



rare voices
A U S T R A L I A[®]

RARE VOICES AUSTRALIA



The unified voice for Australians living with a rare disease

ANNUAL REPORT
Year ended 30 June 2021

CONTENTS

3	About Rare Voices Australia
4	Chair and Chief Executive Officer Report
6	Board Members, Company Secretary and Staff
8	Board Committees
8	Scientific and Medical Advisory Committee
9	Rare Voices Australia Round Table of Companies
10	Our Work in 2020/21
24	Financials
25	Funding of RVA
27	Directors' Report
29	Statement of Comprehensive Income
30	Statement of Financial Position
31	Statement of Changes in Equity
32	Statement of Cash Flows
33	Notes to the Financial Statements
41	Directors' Declaration
43	Auditor's Independence Declaration
44	Independent Auditor's Review Report
46	Acknowledgements

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

Throughout the 2020/21 financial year, RVA continued to provide collaborative leadership for the development and implementation of rare disease policy in Australia. At RVA, we know that effective rare disease policy transforms lives.

Policy is vital to achieving equitable, transparent and consistent systemic change to drive the best outcomes for Australians living with a rare disease. RVA is proud of our role in keeping rare disease policy a priority for Governments, particularly against the backdrop of the COVID-19 pandemic. The Parliamentary Friends of Australians Living with Rare Diseases, Chaired by Trent Zimmerman MP and Dr Mike Freeland MP, has led political support for the rare disease sector. Throughout the 2020/2021 financial year, the formation of a Parliamentary Friends Group in Western Australia was discussed. These discussions culminated in the recent launch of the Parliamentary Friends of People with Rare and Undiagnosed Diseases, Chaired by the Hon Matthew Swinbourn MLC, Hon Donna Faragher MLC and Hon Stephen Pratt MLC. RVA highly values working with these bipartisan Parliamentary Friends groups.

While RVA has been required to make changes to how we work, engage and collaborate due to COVID-19 restrictions across Australia, the values underpinning how we work remain constant.

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

RVA's profile as the national peak body for Australians living with a rare disease continues to grow. While systemic advocacy and policy are core to our work, RVA also continued to provide advisory expertise, contribute to research partnerships and provide mentorship as well as education to RVA Partners (individual rare disease groups).

Organisational Growth

Two new members joined the RVA staffing team during this financial year. Louise Healy, a previous Director and Co-Chair of RVA, initially joined as Stakeholder Engagement and Education Officer and was later promoted to Education and Advocacy Manager. Later in 2021, Falak Helwani also joined our team as Research and Evaluation Officer. These positions were created in response to the increasing demand for education and RVA's increasing role in research.

This organisational growth has continued into the new financial year with the addition of three new team members. This staffing increase was supported in part through Commonwealth Department of Health grants as part of the initial investment in response to the [National Strategic Action Plan for Rare Diseases](#) (the Action Plan). With this grant funding, RVA began to develop a Rare Awareness Rare Education (RARE) Portal – a multipurpose website with rare diseases information and resources customised for the Australian context. RVA is also a consortia partner of the university-led RArEST (Rare Awareness, Education, Support and Training) Project which focuses on rare disease awareness, education, support and training. RVA is also pleased to partner with the Western Australian Department of Health on three projects to progress the implementation of key aspects of the Action Plan in Western Australia.

RVA Scientific and Medical Advisory Committee

After four years as Chair of RVA's Scientific and Medical Advisory Committee (SMAC), Dr Carol Wicking stepped down in 2021 as SMAC Chair but remained on SMAC and the RVA Board. Thank you to Carol for her wonderful work and contribution as SMAC Chair over the last four years. We were pleased to welcome Professor Adam Jaffé as our new SMAC Chair. Adam is a founding member of RVA's SMAC and has always been a strong advocate for national rare disease policy. Thank you to all of our SMAC members who always provide their expertise so generously.

RVA Board

The RVA Board has continued our work with longer term strategic planning for RVA through online meetings and will be pleased to meet face-to-face again in the future, hopefully in 2022. The continued implementation of the Action Plan throughout the financial year, despite restrictions imposed by COVID-19, has been exciting for RVA staff and the RVA Board and we look forward to continuing these developments in the following financial year.

The RVA Board also finalised the drafting of the new Constitution for RVA, following our annual strategic planning day. The Constitution was adopted by all board members. Our thanks to Maddocks Lawyers for their pro bono assistance with this important task.

Our work in refining our risk management, policy and compliance work is ongoing and the RVA Board looks forward to working with our new staff members to enhance our resources in this regard.

Contributions by RVA Partners and Other Stakeholders

The RVA Board and staff are grateful for the interest, time, energy and support provided by all of our RVA Partners and other key stakeholders in working together to achieve RVA's Vision to provide the best outcomes for all Australians living with a rare disease. We look forward to an exciting time ahead and to seeing our collaborative work take us further towards realising our Vision.

BOARD OF DIRECTORS

The RVA Board comprises dedicated and passionate people who have lived experience of rare disease. The board meets regularly and oversees RVA's strategic direction and purpose.

Directors in office during the year 1 July 2020 - 30 June 2021:

Joanna Betteridge (Chair)

Kane Blackman (Deputy Chair)

Raymond Saich OAM

Robert Hendriks

Dr Carol Wicking

Prof Eric Morand

Viswanathan (Vishy) Narayanaswamy

COMPANY SECRETARY

Liyi Chang

Company Secretary, RVA (VIC) Chartered Company Secretary, Institute of Chartered Secretaries and Administrators (UK) Associate Member, Governance Institute of Australia

CHIEF EXECUTIVE OFFICER AND RVA STAFF

RVA staff in employment during the year 1 July 2020 - 30 June 2021:

Nicole Millis (Chief Executive Officer)

Louise Healy

Falak Helwani – commenced April 2021

Sarah Cannata

Anne Hunter

BOARD COMMITTEES

The RVA Board has two subcommittees. The Finance and Risk Committee (the FaR Committee) is Chaired by Viswanathan Narayanaswamy. The FaR Committee is appointed to provide advice to the RVA Board on budget setting, financial and operational risk management and monitoring financial performance.

The second subcommittee is the Nominations Committee, Chaired by Kane Blackman. The Nomination Committee supports and advises the RVA Board on the nomination policies and processes of the Chief Executive Officer, the board and its Directors.

