Rare Voices Australia Ltd

Annual Report 2019-2020

YEAR ENDED 30th JUNE 2020

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ABOUT RARE VOICES AUSTRALIA

Rare Voices Australia (RVA) is Australia's peak body for Australians living with a rare disease. We provide 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 RVA working with all key stakeholders including people living with a rare disease, governments, key peak bodies, researchers, clinicians, and industry.

In accordance with its Constitution, RVA aims to:
- present a unified voice to improve the lives of all Australians affected by rare diseases;
- provide collaborative leadership for the development and implementation of rare disease policy in Australia;
- develop and provide strategic input into planning for rare diseases at both a state and national level;
- advocate for the implementation of services and support for people living with rare diseases;
- foster and support research into rare diseases; and
- maintain links with international organisations to further the other objectives of the organisation.

CHAIR & CEO REPORT

The 2019-2020 financial year has been a milestone period for RVA, and indeed, the entire rare disease sector.

National Strategic Action Plan for Rare Diseases

The start of the financial year saw RVA continue the collaborative development of the National Strategic Action Plan for Rare Diseases (the Action Plan). Following extensive multi-stakeholder consultation, during the latter part of 2019, RVA focussed on working with the Department of Health to strengthen and finalise the Action Plan.

In February 2020, the Minister for Health, the Hon. Greg Hunt MP, officially launched the Action Plan at Parliament House. In his speech, he stated, “This is a transformative moment in Australian history. I accept and acknowledge its (the Action Plan’s) recommendations.” The Government also announced $3.3 million in funding for the next financial year in their initial response to the Action Plan. Importantly, the development of national rare disease policy has bipartisan support and RVA also welcomed Australia’s Shadow Minister for Health, the Hon. Chris Bowen MP, who spoke at the launch. In addition to committing that the Action Plan will be implemented despite who wins the next election, the Shadow Minister said, “The National Strategic Action Plan for Rare Diseases will drive real change to extend and improve the lives of those with rare diseases.”

The launch was held ahead of Rare Disease Day and was attended by key stakeholders in the rare disease sector from all around Australia and even New Zealand. There was a real buzz in the air for what was a long-awaited day for the rare disease community. A decade ago, researchers (Jaffe et al) published an article in the Journal of Paediatrics and Child Health titled, *Call for a national plan for rare diseases*. Since 2010, many amazing and determined people have put in a lot of hard work that led to the Action Plan’s launch, including those in WA Health who supported the call for a national rare disease plan and in the meantime, led the way with their own state-based rare disease plan.

At RVA, we know that effective rare disease policy transforms people’s lives. The Action Plan was developed ‘by the rare disease sector, for the rare disease sector’ and is a comprehensive policy framework. It consists of three interrelated Pillars – Awareness and Education, Care and Support, and Research and Data – and can be summarised into a Plan on a Page. To facilitate greater stakeholder engagement with the Action Plan, RVA developed a range of summary materials and digital resources. The collaborative development and launch of the Action Plan further cemented RVA’s role as the peak body for Australians living with a rare disease.

COVID-19 and RVA Advocacy

Almost immediately after the Action Plan launch, the COVID-19 pandemic escalated in Australia. This impacted face-to-face events and meant RVA had to reschedule the National Rare Disease Summit to 2021. RVA successfully adapted our Mentorship and Education Program, while continuing to advocate strongly and influence policy. Indeed, our advocacy and mentorship activity increased due to COVID-19 which saw RVA lead and support advocacy with success. RVA led communication with the Department of Health and advocacy activity around the impact of COVID-19 on the Life Saving Drugs Program (LSDP). This advocacy resulted in the LSDP supporting rare disease patients by extending the standard 1 May reapplication deadline to 1 November 2020. Additionally, RVA reached out to all state and territory Health Ministers and Chief Health Officers, calling for priority testing and turnaround times for Australians living with a rare disease. Ahead of schools reopening, RVA contacted state education ministers and state Chief Health Officers and advocated for flexible school attendance requirements, while providing templates and resources to support individuals' advocacy. RVA also maintained a COVID-19 page on our website with information and useful links, resources and updates.

In addition to issues related to COVID-19, RVA undertook further work with RVA Partners around access to medicines, and in particular, to medicines already approved for other more common conditions.

Importantly, RVA has continued to ensure personal narratives are central to the discussion, highlighting individual stories of people living with a rare disease and linking them to broader strategic priorities. Individual rare disease organisations have gained a stronger voice by being able to position their own disease specific issues as part of a broader rare disease platform. RVA continued to provide advocacy, mentorship and education to RVA Partners which, this year, focused on broader stakeholder engagement with the Action Plan with RVA speaking at a range of conferences and events

Disability and Rare Disease

Importantly, RVA provided leadership around disability and rare disease. RVA commissioned the McKell Institute to research and deliver the report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases.* The report stands alone and importantly, helped to inform the development of the Action Plan. RVA launched this report at a Parliamentary Event in October 2019 which was attended by Shadow Minister for the NDIS, the Hon. Bill Shorten MP, who invited RVA to participate in Labor's National Disabilities Summit in November 2019.

2020 Rare Disease Day

As the national alliance representing Australia on the global Rare Disease Day Working Group, RVA continued to play a leading role in the collaborative development of annual Rare Disease Day activities. The main objective of Rare Disease Day is to raise awareness among the general public and decision-makers about rare diseases and their impact on people's lives. In 2020, the Action Plan's launch was timed to coincide with Rare Disease Day. RVA was pleased to provide support, as needed, to rare disease advocate, Andrew Bannister, who led work on illuminating 35 landmarks in Australia and around the world to mark Rare Disease Day.

RVA Staffing

RVA has outstanding, dedicated staff. In March 2020, RVA farewelled Policy and Research Officer, Kathryn Milne, and successfully recruited for a new permanent part-time role, Stakeholder Engagement & Education Officer. This new role has enabled us to revise staff roles to continue RVA's strong and effective stakeholder engagement and further resource our important education and valuable communications work. We were very pleased to appoint Louise Healy, who commenced in July 2020, to the new role. A former co-chair of RVA, Louise brings strong rare disease advocacy experience as well as professional qualifications and experience in psychology and education. RVA anticipates developing another permanent part-time staff member role in the 2020-2021 financial year.

Governance of RVA

We have an outstanding and dedicated Board of Directors. In the 2019-2020 financial year, the Board was chaired by Joanna Betteridge, and Kane Blackman was appointed Deputy Chair. During 2020, Dr Tracy Dudding-Byth stepped down from the RVA Board after many years. Tracy was one of the co-founders of RVA and had been an active part of RVA's growth and development and her contribution has been valued and will be missed. The Board will be actively recruiting an additional Director for the 2020-2021 financial year.

