Rare Voices Australia Ltd

Annual Report 2017-2018

YEAR ENDED 30th JUNE 2018

With Compliments

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WHO ARE RARE VOICES AUSTRALIA

Rare Voices Australia (RVA) is Australia's peak body 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 patient-centred focus sees RVA working with key stakeholders including patients, key peak bodies, 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, Rare Voices Australia aims to:

- provide a unified voice to improve the lives of all Australians affected by rare conditions;
- develop and provide strategic input into planning for rare diseases at both state level and national level;
- advocate for the implementation of services and support for people suffering from rare diseases;
- foster and support research into rare diseases including but not limited to research into the prevention of rare diseases and research into methods for alleviating the suffering of people with rare diseases; and to
- maintain links with international organisations in order to further the other objects of the company.

CO-CHAIR'S REPORT

We are very proud of what RVA has been able to achieve in the 2017-2018 year and it has been a privilege to have Co-Chaired RVA during this year. We are very lucky to have a very skilled and dedicated RVA team and to have fellow Board members who are passionate about improving the lives of Australians living with rare diseases. We are both grateful for the opportunity to contribute to this vision.

RVA has an outstanding, dedicated staff and Board of Directors, who are inspired by the challenges they see daily and go on to deliver wonderful outcomes. This year we have welcomed Sarah Cannata to our small staff looking after communications and stakeholder engagement. Her appointment was a direct result of feedback we collected from our partner organisations and other stakeholders seeking more connection both with RVA and with other patient groups. We also added three new Board members and expanded our Scientific and Medical Advisory Board. The new skills added to the team position RVA to achieve even more into the future. Thank you all for sharing your ideas and helping us to serve the rare disease community more completely.

To build organisations like RVA takes so much work and I would like to thank everyone who has given the time and effort required, since RVA was established in 2012, to build an organisation that inspires so much confidence in the government and rare disease sector. This year has seen some fantastic achievements in seeing outcomes from the Life Saving Drugs program review, having an endorsed National Newborn Screening framework, having advocated for bi-partisan support for a national Rare Disease framework and having planned a second RVA Summit bringing together representatives of all stakeholders for key discussions. In raising our voices together we have achieved so much, thank you to you all.

1 in 17 Australians have a rare disease and RVA advocates on their behalf to make it fair for the rare and give patients with a rare disease a unified voice to improve the lives of all Australians affected by rare conditions.

Daily we see the challenges that having a rare disease brings. Through our website, social media, newsletters and direct contact we provide information and support to their patient associations. To tell the story of patients with a rare disease.

In 2020, we are planning another of our RVA Summits where we will be able to bring together some of the patient association leaders, rare disease clinical experts, government, pharmaceutical and research experts, Newborn screening specialists.

Next year will focus on the development and implementation plan for a National Rare disease framework. We are looking forward to having input from all of you in developing this most important policy framework, one we hope will bring clarity, equity and some measure of certainty to all Australians living with a rare disease.

Finally, we need to single out our Chief Executive Officer, Nicole Millis. Nicole's "polite persistence" has seen the realisation or progress of many of our big strategic goals this year. Thank you Nicole.

Raymond Saich and Louise Healy (Co-Chairs)

CHIEF EXECUTIVE OFFICER'S REPORT

2017-2018 has been a pivotal year for RVA, and indeed rare disease. This year has seen RVA develop a clearer purpose, confirming its position as a strong advocacy organisation. We strengthened our call for a National Rare Disease Framework, prioritised effective bipartisan Government relations and improved our partnerships with the rare disease community. This year has seen the growth of RVA's profile as the national rare disease peak body; patient-centred with effective connections with all rare disease stakeholders, patient leaders/ advocates, clinicians, researchers, Governments and policy makers and industry.

The Call for a National Rare Disease Framework: 6 Strategic Priorities became our key policy platform and guided our work for the year. Enabling a more staged progression towards a National Framework, RVA increasingly engaged policy makers, built much needed traction and a growing confidence within Government to tackle rare disease. Over the last financial year RVA has been solution-focused and successful in connecting the rare disease narrative to an achievable policy response. Our message has been that effective rare disease policy transforms patients' lives. The 2017-2018 year saw a real shift in this regard. RVA played a key role in a range of rare disease policy development and reform from Government, including the long-awaited Life Saving Drugs Program reform, access to medicines, focus on rare disease through the Medical Research Future Fund and National Newborn Bloodspot Screening Policy.

