the research community and among health and medical research funders, including the Medical Research Future Fund, has led to targeted investment in rare disease research and the establishment of rare disease research flagships across Australian institutions and universities.
- The Action Plan brought everything into focus. It gave a rare disease organisation a clear structure and validation for its work. It also helped drive optimism among patients, families and clinicians, government recognition as well as targeted investment in rare disease clinical trials.
- The transformation of Australia's Newborn Bloodspot Screening Program from a patchwork of inconsistent state-based practices to a nationally coordinated, transparent and equitable system has created a clear path forward, ensuring all Australian babies can access potentially life-saving screening and timely care.
- The Action Plan has provided a unifying framework and language that shifted the sector from desperation to constructive, solution-focused conversations. Through the Action Plan, rare disease communities, often isolated and marginalised, now feel heard and part of a collective movement with influence.
- The Action Plan has driven unprecedented system-wide buy-in, formally recognising rare diseases as a distinct policy domain. Combined with RVA's coordinated advocacy, it has enabled whole-of-system changes for Australians living with a rare disease.

Empowerment and Participation

- The creation of a new rare disease organisation transformed family isolation into nationwide impact – establishing telehealth nursing, peer support, and a research centre that has driven over \$30 million in funding and two clinical trials.
- A scientist’s personal connection inspired a career pivot into rare disease therapeutics to drive n-of-one treatments and help build a coordinated national approach to future rare disease therapies.
- The establishment of a rare disease organisation transformed a once-isolated group of families who were often dismissed by the health system, into a united, visible, and influential community voice that now drives collective advocacy, collaboration and systemic change.
- The Action Plan unified Australia’s rare disease sector with a shared framework and voice, strengthening collaboration, credibility and visibility across the community, governments and the public. It positioned RVA as the recognised national peak body driving coordinated progress.

Equity and Access

- In 2023, after many years of advocacy, new Medicare item numbers were introduced to fund genetic testing for more than 350 rare diseases that can affect families for generations, significantly reducing the impact of the diagnostic odyssey.
- National implementation of newborn bloodspot screening for a rare life-limiting condition has been life-changing for families, enabling timely access to treatment and preventing irreversible complications that cause lifelong health issues and disability, giving children the chance to survive beyond their third birthday.
- People living with rare disease still face stigma, and dismissal in frontline care, so system-level progress is not consistently reaching day-to-day interactions with GPs and emergency departments. Even with a confirmed diagnosis, patients are being accused of exaggerating or fabricating symptoms, creating barriers to timely and appropriate treatment.
- A rare disease community organisation successfully advocated for reimbursed access to a treatment for their community.*
*Since collecting this story, this achievement has expanded to include reimbursed access to all available therapies for this community.
- National implementation of NBS for a severe life-limiting rare disease has enabled families to access timely, life-saving treatment—saving children’s lives and reducing the burden on families and the health system.

Collaboration and Innovation

- A small, rare disease organisation united families, clinicians and researchers across Australia – turning shared challenges into collective strength. Through collaboration with larger groups and the awareness created by the Action Plan, the community’s voice was amplified, new resources were developed, and compassionate access to life-saving treatment was achieved.
- Australia became the first country worldwide to host four clinical trials for one rare disease – an achievement driven by a decade of community-led advocacy, collaboration, and community education that transformed doubt into real treatment opportunities.
- A Medical Research Future Fund grant enabled research into whole genome sequencing that revolutionised diagnosis for rare syndromes, uncovering hidden mutations, guiding treatment and empowering families with clearer reproductive choices.

Appendix 2: Key Learnings from the Most Significant Change Methodology Work

1. Build and sustain collaborative, nationally aligned networks that include cross-jurisdictional government collaboration, clinical leadership, researchers and rare disease organisations.
2. Embed lived experience and expert clinical expertise in policy, service design and research. Draw on this expertise to identify systemic gaps and guide priorities.
3. Balance broad consultation with strategic action.
4. Use strengths-based, solution-focused language to support constructive policy conversations – engage directly with political leaders.
5. Make change tangible for political leaders through clear, solutions-focused briefs.
6. Align advocacy with political and policy opportunities.
7. Advocacy should be strategic, evidence-based, coordinated, and anchored in the shared language and priorities of the Action Plan.
8. Build and fully resource a skilled and dedicated rare disease workforce – start with pilots to demonstrate what is scalable nationally.
9. Policy commitments must be matched with dedicated funding for implementation. Exploring diversified investment, including government, industry, philanthropic and venture capital funding is essential to driving change.



rare voices
A U S T R A L I A[®]

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