

# Rare Voices Australia Ltd

## Annual Report 2018-2019

YEAR ENDED 30<sup>th</sup> JUNE 2019

With Compliments

Rare Voices Australia Ltd.  
PO Box 138  
Mentone Vic 3194, Australia

**P** +61 (0)497 003 104  
**E** [admin@rarevoices.com.au](mailto:admin@rarevoices.com.au)  
**W** [www.rarevoices.org.au](http://www.rarevoices.org.au)

ABN 69 156 254 303

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## ABOUT RARE VOICES AUSTRALIA

Rare Voices Australia (RVA) is Australia's peak organisation for rare disease, advocating for Australians living with rare disease. We provide a strong, common voice to advocate for health policy and a healthcare system that works for people living with rare disease. Our person-centred focus sees RVA working with key stakeholders including people living with rare disease, peak organisations, governments, researchers, clinicians and industry to promote rare disease, diagnosis, access to treatments, data collection, coordinated care, access to services and coordinated research.

In accordance with its Constitution, RVA aims to:

- provide a unified voice to improve the lives of all Australians affected by rare diseases;
- develop and provide strategic input into planning for rare diseases at both a state level and national level;
- advocate for the implementation of services and support for people living with rare diseases;
- foster and support research into rare diseases;
- maintain links with international organisations in order to further the other objectives of the organisation.

## CHAIR & CEO REPORT

The 2018-2019 year has been important for RVA, and indeed the whole rare disease sector. Our key policy document, 'Call for a National Rare Disease Framework: 6 Strategic Priorities' continued to guide our advocacy and increasingly effective call for a national rare disease plan/framework. The Strategic Priorities of this document - diagnosis, access to treatments, coordinated care, access to services, data collection and research - also became the key topics for the 2018 National Rare Disease Summit. Much time and energy in the second half of 2018 was spent planning for the National Rare Disease Summit which was successfully held in November 2018 in Melbourne, bringing together all rare disease stakeholders: people living with rare disease, rare disease advocates/leaders, clinicians, researchers, policy-makers, government and industry.

Most notably, the Minister for Health opened the 2018 Summit announcing that the Government will commission RVA to work with all stakeholders to deliver the National Strategic Action Plan for Rare Diseases (the Action Plan). The Minister acknowledged the work of RVA, which has "made such a difference... a driving force for change." Through this commitment, which has bipartisan support, the Government has acknowledged the need for national rare disease policy framework; as well as RVA's credibility and profile as the national peak organisation for the Australian rare disease community with strong and effective partnerships with all stakeholders.

The 2019 year began with an extensive stakeholder consultation process around the country, as well as an online survey, to inform the development of the Action Plan. A multi-stakeholder Action Plan Steering Committee was also established and played a key role in setting the initial direction of the Action Plan. It is of the utmost importance that the Action Plan is developed in partnership with the people who it will ultimately affect, and thus, strongly reflects their experiences and ideas for change. Throughout this consultation process, RVA was struck by the strong sense of collaboration and generosity in the sector. The Action Plan is seen as a real opportunity for change amongst stakeholders. We look forward to the finalisation and launch of the Action Plan in early 2020.

RVA has continued to ensure personal narratives are central to the discussion, highlighting individual stories of people living with rare disease and linking them to the 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 & Education, including a number of community engagement workshops, critical for building advocacy capacity in rare disease organisations.

RVA has an outstanding, dedicated staff and Board of Directors.

The Board was grateful for the leadership of Co-Chairs Louise Healy and Raymond Saich who jointly held this role until November 2018. In November, Joanna Betteridge was appointed Chair of the Board and Kane Blackman was appointed Deputy Chair. In June 2019, Viswanathan Narayanaswamy, previously a Consulting Member to our Finance and Risk Committee, joined the Board filling a key skill gap with professional expertise in the accounting and finance field. The Board were delighted to welcome Liyi Chang as our Company Secretary on 18 November 2018.

The Board and all staff met together in May 2019 with an independent facilitator to work through our strategic priorities for the next 3-5 years, to reinvigorate RVA's Mission and Vision and to commence the

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development of a Strategic Plan for RVA that reflects the ongoing positioning of RVA in the light of the organisation's work on the Framework and Action Plan.

The Board and staff have also commenced detailed work on risk management under the leadership of Raymond Saich as the Chair of our Finance and Risk Committee and we have been doing ongoing work in strengthening governance processes and policies for RVA.