SCIENTIFIC AND MEDICAL ADVISORY COMMITTEE

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

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

Dr Carol Wicking – Chair till May 2021

Prof Adam Jaffé – Chair from May 2021

Clin/Prof Gareth Baynam

Dr Kaustuv Bhattacharya

Prof Alan Bittles

Dr Lisa Ewans

Dr Paul Lacaze

Dr Kristen Nowak

Dr Lemuel Pelentsov

Prof John Rasko

Prof Jeff Szer

A/Prof Yvonne Zuryski

RARE VOICES AUSTRALIA ROUND TABLE OF COMPANIES

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

RVA RTC members provide financial support to RVA. All member company logos are listed on the RVA website. RVA facilitates the RTC, holding quarterly meetings/workshops. RTC members nominate up to three representatives with expertise in: patient advocacy; market access for treatments and reimbursement; and government relations. Due to COVID-19, the quarterly meetings in 2020/21 took place via Zoom. These meetings aim to discuss the development as well as availability of treatments and health services in Australia. They also assist in building relationships within the rare disease community in a collaborative atmosphere that facilitates discussion about rare diseases. The meetings provide opportunities for RVA and industry representatives to interact with companies; direct exchange of views with leaders of the rare disease community; opportunities to develop partnerships and collaborations; and timely reports, surveys and analysis relevant to the field of rare diseases from different sources.

Our industry partners for 2020/21 were:

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

OUR WORK 2020–2021

RARE DISEASE ADVOCACY AND POLICY DEVELOPMENT

RVA's core focus continues to be influencing policy and systemic advocacy. RVA works in partnership with almost 90 RVA Partners (rare disease support groups). We also work effectively with all rare disease stakeholders including clinicians, researchers, governments, key peak bodies and industry.

RVA's political advocacy is relationship based. These bipartisan relationships have continued to be developed, fostered and protected during the 2020/21 financial year.

On behalf of the Australian Government, RVA led the collaborative development of the Action Plan, which was launched by the Minister for Health with strong bipartisan support in February 2020. The Action Plan was collaboratively developed by the rare disease sector, for the rare disease sector with a strong evidence base. It continues to provide a framework and policy direction from which the entire rare disease sector can advocate on issues. RVA is now leading the collaborative implementation of the Action Plan, which informs all of RVA's advocacy on a daily basis and is powerful for systemic advocacy. It has authenticity, credibility and consensus. As the Action Plan is a Government policy framework, it encourages alignment with subsequent Government policy.

RVA begins each calendar year with a Parliamentary Event which leverages from Rare Disease Day and raises awareness about rare diseases with Parliamentarians. This provides an opportunity to bring together all stakeholders in the rare disease sector to learn from each other and engage in a collaborative manner. Due to COVID-19, RVA held our first-ever virtual Parliamentary Event in March 2021, which involved a range of Federal and State Parliamentarians. Attendees heard from the Hon Greg Hunt MP, Minister for Health and Aged Care, as well as the Hon Mark Butler MP, Shadow Minister for Health and Ageing. The key theme of the day was Action Plan implementation. Effectively building on from the Parliamentary Event, throughout 2021, RVA organised a number of meetings with Governments, both at the ministerial and departmental levels.

Much of RVA's advocacy work focused on the Parliamentary Inquiry into approval processes for new drugs and novel medical technologies (the Parliamentary Inquiry). The Parliamentary Inquiry commenced following a referral from the Minister for Health to the House of Representatives Standing Committee on Health, Aged Care and Sport (the Standing Committee), Chaired by Trent Zimmermann MP and Dr Mike Freeland MP. The Parliamentary Inquiry had a particular focus on access to the treatment of rare diseases and conditions where there is high and unmet clinical need. RVA was informed by the Minister for Health's office that the Action Plan and RVA's advocacy, which was also echoed by other key stakeholders, were among the key drivers for this Parliamentary Inquiry.

The Parliamentary Inquiry had a clear focus on approval processes in addition to a broad scope that included areas such as drug development, technological innovation, repurposing of medicines, commercial incentives, personalised/precision medicines and clinical trials. There were over 200 Submissions. RVA's Submission was informed by input from our Scientific and Medical Advisory Committee (SMAC) and aligned with the Action Plan. RVA also provided education to RVA Partners to develop their own Submissions, as well consultative advice to other stakeholders as requested. The Standing Committee held 13 Public Hearings. RVA was pleased to be the opening witness at the Public Hearings to ensure that Australians living with a rare disease remained central to the discussions.

Progress was also made on other key systemic issues. RVA continued its advocacy to the National Disability Insurance Agency (NDIA) and the office of the Minister for the National Disability Insurance Scheme, submitting to numerous NDIA consultations. All of RVA's submissions aligned with the Action Plan and the RVA-commissioned report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases*, published by the McKell Institute. RVA also continued our advocacy on access to repurposed medicines, with ongoing engagement with key stakeholders and in partnership with RVA Partners.

Additionally, RVA engaged in considerable advocacy focussing on program delays relating to the assessment of potential rare diseases to be added to the newborn bloodspot screening (NBS) program and the implementation of positive recommendations at a state level. This work has involved engagement with Commonwealth and State and Territory Governments, at both a ministerial and departmental level, NBS Program Managers and relevant patient groups. Key progress has been made. For the first time, the Commonwealth Government is now providing ongoing resourcing to the assessment component. The positioning of NBS under the National Health Reform Agreement (NHRA) also potentially encourages a way forward to progress the implementation challenges. All states have begun to review and improve their implementation processes. RVA looks forward to continuing this work with all Governments and other key stakeholders.

RVA were also pleased to begin work on a Rare Metabolic Disease Workforce white paper with initial work progressing a key priority of the Action Plan – the development of a national rare disease workforce strategy.

Mentorship and Education Program

RVA's Mentorship and Education Program focused on implementation of the Action Plan, specifically **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*'. Informed by stakeholder consultation, this financial year, RVA's Education Program focussed on themes related to governance and funding.

Additionally, RVA provided bespoke mentoring to RVA Partner organisations on a range of topics, including access to treatment, clinical trials, political advocacy, organisational strategy and governance.

