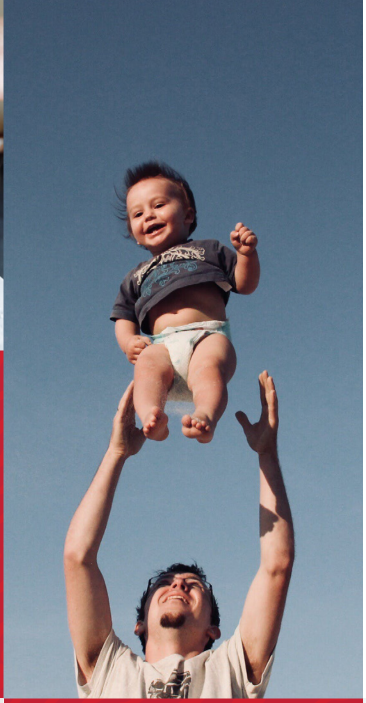


rare voices
AUSTRALIA®

ANNUAL REPORT

Year ended 30 June 2023

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

CONTENTS

ABOUT RARE VOICES AUSTRALIA

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

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

RVA'S VISION

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

RVA'S MISSION

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

CHAIR AND CHIEF EXECUTIVE OFFICER REPORT

RVA continued providing collaborative leadership for the development and implementation of rare disease policy in Australia throughout the 2022/23 financial year. At RVA, we know policy is vital to achieving equitable, transparent and consistent systemic change to drive the best outcomes for Australians living with a rare disease.

As the national peak body for Australians living with a rare disease, RVA continued overseeing the collaborative implementation of the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan), the first nationally coordinated effort to address rare diseases in Australia. Between September and October 2022 and during February 2023, RVA conducted an activity scan—the first measure of Action Plan progress since its launch in 2020—inviting the rare disease sector to share relevant projects, initiatives and achievements. The full status report is available to download via RVA's website. The status report is intended to support all stakeholders to review and refine their approaches for the most effective and efficient path to early implementation of sustainable and systemic change across all Action Plan pillars, priorities, actions and implementation steps.

RVA is proud of our role in ensuring rare disease policy remains a priority for governments and that implementation of the Action Plan garners multipartisan support. The 47th Parliament saw the re-establishment of the Parliamentary Friends of Rare Diseases with Co-Chairs Dr Mike Freelander MP (Member for Macarthur), Senator Wendy Askew (Senator for Tasmania) and Dr Monique Ryan MP (Member for Kooyong). We thank Dr Freelander, Senator Askew and Dr Ryan for their ongoing support as rare disease political champions and look forward to continuing to work together moving forward.

Throughout the 2022/23 financial year, RVA also continued working with the Parliamentary Friends of People with Rare and Undiagnosed Diseases in Western Australia, Co-Chaired by the Hon Matthew Swinbourn MLC, Hon Donna Faragher MLC and Hon Stephen Pratt MLC. Additionally, RVA is advocating for a stronger presence in Queensland's Parliament and is encouraged by the success of our inaugural Queensland Parliamentary Event in November 2023, which was attended by several parliamentarians. RVA highly values working with such strategic and influential non-partisan groups.

Meanwhile, RVA continues to partner with the Western Australian Department of Health on projects to progress the implementation of key aspects of the Action Plan in Western Australia. We hope to work on similar projects with other state and territory governments in the next few years.

RVA's profile as the national peak body

As RVA's profile as the national peak body continues to grow, how we work, engage and collaborate is becoming even more integral to the organisation's longevity and ongoing success. Increasingly, RVA endorsement of a variety of resources is being requested by stakeholders. All endorsement requests are reviewed in line with RVA's Endorsement Criteria.

RVA's team consistently live out our values in how we work:

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

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

RVA Ambassador Program

'Person-centred' is a foundation principle of the Action Plan and is key to RVA's work. Established in 2022 to coincide with the organisation's 10th anniversary and to highlight the importance of lived experience, RVA's Ambassador Program continued in 2023. RVA thanks our ambassadors for participating in this program and for sharing their moving and courageous personal stories. We do not underestimate how challenging sharing personal stories can be.

Organisational Growth

Several new staff members joined RVA's team during the 2022/23 financial year in response to RVA's organisational growth and an increased workload for the Rare Awareness Rare Education (RARE) Portal and RVA's Online Education Portal. The RARE Portal for rare diseases was soft launched at RVA's Rare Disease Day Parliamentary Event in March 2023 and houses the RARE Helpline, which provides Australians living with a rare and complex disease with service navigation support.

RVA's significant staffing increase was supported in part through Commonwealth Department of Health grants as part of investment in response to the Action Plan. This grant funding assisted RVA in continuing to lead the collaborative development of the RARE Portal. RVA also continued our work as a consortium partner of the University of New South Wales-led Rare Disease Awareness, Education, Support and Training (RArEST) Project which focuses on rare disease awareness, education, support and training. Both the RARE Portal and RArEST Project grants will end on 30 June 2024.

RVA is also pleased to be the lead consortium partner on The Navigator Project, which was named the recipient of the Rare and Complex Disease Telehealth Nurse Program grant on 1 June 2023 by the Department of Health and Aged Care. The funding of up to $2.48 million will support the estimated two million Australians living with a rare disease to navigate the health system, including via the assistance of telehealth nurses. This activity commenced in mid-2023 and is scheduled to run over three years.

Research

RVA's role in identifying evidence gaps and proactively partnering with researchers and other experts to address unmet areas of need grew throughout the 2022/23 financial year. In July 2023, RVA and Monash University published *Recommendations for a National Approach to Rare Disease Data: Findings from an Audit of Australian Rare Disease Registries*. The report includes the findings from the Australian Rare Disease Registry Audit project. Additionally, RVA launched the *National Strategy for Australia's Rare Metabolic Disease Workforce* in 2023, an evidence-based, expert-backed framework of goals, recommendations and priority actions that address current high levels of unmet need through a nationally consistent and sustainable workforce. The Action Plan calls for the development of a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics. 'Sustainable systems and workforce' is one of three foundation principles of the Action Plan.

RVA also continued to experience growth in requests and successful applications to partner in rare disease research throughout 2022/23. In line with the Research and Data Pillar of the Action Plan, RVA supports the need for high-quality collaborative research of all types that positively impacts the lives of Australians living with a rare disease. Thank you to RVA's Scientific and Medical Advisory Committee (SMAC) for their ongoing guidance and support in this area.

RVA Scientific and Medical Advisory Committee

RVA's SMAC provides the organisation with medical and clinical perspectives, guidelines and information. In 2023, Dr Carol Wicking and Professor Jeff Szer stepped down from SMAC. RVA thanks you both for your long-standing contributions to SMAC and Australians living with a rare disease.

SMAC Chair, Professor Adam Jaffé, continues to lead SMAC's engagement in several exciting research projects and activities. RVA sincerely thanks our SMAC members who so willingly share their time and expertise with RVA.

RVA Board

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

There were several changes to the RVA Board throughout the 2022/23 period. Dr Carol Wicking and Andrew Carter were appointed Chair and Deputy Chair respectively in December 2022. Thank you to Joanna Betteridge and Kane Blackman who completed their terms as Chair and Deputy Chair. Your contributions over the last three years have been invaluable and we are pleased you both remained on the RVA Board in 2023. Andrew Carter, Kate Henderson and Teresa Pilbeam were formally elected as board members in December 2022. Additionally, Viswanathan (Vishy) Narayanaswamy was elected for a second 3-year term in December 2022.

Kane Blackman and Robert Hendriks formally resigned from the RVA Board as of 13 December 2023. RVA thanks you both for your valuable contribution and wishes you all the best.

Strong governance has been vital to RVA's continued growth during the 2022/23 financial year and our work towards achieving the best outcomes for Australians living with a rare disease. The RVA Board has continued its focus on longer-term strategic planning, and we acknowledge the time and commitment our directors dedicate to RVA.