Clearer articulation of our policy platform also improved our external relationships. Patient groups have told us that it is now easier to collaborate with us. Patient groups also helped drive the Fair for Rare campaign which this year was awarded the 'Best Patients' Campaign in Australia 2017 by the Australian Patients Association. It is a call to Australian Governments to make the health system more responsive to rare disease., to make it Fair for Rare. It kept patient narratives central to the discussion, highlighting individual stories of people living with rare disease and linking them to the broader strategic priorities. Fair for Rare has been crucial to the increased policy traction, and individual rare disease organisations have gained a bigger voice by being able to position their own disease specific issues as part of a broader rare disease platform.

RVA provided staffing and program support to further develop our relationship with patient groups. RVA created a new staffing role 'Stakeholder Engagement and Communications' as well as improving our 'RVA Partner' benefits. RVA provided Advocacy Mentorship & Education, holding a number of successful workshops, with the aim of building their advocacy capacity in rare disease patient organisations.

The achievements of the 2017-2018 year would not have been possible without the strong governance of the Board of Directors, the skill and commitment of the staff, the expertise of our advisory committees and most importantly the support of our RVA Partners. I look forward to the continued work towards a National Rare Disease Framework, working with all towards an Australia that is Fair for Rare and ensures better outcomes for people living with rare disease.

BOARD MEMBERS AND STAFF TEAM

1. 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 – 7, Attended – 2. Leave of absence – from January – July 2018

2. 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 – 7, Attended – 4

3. 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 – 7, Attended – 7

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 – 7, Attended – 7

5. 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:	Appointed 12/11/2017. Eligible – 3, Attended – 3

6. Ms. Joanna Betteridge

Qualifications	Master of Laws (focussed on labour relations law) - Melbourne University (2001) Bachelor of Laws - Melbourne University (1983) Bachelor of Arts (major in psychology) – Melbourne University (1983) Accredited Mediator under the Mediations Act 1997 Graduate Member Australian Institute of Company Directors (2004) Admitted as a barrister and solicitor, Supreme Court of Victoria, April 1985
Experience	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. Accomplished Non Executive Director, particularly in the NFP sector, currently 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.
Board Meeting attendance:	Appointed 23/5/2018

7. Mr. Kane Blackman

Qualifications	Company Directors Course - Australian Institute of Company Directors Master Business Administration - The University of South Australia Grad Diploma of Applied Corporate Governance - Governance Institute of Australia Bachelor of Science (First Class Honours) - The University of Melbourne Diploma of Modern Languages (French) - The University of Melbourne
Experience	Senior Executive, Insurance Commission of Western Australia - Board Member and Lecturer, WA Branch of Governance Institute - Board Member, Angelman Syndrome Association of Australia - Deputy Chairman and Director, Injury Matters - Member of Risk and Governance committee of Board, Netball WA - Deputy Member of Road Safety Council, Government of Western Australia
Board Meeting attendance:	Appointed 23/5/2018

8. 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:	Appointed 23/5/2018

RVA SENIOR EXECUTIVE AND STAFF

1. Nicole Millis

Chief Executive Officer, Rare Voices Australia (VIC)

Nicole Millis is RVA’s Chief Executive Officer. A qualified 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, particularly in regards to access to treatments. Nicole has recently been appointed as 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. 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.

4. Anne Hunter

Administrative Support, Rare Voices Australia (VIC)

Anne works part time for RVA as the Administrative Officer and is based in Victoria. Anne has a personal connection with a rare disease caring for a child, mother, sister with a very rare disease.

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
CHAIR
University of Queensland, Research Engagement, Embryo Development, Ciliopathies, Skeletal Dysplasia (Qld)

A Clin/Prof Gareth Baynam
GSWA/DoH, Facial Analysis, Dysmorphology, Phenotyping (WA)

Prof Alan Bittles
Murdoch/ECO, Community Genetics, Consanguinity, Intellectual Disability (WA)

Prof Adam Jaffe
UNSW/Randwick, Respiratory Disorders, CF, Consumers, Clinicians & Clinical Trials (NHMRC) (NSW)

Julie McGaughran
Director of Genetic Health Queensland

Prof John McNeil
Monash U/Alfred, Epidemiology & Public Health, Registries, Clinical Trials, Biobanking, Ethics & Research Governance (VIC)

Prof Mark Nelson
Menzies Institute/U Tasmania, Chair of General Practice - School of Med (TAS)

Mr Lemuel Pelentsov
Nursing, U South Australia, RDs, (SA)

Prof Jeff Szer
U Melbourne/Royal Melbourne, Hbopathies, Bone Marrow Transplantation (VIC)

A/Prof Yvonne Zurynski
BAppSc, MAppSc, PhD, MHPol (currently enrolled)