Workshops, webinars and tailored mentoring supported RVA Partner organisations to respond to key government consultations in the 2021 financial year, in particular, the House of Representatives' Parliamentary Inquiry into approval processes for new drugs and novel medical technologies in Australia, the review of Medical Services Advisory Committee (MSAC) Guidelines and multiple National Disability Insurance Scheme consultations. We also commenced work on RVA's Online Education Portal in early 2021, which will contain a number of open and partner only resources available to stakeholders on a 24/7 basis.

RVA Partner Organisations

The number of RVA Partner organisations continues to grow. This financial year, we have partnered with almost 90 rare disease organisations. RVA has provided support and guidance to several emerging rare disease organisations. RVA Partners have actively informed the development of several key policy submissions and have collaborated with RVA on important advocacy priorities including drug repurposing and newborn bloodspot screening. Like the Mentorship and Education Program, this work continues to build the capacity of rare disease organisations, as outlined in the Action Plan (*Action 2.1.4*).

2020 National Rare Disease Summit

The biennial National Rare Disease Summit was scheduled to take place on 12–13 November 2020 but was postponed to November 2021 due to the COVID-19 pandemic.

Rare Disease Day Parliamentary Event

RVA's Rare Disease Day Parliamentary Events are positive events that highlight the connection of powerful rare disease personal stories to policy, while also highlighting opportunities for improvement. These events are a tangible way to recognise and encourage rare disease political 'heroes.' Hosted by the Parliamentary Friends of Australians Living with a Rare Disease, RVA's first-ever Virtual Rare Disease Day Parliamentary Event was held on 4 March

2021 due to COVID-19. In addition to providing key stakeholders with an update regarding Action Plan implementation, the virtual event gave attendees the opportunity to engage with Parliamentarians about key rare disease issues.

Over 100 stakeholders, including 14 Commonwealth and State Parliamentarians, participated in the event. All Parliamentarians either presented or co-facilitated breakout sessions. In particular, RVA would like to thank the Minister for Health and Aged Care, the Hon Greg Hunt MP, and the Shadow Minister for Health and Ageing, the Hon Mark Butler MP. Additionally, RVA thanks Trent Zimmerman MP and Dr Mike Freelander MP, Co-Chairs of the Parliamentary Friends of Australians Living with Rare Diseases and the Standing Committee on Health, Aged Care and Sport.

RVA Research Project Partnerships

In 2021, the number and scope of RVA research project partnerships increased and we have refined our project partnership guidelines. Increasingly, researchers from across various institutions have consulted with RVA for our rare disease policy and consumer expertise. RVA has partnered with researchers in a variety of ways including reviewing and contributing to journal articles; consulting on grant applications; agreeing to participate in advisory and steering committees; providing letters of support; and other in-kind contributions. In 2021, we also co-authored a peer-reviewed article in the [Journal of Paediatrics and Child Health](#).

RVA's research project partnerships as at 30 June 2021

Research Project Name	Investigators	Institution/Affiliation
Australian Undiagnosed Disease Network	Prof Tiong Tan, Prof John Christodoulou	Murdoch Children's Research Institute
Rare Metabolic Diseases Workforce White Paper	Dr Angela Jackson, RVA	Equity Economics and Development Partners. Work commissioned by RVA
Neurotherapeutics BRAIN AID Project	Prof Michelle Farrar, Dr Emma Palmer	University of New South Wales and Sydney Children's Hospital Network
KidGen CEDAR: Improving Care and Outcomes of Australians with Genetic Kidney Disease	Dr Andrew Mallet, Lauren Hill	Murdoch Children's Research Institute
Audit of Rare Disease Registries Collecting Australian Data	Prof Susannah Ahern, Dr Rasa Ruseckaite, RVA	Monash University. Work commissioned by RVA
Tasmanian Undiagnosed Diseases Program	Dr Matthew Wallis, Julia Mansour, Dr Tyson Ware	University of Tasmania, Tasmanian Rare and Undiagnosed Diseases Network, Tasmanian Clinical Genetics Service
A new model of care for children with rare genetic epilepsy	Dr John Lawson	Sydney Children's Hospital Network
The National Centre for Applied and Translational Gene Therapeutics	A/Prof Leszek Lisowski, Dr Wendy Gold, A/Prof Michelle Farrar, Prof Ian Alexander, Prof Martin Delatycki	Children's Medical Research Institute

Initial Research Towards an Australian Rare Disease Workforce Strategy

‘Sustainable systems and workforce’ is a foundation principle of the Action Plan. In February 2021, in response to **Priority 1.3 of the Action Plan**, ‘Develop a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics’, RVA commissioned Equity Economics and Development Partners to develop a white paper that will highlight strengths and gaps, examples of best practice and opportunities for further consistency, co-ordination and investment. This work has been guided by a steering committee with strong representation from the Australasian Society for Inborn Errors of Metabolism (ASIM), the special interest group of Human Genetics Society of Australasia (HGSA).

The findings of this work will be available in two stages from 2022. They will pave the way, more broadly, for responsive and sustainable healthcare for all Australians living with a rare disease.

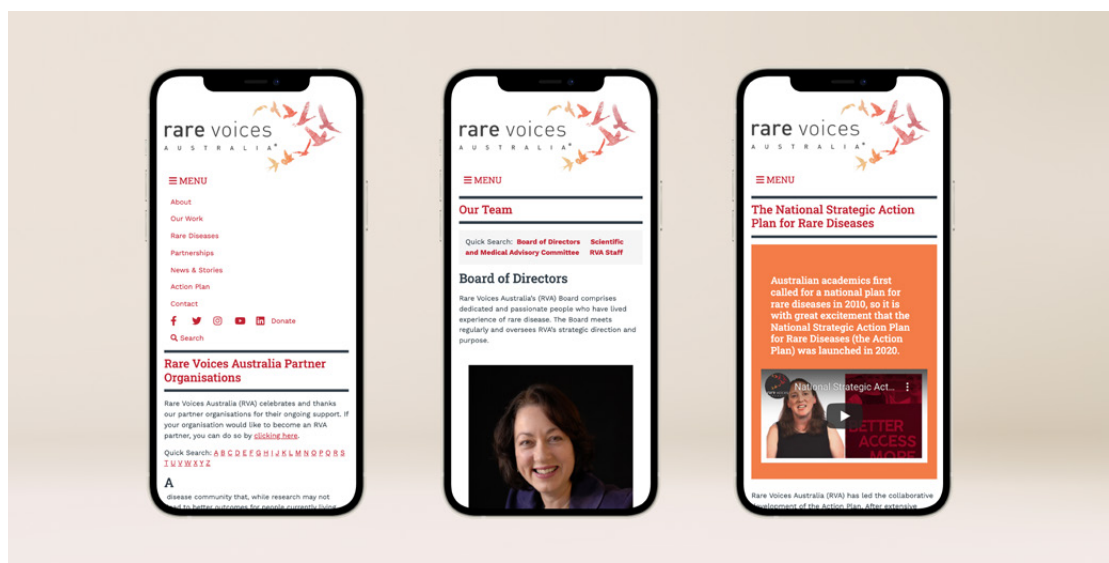
Collaborative Development of the RARE Portal