Contribution of RVA Partners and Other Key Stakeholders

RVA is grateful for the interest, time, energy and support provided by all of our RVA Partner groups/organisations and other key stakeholders in collaborating to achieve RVA's vision to drive the best outcomes for Australians living with a rare disease. The ongoing dedication of the rare disease sector to work together to achieve the best health and wellbeing outcomes for Australians living with a rare disease continues to energise RVA's team. As we look ahead to the 2024 National Rare Disease Summit, we are excited to contemplate what's next for the collaborative implementation of the Action Plan.

BOARD MEMBERS, COMPANY SECRETARY AND STAFF

RVA Board

The RVA Board comprises dedicated Directors, many with lived experience of rare disease. The RVA Board meets regularly and oversees RVA's strategic direction and purpose. More than half of RVA's Board has lived experience or a personal connection to rare disease.

Directors in office from 1 July 2022 to 30 June 2023:

Joanna Betteridge
(Chair until December 2022)

Kane Blackman
(Deputy Chair until December 2022)

Andrew Carter
(Deputy Chair from December 2022)

Kate Henderson

Robert Hendriks

Prof Eric Morand

Viswanathan (Vishy) Narayanaswamy

Teresa Pilbeam

Dr Carol Wicking
(Chair from December 2022)

Company Secretary

Liyi Chang
Chartered Company Secretary, Institute of Chartered Secretaries and Administrators (UK) Member, Australian Institute of Company Directors. Associate Member, Governance Institute of Australia.

Chief Executive Officer and Staff

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

RVA staff in employment during the year 1 July 2022 to 30 June 2023:

Nicole Millis
Chief Executive Officer

Jess Brooklyn
Education Project Officer

Sarah Cannata
Communications Manager

Dr Amanda Choo
Resources and Information Officer

Freya French
Project Officer – Mental Health & Wellbeing

Malcolm Fung
Operations 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, Administrative Manager

BOARD COMMITTEES

The RVA Board has two subcommittees, the Finance and Risk Committee (the FaR Committee) and the Nomination, People and Culture Committee (the NPC Committee). The FaR Committee is Chaired by Vishy Narayanaswamy and provides advice to the RVA Board on budget setting, financial and operational risk management and monitoring financial performance. The NPC Committee was Chaired by Dr Carol Wicking until she was appointed Chair of the RVA Board in December 2022. Since, the NPC Committee has been Chaired by Kate Henderson; its objective is to assist the RVA Board to carry out its responsibilities (including board recruitment and employing the appropriate policies, systems and processes to achieve the desired outcomes).

RVA SCIENTIFIC AND MEDICAL ADVISORY COMMITTEE

SMAC provides the organisation with medical and clinical perspectives, guidelines and information as needed.

Terms of Reference (PDF)

SMAC members from 1 July 2022 to 30 June 2023:

Prof Adam Jaffé (Chair)

Clin/Prof Gareth Baynam

Dr Kaustuv Bhattacharya

Dr Lisa Ewans

A/Prof Paul Lacaze

Dr Kristen Nowak

Dr (Elizabeth) Emma Palmer

Prof John Rasko

Prof Jeff Szer

Yarlalu Thomas

Dr Carol Wicking

Prof Yvonne Zurynski

RVA ROUND TABLE OF COMPANIES

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

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

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

The meetings/workshops provide opportunities for RVA and industry representatives to:

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

Discussion topics for 2022/23 included:

- Rare disease registries and data collection
- Medicines Australia's Rare Disease Industry Working Group
- Health Technology Assessment Policy and Methods Review
- Projects, research and initiatives for early diagnosis of rare diseases in Australia
- Newborn Bloodspot Screening (NBS) program expansion
- Advocacy priorities
- The National Disability Insurance Scheme and rare diseases
- Research updates
- Education updates

OUR WORK
2022/23

RARE DISEASE ADVOCACY AND POLICY DEVELOPMENT

Influencing policy and driving systemic advocacy continues to be central to RVA's work as effective rare disease policy transforms lives.

RVA formally collaborates with and strengthens over 100 RVA Partner groups/organisations. We also work effectively with other key rare disease stakeholders, including people living with a rare disease, clinicians, researchers, governments, key peak bodies and industry.

RVA's team has extensive rare disease and professional expertise and is sought by stakeholders for our rare disease policy and consumer expertise. RVA personnel have professional expertise in social work, psychology, research, sociology, operations/compliance and communications.

Founded in 2012, RVA has spent over a decade actively building and maintaining partnerships with key stakeholders in the rare disease sector. RVA's political advocacy is relationship based. These multipartisan relationships have continued to be developed, fostered and protected during the 2022/2023 financial year. RVA's role as a credible and informed peak body continues to grow. When engaging with RVA, politicians frequently state the importance of being able to easily engage with the rare disease sector via a credible and informed national peak body such as RVA with a strong understanding of policy, systems and the sector. RVA's credibility as the national peak body and growing profile uniquely positions us to act as the unified voice for the estimated two million Australians living with a rare disease.

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

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

Between September and October 2022 and during February 2023, RVA conducted an activity scan—the first measure of Action Plan progress since its launch in 2020—inviting the rare disease sector to share their projects, initiatives and achievements. Preliminary findings were shared at the 2022 National Rare Disease Summit. A summary of the findings were also shared with attendees at RVA's 2023 Rare Disease Day Parliamentary Event. The full status report is available via RVA's website.

This status report is a means of introspection for the whole sector. The results are intended to support all stakeholders to review and refine their approaches for the most effective and efficient path to early implementation of sustainable and systemic change across all pillars, priorities, actions and implementation steps.

Submissions

- Capability and Culture of the National Disability Insurance Agency
- Pharmaceutical Benefits Scheme (PBS) Post-market Review (PMR) Framework
- Australian Commission on Safety and Quality in Health Care's Consultation on the Framework for Australian clinical quality registries Second Edition
- Revised National Medicines Policy
- NDIA Independent Review
- HTA Policy and Methods Review

Political Advocacy Updates

- NBS
- *Rare Metabolic Disease Workforce White Paper: Towards a Strengthened Rare Disease Workforce for Australia*
- National Disability Insurance Scheme Independent Review
- Future Governance and Administration of Australian Health and Medical Research Funding
- Health Technology Assessment Policy and Methods Review – Consultation 1
- *National Strategy for Australia's Rare Metabolic Diseases Workforce*
- *2023 Status Report: Implementing the National Strategic Action Plan for Rare Diseases*
- Medical Services Advisory Committee (MSAC) application process
- *Recommendations for a National Approach to Rare Disease Data: Findings from an Audit of Australian Rare Disease Registries*

The Navigator Project

In June 2023, The Navigator Project was named the recipient of the Rare and Complex Disease Telehealth Nurse Program grant by the Department of Health and Aged Care. Read the Australian Government's media release. RVA is the lead consortium partner on The Navigator Project, which was awarded funding of up to $2.48 million to support Australians living with a rare disease to navigate the health system, including via the assistance of telehealth nurses. Work on The Navigator Project is well underway and is scheduled to run over three years as of mid-2023.

The Navigator Project has three core components:

The RARE Helpline:
Provides service navigation support to Australians living with a rare and complex disease. The RARE Helpline has been fully operational since October 2023 after RVA operated an interim helpline from July 2023.

Telehealth nurse service navigation trial sites:
Provides targeted nurse-led support for people with highly complex conditions or issues where information and access to services may be restricted or particularly challenging.

Engagement with three consumer-led rare and complex disease organisations:
Contributes to The Navigator Project's overall data collection and reporting.

Read more about The Navigator Project on RVA's website.

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

The RArEST Project is a collaboration between RVA, the University of New South Wales, the University of Western Australia and Macquarie University. The RArEST Project was awarded $1.9 million in funding from the Australian Government with the intent to develop and deliver rare disease awareness resources, education, support and training. The grant is scheduled to end on 30 June 2024.