RVA is grateful for the continued professional expertise and advice provided by our Scientific & Medical Advisory Committee (SMAC) led by Chair Carol Wicking. Throughout the year, SMAC welcomed Dr Kristen Nowak (March 2019), Dr Lisa Ewans (July 2018), and Dr Kaustuv Bhattacharya (June 2019). We thanked the following members for their valuable contributions who stepped down during the year – Julie McGaughran, Prof. John McNeil and Prof. Mark Nelson.

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

BOARD MEMBERS, COMPANY SECRETARY AND STAFF TEAM

**RVA BOARD**



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### 1. Ms. Joanna Betteridge

Qualifications	<p>Master of Laws (focussed on labour relations law) - Melbourne University (2001)</p> <p>Bachelor of Laws - Melbourne University (1983)</p> <p>Bachelor of Arts (major in psychology) – Melbourne University (1983)</p> <p>Accredited Mediator under the Mediations Act 1997</p> <p>Graduate Member Australian Institute of Company Directors (2004)</p> <p>Admitted as a barrister and solicitor, Supreme Court of Victoria, April 1985</p>
Experience	<p>Principal of Betteridge Legal Consulting, specialist legal practice acting for and representing employers and senior executives in relation to employment and OHS related matters including recruitment, termination, performance management, misconduct and contractual disputes.</p> <p>Accomplished Non Executive Director, particularly in the NFP sector, former Chair of TEAR Australia and Director with Light Melbourne Inc. Significant past experience in welfare and health sectors. Graduate member of AICD since 2004. Interested in expanding Governance portfolio.</p>
Board Meeting attendance:	Eligible – 11, Attended – 11

### 2. Mr. Kane Blackman

Qualifications	<p>Company Directors Course - Australian Institute of Company Directors</p> <p>Master Business Administration - The University of South Australia</p> <p>Grad Diploma of Applied Corporate Governance - Governance Institute of Australia</p> <p>Bachelor of Science (First Class Honours) - The University of Melbourne</p> <p>Diploma of Modern Languages (French) - The University of Melbourne</p>
Experience	<p>Senior Executive, Insurance Commission of Western Australia</p> <ul style="list-style-type: none"> <li>- Board Member and Lecturer, WA Branch of Governance Institute</li> <li>- Board Member, Angelman Syndrome Association of Australia</li> <li>- Deputy Chairman and Director, Injury Matters</li> <li>- Member of Risk and Governance committee of Board, Netball WA</li> <li>- Deputy Member of Road Safety Council, Government of Western Australia</li> </ul>
Board Meeting attendance:	Eligible – 7, Attended – 7

### 3. Dr Tracy Elizabeth Dudding-Byth

Qualifications	MBBS PhD Clinical Geneticist
Experience	Clinical Geneticist, Hunter Health, Newcastle mother of a child with a rare disease
Special Responsibilities	Medical perspective/Genetics perspective
Board Meeting attendance:	Eligible – 3, Attended – 3. Leave of absence – from November 2018 – March 2019

### 4. Ms. Louise Healy

Qualifications	P/Grad. Dip (Psych), B.A University of Queensland.
Experience	Former Vice President of the Metabolic Dietary Disorders Association and has been involved in managing advocacy and wellbeing programs to support members of this organisation since 2012



Board Meeting attendance: Eligible – 5, Attended – 5. Leave of absence – from November 2018 – March 2010

## 5. Robert Hendriks

**Qualifications** Graduated as Medical Doctor from the University of Amsterdam, Netherlands  
MBA from the Erasmus University, Netherlands.  
Graduate of the Australian Institute of Company Directors

**Experience** General Manager Asia and Chief Marketing Officer of healthcare company  
15 years' experience as an international senior executive in the Pharmaceutical, Biotech, Natural Medicines and Medical Devices industries.  
Former Managing Director of a pharmaceutical company that pioneered the development and delivery of transformative therapies for patients affected by rare and debilitating diseases.

Board Meeting attendance: Eligible – 0, Attended – 0. Leave of absence – July 2018 – June 2019

## 6. Mr. Eric Morand

**Qualifications** MD, Medicine, Monash University  
FRACP, Royal Australasian College of Physicians  
PhD, Medicine, Monash University

**Experience** Medical Leader - Head of School of Clinical Sciences, Monash University  
Research Leader, Rheumatology basic science and clinical research  
Consultant physician in rheumatology  
Specialist in SLE and RA  
Founder, Lupus Clinic, Monash Medical Centre  
Director, Rheumatology, Monash Health  
Biotech and Pharma Consultant.