OUR INDUSTRY PARTNERS IN 2017/2018

Alexion Pharmaceuticals Australasia

Amicus Therapeutics

Biogen Idec Australia Pty Ltd

BioMarin Pharmaceutical Australia Pty Ltd

CSL Limited

Menarini Australia Pty Ltd

Sanofi Genzyme Australia

Pfizer Australia Pty Limited

Shire Australia Pty Ltd

Vertex Pharmaceuticals (Australia) Pty Ltd

OUR WORK IN 2017-2018

Fair for Rare Awareness Campaign

FAIR FOR RARE
A FAIR GO FOR AUSTRALIANS LIVING WITH RARE DISEASE

Following on from its successful development and launch, RVA utilised the key messages of Fair for Rare campaign to guide and position all areas of RVA’s communication, resource development, stakeholder engagement and advocacy. Fair for Rare provide impetus for stakeholder engagement and collaboration. It has always kept patient narratives 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 also gained a bigger voice by being able to position their own disease specific issues as part of a broader rare disease framework. By effectively connecting the rare disease narrative to an achievable policy response, it demonstrates how effective rare disease policy transforms patients’ lives. Fair for Rare has been and remains crucial to this policy traction. Fair for Rare was a groundswell educative and interactive campaign to call for a fairer health system for Australians with rare disease, for the development of a National Rare Disease Framework For the Fair for Rare campaign, RVA won the Australian Patients Association’s award for the ‘Best Patients Campaign 2017’.

Advocacy for a National Rare Disease Framework


FAIR FOR RARE

CALL FOR A
National Rare Disease Framework
6 Strategic Priorities

rare voices

Under the Fair for Rare campaign, RVA presented their key policy document 'Call for a National Rare Disease Framework: 6 Strategic Priorities' to the Hon. Greg Hunt MP, Minister for Health and to Shadow Minister for Health, Catherine King.

Throughout the 2017-2018 year, in response to this, there were significant and substantial effective policy development and reform. RVA actively contributed to many of these policy successes, particularly in areas of Diagnosis, Access to Treatments and Research.

The Framework strategy guided our work throughout 2017-2018. This clearer articulation of our policy platform greatly benefitted RVA's external relationships. It was easier for other groups to collaborate effectively with us.

Advocacy Mentorship & Education

In recognition that patient groups have varying levels of expertise and experience in advocacy, RVA helped build the advocacy capacity of rare disease patient groups through its pilot Mentorship & Education project which provided customised advocacy mentoring of specific rare disease patient groups and advocacy workshops. RVA ran three 'Advocacy' Education workshops for Rare Disease patient leaders and advocates in Melbourne, Sydney and Brisbane. Topics included: engaging your community; developing/ improving key messages; better use of patient narratives; engaging your MP, strategies to influence politicians, using media.

RVA Partner Program

In 2017-2018 RVA began a review of our member program, initially focussing on improving our engagement with rare disease patient organisations. Improvements have included a rebranding to 'RVA Partners' and improved 'Partner' benefits. These include formalised RVA social media promotion, improved access to Advocacy Education and networking opportunities, exclusive Mentorship support, and access to increased profile on RVA website. This activity has been prioritised and resourced by the creation of and recruitment to a Stakeholder Engagement and Communications role at RVA.

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, includes the Working With Pharmaceutical Industry Policy.

In 2017-2018 SMAC has played an increasingly important role in the work of RVA particularly in the development of rare disease policy for better health outcomes for people living with rare disease. SMAC has a registry sub-committee and this sub-committee has led the development of the National Alliance of Rare Disease Registries. The Alliance aims to promote patient-centred best practice, encourage uniformity around key principles and commit to further developing a growing understanding of the national Rare Disease picture

The RVA Round Table of Companies (RTC) is a group of pharmaceutical companies who 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, patient organisations and relevant key stakeholders. All RVA RTC members support RVA's mission as the unified voice improving the lives of all Australians affected by rare disease.

RVA website and Social Media

RVA maintains a dynamic website to keep in touch with our RVA Partners and supporters. RVA is also active in social media, particularly Facebook and Twitter.

In 2017-2018 this area was strengthened with dedicated resourcing through the creation of a Stakeholder Engagement and Communications Role in our Staff team.

RVA Newsletter

RVA publishes a monthly e-newsletter which is sent to all our RVA Partners and supporters. In each newsletter RVA features a patient story, positioned under Fair for Rare and clearly linked to a Strategic Priority. The e-news is the key method of communication to our stakeholders, providing relevant news from Australia and globally, and highlighting the work of RVA and RVA partner organisations.