The RArEST Project comprises three streams:

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

Stream 2: Health professional education, support and training

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

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

The RArEST Project addresses several of the key priorities, actions and implementation steps identified across the Awareness and Education and Care and Support Pillars in the Action Plan. Initiatives include Rare Disease Project ECHO® (a community of clinical learning practice to increase awareness of rare diseases and provide health professionals with multidisciplinary peer learning and evidence-based, clinically informed expert support to deliver contemporary best practice health care nationally); Rare Disease 101 Australia (e-learning modules for health professionals devised in collaboration with Medics4RareDiseases); Mental Health First Aid Training for RVA Partner groups/organisations; the Australian Rare Disease Organisations Community of Practice; and the National Recommendations for Rare Disease Health Care (to be launched in 2024). At the completion of the grant, all deliverables will be accessible from this dedicated RArEST Project page on RVA's website.

AWARENESS AND EDUCATION

Rare Awareness Rare Education (RARE) Portal for Rare Diseases

The RARE Portal for rare diseases was launched at RVA's 2023 Rare Disease Day Parliamentary Event and is a key Action Plan deliverable. The RARE Portal is a living website in ongoing development, with new information added regularly. The site also houses the RARE Helpline, which provides service navigation support for Australians living with a rare and complex disease. Moving forward, the RARE Helpline will inform RARE Portal content.

Thank you to everyone involved in the multi-stakeholder consultation process for the RARE Portal to date, particularly our RVA Partner groups/organisations that are working with us to develop the individual rare disease pages. RVA will continue reaching out to RVA Partner groups/organisations to be involved in the consultation process.

CARE AND SUPPORT

Newborn Bloodspot Screening

On 13 June 2023, the Department of Health and Aged Care updated its website to state they are "working with states and territories to expand Australia's NBS programs, and make sure all babies born have access to the same screening". This milestone agreement ensures timely and consistent screening and wrap around care. Read the media release issued by the Department of Health and Aged Care for more information about these changes.

In addition to listing conditions currently screened, moving forward, the website also lists the following for transparency:

- Conditions not consistently screened for, agreed for implementation
- Conditions currently under review, not currently screened for
- Conditions identified for NBS technical advice

For the first time in 60 years, Australia has an agreed national list of NBS conditions and there is specific funding to achieve consistency across the nation. Additionally, these changes cement Australia as a world leader in NBS. As outlined in the Action Plan, early diagnosis is critical for better outcomes as it enables the best immediate treatment and care.

RVA welcomed this milestone announcement as this marks the end of the NBS postcode lottery and enables children and families to access screening and vital specialist care. Previously, it has taken anywhere from 5 to 14 years for new conditions to be included for screening.

National Disability Insurance Scheme

During the 2022/23 financial year, RVA continued our National Disability Insurance Scheme (NDIS) advocacy to address systemic issues and gaps for people living with a rare disease who are also NDIS applicants or participants. RVA will continue engaging in ongoing advocacy to the National Disability Insurance Agency (NDIA) and the Minister for the NDIS. RVA is now recognised by the NDIA as a key peak body, and in that capacity, is meeting monthly with the NDIA's stakeholder engagement team to discuss opportunities for co-design and consultation with the NDIA.

Significant work is needed to contribute to the systemic changes required for the NDIS to better respond to the needs of Australians living with a rare disease. Throughout 2022/23, RVA continued providing updates to stakeholders regarding progress made and is liaising on an ongoing basis with our RVA Partner groups/organisations, in addition to ensuring alignment with the Action Plan and the report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases*.

Refreshed National Medicines Policy

In December 2022, the Hon Mark Butler MP, Minister for Health and Aged Care, announced the refreshed National Medicines Policy (NMP). RVA was actively involved in the NMP Review and contributed in several ways, including lodging several submissions and participating in a one-on-one interview with the NMP Review's Expert Advisory Committee. RVA welcomed the refreshed NMP which, importantly for rare disease, has a much stronger focus on innovation and continuous improvement as well as being more person-centred. Throughout the consultation, RVA (and many others) highlighted the need to improve the governance, implementation and evaluation sections of the NMP. Although these were strengthened throughout the consultation process, RVA would have liked to see these sections also require the identification of gaps or misalignment with the NMP and how this will be addressed. Nevertheless, RVA feels the NMP is much improved and clearly reflects consideration of stakeholder feedback, including RVA's input.

Health Technology Assessment Policy and Methods Review

In 2021, the Australian Government agreed to support an independent review of Health Technology Assessment (HTA) policy and methods used by the Pharmaceutical Benefits Advisory Committee (PBAC) to assess new medicines for listing on the Pharmaceutical Benefits Scheme (PBS), contemporary research and relevant methodologies and purchasing practices used by comparable international jurisdictions. Equitable access to health technology is a key priority of the Action Plan. RVA, alongside the rare disease sector, has been actively advocating for reform that makes HTA for rare disease therapies more fit-for-purpose. Most recently, RVA has been advocating to ensure that consumers lead the co-design of an enhanced consumer engagement process.

RESEARCH AND DATA

Recommendations for a National Approach to Rare Disease Data

In July 2023, RVA and Monash University published *Recommendations for a National Approach to Rare Disease Data: Findings from an Audit of Australian Rare Disease Registries*. The report includes the findings from the Australian Rare Disease Registry Audit project, led by Monash University registry experts, Professor Susannah Ahern and Dr Rasa Ruseckaite. Importantly, the report also includes strategic recommendations and associated implementation priorities for a national approach to rare disease data.

RVA played a pivotal role in overseeing this critical work in recognition of the importance of rare disease registries. A nationally coordinated and systemic approach to the collection and use of rare disease data, including registries, is a key Action Plan priority. The strategic recommendations and implementation priorities detailed in the report are a critical step towards achieving this goal. RVA is engaging in ongoing conversations with relevant stakeholders to drive timely implementation of the strategic recommendations.

MENTORSHIP AND EDUCATION PROGRAM

During the 2022/23 financial year, RVA continued building on the success of its Mentorship & Education Program, which focuses on implementation of the Action Plan and building the advocacy capacity of the rare disease sector. (Action 2.1.4 of the Action Plan, "Develop the capacity of rare disease organisations to represent and advocate for people living with a rare disease and their families"). The Mentorship & Education Program also includes education to the broader rare disease sector and has become core to RVA, leveraging from the Action Plan.

To 30 June 2023, RVA provided a total of 158 instances of customised mentorship and strategy support to RVA Partner groups/organisations and other stakeholders. Mentoring has covered a broad range of areas, including NBS, clinical trials and the role of rare disease organisations, policy and systemic advocacy, HTA, awareness and education strategies, developing a Scientific and Medical Advisory Committee, Medicines Australia's Code of Conduct Guidelines, working with researchers, applying for funding, input into submissions, the Medicare Benefits Schedule (MBS) Review and political advocacy. This work has helped to build the advocacy capacity of rare disease groups/organisations to effectively respond to their specific advocacy needs. Support is available to all RVA Partner groups/organisations as well as emerging rare disease groups/organisations and provides mentorship and strategy guidance for community and stakeholder engagement, policy and government relations. This work also includes a formal program consisting of social media promotion and facilitates peer-to-peer networking with rare disease group leaders through RVA's closed Facebook group for RVA Partner groups/organisations.

A significant focus of the Mentorship & Education Program is providing tailored support for HTA, research and clinical trials and governance for rare disease groups/organisations. Since its launch in December 2021, RVA has continued adding resources and courses to our Online Education Portal, which provides free and restricted resources to all stakeholders available on a 24/7 basis.

Customised Education Sessions

RVA has provided customised education sessions on request to several RVA Partner groups/organisations throughout 2022/23. These sessions were designed to meet the specific needs of the relevant rare disease community and build capacity across a range of areas aligned with the Action Plan pillars.