2020 Strategic Plan

The Board, along with all staff, gathered virtually in May 2020 with an independent facilitator to work through RVA's strategic priorities for the next three years. Further work on the strategic plan continued in the 2020-2021 financial year, refining and testing the priorities identified in our May gathering, which included articulating and refining our Vision, Mission and Philosophy. The strategic plan consists of the following focus areas:

- Stewardship of the Action Plan
- Driving or advocating for progress under each Pillar of the Action Plan (Awareness and Education, Care and Support, and Research and Data)
- Continuing to build RVA as the recognised peak body in the sector for Australians living with a rare disease
- Organisational sustainability

Constitutional Review

The Board and staff also commenced detailed work on a constitutional review, to update RVA's Constitution and to ensure that RVA's Purpose would be consistent with the Action Plan and RVA's future strategic priorities.

RVA is grateful to Maddocks Lawyers, for their pro bono assistance in drafting an updated Constitution for RVA.

The constitutional review also sought to strengthen the governance processes of RVA to bring them up to best practice for a not-for-profit organisation, including:

- Setting reasonable terms of appointment for Directors
- The annual appointment or reappointment of a Chair and Deputy Chair to encourage accountability for performance, and to allow more directors to contribute to these leadership roles during their terms
- Allowing for decisions to be made using electronic/digital options – this is particularly important for a national board

It is anticipated that the updated Constitution will be adopted at the 2020 Annual General Meeting (AGM).

RVA Committees

Viswanathan (Vishy) Narayanaswamy, a Director of RVA and an accountant, took over the role of Chair of our Finance and Risk Committee from long-standing Chair, Raymond Saich. The Board is grateful to Raymond for his dedicated leadership of this committee and appreciates his ongoing contribution to the work of the committee. The Board looks forward to the valuable work of the committee as it continues its role in refining and improving our governance, finance and risk procedures, under Vishy's leadership.

RVA is also grateful for the continued professional expertise and advice provided by our Scientific & Medical Advisory Committee (SMAC) led by Chair, Dr Carol Wicking, a Director of RVA. This year, we welcomed Professor John Rasko to SMAC.

Contribution by Partners and Stakeholders

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

BOARD MEMBERS, COMPANY SECRETARY AND STAFF TEAM

Joanna Betteridge BA, LLB, LLM, GAICD

CHAIR, Rare Voices Australia (VIC)

Joanna Betteridge, Principal of Betteridge Legal Consulting, is an employment and workplace safety lawyer and consultant and an accredited mediator. Joanna is also a Senior Fellow at Monash University and lectures in its Law Faculty post graduate program including lecturing in anti-discrimination law. Joanna is the immediate past Chair of the TEAR Australia Board (a global aid and development organisation) and has held a number of board roles in a variety of not for profit and Government boards since 2003. Joanna sat for many years on the committee of the Australian MPS Society, becoming involved soon after her two nephews, Jack and Tom, were diagnosed with MPS III, Sanfilippo Syndrome, in 1998.

Board meeting attendance: *Eligible – 13, Attended – 12*

Kane Blackman

DEPUTY CHAIR, Rare Voices Australia (WA)

Kane is a senior executive with the Western Australian Government at the Insurance Commission, which provides injury and liability insurances, and related investment functions. Prior to the public sector, Kane worked in various Australian and international resource companies and in private equity. Kane is a non-executive director of Therapy Focus, the largest provider of therapy services to people with disability in WA. He is a member of the WA Minister for Health's Precision Health Council, the WA Minister for Disability's Advisory Council, and a deputy member of the WA Minister for Road Safety's Council. Kane is also a State Committee member of the Governance Institute, a lecturer in corporate governance and a chartered company secretary.

Kane has a son with Angelman Syndrome and is the Deputy President of the Angelman Syndrome Association Australia. Kane is also the Chair of RVA's Nomination Committee.

Board meeting attendance: *Eligible – 7, Attended – 6*

Tracy Dudding-Byth

Director, Rare Voices Australia (NSW)

Dr Tracy Dudding-Byth is a full-time consultant clinical geneticist at Hunter Genetics and the NSW Genetics of Learning Disability (GOLD) service. Her training in internal medicine and clinical genetics has been combined with clinical research in the areas of genetic epidemiology and rare genetic diseases. Tracy is leading an innovative project evaluating the use of 2D facial recognition technology for matching the gestalt of individuals with known and unknown syndromic forms of intellectual disability.

Tracy has a personal connection with a rare disease called Neurofibromatosis type 1 (NF1). She plans to combine her passion in this area with her clinical genetics knowledge to work on developing a targeted molecular therapy to reduce the numbers of cutaneous neurofibromas.

Tracy is a founding director of Rare Voices Australia and sits on the medical advisory committee of the Steve Waugh Foundation, an Australian charity for children with rare diseases.

Board meeting attendance: *Eligible – 6, Attended – 4. Resigned 30/04/2020.*

Louise Healy

Director, Rare Voices Australia (QLD)

Louise has post-graduate qualifications in psychology and has managed a consulting business for the past seven years. Her connection with rare conditions began when her first child was born with a rare metabolic disorder. Louise has been involved in rare disease support and advocacy for over 10 years and she is the current Vice President of the Metabolic Dietary Disorders Association (MDDA). She has led successful advocacy campaigns for access to medicines and support programs for people with rare disorders of protein metabolism. Louise is a previous RVA Board member, current member of the Queensland Genomics Community Advisory Board and a founding Board member of the Global Association for PKU.

Board meeting attendance: *Eligible – 1, Attended – 0. Resigned 11/08/2019*

Robert Hendriks MD, MBA, GAICD

Director, Rare Voices Australia (NSW)

Robert Hendriks graduated as a Medical Doctor from the University in Amsterdam and as a Master of Business Administration in Rotterdam. Robert has over 20 years' experience as an international senior executive in the Pharmaceutical, Biotech, Natural Medicines and Medical Devices industries and currently is the Chief Executive Officer of global healthcare company SFI. Robert's connection with rare diseases began in 2010 in his role as Managing Director of a pharmaceutical company that pioneered the development and delivery of therapies for patients affected by rare diseases. Robert worked with the Department of Health and Ageing to ensure patients have access to the products needed to treat their rare diseases. He is also a graduate of the Australian Institute of Company Directors.