Board Meeting attendance: Eligible – 7, Attended - 6

## 6. Mr. Viswanathan Narayanaswamy (Vishy)

**Qualifications** Chartered Accountant CA (ANZ)  
Chartered Accountant (The Institute of Chartered Accountants of India)  
Graduate Diploma of Applied Tax Law – The Tax Institute of Australia  
Bachelor of Commerce – Mumbai University

**Experience** Director – The Sydney Blood Cancer Research Institute Ltd  
KPMG India Assurance – Financial Services 2006-2014  
Senior Manager – PWC Australia Assurance – Financial Services 2014-Present

Board Meeting attendance: Appointed – 20/6/2019 - Eligible – 1, Attended - 1

## 8. Mr. Raymond Saich OAM

**Qualifications** Engineer (Full Tech Cert)

**Experience** President of the Australian Pompe Association  
Personal connection with rare diseases  
Former National Service Manager for a multinational Imaging Company and  
Trustee Director of their Superannuation company

Board Meeting attendance: Eligible – 11 - Attended – 11



## 9. Assoc Prof. Carol Wicking

Qualifications	Masters Degree, Biochemistry/Genetics, University of Melbourne
Experience	Associate Professor Carol Wicking is the Chair of the RVA Scientific and Medical Advisory Committee and is a member of the RVA Board of Directors. Carol was involved in medical research for almost 30 years, primarily investigating the genetic and mechanistic basis of a number of rare diseases including cystic fibrosis, naevoid basal cell carcinoma syndrome and a class of rare diseases known as ciliopathies. She currently works as a consultant in genomics
Board Meeting attendance:	Eligible – 7, Attended – 7

## COMPANY SECRETARY

RVA appointed a Company Secretary, Miss Liyi Chang on 18 November 2018.

## RVA SENIOR EXECUTIVE AND STAFF



### 1. Nicole Millis

#### Chief Executive Officer, Rare Voices Australia (VIC)

Nicole Millis is RVA's Chief Executive Officer. An experienced social worker with a background in families, disability and program management; and previously the National Manager of MPS & Related Diseases Society Australia, Nicole has both personal and professional experience of the rare disease sector. She has significant experience in rare disease advocacy. Nicole is also the consumer nominee on the Life Saving Drugs Program Expert Panel.

### 2. Sarah Cannata

#### Stakeholder Engagement and Communications Officer (VIC)

Sarah Cannata is a passionate storyteller, a qualified journalist, a Public Relations consultant and has over 7 years' worth of experience in Communications. Sarah has extensive experience working in the not-for-profit sector thanks to her time with Campaign for Australian Aid and is committed to using her skills to benefit all Australians living with a rare disease.

### 3. Kathryn Milne

#### Research and Policy Officer

Kathryn Milne 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.

### 4. Anne Hunter

#### Administrative Officer, Rare Voices Australia (VIC)

Anne Hunter is experienced in office management, P.A. support, event planning and bookkeeping. Anne has a personal connection living with a rare disease. Anne enjoys working for such a passionate and person centred organisation. Anne also works for Fabry Australia.

### 5. Amy Mills

#### Social Media Officer, Rare Voices Australia (NSW)

Amy Mills is the Social Media Officer for Rare Voices Australia (RVA) and served as a Board member in 2015. She lives with Cystic Fibrosis and is an outspoken advocate for change within the rare disease community. Amy uses art as a way to question and express emotion about her experience of living with Cystic Fibrosis. She is passionate about informing RVA's rare disease community and encouraging community collaboration and connection. Amy resigned from her position with RVA on 26<sup>th</sup> April 2019.

## BOARD COMMITTEE

The Board has one committee – the Finance and Risk Committee, Chaired by Raymond Saich. The Committee is appointed to provide advice to the Board on budget setting, financial and operational risk management and monitoring financial performance.

## SCIENTIFIC MEDICAL ADVISORY COMMITTEE

### Assoc Professor Carol Wicking (QLD)

#### CHAIR



Has over 30 year's experience in medical research, primarily investigating the genetic and mechanistic basis of a number of rare diseases including cystic fibrosis, naevoid basal cell carcinoma syndrome and a class of rare diseases known as

ciliopathies.