RVA has been collaboratively developing the Rare Awareness Rare Education (RARE) Portal for rare diseases, which will house rare disease information, services and resources customised for the Australian context. In June 2021, we launched the official RARE Portal logo. As part of our collaborative approach to research, RVA began a multistakeholder consultation process to evaluate the needs of all stakeholders in the rare disease sector so that we can deliver a portal based on these unmet needs. The RARE Portal will be launched in late 2022 and is another key deliverable of the Action Plan (**Action 2.1.2.1.**)

RVA Website

RVA launched our new website in December 2020. In designing the new site, we focused on enhancing the user experience, while retaining our person-centred focus and serving all key stakeholders in the rare disease sector. In the 2020/21 financial year, the RVA website was visited by 23,000 users who engaged in over 36,000 sessions.

RVA also manages the Rare Disease Day Australia website, which plays an important role in RVA's Rare Disease Day communications. In the 2020/21 financial year, the Rare Disease Day Australia website was visited by 3,800 users who engaged in over 5,000 sessions.



Social Media

Social media remains central to RVA's Communications Strategy. RVA's Facebook, Twitter, LinkedIn, Instagram and YouTube channels, continue to grow steadily organically. Below is a follower breakdown according to each platform as at 30 June 2021:

- Facebook: 6,929 followers
- Twitter: 2,670 followers
- Instagram: 1,036 followers
- LinkedIn: 471 followers

RVA's YouTube channel houses 50 videos.

RVA also moderates a closed Facebook group where RVA Partner organisation leaders have the opportunity to connect, engage and share leadership/management strategies that are relevant to the sector. Additionally, the Rare Disease Day Australia Facebook page had 4,793 followers.



Facebook
6,929 followers



Twitter
2,670 followers



Instagram
1,036 followers



LinkedIn
471 followers



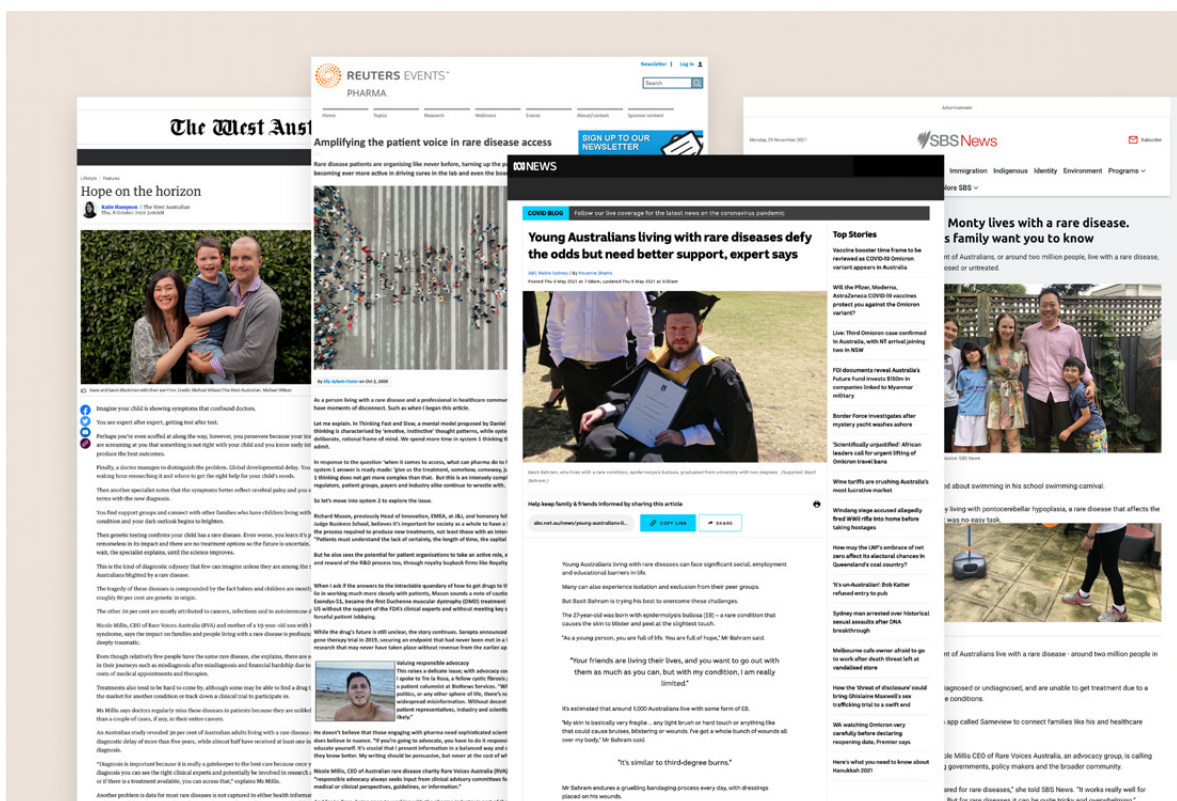
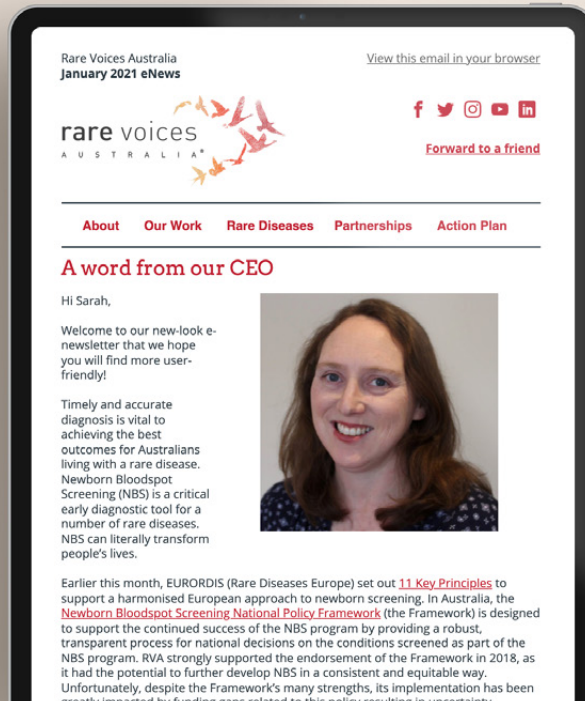
YouTube Channel
50 videos