Board meeting attendance: *Eligible – 13, Attended – 7*

Eric Morand MBBS (Hons), FRACP, PhD

Director, Rare Voices Australia (VIC)

Professor Eric Morand is Professor and Head of the School of Clinical Sciences at Monash Health, Monash University's largest clinical school. He is also a specialist rheumatologist, and Head of the Monash Health Rheumatology Unit, the largest in Australia. He specialises in research and clinical care of systemic lupus erythematosus, as well as complex rheumatic diseases and rheumatoid arthritis. He is founder of the Monash Lupus Clinic, Australia's largest research-grounded clinic for patients with SLE, a founding member of the Australian Lupus Registry & Biobank, and Chair of the Asia Pacific Lupus Collaboration.

Board meeting attendance: *Eligible – 7, Attended - 5*

Viswanathan Narayanaswamy (Vishy)

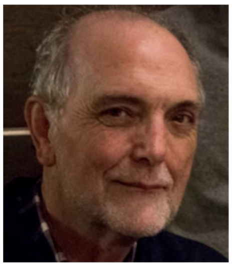
Director, Rare Voices Australia (NSW)

Vishy is a Chartered Accountant by profession and has over 18 years' worth of experience in accounting, auditing and taxation. Vishy is a member with the Institute of Chartered Accountants of Australia and New Zealand and the Institute of Chartered Accountants of India. He is currently working as a senior manager in a public accounting firm in Sydney. Vishy will be supporting the Board with finance and accounting related matters. Vishy was diagnosed with PNH disease, a rare blood disorder in 2008 and is receiving treatment since then.

Board meeting attendance: *Eligible – 13, Attended - 9*

Raymond Saich OAM

Director, Rare Voices Australia (NSW)



Raymond is the President of the Australian Pompe Association and a Director of the International Pompe Association. He is a Pompe patient and started treatment for his Pompe disease with enzyme replacement therapy in 2007 and is now one of the longest treated Pompe patients in Australia. Raymond has been a strong advocate for people living with a rare disease since receiving his diagnosis in 2002. Prior to retirement, Raymond was a senior manager with an Australian multinational diagnostic imaging company and played a major role in the introduction of both CT and MRI scanning in Australia.

Board meeting attendance: *Eligible – 13, Attended – 12*

Carol Wicking

Director, Rare Voices Australia (QLD)

Dr Carol Wicking received her BSc (Hons) and MSc from the University of Melbourne and her PhD from the University of London. She has over 25 years' worth of research experience, primarily investigating the molecular and cellular basis of a number of rare diseases including cystic fibrosis, naevoid basal cell carcinoma syndrome and a class of rare diseases known as ciliopathies. Carol is a past President of the Australian and New Zealand Society for Cell and Developmental Biology and current Chair of the Board of Phenomics Australia. She is currently an independent consultant and an Honorary Associate Professor at the Institute for Molecular Bioscience at the University of Queensland. Carol is also the Chair of RVA’s Scientific and Medical Advisory Committee.

Board meeting attendance: *Eligible – 7, Attended – 5*

COMPANY SECRETARY

Liyi Chang

Company Secretary, Rare Voices Australia (VIC)

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

RVA SENIOR EXECUTIVE AND STAFF

Nicole Millis

Chief Executive Officer, Rare Voices Australia (VIC)

A qualified social worker, Nicole has both personal and professional experience in the rare disease sector. Nicole has over 12 years' worth of experience in rare disease advocacy, particularly in regard to access to treatments. Since 2018, Nicole has held the role of consumer nominee on the Life Saving Drugs Program Expert Panel. Under Nicole's guidance, RVA led the collaborative development of the National Strategic Action Plan for Rare Diseases, the first nationally coordinated effort to address rare diseases in Australia.

Sarah Cannata

Stakeholder Engagement and Communications Officer (VIC)

Sarah is a passionate storyteller, a qualified journalist, and has over 10 years' worth of experience working in Communications. A published author, Sarah has extensive experience across a range of sectors, particularly in the not-for-profit space. She is committed to using her skills to benefit Australians living with a rare disease.

Kathryn Milne

Research and Policy Officer

Kathryn is an experienced policy worker, with a background in state government working in housing and homelessness, and in the private sector consulting in the health, ageing and human services sector. Kathryn is committed to making a positive difference to the lives of vulnerable and disadvantaged Australians, and is dedicated to fostering the strength and capacity of individuals, families and communities. Contract completed 12/3/20.

Anne Hunter

Administrative Officer, Rare Voices Australia (VIC)

Anne is experienced in office management, P.A. support, event planning and bookkeeping. She has a personal connection living with a rare disease and supporting her daughter who also has Fabry Disease. Anne enjoys working for a passionate and person-centred organisation. Anne also sits on the Fabry Australia Committee.

BOARD COMMITTEE

The Board has two subcommittees – the Finance and Risk Committee (the FaR Committee), Chaired by Raymond Saich till December 2019 and then by Viswanathan Narayanaswamy from January 2020 onwards. The Committee is appointed to provide advice to the 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

Dr Carol Wicking (QLD)

Chair SMAC and Director, Rare Voices Australia

Dr Carol Wicking received her BSc (Hons) and MSc from the University of Melbourne and her PhD from the University of London. She has over 25 years' worth of research experience, primarily investigating the molecular and cellular basis of a number of rare diseases including cystic fibrosis, naevoid basal cell carcinoma syndrome and a class of rare diseases known as ciliopathies. Carol is a past President of the Australian and New Zealand Society for Cell and Developmental Biology and current Chair of the Board of Phenomics Australia. She is currently an independent consultant and an Honorary Associate Professor at the Institute for Molecular Bioscience at the University of Queensland. Carol is also a Director on the RVA Board.

A Clin/Prof Gareth Baynam (WA)

Western Australian Register of Developmental Anomalies, GSWA, WADoH, Centres of Expertise, Phenotyping, Digital Health

Professor Gareth Baynam is a Head of the Western Australian Register of Developmental Anomalies (birth defects and cerebral palsy registers), Clinical Geneticist and Program Director of the Undiagnosed Diseases Program WA; Board Member of the Undiagnosed Diseases Network International; and Adjunct Genomics Policy Officer in the Western Australian Health Department. He is affiliated with the University of Western Australia; Curtin University, Murdoch University, Notre Dame University, Melbourne University; and Telethon Kids Institute. He is the Founder of an integrated suite of cross-sector and community engaging initiatives to improve the lives of people living with rare diseases including Project Y, Cliniface and Lyfe Languages. He Chairs and/or is one the Executive or Advisories of multiple international rare diseases initiatives and has personal connections to rare diseases.