### A Clin/Prof Gareth Baynam (WA)



Clinical Geneticist and Adjunct Genomics Policy Officer in the Western Australian Health Department.

### Kaustuv Bhattacharya (QLD)



A UK trained metabolic physician. He moved to Sydney, in June 2008 and became the department head of metabolic services at Sydney Children's Hospitals Network, before moving to Brisbane in 2019 where he is now practicing as a specialist

paediatric metabolic physician at Queensland Children's Hospital.

### Prof Alan Bittles (WA)



Adjunct Professor and Research Leader in the Centre for Comparative Genomics, Murdoch University, Perth, Australia and Adjunct Professor of Community Genetics in the School of Medical Sciences, Edith Cowan University, where he was Foundation Professor of Human Biology and Director of the Centre for Human Genetics from 1993-2005.

### Lisa Ewans (NSW)



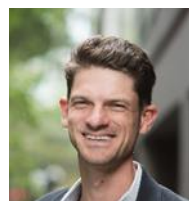
Clinical Geneticist at Royal Prince Alfred Hospital, Sydney, a Clinical Associate Lecturer at The University of Sydney, and is completing a PhD at the University of NSW and the Garvan Institute of Medical Research.

### Prof Adam Jaffe (NSW)



The John Beveridge Professor and Head of the Discipline of Paediatrics at the University of NSW, Associate Director of Research for Sydney Children's Hospitals Network (Randwick) and a Paediatric Respiratory Consultant at Sydney Children's Hospital, Randwick.

### Paul Lacaze (VIC)



Geneticist and Head of Public Health Genomics at Monash University.

**Prof John McNeil (VIC)**



Monash U/ Alfred, Epidemiology & Public Health, Registries, Clinical Trials, Biobanking, Ethics & Research Governance (VIC). Stepped down from SMAC March 2019.

**Mr Lemuel Pelentsov (SA)**



Lecturer at the University of South Australia, School of Nursing and Midwifery.

**Prof Mark Nelson (TAS)**



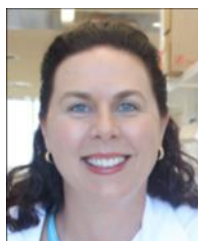
Menzies Institute/ U Tasmania, Chair of General Practice - School of Med (TAS). Stepped down from SMAC March 2019.

**Prof Jeff Szer (VIC)**



Professor/Director of the Department of Clinical Haematology & Bone Marrow Transplant Service at Royal Melbourne Hospital (RMH) and Director of the Western and Central Melbourne Integrated Cancer Service.

**Dr Kristen Novak (WA)**



Director of the Office of Population Health Genomics (OPHG) within the WA Department of Health.

**A/Prof Yvonne Zurynski (NSW)**



Associate Professor, Health System Sustainability, and leads the activities of the central coordinating unit of the NHMRC Partnership Centre for Health System Sustainability, Australian Institute of Health Innovation, Macquarie University.

## OUR INDUSTRY PARTNERS IN 2018/2019

### 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  
Sanofi Genzyme Australia  
Shire Australia Pty Ltd  
Vertex Pharmaceuticals (Australia) Pty Ltd

### Other Industry Partners

AbbVie Inc

## OUR WORK IN 2018-2019

### 2018 National Rare Disease Summit: Fair for Rare



The Summit theme was 'Fair for Rare' and topics included the 6 Strategic Priorities – diagnosis, access to treatments, coordinated care, access to services, data collection and research. Across two days, 142 delegates engaged in 46 sessions including presentations, Q&A panels and workshops. A diverse range of speakers reflected the various stakeholder perspectives. The Summit was a mixture of plenary sessions and breakout workshops whilst also providing ample networking opportunities. We asked delegates to actively participate, ask questions, make comments, network, share their perspective, learn from others, be friendly/accessible, and to listen. They did this and more. We at RVA were blown away by the amount of enthusiasm, collaboration and support in the room. There was a real buzz and we look forward to doing it again in 2020.