RVA eNewsletter

In January 2021, RVA launched a new eNewsletter design to enhance user experience and better cater for key stakeholders in the rare disease sector. RVA's monthly eNewsletter is distributed to a steadily growing database consisting of all key rare disease stakeholders. Each edition features:

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

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



Media

As RVA's profile continued to build over the 2020/21 financial year, media increasingly sought RVA's expert commentary as the national peak body for Australians living with a rare disease. RVA continued to strengthen its existing relationships with journalists and media covering relevant beats in health, politics, disability and other areas. All media coverage is featured on the RVA website.

Coverage generated around 2020 Rare Disease Day (28 February) was a key media highlight. To mark the day and generate awareness for Rare Disease Day, RVA was involved in securing or was featured in the following media coverage:

- Sunday Extra – ABC Radio National segment (radio)
- SBS news (TV and online)
- 2GB NSW (radio)
- NewsCorp (online)
- The Advocate (online)
- Source Kids Magazine (online)

Committees/Advisory Groups Participation

Advisory Committees with representation from RVA:

Rare Diseases Now (RDNow) Consumer Engagement Committee (VIC)
 Victorian Newborn Bloodspot Screening Committee
 Gene Therapy Advisory committee (NSW)
 EvoHealth Cell & Gene Therapy Advisory Committee
 Queensland Genomics Impact Assessment Focus Group
 Queensland Genomics Community Advisory Group
 NCAAG National Congenital Anomaly Advisory Group
 World Health Organization (WHO) Collaborative Global Network 4 Rare Disease Panel of Experts
 Health Direct Australia national Information Partner group
 Global Rare Disease Day Steering Committee
 Global Rare Disease Day Outreach Group

Other related appointments of RVA's Chief Executive Officer:

Consumer Nominee on the Life Saving Drugs Program Expert Panel
 MRFF 2020 Genomics Health Futures Mission Grant Assessment Committee

RVA Speaking Engagements

Date	Event
August 2020	Phenomics Australia Strategic Forum: 'Why research is so important in rare disease'
October 2020	Reuters Pharma Australia: 'How does effective advocacy result in policy'
November 2020	Australian Functional Genomics Conference: 'Continued need for further research into rare diseases'
November 2020	Human Genetics society of Australasia (HGSA) Conference Poster Presentation: 'The National Strategic Action Plan for Rare Diseases: a collaborative multi-stakeholder approach to effective rare disease policy reform' Poster presentation
November 2020	EURORDIS Global Webinar Presentation Co-facilitated with Rare Disease Advocate, Andrew Bannister: 'How to Illuminate Buildings for Rare Disease Day'
December 2020	Asia Pacific Alliance of Rare Disease Organisations (APARDO) conference: 'Unique Origins of Rare Disease Activities in the APAC Region – Australia's Life Saving Drug Program (LSDP)' and 'Advancing Rare Disease Policy and Actions in the APAC Region – Australia's National Strategic Action Plan for Rare Diseases'
March 2021	Consumer Health Forum (CHF) Shifting Gears Summit: 'The National Strategic Action Plan for Rare Diseases: A Consumer-Led, Collaborative, Multi-Stakeholder Approach to Effective Rare Disease Policy Reform'
April 2021	Takeda Australia 'People We Serve' Diversity and Inclusion event: 'Learnings from RVA'
May 2021	Patient Voice Initiative 'Uncertainty in the Pharmaceutical Benefits Advisory Committee (PBAC) process and their impact on patient groups'

Policy Submissions

- 1** Parliamentary Inquiry into approval processes for new drugs and novel medical technologies - House of Representatives Standing Committee on Health, Aged Care and Sport, Chaired by Trent Zimmermann MP and Dr Mike Freeland MP
 - Developed RVA's own submission.
 - Provided education to RVA Partners to assist with lodging their submissions.
 - Provided consultative advice to other stakeholders (clinicians, researchers and industry) as requested.
 - Opening witness at the Public Hearings.
- 2** Medical Research Future Fund (MRFF) Australian Medical Research and Innovation Priorities for 2020/22.
- 3** Medical Services Advisory Committee (MSAC) Guidelines Review.
- 4** Consultation on the approach to introduce mitochondrial donation in Australia.
- 5** Joint Standing Committee on the National Disability Insurance Scheme's (NDIS) Parliamentary Inquiry into Independent Assessments.
- 6** Therapeutic Goods Administration (TGA) Consultation on repurposing about this important issue.
- 7** Pharmaceutical Benefits Advisory Committee (PBAC) consumer comments x2. Note: RVA does not routinely provide submissions to PBAC applications for rare disease. RVA will only provide submissions for medicines in cases where we feel doing so also addresses a systemic rare disease gap or priority (for example, reduced burden of treatment, alternative types of evidence etc.). Generally, RVA focuses on supporting our RVA Partner organisations through our Mentorship Program to actively and effectively participate in these processes.
- 8** Preventative Health Strategy Consultation.
- 9** Western Australia Newborn Bloodspot Screening Policy Consultation.
- 10** NDIS Access and Eligibility Consultation
 - Developed RVA's own submission.
 - Provided consultation with National Disability Insurance Agency (NDIA) and partners to support development of their submissions.
 - Provided mentoring and support to RVA Partners to develop their submissions.