Dr Kaustuv Bhattacharya (NSW)

Specialist Metabolic Physician, Queensland Lifespan Metabolic Service

Dr Kaustuv Bhattacharya is a UK trained metabolic physician. He moved to Sydney, Australia in June 2008 and became the department head of metabolic services at Sydney Children's Hospitals Network before completing a sabbatical at Queensland Lifespan Metabolic Service in 2019. He returned to Sydney in 2020. He is a conjoint senior lecturer for Sydney University having completed a range of published therapeutic research for rare conditions. He has strongly advocated for rare disease therapeutic research and clinical infrastructure and will be the chairperson for the International Congress of Inborn Errors of Metabolism in Sydney in 2021.

Professor Alan Bittles, OAM (WA)

ECU/Murdoch, Community Genetics, Consanguinity, Intellectual Disability

Prof. Alan Bittles received his PhD from Queen's University, Belfast, ScD from Trinity College, University of Dublin, and is a Fellow of the Royal College of Pathologists. He is Emeritus Professor of Community Genetics in the School of Medical and Health Sciences, Edith Cowan University and Adjunct Professor in the Centre for Comparative Genomics, Murdoch University, Perth, Australia. His present research centres on the impact of consanguinity and genetic sub-structure on disease gene expression, haemoglobinopathies, and intellectual and developmental disability, with projects in Australia, India and the UK. Prof. Bittles was Inaugural Chair of RVA SMAC from 2015-2017 and in 2017 he was appointed a Member of the Order of Australia (AM) for services in Medical Genomics.

Dr Lisa Ewans (NSW)

Clinical Geneticist

Dr Lisa Ewans is a Clinical Geneticist at Royal Prince Alfred Hospital and Sydney Children's Hospital and a Clinical Lecturer at The University of Sydney. She obtained her MBBS and BSc (Neuroscience) at Imperial College London before moving to Sydney to continue paediatric training, and received her Fellowship of the RACP in clinical genetics. In her practice, she sees a range of patients with rare genetic disorders of all ages, advocating for their care. She is completing a PhD in genomics applied to the diagnosis of rare genetic disorders through the Garvan Institute of Medical Research and UNSW. Her research and clinical interest is to help individuals with suspected but unsolved rare genetic disorders to find a diagnosis, and is co-leading a new undiagnosed diseases program through the Sydney Children's Hospital Network.

Professor Adam Jaffe (NSW)

UNSW/Randwick, Respiratory Disorders, CF, Consumers, Clinicians & Clinical Trials (NHMRC)

Professor Adam Jaffe (BSc (Hons) MBBS MD FRCP FRCPCH FRACP FThorSoc) is the John Beveridge Professor of Paediatrics and Head of the School of Women's and Children's Health, UNSW Medicine, and a Paediatric Respiratory Consultant at Sydney Children's Hospital, Randwick. Professor Jaffé was appointed as Consultant in Paediatric Research at Great Ormond Street Hospital for Children and headed up Respiratory Medicine research at the Institute of Child Health London in 2001. Jaffe chairs the Young Lungs program of Lung Foundation Australia and is on Lung Foundation Australia's Rare Lung Diseases Committee. He is on the medical and scientific advisory committee of Rare Voices Australia and previously Asthma Australia. He was on the Lung Foundation Australia committee writing the National Strategic Plan for Lung Conditions (2019) and a member of the National Strategic Action Plan for Rare Diseases, Rare Voices Australia. His interests lie in the areas of asthma, cystic fibrosis, childhood respiratory infections and rare 'orphan' lung diseases.

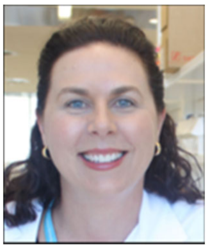
Dr Paul Lacaze (VIC)

U Monash U/Alfred, Genomics, Cohort Studies, Biobanking, Rare Disease Registries

Dr Paul Lacaze is a geneticist and Head of Public Health Genomics at Monash University. He conducts research into the role of genetic data in public and population health, through large-scale cohort studies, biobanks, clinical trials and registries. He leads genomics for the ASPREE study, Australia's largest clinical trial and study of healthy ageing in >15,000 Australians, and works with the Monash Registries Science Unit in the area of rare disease registries. He conducts research into the ethical, legal and social issues associated with use of genomic information in society. He founded the Australian Non-Genetic Discrimination Working Group, a national body advocating for regulatory change around the use of genetic test results in life insurance. He is passionate about developing a National Plan and Alliance for Rare Disease Registries in Australia.

Dr Kristen Nowak (WA)

Director, Office of Population Health and Genomics, WA Department of Health



Dr Kristen Nowak has over 20 years' experience as a medical researcher in the rare diseases field, focusing on finding new disease genes and evaluating potential therapies. Her office has a strong focus on the translation of evidence-based genomic and screening technology into the health system, and a longstanding emphasis on improving the healthcare journey of people with rare diseases. Kristen is a member for the Standing Committee on Screening, and the Project Reference Group on Health Genomics. She is also chair of the national Newborn Bloodspot Screening Program Management Committee. Kristen is an Honorary Research Fellow at the Harry Perkins Institute of Medical Research and an Adjunct Senior Lecturer at the University of Western Australia.

Dr Lemuel Pelentsov (SA)

Senior Lecturer, UniSA, RDs

Lemuel Pelentsov is Program Director for the Bachelor of Nursing (Theory), University of South Australia. Since his eldest son's diagnosis of a rare disease in 2008, Dr Pelentsov has been a passionate nurse-researcher investigating the support needs of parents and families with rare diseases. In his PhD, he developed the Parental Needs Scale for Rare Diseases (PNS-RD) – a tool which is now being used by researchers and clinicians in numerous countries. He has multiple publications and has presented his research at numerous national (Australian) and international conferences.

Professor John Rasko AO (NSW)

Director, Department of Cell and Molecular Therapies, Royal Prince Alfred Hospital and the Gene and Stem Cell Therapy Program, Centenary Institute, University of Sydney

Professor John Rasko is an Australian pioneer in the application of adult stem cells and genetic therapy, and President (2018-20) of the International Society for Cell & Gene Therapy. He is a clinical haematologist, pathologist and scientist with an international reputation in gene and stem cell therapy, experimental haematology and molecular biology. In over 170 publications he has contributed to the understanding of stem cells and blood cell development, gene therapy technologies, cancer causation and treatment, human genetic diseases and molecular biology. John has served on a number of hospital, state and national bodies. He is the recipient of national and international awards in recognition of his commitment to excellence in medical research, including appointment as an Officer of the Order of Australia.