## Development of the National Strategic Action Plan for Rare Diseases

Between late 2018 and mid-2019, RVA undertook a stakeholder consultation process that began with an externally facilitated Roundtable meeting with the newly-created Action Plan Steering Committee comprising of multiple stakeholders, RVA staff, and the Department of Health staff. Further stakeholder consultations were held in Sydney, Melbourne, Perth and Brisbane; as well as a targeted consultation with pharmaceutical industry representatives. There was also ongoing communication and discussions with members of the Action Plan Steering Committee and RVA Scientific & Medical Advisory Committee, as well as interviews with representatives from state and territory governments. RVA also created and gathered input through an online survey which was promoted via RVA Partner organisations and other RVA contacts. The consultation process was undertaken in an iterative manner, with each subsequent consultation building on the findings that emerged in those prior. These stakeholder consultations truly shaped the developing Action Plan – developed by the rare disease sector for the rare disease sector.

## Rare Disease Policy Development

RVA contributed to other key policy work during the year, 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 NDIS. This included the facilitation of a focus group and online survey. The report 'Disability and Rare Disease: towards person-centred care for Australians with rare diseases' was subsequently published in September 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 & Education project which provided customised advocacy mentoring of specific rare disease support groups and advocacy workshops. RVA ran three 'Advocacy' Education workshops for rare disease organisation leaders and advocates in Sydney, Perth, Melbourne and Brisbane, focusing on the importance of better engagement of their communities; and how they can make the most of RVA's media platforms to assist with this.



## RVA Partner Program



In 2018-2019, RVA continued to improve our engagement with rare disease organisations. The number of RVA Partners has steadily grown to over 70. Most pleasing is the increased utilisation of the term 'RVA Partner'. Rare disease organisations increasingly refer to themselves as RVA Partners to increase their profile and voice in advocacy.

## Rare Disease Day Parliamentary Event



RVA was pleased to hold a Rare Disease Day (RDD) Parliamentary Event on 20 February in Canberra. We had strong bipartisan support with over 25 Parliamentarians attending or represented, including the Minister for Health, Hon Greg Hunt MP and the Shadow Minister for Health, Hon. Catherine King MP. Hosted by Hon Trent Zimmerman MP and Hon Steve Georganas MP, many Parliamentarians who attended have actively advocated on rare disease issues,

engaged with RVA and the rare disease community and provided support to constituents on rare disease issues. We also welcomed leaders from some of our RVA Partner organisations. Everyone may have been representing a different, individual rare disease support group but we all came together under the RVA banner.

The RDD theme for this year was: 'Bridging health & social care'. It highlighted two of our priority areas – coordinated care and access to services. At the Parliamentary Event, RVA announced our recent partnership with the McKell Institute to begin the development of a white paper and much needed research on rare disease and access to services, including a focus on the NDIS. The event included speakers from RVA Partners, Genetic and Rare Disease Network (GaRDN) and Syndromes Without A Name (SWAN).

## 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 rare disease. In particular, SMAC played a pivotal role in the development of the draft National Strategic Action Plan for Rare Diseases, both through membership of the Steering Committee and through targeted input into the Action Plan at various stages.

In 2019-2020, SMAC continued to support the work of its Registry sub-committee that oversees the development of a National Alliance of Rare Disease Registries. The Alliance aims to promote a unified approach to person-centred best practice, encourage uniformity around key principles and commit to further developing a growing understanding of the national rare disease picture. The work of the Registry



sub-committee will continue to be important, as the pressing need for reliable and unified rare disease registries was stressed in the draft National Strategic Action Plan for Rare Diseases.

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 being 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.

The quarterly meetings are aimed to discuss the development as well as availability of treatments and health services in Australia. They also build relationships within the rare disease community in a collaborative atmosphere that facilitates discussion on rare diseases. The meetings provide:

- Opportunities to interact with other companies
- Opportunities for direct exchange of views with leaders of the rare disease community
- Opportunities to develop partnerships and collaborations
- All member company logos are listed on the RVA website
- Timely reports, surveys and analysis relevant to the field of rare diseases from different sources

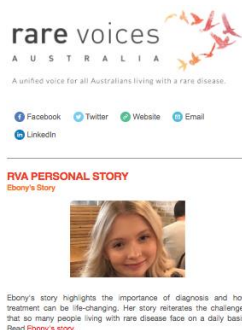
## **RVA Media**

As Australia's peak organisation for rare disease, RVA continued to be sought out by the Australian media in 2018-2019 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 and other topics. RVA will continue building on this momentum and key media relationships in the lead up to the launch of National Strategic Action Plan for Rare Diseases.