Government Grants

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

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

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

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

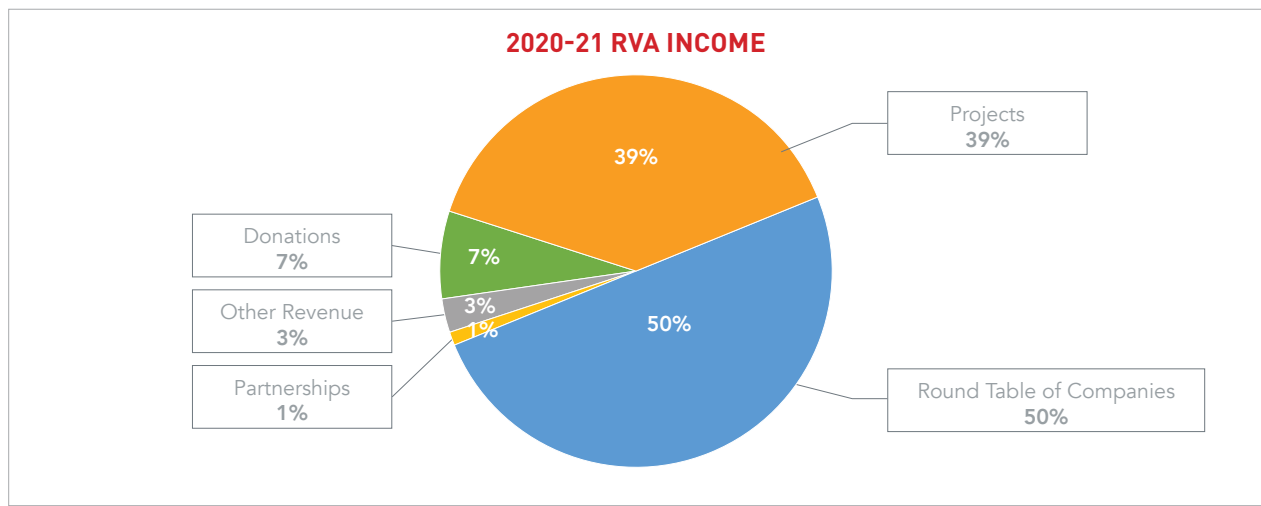
Action 2.1.2: *Build a broad range of care and support services that are responsive to the changing needs of people living with a rare disease and their families.*

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

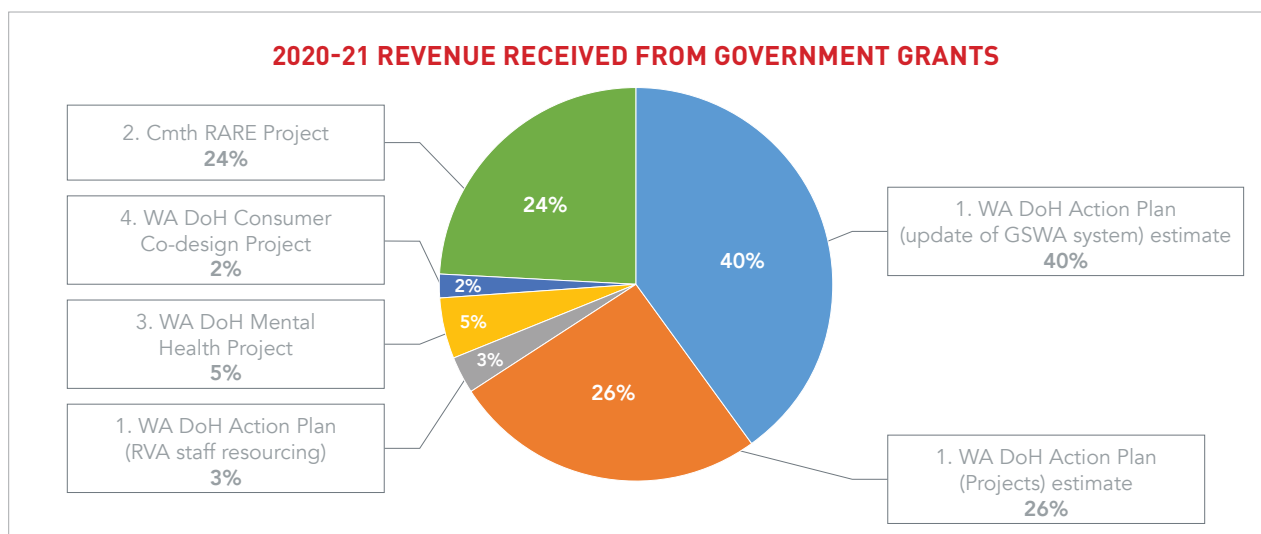
FINANCIALS

Funding of RVA

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



There has been an increased government investment in response to the Australian Government's National Strategic Action Plan for Rare Diseases. RVA has been the recipient of some of this investment, in collaboration with strategic partners and consortia including the University of NSW, Macquarie University, University of WA, Commonwealth Department of Health and WA Department of Health. These grants will accelerate the implementation of several key items in the Action Plan over the next three years.



1. Co-Design, Evaluation and Implementation of Initiatives from the National Strategic Action Plan for Rare Diseases in the Western Australian Health System
2. Rare Diseases – Awareness and Education: Rare Awareness Rare Education (R.A.R.E.) Project
3. Co-Design and Implementation of Mental Health Supports for People Living with Rare Diseases in Western Australia
4. Building WA's capacity for consumer co-design and co-production of health system policies, projects and programs

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303

Annual Report for the year ended 30 June 2021

CONTENTS

Directors' Report

Statement of Comprehensive Income

Statement of Financial Position

Statement of Changes in Equity

Statement of Cash Flows

Notes to the Financial Statements

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 2021.

Directors

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

JOANNA BETTERIDGE
KANE BLACKMAN
ROBERT HENDRIKS
RAYMOND SAICH
CAROL WICKING
ERIC MORAND
VISWANATHAN NARAYANASWAMY

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

Operating Result

The profit for the company for the financial year ended 30 June 2021 amounted to \$68,187
(30 June 2020 - \$121,002)

Principal Activities

The principal activities of the company during the course of the year was 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.

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.

RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Director's Report

Dividends

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

Share Options

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

Company Limited by Guarantee

The Company is incorporated under the Corporations Act 2001 as a Company Limited by Guarantee. If the company is wound up, the Constitution states that each member is required to contribute a maximum of \$10 each towards meeting any outstanding obligations of the Company. As at 30 June 2021, the total amount that members of the Company are liable to contribute if the entity is wound up is \$100.

Directors Benefits

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

Indemnifying Officer or Auditor

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

Proceedings on Behalf of Company

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

Auditors Independence Declaration

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

Signed in accordance with a resolution of the director:



JOANNA BETTERIDGE

Director

Dated: 8 December 2021

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Statement of Comprehensive Income
For the year ended 30 June 2021

	Note	2021 \$	2020 \$
Revenue	2	456,215	605,000
Other revenue	2	54,129	59,466
Depreciation		(1,032)	-
Employee benefit expenses		(306,775)	(258,949)
Other expenses		(134,350)	(284,515)
Profit before income tax		68,187	121,002
Income tax expense		-	-
Profit for the year after income tax		68,187	121,002
Other Comprehensive Income for the year		-	-
Total Comprehensive Income for the year		68,187	121,002

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
Statement of Financial Position as at 30 June 2021
ABN 69 156 254 303

	Note	2021 \$	2020 \$
Assets			
Current Assets			
Cash and cash equivalents	3	1,863,938	630,823
Trade and other receivables	4	797	720,610
Total Current Assets		1,864,735	1,351,433
Non-Current Assets			
Property, plant and equipment	5	2,925	-
Total Non-Current Assets		2,925	-
Total Assets		1,867,660	1,31,433
Liabilities			
Current Liabilities			
Trade and other payables	6	1,223,032	788,581
Provisions	7	34,277	20,688
Total Current Liabilities		1,257,309	809,269
Total Liabilities		1,257,309	809,269
Net Assets		610,351	542,164
Equity			
Retained profits		610,351	542,164
Total Equity		610,351	542,164

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 2021

	Other Reserves	Retained Earnings	Total
Balance at 1 July 2019	-	421,161	421,161
Comprehensive income			
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	121,002	121,002
Balance at 30 June 2020	-	542,164	542,164
Comprehensive income			
Profit attributable to the members	-	68,187	68,187
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	68,187	68,187
Balance at 30 June 2021	-	610,351	610,351

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 2021

	2021	2020
	\$	\$
Cash Flow From Operating Activities		
Receipts from customers	1,217,861	49,060
Payments to Suppliers and employees	6,918	(107,212)
Interest received	4,903	5,136
Cash Flow Boost	7,392	22,176
Net cash provided by (used in) operating activities (note 8)	<u>1,237,074</u>	<u>(30,840)</u>
Cash Flow From Investing Activities		
Payment for:		
Payments for property, plant and equipment	(3,959)	-
Net cash provided by (used in) investing activities	<u>(3,959)</u>	<u>-</u>
Cash Flow From Financing Activities		
Repayment of borrowings	-	-
Net cash provided by (used in) financing activities	<u>-</u>	<u>-</u>
Net increase (decrease) in cash held	1,233,115	(30,840)
Cash at the beginning of the year	630,823	661,663
Cash at the end of the year (note 3)	<u>1,863,938</u>	<u>630,823</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 2021

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

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES

Basis of Preparation

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

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

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

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

Accounting Policies

a. Revenue Recognition

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

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

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

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

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements for the year ended 30 June 2021

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

a. Revenue Recognition (continued)

Donations and bequests are recognized as revenue when received.

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

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

b. Property, Plant and Equipment

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

Plant and Equipment

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

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

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

Depreciation

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

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

c. Cash and Cash Equivalents

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

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements for the year ended 30 June 2021

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

d. Accounts Receivable and Other Debtors

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

e. Goods and Services Tax (GST)

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

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

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

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

f. Income Tax

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

g. Provisions

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

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

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements for the year ended 30 June 2021

NOTE 1: SIGNIFICANT ACCOUNTING POLICIES (continued)

h. Comparative Figures

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

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

i. Trade and Other Payables

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

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED
ABN 69 156 254 303
Notes to the Financial Statements for the year ended 30 June 2021

	2021	2020
	\$	\$
Note 2: Revenue and Other Income		
Revenue:		
Sponsorships	257,500	145,000
Special projects	198,714	460,000
	456,214	605,000
Other revenue:		
Donations & memberships	40,333	32,155
Interest revenue	4,903	5,136
Other revenue	8,892	22,176
Total Revenue	510,342	664,467

Note 3: Cash and cash equivalents

Bank accounts:		
WBC Cheque Account	20,797	15,688
WBC Cash Reserve Account	1,209,524	283,098
WBC Debit Card	1,875	2,179
Other cash items:		
Term Deposits	631,741	329,858
	1,863,938	630,823

Reconciliation of Cash:

Cash at the end of the financial year as shown in the statement of cash flows is reconciled to items in the statement of financial position as follows:

- Cash and cash at bank	1,863,938	630,823
	1,863,938	630,823

Note 4: Trade and other receivables

Current

Trade debtors	797	720,610
	797	720,610

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 2021

	2021 \$	2020 \$
Note 5: Property, plant and equipment		
Plant and equipment:		
- At cost	18,169	18,169
- Less: Accumulated depreciation	(18,169)	(18,169)
Office equipment:		
- At cost	3,958	-
- Less: Accumulated depreciation	(1,032)	-
	2,925	-
Note 6: Trade and other payables		
Current		
Trade creditors	1,129	1,447
Revenue received in advance	1,178,750	723,000
ATO liability	36,253	(5,939)
GST payable	(30)	65,378
Superannuation payable	7,289	4,695
Other payroll liabilities	(358)	-
	1,223,033	788,580
Note 7: Provisions		
Current		
Provision for annual leave	34,277	20,688
	34,277	20,688

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 2021

	2021 \$	2020 \$
Note 8. Reconciliation Of Cash		
Reconciliation Of Net Cash Provided By/Used In Operating Activities To Net Profit		
Profit (loss) after income tax	68,187	121,002
Non-cash flows in profit		
Depreciation	1,032	-
Changes in assets and liabilities:	719,813	(588,095)
(Increase) decrease in trade and other receivables	434,453	431,867
Increase (decrease) in trade and other payables	13,589	4,386
Net cash provided by operating activities	1,237,074	(30,840)
(Increase) decrease in property, plant and equipment	(3,959)	-
Net cash provided by investing activities	(3,959)	-
Net increase (decrease) in cash held	1,233,113	(30,840)

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 2021

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
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 2021 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2021 and performance of the Company for the year then ended; and in the Board's opinion, there are reasonable grounds to believe that RVA will be able to pay its debts as and when they become due and payable. This statement has been made in accordance with a resolution of the Board made on 8 December 2021.