Professor Jeff Szer (VIC)

University of Melbourne/Peter Mac and Royal Melbourne, Hbopathies, Bone Marrow Transplantation

Jeff Szer AM is a senior haematologist in the Clinical Haematology Department at Peter MacCallum Cancer Centre and The Royal Melbourne Hospital (RMH) and Director of the Western and Central Melbourne Integrated Cancer Service. He established the first adult BMT centre in Melbourne in 1984 and has clinical research interests in all areas of haematology in particular improving the outcomes of treatment for leukaemia, lymphoma and myeloma and the non-malignant conditions of Gaucher disease and paroxysmal nocturnal haemoglobinuria. He is Past President of the Worldwide Network for Blood and Marrow Transplantation (WBMT) and is current President of the World Marrow Donor Association (WMDA). Jeff sits on a number of national and international committees and organisations involved in haematology and was a member of the Gaucher Disease Advisory Committee and chaired the PNH Disease Advisory Committee of the Life Saving Drugs Program of the Australian Department of Health and Ageing until the committees were disbanded in May 2014.

Associate Professor Yvonne Zuryski (NSW)

BAppSc, MAppSc, MHpol, PhD

Yvonne Zurynski is Associate Professor of Health System Sustainability at the Australian Institute of Health Innovation, Macquarie University and leads the Coordinating Centre of the NHMRC Partnership Centre in Health Systems Sustainability. She is Adjunct Associate Professor, University of Tasmania and Honorary Associate Professor at The University of Sydney and Curtin University, in Perth, Western Australia. As a mixed methods researcher, implementation scientist, epidemiologist, program evaluator and policy analyst, she consolidates broad knowledge and understanding of complex systems from different viewpoints. Using novel co-design approaches she has led evaluations of complex integrated care interventions for children and adults with chronic, complex, and rare disease. She was instrumental in the call for a national rare disease strategy in 2009 and contributed significantly to the Care and Support Pillar of the National Strategic Action Plan for Rare Diseases.

OUR INDUSTRY PARTNERS IN 2019/2020

Round Table of Companies

Alexion Pharmaceuticals Australasia
Amicus Therapeutics
Biogen Idec Australia Pty Ltd
BioMarin Pharmaceutical Australia Pty Ltd
CSL Limited
Menarini Australia Pty Ltd
Pfizer Australia Pty Limited
PTC Therapeutics Australia Pty Limited
Sanofi Genzyme Australia
Shire Australia Pty Ltd
Vertex Pharmaceuticals (Australia) Pty Ltd

OUR WORK IN 2019/2020

Rare Disease Policy Development

In addition to the the Action Plan, RVA contributed to other key policy work in 2019/2020, including working with the McKell Institute towards the development of a white paper report on rare disease and disability, particularly in the context of the National Disability Insurance Scheme (NDIS). This included the facilitation of a focus group and online survey. The report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases,* was subsequently published in October 2019.

RVA also contributed to the Asia Pacific Economic Cooperation Action Plan on Rare Diseases, facilitating input from RVA Partner organisations, RVA's Scientific & Medical Advisory Committee and the RVA Round Table of Companies.

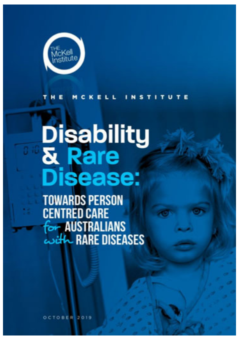
Advocacy, Mentorship & Education

RVA continued to help build the advocacy capacity of rare disease organisations through its Mentorship and Education program which provided customised advocacy mentoring for specific rare disease support groups. In 2020, RVA's Speakers Program focused on encouraging key stakeholders in the sector to engage with the Action Plan. Speakers provided education about rare disease, the importance of the Action Plan and how the sector can use the policy document to drive implementation and change. Additionally, RVA developed a suite of communication materials including summary pages and videos to facilitate communication about the Action Plan.

RVA Partner Program

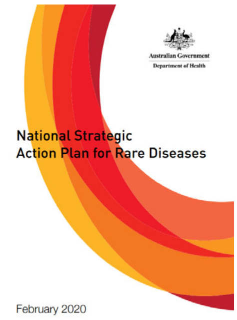
Throughout 2019-2020, RVA continued to improve its engagement with rare disease organisations and individuals. The number of RVA Partner organisations has steadily grown to around 80 organisations with retention rates remaining steady since the 2018 National Rare Disease Summit. Rare disease organisations continue to refer to themselves as 'RVA Partners' as a way to increase their profile and voice in the advocacy space.

Rare Disease Day Parliamentary Event



In October 2019, RVA launched the report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases* (the report), at Parliament House. The event was hosted by the co-convenors of the Standing Committee on Health, Trent Zimmerman MP, and Dr Mike Freelander MP. The report highlights significant unmet need and the need for the health and disability sectors to collaborate to provide person-centred care, particularly in the context of the NDIS. RVA presented the report to the Minister for the NDIS, the Hon Stuart Robert MP, and Shadow Minister for the NDIS, the Hon Bill Shorten MP. RVA's CEO, Nicole Millis, and Angela Jackson, an experienced public sector economist who was involved with the development of the report, spoke at the event. A total of 16 MPs and Senators attended the Parliamentary Event, in addition to 14 advisers who represented Ministerial and Senator offices. RVA Partner organisation leaders and industry were also in attendance.

Development of the National Strategic Action Plan for Rare Diseases



The development of the Action Plan continued from mid-2019 until its launch in February 2020. Ongoing communication and discussions between RVA and Department of Health staff took place throughout this period. Additionally, communication and discussion continued with members of the Action Plan Steering Committee and RVA's Scientific & Medical Advisory Committee, as needed. Alongside the extensive stakeholder consultation process, these discussions informed and shaped the Action Plan, which was developed 'by the rare disease sector, for the rare disease sector'.

Launch of the National Strategic Action Plan for Rare Diseases

With bipartisan support, the Minister for Health, the Hon Greg Hunt MP, launched the Action Plan in February 2020 at Parliament House in the lead up to Rare Disease Day. Minister Hunt emphatically "accepted and endorsed" the Action Plan and committed to its implementation. The Shadow Minister for Health, the Hon Chris Bowen MP, also spoke at the event, committing to the Action Plan's implementation regardless of which party wins the next election.

The event was hosted by the co-convenors of the Standing Committee on Health, Trent Zimmerman MP, and Dr Mike Freelander MP. RVA's CEO, Nicole Millis, and Deputy Chair and RVA Director, Kane Blackman, also gave speeches. There was strong bipartisan support at the Parliamentary Event, which was very well attended by all key stakeholders in the rare disease sector, including RVA Partner organisations and departmental attendees (representatives from the Australian Institute of Health and Welfare, Australian Government Department of Health's Chronic Disease Policy Section etc.). Over 100 people attended the event, including 14 MPs/Senators.