## **RVA Website and Social Media**

RVA maintains a dynamic website that serves all key stakeholders in the rare disease community. RVA also reaches out and updates its community via its Facebook, Twitter, LinkedIn and Instagram social media channels. Additionally, RVA moderates a closed Facebook group where RVA Partner organisation leaders have the opportunity to connect, engage and collaborate with each other.

## RVA Newsletter



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 from the perspective of someone living with a rare disease that is positioned under the Fair for Rare banner and is clearly linked to one of RVA's strategic priorities as outlined in RVA's *Call for a National Rare Disease Framework: 6 Strategic Priorities*. Each edition also 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 disease stemming from Australia and globally. The e-newsletter is one of RVA's key communication channels and is also published on the RVA website.

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## Conferences, Events and Consultations

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

Date	Event
<b>Jul 2018</b>	26 - LSDP Workshop - Program efficiencies 30 - Medical Research Future Fund Public Consultation
<b>Aug 2018</b>	6-7 - HGSA Symposium 9-10 - APEC Rare Disease Network/RVA consultation 30 - GSNV Strengthening the Support Sector, Victoria
<b>Sep 2018</b>	12 - Australian Patient Organisation Standing Committee meeting 17 - International Rare Disease Research Consortium (IRDiRC) Patients' Advocates Constituents Committee (PACC) 17-18 - PharmAus 18 18 - Life Savings Drug Program (LSDP) working group meeting
<b>Oct 2018</b>	
<b>Nov 2018</b>	16-17 - National Rare Disease Summit
<b>Dec 2018</b>	
<b>Jan 2019</b>	6 - Planning meeting with EURORDIS Rare Disease Day
<b>Feb 2019</b>	3-5 - Illumina Patient Advocacy Summit, San Diego 20 - Rare Disease Day Parliamentary Event 26 - National Strategic Action Plan - Round Table Consultation, Sydney 26 - Stakeholder Consultation and Community Engagement Education Workshop, Sydney 28 - 2019 Rare Disease Day Tennathon, Victoria 28 - Rare Disease Day Event, Victoria
<b>Mar 2019</b>	12 - Access to Services Round Table (McKell Institute) 12 - National Strategic Action Plan for Rare Diseases stakeholder consultation 21 - Patient Voice Initiative's workshop - Influencing Decisions about Medicines and Healthcare Treatments, Tasmania 25 - National Strategic Action Plan for Rare Diseases Consultation meeting, Perth 25 - Community Engagement Workshop, Perth
<b>Apr 2019</b>	2 - 2019-2020 Federal Health Portfolio Budget Briefing 3 - Research Australia Breakfast 8 - National Strategic Action Plan for Rare Diseases - Industry Consultation, Sydney 15 - Medicines Status Website Update 29 - National Strategic Action Plan for Rare Diseases Consultation meeting, Brisbane 29 - Community Engagement Workshop, Brisbane
<b>May 2019</b>	30 - Stronger Together - Innovative collaboration for funding success in health and medical research - Research Australia
<b>Jun 2019</b>	1 - CDH Australia Conference, Brisbane 18 - Victorian newborn bloodspot screening committee 24 - Expert Panel -HTA workshop Canberra

## Policy Submissions

Over the last year RVA has prepared and presented the following Policy submissions

Date	Policy Submission
<b>Aug 2018</b>	Medical Research Future Fund (MRFF) Priorities Submission
<b>Sep 2018</b>	RVA/RCA Joint Letter to Minister - Reforms to Orphan Drug Designation
<b>Ap 2019</b>	PBS Process Improvement: Public Consultation Submission & New Medicine Status Website (Consumer View) Policy Submissions
<b>Jun 2019</b>	PBAC Submission Spinraza - Spinal Muscular Atrophy

## AUDIT 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 2019 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2019 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 25 November 2019.



Joanna Betteridge

## Auditor's Independent Declaration

The lead auditors' independence declaration for the year ended 30 June 2019 has been received and can be found on the financial report.

**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

Rare Voices Australia Limited

We have reviewed the financial statements of Rare Voices Australia Limited for the financial period ended 30 June 2019.