Topics covered in 2022/23:

- Governance of rare disease groups/organisations, including establishing boards and scientific and medical advice
- Establishment of rare disease groups/organisations
- Advocacy
- Providing consumer comments
- Engaging with HTA

RVA Partner Groups/Organisations

The number of RVA Partner groups/organisations continues to grow. We have partnered with over 100 rare disease groups/organisations throughout the 2022/23 financial year. RVA has provided support and guidance to several emerging rare disease groups/organisations. RVA Partners have actively informed the development of several key policy submissions and have collaborated with RVA on important advocacy priorities, including drug repurposing and NBS. Like the Mentorship & Education Program, this work continues to build the capacity of rare disease groups/organisations, as outlined in the Action Plan (Action 2.1.4).

Rare Disease Education

RVA has provided the following webinars, resources and on-demand education programs in 2022/23:

- Health Technology Assessment Policy and Methods Review webinar and response guide
- Social media training for rare disease groups/organisations, including building an online community and social media risk management
- NBS expansion
- Genomics and NBS research
- Preferences for genomic testing research

Priority populations

Several priority populations were identified in the Action Plan, including Aboriginal and Torres Strait Islander people; those from culturally and linguistically diverse backgrounds; and people living in regional, rural and remote areas.

To address the gaps and challenges highlighted in the Action Plan in relation to these priority populations, RVA engaged in a consultation process with key stakeholders related to each priority population when developing the following resources:

- Rare Disease Resources for the Aboriginal and Torres Strait Islander Community
- Rare Disease Resources for Regional, Rural and Remote Communities
- Rare Disease Resources for the Multicultural Community

RVA AMBASSADOR PROGRAM

RVA's 10th Anniversary Ambassador Program (the Ambassador Program) was launched in 2022 to celebrate the organisation's 10th year. The overarching theme of the Ambassador Program is, *Illuminating People Living with a Rare Disease*. Due to its overwhelming success, the Ambassador Program continued in 2023 with each ambassador bringing their own unique lived experience of rare disease.

RVA Ambassadors throughout the 2022/23 financial period:

Katie Alexander

Andrew Bannister

Lachy Beckett

Ryan Brown *(joined in August 2023)*

Nathan Charles *(until January 2023)*

Ebony Callaghan

Tim Fulton

Tammie Rees

Beck Webber

Renae Wood

RVA
EVENTS

RARE DISEASE DAY PARLIAMENTARY EVENTS

Celebrating 10 Years of Rare Disease Advocacy: Influencing Policy and Transforming Lives – 5 September 2022

In December 2021, RVA made the strategic decision to postpone our annual Rare Disease Day Parliamentary Event until after the Federal election in May 2022 due to the lack of sitting days and the ongoing impacts of COVID-19. RVA typically organises a Parliamentary Event for Rare Disease Day (marked on the last day of February annually). The Parliamentary Event provided an opportunity for the rare disease sector to continue fostering strong relationships with all political parties and to welcome newly elected members of the 47th Federal Parliament, while introducing them to key rare disease issues. Most importantly, we highlighted the experiences of the estimated two million Australians living with a rare disease to a new Minister for Health and Aged Care. Leading into the event, RVA worked with Dr Freelander to re-establish the Parliamentary Friends of Australians Living with Rare Diseases (the Parliamentary Friends). The Parliamentary Friends aims to provide a non-partisan forum for parliamentarians to meet and interact with intended stakeholder groups on matters relating to rare diseases. Read more about the Parliamentary Event on RVA's website.

Ensuring Equity for Australians Living With a Rare Disease – 8 March 2023

In 2023, RVA resumed organising our annual Parliamentary Event to coincide with Rare Disease Day. The event was hosted by Dr Mike Freelander MP and the theme was *Ensuring Equity for Australians Living With a Rare Disease*. RVA was pleased to provide a progress update on implementation of the Action Plan, which requires ongoing multipartisan collaboration and support. It was fantastic to see so many political attendees, including over 20 parliamentarians and Assistant Ministers in attendance to support Rare Disease Day and the rare disease community. Read a recap of 2023 Rare Disease Day on RVA's website.

Rare Disease Day

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

2022 NATIONAL RARE DISEASE SUMMIT

Feedback from attendees

> *"I just left with such a buzz and so much joy. I can't fault it. It was tiring and overwhelming but so fabulous."*
>
> – RVA Ambassador

> *"As my first time attending, I enjoyed all aspects of the Summit. The ambassadors' personal stories were incredibly powerful and emphasised why RVA is so vital for the rare disease community."*
>
> – RVA Partner group/organisation representative

> *"It [the Action Plan] now does not sit as a document but has had life through ideas breathed into it."*
>
> – Industry

> *"[The] Whole meeting was excellent as well as the networking. Ambassador stories give the purpose to RVA policies."*
>
> – Clinician

> *"This was honestly one of the best conferences I have been to with a good mix of presentations, Q&A and highly interactive workshops. The Summit was also the perfect size – not too big and not too small. Large enough to have a diverse set of attendees but small enough that you had the opportunity to cross paths with many others."*
>
> – Researcher

In November 2022, RVA hosted our first face-to-face National Rare Disease Summit (the Summit) since 2018 due to COVID-19. The theme was *From Vision to Action: Celebrating 10 Years of Rare Disease Advocacy and Shaping the Next Decade*. It was a pleasure to bring together key rare disease stakeholders to create a rare disease roadmap for the next 10 years, focusing on the Action Plan. RVA also organised a Gala Event on the first night of the Summit to celebrate RVA's 10th anniversary and 10 years of rare disease advocacy that influences policy and transforms lives. RVA acknowledges and thanks all stakeholders, speakers and workshop facilitators who helped to make the Summit a success.

Special thanks to Minister Butler and Senator the Hon Anne Ruston, Shadow Minister for Health and Aged Care, for pre-recording video messages for the Summit. We also thank Dr Freelander for joining us in person.

Read a recap of the Summit on RVA's website, including a summary delivered by then RVA Chair, Joanna Betteridge.

RVA'S ONLINE EDUCATION PORTAL

RVA continues to add resources and courses to complement the workshops, webinars and customised mentoring support provided to RVA Partner groups/organisations and the rare disease sector. Available 24/7, RVA's Online Education Portal contains several free and restricted resources.

Courses/resources added in 2022/23:

- Rare Disease Resources for the Aboriginal and Torres Strait Islander Community
- Rare Disease Resources for Regional, Rural and Remote Communities
- Rare Disease Resources for the Multicultural Community
- A Guide for Rare Disease Organisation Leaders in Australia
- RARE Portal Sneak Peek
- RVA Education: Genomics and Newborn Bloodspot Screening Research
- RVA Education: Health Technology Assessment Policy and Methods Review – Rare Disease Sector Webinar
- RVA Education: Applying Mental Health First Aid in a Rare Disease Context
- RVA Education: Expanding Newborn Bloodspot Screening – Progress Made and Next Steps Webinar
- RVA Education: Writing Effective Government Submissions – A Guide for Rare Disease Organisations
- RVA Education: Facebook Groups and Social Media Risk Training for Rare Disease Organisations

RVA RESEARCH AND PROJECT PARTNERSHIPS

Across the 2022/23 financial year, the number and scope of RVA research and project partnerships continued to grow. RVA is a highly sought-after partner for grant applications and pilot projects. The rare disease sector is increasingly recognising and valuing RVA as a credible source of rare disease policy and health systems information, and a vital link to a growing number of rare disease groups/organisations.