RVA Advisory Committees

RVA continued to meet quarterly with its Round Table of Companies and Scientific & Medical Advisory Committee (SMAC). Both Committees are governed by RVA and facilitated by key RVA staff. They are supported by Terms of Reference and RVA policy guidelines, including the *Working With Pharmaceutical Industry Policy*.

During the 2019-2020 year, SMAC continued to provide support and advice to RVA on a range of matters relevant to research and health outcomes for Australians living with a rare disease. Following the launch of the Action Plan in February, SMAC was involved in developing strategies to help underpin implementation. In support of the Research and Data Pillar of the Action Plan, SMAC worked to develop guidelines to facilitate meaningful research partnerships between RVA and researchers and clinicians, to ensure a person-centred approach to research. Further drawing on the Action Plan, SMAC worked with RVA to raise awareness of the issues facing people living with a rare disease, including those issues specifically related to the COVID-19 pandemic. This resulted in a journal article and an RVA statement outlining approaches to ensure the rare disease community is protected in the national response to COVID-19.

The RVA Round Table of Companies (RTC) is a group of pharmaceutical companies that share a common interest in rare diseases and orphan drug development. RVA RTC members provide financial support to RVA and in return, their company benefits from the constructive dialogue developed between industry, rare disease organisations and relevant key stakeholders. All RVA RTC members support RVA's mission as the unified voice to improve the lives of all Australians affected by rare disease.

In 2020, the number of representatives eligible to attend each RVA RTC quarterly meeting was increased from two to three representatives to ensure relevant expertise in:

- company patient advocacy;
- market access for treatments and reimbursement; and
- government relations.

Due to COVID-19, the quarterly meetings in 2020 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 on rare diseases. The meetings provide:

- opportunities for RVA and industry representatives to interact with companies;
- opportunities for 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.

All member company logos are listed on the RVA website

RVA Media

New plan for grappling with rare diseases

Greta Stonehouse

National

Health Minister Greg Hunt wants to speed up the diagnosis and improve treatment of rare diseases.

When Kane Blackman's son started experiencing severe symptoms of an unknown condition, he was told his child was delayed and would eventually catch up.

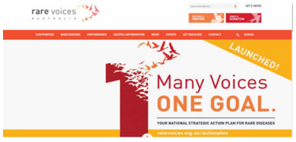
As Australia's peak body for Australians living with a rare disease, RVA continued to be sought out by the Australian media in 2019-2020 as an authority to comment on rare disease related issues in Australia. RVA also strengthened ongoing relationships with journalists and media covering relevant beats in health, politics, disability, and other areas.

Media highlights:

- To coincide with the launch of the *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases* report, a news exclusive ran with News Corp's readership base of 4.3 million Australians.

- The launch of the Action Plan was covered by the Herald Sun and News.com.au, where the article was heavily syndicated. In total, there were 120 pieces of coverage about the Action Plan, resulting in over 22 million potential impressions.

RVA Website and Social Media



RVA maintains a dynamic online presence that serves all key stakeholders in the rare disease sector. In the 2019-20 financial year, the RVA website was visited by 22,000 users. RVA also communicates with its community via its Facebook, Twitter, LinkedIn and Instagram social media channels, which continue to grow steadily organically. Additionally, RVA moderates a closed Facebook group where RVA Partner organisation leaders have the opportunity to connect, engage and collaborate with each other.

In February 2020, the Steve Waugh Foundation gifted the Rare Disease Day Australia website and Facebook page to RVA.

RVA Newsletter

Rare Voices Australia: September 2020 e-news

View this email in your browser

rare voices
AUSTRALIA

A unified voice for all Australians living with a rare disease.

RVA PERSONAL STORY

Tim's Story

Tim's story highlights how living with a rare disease does not only affect a person's health, it impacts every facet of their life, including employment and mental and physical health. Read Tim's story.

RVA distributes a monthly e-newsletter that is sent to an email database consisting of all key stakeholders. Each monthly e-newsletter features a personal story shared by an individual living with a rare disease. RVA links each story back to the Action Plan. Each e-newsletter features an editorial from RVA's CEO highlighting RVA's work and updates, news from our RVA Partners, as well as relevant information about rare diseases from Australia and around the world. The e-newsletter is one of RVA's key communication channels and is also published on the RVA website.

Committees/Advisory Groups participation

During 2019-2020, RVA participated in the following advisory committees/groups:

1. International Rare Disease Research Consortium (IRDiRC) Patient Advocacy Constituents Committee (PACC)
2. Global Rare Disease Day Working Group
3. Victorian Newborn Bloodspot Screening Committee
4. RD Now Community Engagement Committee
5. Sydney Children's Hospital Network Gene Therapy Advisory Committee

In addition, separate to her RVA work, CEO Nicole Millis is the consumer nominee on the Life Saving Drugs Program Expert Panel.

Conferences, Events and Consultations

Over the last financial year, RVA staff and volunteers have facilitated, presented at or participated in the following:

Date	Event
Jul 2019	Canberra Health Summit – invited delegate Mackenzie's Mission Patient Support Group Consultation – invited delegate
Aug 2019	Thalassaemia and Sickle Cell Australia afternoon tea – invited delegate Rare Find Foundation launch – invited delegate Lysosomal Storage Disorders Summit – RVA speaker Takeda Meeting with Head of APAC – RVA speaker MAA National Myasthenia Gravis Conference – RVA speaker Human Genetics Society Australasia, Wellington – delegate GSNV Strengthening the Sector – RVA speaker
Sep 2019	Spinal Muscular Atrophy Assoc Parliamentary Event – RVA speaker/emcee Australian Genomics Conference - delegate
Oct 2019	RVA Parliamentary Event – RVA speaker
Nov 2019	Labor Disabilities Summit – invited delegate
Dec 2019	
Jan 2020	National Medicines Policy Review Workshop – invited delegate
Feb 2020	Rare Friends Far North Queensland Rare Disease Day Fun Run – RVA speaker Rare Disease Day Garden Party High Tea – invited delegate Parliamentary Friends of Medicine Event on Gene Therapy – RVA speaker John Curtin School Public Lecture, Australian National University – RVA speaker National Strategic Action Plan for Rare Diseases Launch – RVA speaker
Mar 2020	Rare Disease Day Community Event -Sydney – RVA speaker Save our Sons Duchenne Conference – invited delegate
Apr 2020	
May 2020	Consumer Health Form webinar - delegate
Jun 2020	Scoping a genomic support network for Queensland patients – invited delegate CGN4RD Focus Group – WHO Western Pacific – invited delegate

Policy Submissions

Over the last financial year, RVA has prepared and presented the following policy submissions and Position Statements:

Date	**Policy Submission**
Apr 2020	COVID-19 pandemic: critical care guidelines for Australians living with a rare disease
Nov 2019	NHMRC Response for Mitochondrial Donation: Ethical and Social Issues for Community Consultation
Dec 2019	Pre budget submission to Treasury
Jun 2020	PBAC online comment submitted for Nusinersen (Spinraza) application for SMA PBAC online comment submitted for Ravulizumab (Ultomirus) application for PNH
Jun/Jul 2020	Consultation Survey on MSAC Application 1573 Reproductive carrier screening for fragile X syndrome, Spinal Muscular Atrophy and Cystic Fibrosis

AUDIT DECLARATION

The Board of RVA declares that the accompanying financial report is presented fairly in accordance with applicable Australian Accounting Standards and is consistent with the Company's 30 June 2020 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2020 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 10 December 2020.