As lead engagement partner for the review engagement, I declare that, to the best of my knowledge and belief, there have been:

- no contraventions of the independence requirements of the Corporations Act 2001 in relation to the review; and
- 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  
6th November 2019

14-18 Lee Street, Sydney NSW 2000  
T: +61 2 9211 6000 F: +61 2 9211 6166  
E: [info@travelaccounting.com.au](mailto:info@travelaccounting.com.au)  
W: [www.travelaccounting.com.au](http://www.travelaccounting.com.au)



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ACCOUNTANTS



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

With Compliments

Rare Voices Australia Ltd.  
PO Box 138  
Mentone Vic 3194, Australia

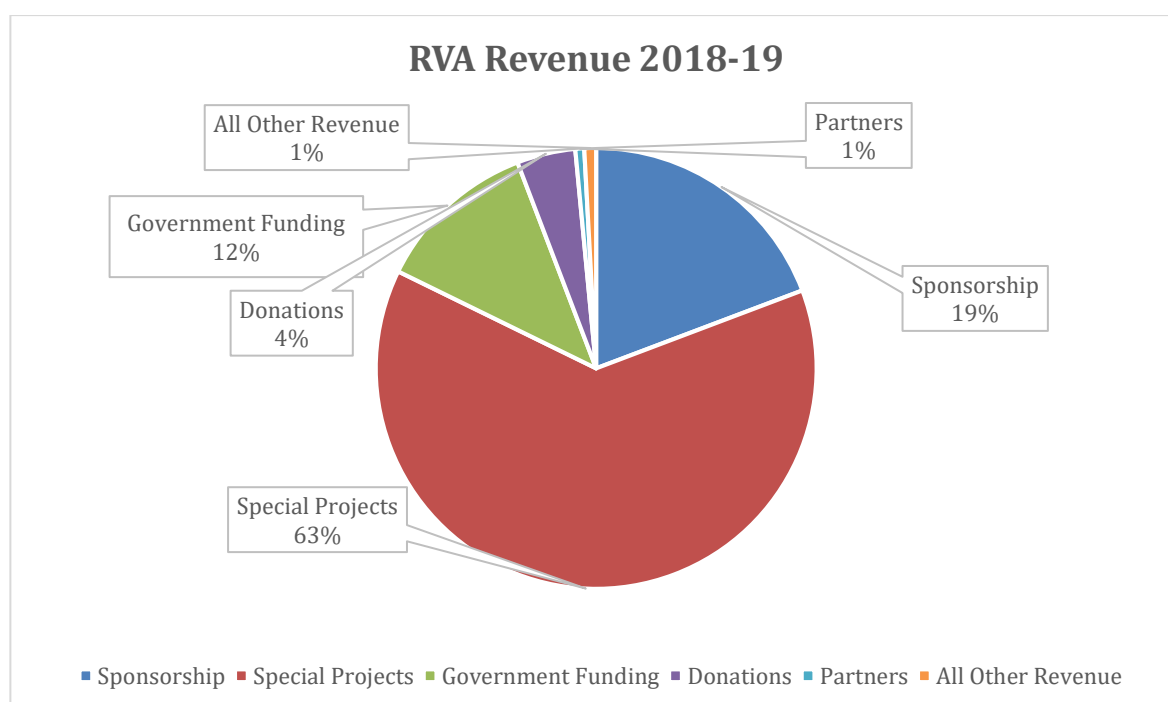
P +61 (0)497 003 104  
E [admin@rarevoices.com.au](mailto:admin@rarevoices.com.au)  
W [www.rarevoices.org.au](http://www.rarevoices.org.au)

ABN 69 156 254 303

## 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 2019 the total amount that Members of the Company are liable to contribute if the entity is wound up is \$100.

## STATEMENT OF FINANCIAL POSITION

As at 30 June 2019

	Note	2019 \$	2018 \$
<b>CURRENT ASSETS</b>			
Cash and cash equivalents	3	661,663	459,205
Trade and other receivables	4	132,515	50,261
<b>TOTAL CURRENT ASSETS</b>		<u>794,178</u>	<u>509,466</u>
<b>NON-CURRENT ASSETS</b>			
Property, plant and equipment	5	-	3,439
<b>TOTAL NON-CURRENT ASSETS</b>		<u>-</u>	<u>3,439</u>
<b>TOTAL ASSETS</b>		<u>794,178</u>	<u>512,905</u>
<b>CURRENT LIABILITIES</b>			
Trade and other payables	6	356,715	201,936
Provisions	7	16,302	10,370
<b>TOTAL CURRENT LIABILITIES</b>		<u>373,017</u>	<u>212,306</u>
<b>TOTAL LIABILITIES</b>		<u>373,017</u>	<u>212,306</u>
<b>NET ASSETS</b>		<u>421,161</u>	<u>300,599</u>
<b>EQUITY</b>			
Retained earnings		421,161	300,599
<b>TOTAL EQUITY</b>		<u>421,161</u>	<u>300,599</u>