To manage capacity and growing demands, RVA has continued to refine our Research Partnership Guidelines and application process to ensure we have an active and meaningful role in research that is appropriately recognised, and aligns with RVA's research priorities and the Action Plan. In response to requests from the sector, 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 RVA research/project partnerships as of 30 June 2023

Research Project Name	Key Investigators	Institution/Affiliation
Targeted, adaptive genomics for ethical, evidence-based expansion of newborn screening	Prof Natalie Taylor	University of New South Wales
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
University of New South Wales RNA Institute End User Advisory Committee (EUAC)	Pall Thordarson	University of New South Wales
A national long-read genome sequencing program to improve rare disease diagnosis	Dr Ira Deveson	Garvan Institute of Medical Research
Embedding genomics in primary care: using implementation science to design a robust national approach	Prof Jeffrey Braithwait	Macquarie University
Genie! A web-based AI platform supporting site preparedness for rAAV gene therapy	Prof John Rasko	Royal Prince Alfred Hospital
Sydney Local Hospital District Rare Disease Steering Committee*	Prof John Rasko	Royal Prince Alfred Hospital
Pathways to benefit for Indigenous Australians in genomic medicine	Prof Alex Brown	South Australian Health and Medical Research Institute
PERSYST: Pathogenic evaluation of recalcitrant variants by SYStematic transactivation	Prof Jozef Gecz	University of Adelaide
Assessing benefits of extended genomic newborn screening trialled on 100,000 infants from Generation Victoria	A/Prof David Godler	Murdoch Children's Research Institute
gEnomics4newborns: Integrating ethics and equity with effectiveness and economics for genomic newborn screening	A/Prof Sarah Norris	University of Sydney
Ethical governance for clinical and genomic data	Prof Ainsley Newson	University of Sydney
Newborn screening model using integrated multi-omics in South Australia (NewbornsInSA)	A/Prof Karin Kassahn	South Australia Pathology
Rare Care Centre*	Clin/Prof Gareth Baynam	Perth Children's Hospital

*Project partnerships

Research Project Name	Key Investigators	Institution/Affiliation
A Phase 2A/2B placebo-controlled randomised clinical trial to test the ability of triheptanoin to protect primary airway epithelial cells obtained from patients with ataxia-telangiectasia against death induced by glucose deprivation	Prof David Coman	The University of Queensland
KidGen Clinics, Education, Data and Research (KidGen CEDAR): Improving care and outcomes of Australians with genetic kidney disease	Prof Andrew Mallett	Murdoch Children's Research Institute
Australian Undiagnosed Disease Network	Dr Tiong Tan, Prof John Christodoulou	Murdoch Children's Research Institute
Australian Functional Genomics Network	Dr Tessa Mattiske	Murdoch Children's Research Institute
RArEST Project	Dr (Elizabeth) Emma Palmer, Prof Adam Jaffé, Prof Michelle Farrar, Clin/Prof Gareth Baynam, Prof Yvonne Zurynski, Nicole Millis, Louise Healy	RVA, University of New South Wales, University of Western Australia, Macquarie University
Missed opportunities in clinical practice: Tools to enhance healthcare providers' awareness and diagnosis of rare diseases in Australia	Dr Jane Desborough	Australian National University
National survey on community inclusion	Kayleen Lenzo, Sylvana Mahmic	Plumtree Children's Services
The insurance and genetics moratorium (A-GLIMMER) study	Dr Jane Tiller, A/Prof Paul Lacaze	Monash University

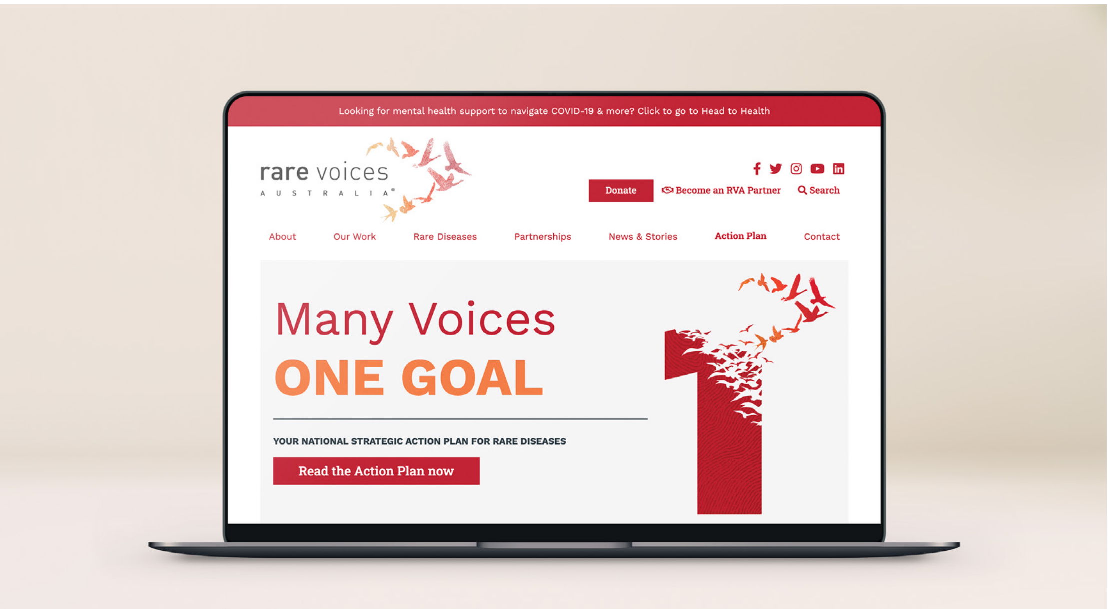
For confidentiality purposes, RVA partnerships that are still under review by granting bodies have not been included in this table.

COMMUNICATIONS

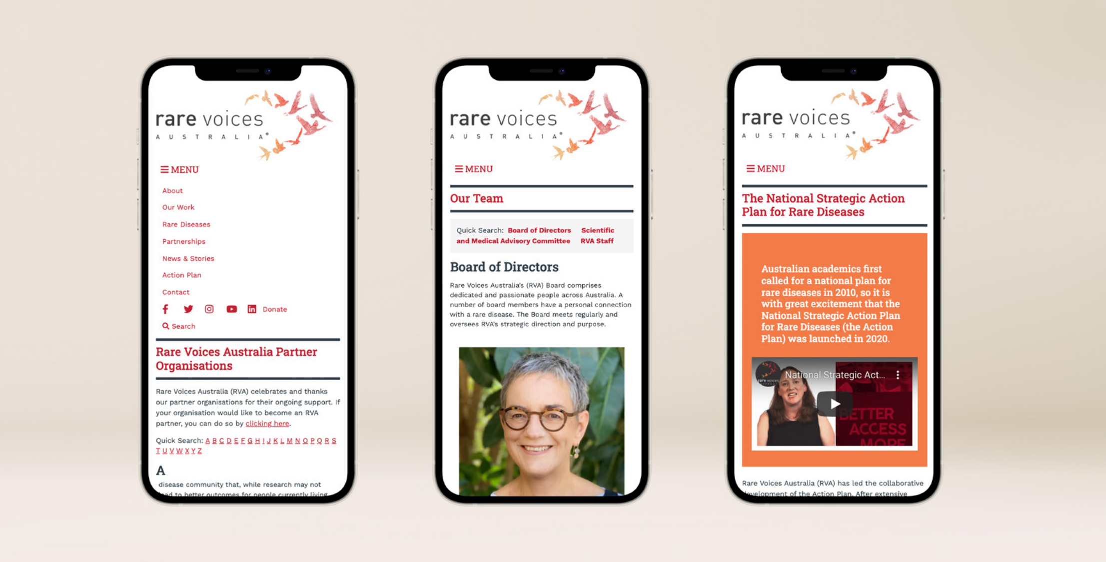
COMMUNICATIONS

RVA Website

RVA's main website continues to gain traction as a central source of information for all stakeholders in the rare disease sector. The site continues to be refined with the aim of enhancing the user experience and address accessibility needs, while retaining a person-centred focus. In the 2022/23 financial year, RVA's website was visited by almost 43,000 users. In 2023, RVA made the strategic decision to redirect the Rare Disease Day Australia website to RVA's main website given the official Rare Disease Day website is the best place to source information about Rare Disease Day and RVA's ongoing efforts to reduce duplication.



Looking for mental health support to navigate COVID-19 & more? Click to go to Head to Health



Rare Voices Australia Partner Organisations

Rare Voices Australia (RVA) celebrates and thanks our partner organisations for their ongoing support. If your organisation would like to become an RVA partner, you can do so by clicking here.