Joanna Betteridge

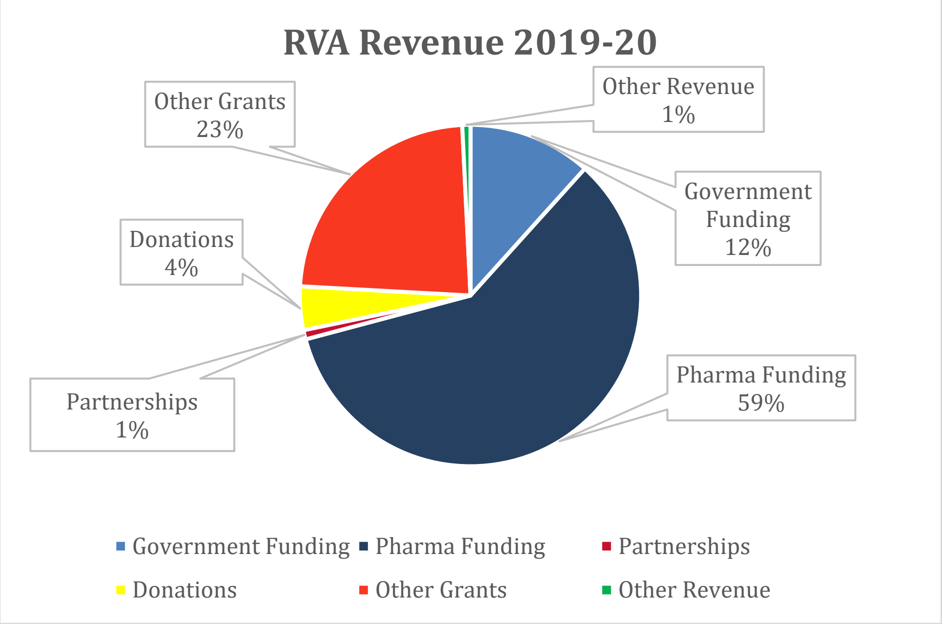
Auditor's Independent Declaration

The lead auditors' independence declaration for the year ended 30 June 2020 has been received and can be found on the financial report.

FINANCIAL REPORT

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 RVA Partner fees and donations from the public.



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 2020, the total amount that members of the Company are liable to contribute if the entity is wound up is $100.

RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Financial Report for the year ended 30 June 2020

CONTENTS

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 2020.

Directors

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

JOANNA BETTERIDGE
CAROL WICKING
ERIC MORAND
KANE BLACKMAN
RAYMOND SAICH
ROBERT HENDRIKS
VISWANATHAN NARAYANASWAMY
LOUISE HEALY (resigned on 12th Aug 2019)
TRACY DUDDING (resigned on 30th April 2020)

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 2020 amounted to $121,002

(30 June 2019 - $120,562)

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.

Dividends

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

Share Options

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

Directors Benefits

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

Indemnifying Officer or Auditor

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

Proceedings on Behalf of Company

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

Auditors Independence Declaration

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

Signed in accordance with a resolution of the director:

____

JOANNA BETTERIDGE

Director

Dated: 10th December 2020

RARE VOICES AUSTRALIA LIMITED
Statement of Financial Position as at 30 June 2020
ABN 69 156 254 303

	Note	2020 $	2019 $
Assets			
Current Assets			
Cash and cash equivalents	3	630,823	661,663
Trade and other receivables	4	720,610	132,515
Total Current Assets		**1,351,433**	**794,178**
Non-Current Assets			
Property, plant and equipment	5	-	-
Total Non-Current Assets		-	-
Total Assets		**1,351,433**	**794,178**
Liabilities			
Current Liabilities			
Trade and other payables	6	788,581	356,715
Provisions	7	20,688	16,302
Total Current Liabilities		**809,269**	**373,017**
Total Liabilities		**809,269**	**373,017**
Net Assets		**542,164**	**421,161**
Equity			
Retained profits		542,164	421,161
Total Equity		**542,164**	**421,161**

The accompanying notes form part of these financial statements.

RARE VOICES AUSTRALIA LIMITED

ABN 69 156 254 303

Statement of Comprehensive Income

For the year ended 30 June 2020

	Note	2020 $	2019 $
Revenue	2	605,000	709,552
Other revenue	2	59,467	43,742
Depreciation		-	(5,857)
Employee benefit expenses		(258,949)	(201,344)
Other expenses		(284,515)	(431,388)
Profit before income tax		**121,002**	**120,562**
Income tax expense		-	-
Profit for the year after income tax		**121,002**	**120,562**
Other Comprehensive Income for the year		**-**	**-**
Total Comprehensive Income for the year		**121,002**	**120,562**

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 2020

	Other Reserves	Retained Earnings	Total
Balance at 1 July 2018	-	300,599	300,599
Comprehensive income			
Other comprehensive income for the year			
Total comprehensive income for the year attributable to members of the entity	-	120,562	120,562
Balance at 30 June 2019	**-**	**421,161**	**421,161**
Comprehensive income			
Profit attributable to the members	-	121,002	121,002
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**

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 2020

	2020 $	2019 $
Cash Flow From Operating Activities		
Receipts from customers	49,060	800,287
Payments to Suppliers and employees	(107,212)	(600,904)
Interest received	5,136	5,492
Cash Flow Boost	22,176	-
Net cash provided by (used in) operating activities (note 8)	**(30,840)**	**204,875**
Cash Flow From Investing Activities		
Payment for:		
Payments for property, plant and equipment	-	(2,417)
Net cash provided by (used in) investing activities	**-**	**(2,417)**
Cash Flow From Financing Activities		
Repayment of borrowings	-	-
Net cash provided by (used in) financing activities	**-**	**-**
Net increase (decrease) in cash held	(30,840)	202,458
Cash at the beginning of the year	661,663	459,205
Cash at the end of the year (note 3)	**630,823**	**661,663**

The accompanying notes form part of these financial statements.