The accompanying notes form part of these financial statements

## STATEMENT OF COMPREHENSIVE INCOME AND EXPENDITURE AND OTHER COMPREHENSIVE INCOME

For the year ended 30 June 2019

	Note	2019 \$	2018 \$
<b>CLASSIFICATION OF EXPENSES BY NATURE</b>			
Revenue	2	753,294	277,202
Other income		-	-
Employee benefits expense		(5,932)	(3,670)
Depreciation and amortisation expenses		(5,857)	(1,105)
Other expenses		(620,943)	(239,001)
Profit / (loss) before income tax		<u>120,562</u>	<u>33,426</u>
Income tax expense		-	-
Profit / (loss) attributable to members of the company		<u>120,562</u>	<u>33,426</u>
Other comprehensive income		-	-

## STATEMENT OF CHANGES IN EQUITY

For the year ended 30 June 2019

	Other Reserves \$	Retained Earnings \$	Total \$
Balance at 1 July 2017	-	267,173	267,173
Profit (loss) attributable to members	-	33,426	33,426
Balance at 30 June 2018	-	300,599	300,599
Profit (loss) attributable to members	-	120,562	120,562
Balance at 30 June 2019	-	421,161	421,161

The accompanying notes form part of these financial statements

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PO Box 138  
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P +61 (0)497 003 104  
E admin@rarevoices.com.au  
W www.rarevoices.org.au

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## AUDITOR'S REVIEW REPORT

**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 2019, 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 2019 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*.

With Compliments

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### 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 2019 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  
6<sup>th</sup> November 2019

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## 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 our Fair for Rare work 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.

### RVA's 2018-19 Partner Organisations (specific rare disease organisations):

Angelman Syndrome Association Australia Inc  
 Australian Mitochondrial Foundation Australia  
 ausEE Inc  
 Australian Addisons Disease Association  
 Australia Alopecia Areata Foundation Inc  
 Australian Cystinosis Support Group  
 Australian NPC Disease Foundation Inc  
 Australian Pompe Association Inc  
 Australian Sickle Cell Advocacy Inc  
 Batten Disease Support & Research Association  
 BrAshA-T  
 Congenital Diaphragmatic Hernia Australia  
 Charles Bonnet Syndrome Foundation  
 Fabry Australia  
 Fibrodysplasia Ossificans Progressiva Australia  
 Fragile X Association of Australia  
 Friedreich Ataxia Research Association  
 Gaucher Association of Australia and New Zealand  
 HAE Australasia Ltd  
 Haemochromatosis Australia  
 HCU Network Australia  
 Immune Deficiencies Foundation Australia  
 Jack's Butterflies  
 Leukodystrophy Australia  
 Leukodystrophy Resource & Research Org Inc  
 Metabolic Dietary Disorders Association  
 MPS Australia  
 Multiple Sclerosis Australia  
 Muscular Dystrophy Association of WA  
 Muscular Dystrophy Foundation Ltd  
 Muscular Dystrophy Qld  
 Myasthenia Alliance Australia  
 Myasthenia Gravis Association Qld Inc  
 Narcolepsy Australia  
 PCD Australia Inc

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Phelan-McDermid Syndrome Foundations Australia  
PNDU  
PNH Support Association Australia  
Prader-Willi Research Foundation Australia Limited  
Prader-Willi Syndrome Association of Victoria  
PSC Support Australia Inc  
Pseudomyxoma Survivor  
Rett Syndrome Association of Australia Inc.  
Sanfilippo Children's Foundation  
Save Our Sons Duchenne Foundation  
Sleep Disorders Australia  
Spinal Muscular Atrophy Australia Inc  
Thalassaemia and Sickle Cell Australia  
The Australian Dercums Disease Support Group  
The Myositis Association Australia  
Tuberous Sclerosis Australia

#### Peak Organisations

Genetic Alliance of Australia  
Genetic and Rare Disease Network  
Genetic Service Network of Victoria  
Syndromes Without A Name

In 2018-19 RVA was also supported by 34 Individual/Other Partners.