Quick Search: A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

A

disease community that, while research may not

Our Team

Quick Search: Board of Directors Scientific and Medical Advisory Committee RVA Staff

Board of Directors

Rare Voices Australia's (RVA) Board comprises dedicated and passionate people across Australia. A number of board members have a personal connection with a rare disease. The Board meets regularly and oversees RVA's strategic direction and purpose.

The National Strategic Action Plan for Rare Diseases

Australian academics first called for a national plan for rare diseases in 2010, so it is with great excitement that the National Strategic Action Plan for Rare Diseases (the Action Plan) was launched in 2020.

Rare Voices Australia (RVA) has led the collaborative

Social Media

Social media continues to be another important touchpoint for RVA. RVA's Facebook, Twitter, LinkedIn, Instagram and YouTube channels continued to grow steadily and organically in the 2022/23 financial year. Below is a follower breakdown by platform as of 30 June 2023:

Facebook	X (formerly Twitter)	Instagram	LinkedIn	YouTube
11,000 followers	2,914 followers	1,533 followers	1,293 followers	52 videos

In 2023, RVA made the strategic decision to merge the Rare Disease Day Australia and RVA Facebook pages given the noticeable overlap in followers and our ongoing efforts to reduce duplication.

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

RVA Monthly eNewsletter

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

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

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

Rare Awareness Rare Education (RARE) Portal eNewsletter

RVA distributed our first RARE Portal eNewsletter update in August 2023 to showcase the progress made on the site since its launch in March 2023. The eNewsletter database continues to grow steadily and RVA has been encouraged by stakeholders' interest and willingness to contribute to the RARE Portal. Read the first eNewsletter via RVA's website.

In time, we envision that the RARE Portal eNewsletter will become another key communication tool, particularly with the launch of the RARE Helpline. Relevant content will be cross promoted via RVA's social media channels.

Media

Media is increasingly seeking RVA's expertise as our profile as the national peak body for Australians living with a rare disease continues to grow. RVA is often the first port of call for media looking to cover rare diseases broadly or specific rare diseases. Where appropriate, we connect our RVA Partner groups/organisations with media and provide mentorship and guidance as needed. Throughout the 2022/23 financial year, RVA continued to strengthen its existing relationships with journalists and media covering relevant beats in health, politics, research, disability and other areas.

RVA was featured in the following media outlets/newswire services in the 2022/23 financial year:

- MedNews
- Orphanet News
- Perth Now
- Australian Associated Press

COMMITTEE/ADVISORY GROUP PARTICIPATION

RVA have provided input on the following advisory panels/consultations in 2022/23:

- Australian Undiagnosed Disease Network (UDN-Aus) – Murdoch Children's Research Institute
- GeneEQUAL – NSW Department of Health
- Gene Therapy Advisory Committee (New South Wales)
- Cell and Gene Therapy Whitepaper Scorecard – EvoHealth
- University of New South Wales RNA Institute End User Advisory Group
- Clinical Trials Roundtable – Australian Clinical Trials Alliance
- National One Stop and National Clinical Trials Front Door Project
- Member of the Ethical Legal Social Issues Working group in the GeneSCAN Consortium
- Member of the Policy Working Group in the GeneSCAN Consortium
- PERSYST (RVA Research Partner) Consumer Advisory Group
- LINEAGE (RVA Research Partner) Project Advisory Committee
- TAG NBS (RVA Research Partner) Project Steering Committee
- Generalisable evaluation framework for high upfront-cost gene therapies: clinical, financial, ethico-legal and cultural considerations (RVA Research Partner) Project Advisory Board
- Rare Diseases International Regional Round Table
- National Congenital Anomalies Advisory Group
- Rare Disease Day Outreach Committee and Steering Committee
- United Nations Resolution
- Rare Diseases Now (RDNow)
- University of Technology Sydney Genetic Counselling Industry Advisory Board
- International Rare Diseases Research Consortium (IRDiRC) Joint Consortium Assembly & Scientific Committee
- International Rare Diseases Research Consortium Patient Advocates Constituent Committee (IRDiRC PACC)
- Victorian NBS Committee
- National Congenital Anomaly Advisory (NCAAG) Group
- World Health Organization (WHO) Collaborative Global Network 4 Rare Disease Panel of Experts
- Health Direct Australia National Information Partner
- Enhanced Consumer Engagement Process Co-design Group
- Health Technology Assessment Consumer Consultative Committee – Conversations for Change Advisory Group
- Genetic Service Western Australia Clinical Service Working Group
- Genetic Service Western Australia Clinical Service Review Go-design group
- RArEST Project Clinical Education Working Group

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

- Consumer Nominee on the Life Saving Drugs Program Expert Panel
- Enhanced Consumer Engagement Process Co-design Group
- Consumer Advocate Expert Advisory Group on Genomics Australia