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.

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.

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.

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.

	2020 $	2019 $

Note 2: Revenue and Other Income

	2020 $	2019 $
Revenue:		
Sponsorships	145,000	145,000
Special projects	460,000	564,552
	605,000	**709,552**
Other revenue:		
Donations & memberships	32,155	37,243
Interest revenue	5,136	5,492
Other revenue	22,176	1,007
Total Revenue	**664,467**	**753,294**

Note 3: Cash and cash equivalents

	2020 $	2019 $
Bank accounts:		
WBC Cheque Account	15,688	17,797
WBC Cash Reserve Account	283,098	466,942
WBC Debit Card	2,179	1,711
Other cash items:		
Term Deposits	329,858	175,214
	630,823	**661,664**

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:

	2020 $	2019 $
- Cash and cash at bank	630,823	661,664
	630,823	**661,664**

Note 4: Trade and other receivables

	2020 $	2019 $
Current		
Trade debtors	720,610	132,515
	720,610	**132,515**

The accompanying notes form part of these financial statements.

Note 5: Property, plant and equipment

	2020 $	2019 $
Plant and equipment:		
- At cost	18,169	18,169
- Less: Accumulated depreciation	(18,169)	(18,169)
	-	-

Note 6: Trade and other payables

Current

	2020 $	2019 $
Trade creditors	1,447	751
Revenue received in advance	723,000	330,000
ATO liability	(5,939)	7,507
GST payable	65,378	11,937
Superannuation payable	4,695	5,592
Other payroll liabilities	-	928
	788,581	**356,715**

Note 7: Provisions

Current

	2020 $	2019 $
Provision for annual leave	20,688	16,302
	20,688	**16,302**

Note 8. Reconciliation Of Cash

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

	2020 $	2019 $
Profit (loss) after income tax	121,002	120,562
Non-cash flows in profit		
Depreciation	-	5,857
Changes in assets and liabilities:		
(Increase) decrease in trade and other receivables	(588,095)	(82,254)
Increase (decrease) in trade and other payables	431,867	154,778
Increase (decrease) in sundry provisions	4,386	5,932
Net cash provided by operating activities	**(30,840)**	**204,875**

The accompanying notes form part of these financial statements.

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 2020 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2020 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 17th November 2020.

Director: Joanna Betteridge

Dated: 10th December 2020

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 2020

	2020 $	2019 $
Income		
Sponsorships	145,000	145,000
Special projects	460,000	564,552
Donations and memberships	32,155	37,243
Interest received	5,136	5,492
Other revenue	22,176	1,007
	664,467	753,294
Expenditure		
Accountancy, audit and legal	10,580	10,480
Consultancy	181,441	108,793
Bank fees	653	772
Depreciation	-	5,857
Meeting and conference expenses	611	1,140
Board/governance expenses	1,333	11,163
Project expenses	21,607	233,176
Office supplies	887	411
Telephone and internet	3,597	3,686
Travel and accommodation	36,363	29,319
Computer expenses	-	1,124
Insurance	4,111	4,565
Subscriptions	5,902	6,068
Website cost	12,889	12,192
Salaries and wages	232,486	178,458
Annual leave provision	4,386	5,932
Superannuation	22,077	16,954
Other expenses	4,541	2,642
	543,464	632,732
PROFIT / (LOSS) FROM ORDINARY ACTIVITIES BEFORE INCOME TAX	121,002	120,562

The accompanying notes form part of these financial statements.

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 2020, 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
10th December 2020

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E: info@travelaccounting.com.au
W: www.travelaccounting.com.au

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Tax agent 25837834
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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 2020, 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 2020 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 2020 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
10th December 2020

ACKNOWLEDGEMENTS

RVA highly values our relationship with our RVA Partner organisations, rare disease support groups that not only provide support to rare disease communities on the ground, but have also guided and contributed to the collaborative development of the Action Plan and the broader rare disease advocacy efforts. RVA knows we can only truly make a difference to the Australian rare disease community through this collaboration.

2019-20 RVA Partner Organisations (75 specific rare disease organisations):

Angelman Syndrome Association Australia
ausEE Inc.
Australian Addisons Disease Association
Australian Alopecia Areata Foundation Inc
Australian Cystinosis Support
Australian NPC Foundation
Australian Pompe Association
Australian Sickle Cell Advocacy
Batten Disease Support & Research
BrAshA-T
CDH Australia
CHARGE Syndrome Association of Australasia
Charles Bonnet Syndrome Foundation
Cystic Fibrosis ACT
DEBRA Australia
Dup15q Australia
Fabry Australia
Fanconi Anaemia Support Australasia
FOP Australia
Foundation For Angelman Syndrome Therapeutics
FoxG1 Foundation Australia
Fragile X Australia
Friedreich Ataxia Research Association
Gaucher Association of Australia and New Zealand
HAE Australasia
Haemochromatosis Australia
HCU Network Australia
Help for Hirschsprung Disease
Huntingtons Victoria
Immune Deficiencies Foundation Australia
ISMRD
ITP Australia
Jack's Butterflies
Kennedy's Disease Downunder
Leukodystrophy Australia
Leukodystrophy Resource & Research Organisation
Mal de Debarquement Syndrome Australia
Metabolic Dietary Disorders Association
Mission Massimo
Mito Foundation
MND Australia
MPN Alliance Australia
MPS & Related Diseases Society Australia
Multiple Sclerosis Australia
Muscular Dystrophy Foundation Australia

Muscular Dystrophy Qld
Myasthenia Alliance Australia
Myasthenia Gravis Association Qld
Narcolepsy Australia
ONE in 5000 Foundation
Parental Nutrition Down Under (PNDU)
PCD Australia
PFIC Network
Phelan-McDermid Syndrome Foundation Australia
PKU Association of NSW
PNH Support Association of Australia
Prader Willi Research Foundation Australia
Prader-Willi Syndrome Association of Victoria
PSC Support Australia
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 Australia
Spinal Muscular Atrophy Australia
Thalassaemia and Sickle Cell Australia
The Aarskog Foundation
The Australasian Mastocytosis Society
The Australian Dercums Diseease Support Group
The Myositis Association Australia
Tuberous Sclerosis Australia
UsherKids Australia

State Peak Organisations
Genetic Alliance Australia (NSW)
Genetic and Rare Disease Network (WA)
Genetic Support Network of Victoria

Undiagnosed Peak Organisation
Syndromes Without A Name Australia

In 2019-2020, RVA also had 22 Individual/Other Partners.