Director: Joanna Betteridge

Dated: 8 December 2021

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 2021

	2021 \$	2020 \$
Income		
Sponsorships	257,500	145,000
Special projects	198,714	460,000
Donations and memberships	40,333	32,155
Interest received	4,903	5,136
Other revenue	8,892	22,176
	510,344	664,467
Expenditure		
Accountancy, audit and legal	13,590	10,580
Consultancy	42,294	181,441
Bank fees	744	653
Depreciation	1,032	-
Meeting and conference expenses	2,427	611
Board/governance expenses	-	1,333
Project expenses	31,753	21,607
Office supplies	807	887
Telephone and internet	3,501	3,597
Travel and accommodation	4,706	36,363
Computer expenses	-	-
Insurance	4,867	4,111
Subscriptions	7,869	5,902
Website cost	20,716	12,889
Salaries and wages	267,749	232,486
Annual leave provision	13,590	4,386
Superannuation	25,436	22,077
Other expenses	1,070	4,541
	442,157	543,464
PROFIT / (LOSS) FROM ORDINARY ACTIVITIES BEFORE INCOME TAX	68,187	121,002

The accompanying notes form part of these financial statements.

DN
French & French
Accounting, Tax & Advisory

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

Auditor's Independence Declaration

As lead auditor for the review of Rare Voices Australia Limited for the year ended 30 June 2021, 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
8th November 2021

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DN
French & French

Accounting, Tax & Advisory

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

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

Report on the financial report

We have reviewed the accompanying financial report, being a special purpose financial report, of Rare Voices Australia Limited (the Company) which comprises the statement of financial position as at 30 June 2021, the statement of comprehensive income, statement of changes in equity and statement of cash flows for the year ended on that date, selected other explanatory notes and the directors' declaration.

Directors' responsibility for the financial report

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

Auditor's responsibility

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

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

Independence

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

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 2021 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

8th November 2021

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INSTITUTE OF
PUBLIC
ACCOUNTANTS*



Tax agent
25637634



* Limited liability by a scheme approved under professional Standards Legislation

ACKNOWLEDGEMENTS

Acknowledgements

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

2020/21 RVA Partner Organisations (88 specific rare disease organisations):

Alpha-1 Organisation Australia	Genetic Alliance Australia
Angelman Syndrome Association Australia	HAE Australasia Ltd
ausEE Inc	Haemochromatosis Australia
Australian Addisons Disease Association	HCU Network Australia
Australian Cystinosis Support Group	Help for Hirschsprung Disease
Australian Dysphonia Network	HSP Research Foundation
Australian NPC Disease Foundation Inc	Huntington's New South Wales
Australian Pompe Association	Huntington's Victoria
Australian Sickle Cell Advocacy Inc	Huntington's Western Australia (Inc)
BrAshA-T Ltd	Immune Deficiencies Foundation Australia
CHARGE Syndrome Association of Australasia	International Foxg1 Foundation Australia
Charles Bonnet Syndrome Foundation	ISMARD
Childhood Dementia Initiative	ITP Australia
CMCT-OVM	Jack's Butterflies
Congenital Adrenal Hyperplasia Support Group Australia	Kennedy's Disease Downunder
Daniel Ferguson Foundation	Leukodystrophy Australia
DEBRA Australia	Leukodystrophy Resource & Research Org
Duchenne Australia	Mal de Debarquement Syndrome Australia
Dup15q Australia	Metabolic Dietary Disorders Association
Fabry Australia	Mission Massimo Foundation
Fanconi Anaemia Support	Mito Foundation
FOP Australia	MND Australia
Foundation for Angelman Syndrome Therapeutics Australia	MPN Alliance Australia
FOXG1 Research Foundation Australia	Multiple Sclerosis Australia
Fragile X Association of Australia	Muscular Dystrophy Association New South Wales
Friedreich Ataxia Research Association	Muscular Dystrophy Association of Western Australia
Gaucher Association of Australia and New Zealand	Muscular Dystrophy Foundation Ltd

Myasthenia Alliance Australia
 Myasthenia Gravis Assn Queensland
 Myositis Association Australia - Inc.
 Narcolepsy Australia
 One in 5000 Foundation
 Parenteral Nutrition Down Under (PNDU)
 PCD Australia
 Peutz Jeghers Syndrome Australian Support
 PFIC Network
 Phelan-McDermid Syndrome
 PNH Support Association of Australia
 Prader Willi Research Foundation
 Prader-Willi Syndrome Association of Victoria
 PSC Support Australia Inc
 Pseudomyxoma Survivor
 Rare Find Foundation
 Rett Syndrome Association of Australia
 Sanfilippo Children's Foundation
 Save Our Sons Duchenne Foundation

SCN2A Australia
 Sleep Disorders Australia
 Sotos Syndrome Australasia
 Spinal Muscular Atrophy Australia
 Superficial Siderosis Research Alliance
 Syndromes Without a Name (SWAN) Australia
 Team Telomere
 Thalassaemia and Sickle Cell Australia
 The Australasian Mastocytosis Society
 The Homer Hack
 The PKU (Phenylketonuria) Association of NSW
 Tuberous Sclerosis Australia
 UsherKids Australia
 Victorian Clinical Genetics Services
 XLH Australia

In 2020/2021, RVA also had 22 Individual Partners

RVA Affiliations

Asia Pacific Alliance of Rare Disease Organisations (APARDO)
 Consumer Health Forum
 EURORDIS
 Human Genetics Alliance Australia
 International Rare Diseases Research Consortium Patient Advocates Constituent Committee (IRDiRC PACC)
 Rare Diseases International
 Research Australia



rare voices
A U S T R A L I A[®]

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