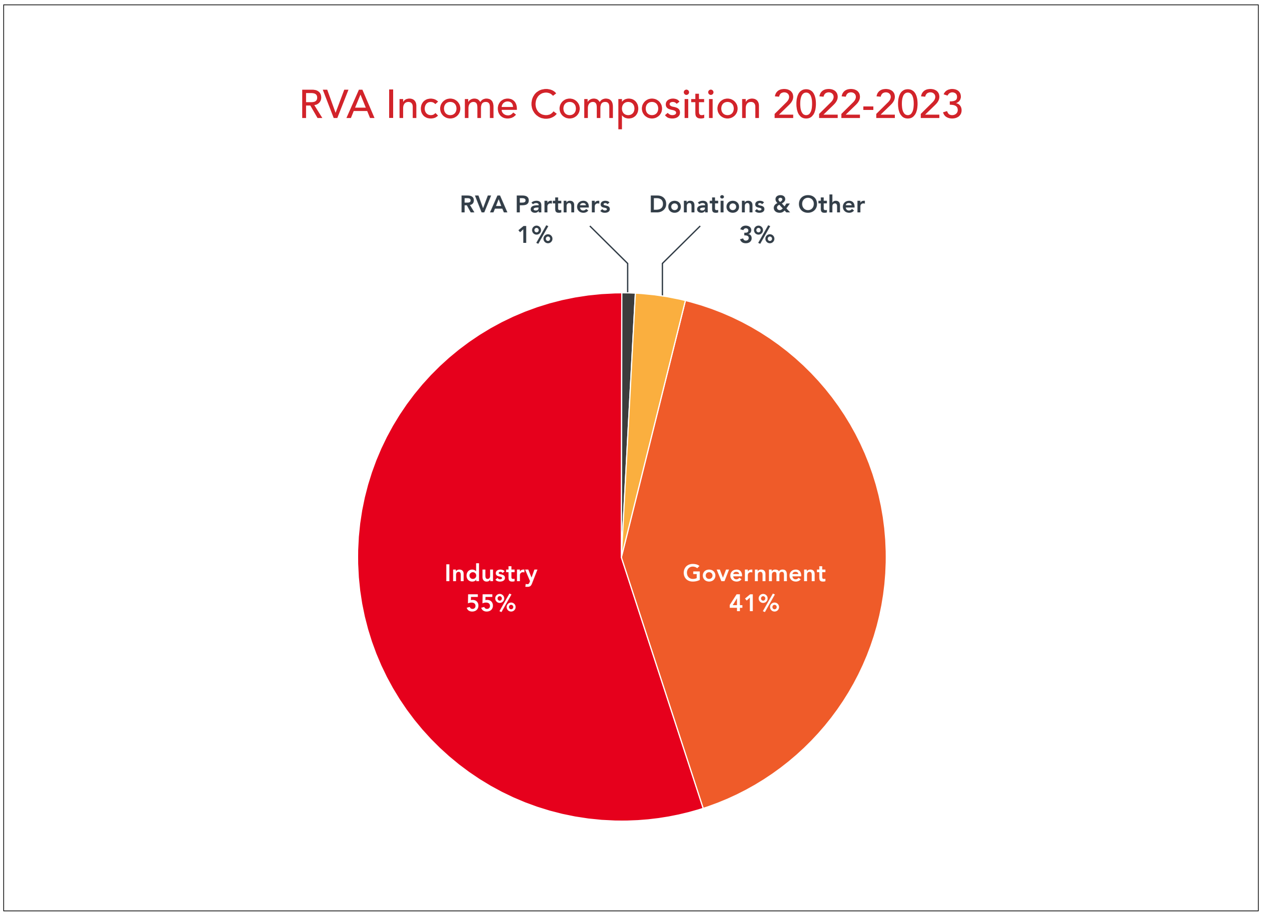
RVA SPEAKING ENGAGEMENTS

Date	Event
August 2022	Consumers and Consumer Advocates Webinar: Consumers Health Forum of Australia
August 2022	Consumer Partnership Webinar: ARCS Australia
August 2022	Australian Autoinflammatory Disease Symposium
September 2022	Rare Diseases International (RDI) Webinar
October 2022	Rare Disease Project ECHO®: Rare Disease Facts and Figures and the Importance of Lived Experience
October 2022	Health Technology Assessment Consumer Consultative Committee Conversations for Change Symposium
October 2022	Murdoch Children's Research Institute on the National Strategic Action Plan for Rare Diseases
October 2022	Metabolic Dietary Disorders Association (MDDA) Queensland Family Retreat
November 2022	Australasian Society for Inborn Errors of Metabolism Special Interest Group (ASIEM-SIG)
November 2022	MedConnect Live - Rare Disease: Uniting Genetics and Breakthrough Medicine
November 2022	World Health Organization's Collaborative Global Network 4 Rare Disease (West Pacific) Panel of Experts Meeting
November 2022	Rare Disease Project ECHO®: Mental Health and Wellbeing Challenges for People Living with a Rare Disease
February 2023	Patient Voice Initiative Webinar
March 2023	Mental Health 101 for XLH – XLH Australia
May 2023	Rare Disease Project ECHO®: Partnering with Patient Advocacy Groups
May 2023	Parliamentary Friends of People with Rare and Undiagnosed Diseases WA: 'Hope in Clinical Trials: Advancing Research for Rare Diseases'
June 2023	Health Technology Assessment international (HTAi) Annual Meeting: HTAi Interest Group on Rare Diseases – Developing a Workplan
June 2023	HTAi Consumer Consultative Committee (CCC): (Changing Conversations) Evaluating New Genetic and Genomic Tests in Health Technology Assessment: How to Define and Measure Value
June 2023	ARCS Australia Annual Conference: Better Patient Outcomes: Do We Need a New Approach to Regulatory Decisions for Emerging Technologies Across the Product Life Cycle?

FINANCIALS

FUNDING OF RVA

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



RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Annual Report

For the year ended 30 June 2023

M G ARTHUR & ASSOCIATES
Accounting • Taxation • Business Services

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

Phone: 02 9639 4420 Fax: 02 9639 4470

RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Annual Report for the year ended 30 June 2023

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RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Director's Report

Your directors present their report on the company for the financial year ended 30 June 2023.

Directors

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

ANDREW CARTER
CAROL WICKING
ERIC MORAND
JOANNA BETTERIDGE
KANE BLACKMAN
KATE HENDERSON
ROBERT HENDRIKS
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 2023 amounted to $152,391.

(30 June 2022 - $128,707)

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 Voices 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 Voices Australia Ltd does not provide for share options. As such, no options over issued shares or interests were granted during or since the end of the financial year and there were no options outstanding at the date of this report.

Directors Benefits

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

Indemnifying Officer or Auditor

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

Proceedings on Behalf of Company

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

Auditors Independence Declaration

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

Signed in accordance with a resolution of the director:

C. Wicking

Director: Carol Wicking

Dated: 13th December 2023

RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Statement of Comprehensive Income

For the year ended 30 June 2023

	Note	2023 $	2022 $
Revenue	2	1,171,240	1,056,464
Other revenue	2	45,274	89,351
Depreciation		(4,132)	(3,584)
Employee benefit expenses		(669,752)	(570,504)
Other expenses		(390,239)	(443,020)
Profit before income tax		**152,391**	**128,707**
Income tax expense		-	-
Profit for the year after income tax		**152,391**	**128,707**
Other Comprehensive Income for the year		**-**	**-**
Total Comprehensive Income for the year		**152,391**	**128,707**

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 2023

	Note	2023 $	2022 $
Assets			
Current Assets			
Cash and cash equivalents	3	2,374,355	1,841,616
Trade and other receivables	4	22,165	44,412
Total Current Assets		**2,396,520**	**1,886,028**
Non-Current Assets			
Property, plant and equipment	5	4,296	8,428
Total Non-Current Assets		**4,296**	**8,428**
Total Assets		**2,400,816**	**1,894,456**
Liabilities			
Current Liabilities			
Trade and other payables	6	1,426,038	1,075,157
Provisions	7	83,330	80,242
Total Current Liabilities		**1,509,368**	**1,155,399**
Total Liabilities		**1,509,368**	**1,155,399**
Net Assets		**891,448**	**739,058**
Equity			
Retained profits		891,448	739,058
Total Equity		**891,448**	**739,058**

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 2023

	Other Reserves	Retained Earnings	Total
Balance at 1 July 2021	-	610,351	610,351
Comprehensive income			
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	128,707	128,707
Balance at 30 June 2022	**-**	**739,058**	**739,058**
Comprehensive income			
Profit attributable to the members	-	152,391	152,391
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	152,391	152,391
Balance at 30 June 2023	**-**	**891,449**	**891,449**

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 2023

	2023 $	2022 $
Cash Flow From Operating Activities		
Receipts from customers	1,224,125	1,187,106
Payments to Suppliers and employees	(704,917)	(1,202,273)
Interest received	13,533	1,931
Net cash provided by (used in) operating activities (note 8)	**532,741**	**(13,236)**
Cash Flow From Investing Activities		
Payment for:		
Payments for property, plant and equipment	-	(9,086)
Net cash provided by (used in) investing activities	**-**	**(9,086)**
Cash Flow From Financing Activities		
Repayment of borrowings	-	-
Net cash provided by (used in) financing activities	-	-
Net increase (decrease) in cash held	532,741	(22,322)
Cash at the beginning of the year	1,841,615	1,863,938
Cash at the end of the year (note 3)	**2,374,356**	**1,841,615**

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 2023

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

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES

Basis of Preparation

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

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

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

New or amended Accounting Standards and Interpretations adopted

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

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

Accounting Policies

a. Revenue Recognition

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

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

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

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

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Notes to the Financial Statements

For the year ended 30 June 2023

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

a. Revenue Recognition (continued)

Donations and bequests are recognized as revenue when received.

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

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

b. Property, Plant and Equipment

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

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

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

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

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

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

c. Cash and Cash Equivalents

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

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Notes to the Financial Statements

For the year ended 30 June 2023

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

d. Accounts Receivable and Other Debtors

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

e. Goods and Services Tax (GST)

Revenues, expenses, and assets are 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 2023

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

h. Comparative Figures

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

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

i. Trade and Other Payables

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

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Notes to the Financial Statements

For the year ended 30 June 2023

Note 2: Revenue and Other Income

	2023 $	2022 $
Revenue:		
Sponsorships	874,140	894,099
Special projects	297,100	162,365
	1,171,240	**1,056,464**
Other revenue:		
Donations & memberships	31,742	87,420
Interest revenue	13,533	1,931
	45,274	**89,351**

Note 3: Cash and cash equivalents

	2023 $	2022 $
Bank accounts:		
WBC Cheque Account	22,795	19,286
WBC Cash Reserve Account	2,039,264	1,489,986
WBC Debit Card	1,876	1,236
Other cash items:		
Term Deposits	310,421	331,107
	2,374,356	**1,841,616**

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:

	2023 $	2022 $
- Cash and cash at bank	2,374,356	1,841,616
	2,374,356	**1,841,616**

Note 4: Trade and other receivables

	2023 $	2022 $
Current		
Trade debtors	22,165	44,412
	22,165	**44,412**

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 2023

Note 5: Property, plant and equipment

	2023 $	2022 $
Plant and equipment:		
- At cost	18,168	18,168
- Less: Accumulated depreciation	(18,168)	(18,168)
Office equipment:		
- At cost	13,045	13,045
- Less: Accumulated depreciation	(8,749)	(4,617)
	4,296	8,428

Note 6: Trade and other payables

Current

	2023 $	2022 $
Trade creditors	10,165	22,909
Refund to Customers	11,000	0
Revenue received in advance	1,274,500	1,012,476
ATO liability	113,884	2,611
GST payable	1,091	1,973
Superannuation payable	15,876	14,204
Other payroll liabilities	-478	20,984
	1,426,038	**1,075,157**

Note 7: Provisions

Current

	2023 $	2022 $
Provision for long service leave	21,508	17,152
Provision for annual leave	61,822	63,089
	83,330	**80,242**

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 2023

Note 8. Reconciliation Of Cash

Reconciliation Of Net Cash Provided By/Used In Operating Activities To Net Profit

	2023 $	2022 $
Profit (loss) after income tax	152,392	128,707
Non-cash flows in profit		
Depreciation	4,132	3,584
Changes in assets and liabilities:		
(Increase) decrease in trade and other receivables	22,247	(43,615)
Increase (decrease) in trade and other payables	350,882	(147,875)
Increase (decrease) in sundry provisions	3,088	45,965
Net cash provided by operating activities	**532,741**	**(13,234)**
(Increase) decrease in property, plant and equipment	0	(9,086)
Net cash provided by investing activities	**0**	**(9,086)**
Net increase (decrease) in cash held	**532,741**	**(22,320)**

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 2023

Note 9. Entity Details

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

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

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Detailed profit and Loss Statement
For the year ended 30 June 2023

	2023 $	2022 $
Income		
Sponsorships	874,140	894,099
Special projects	297,100	162,365
Donations and memberships	31,742	87,420
Interest received	13,533	1,931
	1,216,514	1,145,816
Expenditure		
Accountancy, audit and legal	15,850	18,471
Consultancy	73,357	303,991
Bank fees	1,516	1,188
Depreciation	4,132	3,584
CRM Costs	5,702	-
Board/governance expenses	20,904	10,705
Legal fees	1,920	-
Office supplies	3,832	2,161
Telephone and internet	9,751	6,299
Travel and accommodation	71,214	9,551
Insurance	11,932	7,759
Subscriptions	11,368	9,700
Summit Expenses	116,972	48,566
Website cost	14,847	16,127
Salaries and wages	603,644	476,920
Annual leave provision	-1,268	28,812
Long service leave provision	4,356	17,152
Superannuation	63,020	47,620
Other expenses	31,074	8,501
	1,064,123	1,017,110
PROFIT / (LOSS) FROM ORDINARY ACTIVITIES BEFORE INCOME TAX	152,391	128,707

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 2023 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2023 and performance of the Company for the year then ended; and in the Board's opinion, there are reasonable grounds to believe that RVA will be able to pay its debts as and when they become due and payable. This statement has been made in accordance with a resolution of the Board made on 13th December 2023.

C. Wicking

Director: Carol Wicking

Dated: 13th December 2023

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 2023, 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

13th December 2023

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* *Limited liability by a scheme approved under professional Standards Legislation*

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 special purpose financial report, of Rare Voices Australia Limited (the Company) which comprises the statement of financial position as at 30 June 2023, 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 2023 and its performance for the year ended on that date; and complying with Australian Accounting Standards and the *Australian Charities and Not-for-profits Commission Regulations 2013*. As the auditor of Rare Voices Australia Limited, ASRE 2415 requires that we comply with the ethical requirements relevant to the review of the financial report.

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

Independence

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

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 2023 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
13th December 2023

ACKNOWLEDGEMENTS

ACKNOWLEDGEMENTS

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

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

2022/23 RVA Partner Organisations:

Alpha-1 Organisation Australia

Angelina Cask Neurological Research Foundation

Angelman Syndrome Association Australia

AusEE

Australia and New Zealand Vasculitis Society

Australian Addisons Disease Association

Australian Cystinosis Support Group

Australian Pituitary Foundation

Australian Pompe Association

Batten Disease Support & Research Association Australia

Brain Tumour Alliance Australia

Congenital Diaphragmatic Hernia (CDH) Australia

Childhood Dementia Initiative

Children's Tumour Foundation of Australia

Congenital Adrenal Hyperplasia Support Group Australia

Cystic Fibrosis Queensland

Cystic Fibrosis WA

DEBRA Australia

Duchenne Australia

Ehlers Danlos Syndrome Australia National Support Group

Fabry Australia

Fanconi Anaemia Support

Familial Mediterranean Fever & Autoinflammatory Diseases Australia

Fibrodysplasia Ossificans Progressiva (FOP) Australia

Foundation for Angelman Syndrome Therapeutics Australia

Fragile X Association of Australia

Friedreich Ataxia Research Association

FSHD Global Research Foundation

Gaucher Association of Australia and New Zealand

Genetic Alliance Australia

Genetic Cures for Kids (Our Moon's Mission)

HAE Australasia

Haemochromatosis Australia

HCU Network Australia

Huntington's NSW

Huntington's Victoria

Huntington's WA

Hypersomnolence Australia

Immune Deficiencies Foundation Australia

International Advocate for Glycoprotein Diseases (ISMRD)

Idiopathic Thrombocytopenia Purpura (ITP) Australia

Jack’s Butterflies

Kennedy’s Disease Downunder

Leukemia Foundation on behalf of MPN Alliance Australia

Leukodystrophy Australia

Leukodystrophy Resource & Research Organisation

Living with LAM

Maddie Riewoldt’s Vision

Malan Syndrome Foundation

Metabolic Dietary Disorders Association

Mito Foundation

Motor Neurone Disease (MND) Australia

Moyamoya Disease

Multiple Sclerosis Australia

Neuromuscular WA

Muscular Dystrophy Foundation

Muscular Dystrophy Qld

Myasthenia Alliance Australia

Myasthenia Gravis Association of Qld

Narcolepsy Australia

Parenteral Nutrition Down Under (PNDU)

Primary Ciliary Dyskinesia (PCD) Australia

Peutz Jeghers Syndrome Australia Support Group

Progressive Familial Intrahepatic Cholestasis (PFIC) Network

Pulmonary Hypertension Association Australia

Phelan-McDermid Syndrome Foundation Australia

PNH Support Association of Australia

Prader Willi Research Foundation

Primary Sclerosing Cholangitis (PSC) Support Australia

Rare Find Foundation

Rett Syndrome Association of Australia

Save Our Sons Duchenne Foundation

Scleroderma Australia

Scleroderma Victoria

SCN2A Australia

Sleep Disorders Australia

Sotos Syndrome Australia

Spinal Muscular Atrophy Australia

Team Telomere

Thalassaemia and Sickle Cell Australia

The Australian Cystinosis Foundation

The Phenylketonuria Association of NSW

Through the Unexpected

Tuberous Sclerosis Australia

UsherKids Australia

Genetic Support Network Victoria

XLH Australia

Individual Partners

During the 2022/23 financial period, RVA had 25 individual partners.

AFFILIATIONS

Australian Ethical Health Alliance

Asia Pacific Alliance of Rare Disease Organisations (APARDO)

Child UnLimited

Consumers Health Forum of Australia

EURORDIS – Rare Diseases Europe

Genetic and Rare Diseases (GARD) Information Center

Healthdirect Australia

Health Technology Assessment International (HTAi)

Human Genetics Society of Australasia

Rare Diseases International

Research Australia

rare voices
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youtube.com/channel/Rare Voices Australia