Conferences and Events

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

Date	Event
July 2017	24th – National Patient and Carer Organisation Standing Committee meeting 27th – Victorian Newborn Bloodspot Screening Committee meeting
August 2017	4th – HTA – Consumer Consultative Committee workshop 16th – Presented at Spinal Muscular Atrophy Parliamentary Day 18th – Australian Genomics ‘Genomics in the Community’ Workshop 23rd – Consumer Health Forum: Round Table with Minister Hunt 30th – Presented at Paediatric Trials Network Australia
September 2017	5th - Medicines Australia – PharmAus 2017 6th - Participated in Patient Group and Medicines Australia Leaders Breakfast
October 2017	12th – International Rare Diseases Research Consortium (IRDiRC): Patient Advocates Constituent Committee (PACC) meeting 17th – National Patient and Carer Organisation standing committee meeting
November 2017	2nd - Presented at QGHA Genomics in Community Brisbane 13th - Facilitated the “Building Your Advocacy Capacity” workshop as part of the Education and Mentorship Program - Melbourne 24th – Facilitated the “Building Your Advocacy Capacity” workshop as part of the Education and Mentorship Program - Sydney
December 2017	5th - Facilitated the “Building Your Advocacy Capacity” workshop as part of the Education and Mentorship Program – Brisbane 12th – HTA Consumer consultative Committee Workshop
January 2018	17th – IRDiRC Consortium Assembly 18th – Medical Research Future Fund: Rare Cancers and Rare Diseases announcement (Melbourne) 24th – Medical Research Future Fund: Rare Cancers and Rare Diseases announcement (Sydney) 27th – IRDiRC PACC meeting 30th – Life Saving Drugs Program (LSDP) Briefing meeting
February 2018	15th – Partnered with RVA Partner, Metabolic Dietary Disorders Association (MDDA) Parliamentary Event 28th – Genetic & Rare Disease Netowrk’s WA ‘Insights in Lights’ – Rare Disease Day Symposium
March 2018	8th – Sanofi Rare Disease Day Event 19th National Patient and Carer Organisation Standing Committee meeting 27th – Research Australia – Health and Medical Research Pre-Election Summit
April 2018	17th National Patient & Carer Organisation Standing Committee meeting with Minister Hunt
May 2018	7th – IRDiRC PACC meeting 8th – 2018-19 Federal Health Portfolio Budget Briefing 14th – Attended PharmaDispatch Conference 15th – LSDP Sponsor Workshop 29th – LSDP Sponsor Workshop 31st – Australian Patients Association Awards Night
June 2018	12th – LSDP Sponsor Workshop

Policy Submissions

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

Date	Policy Submission
Jan 2018	Submission to the Senate Inquiry regarding the Therapeutic Goods Amendment (2017 Measures No 1) Bill 2017 Consultation Draft Implementation Plan for the National Health Genomics Policy Framework (Jan 2018)
Dec 2017	RVA Pre-Budget Submission

AUDIT DECLARATION

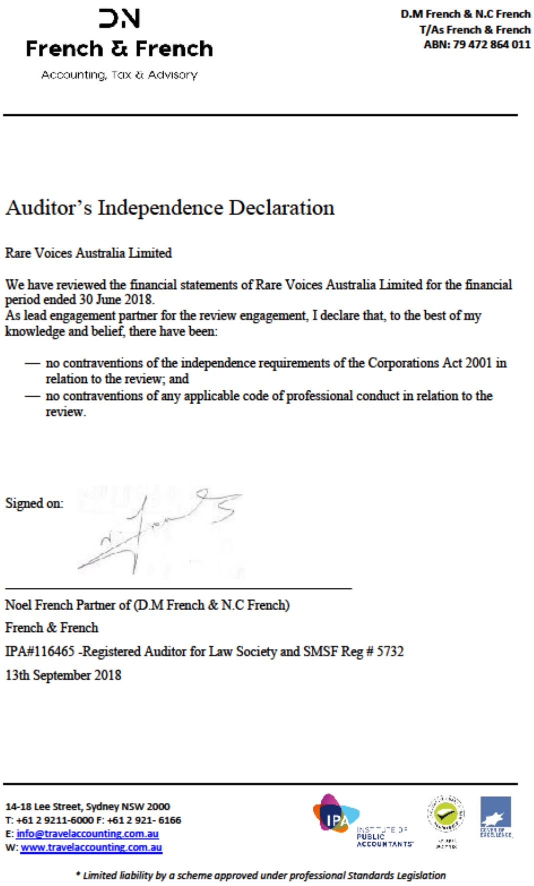
The Board of RVA declares that the accompanying concise financial report is presented fairly in accordance with applicable Australian Accounting Standards and is consistent with the Company's 30 June 2018 financial report.

The financial statements and notes give a true and fair view of the financial position as at 30 June 2018 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 it debts as and when they become due and payable. This statement has been made in accordance with a resolution of the Board made on 25th September 2018.

Raymond Saich
Louise Healy and Raymond Saich (Acting Chairs)

Auditors Report

The lead auditors' independence declaration for the year ended 30 June 2018 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 2018.
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
13th September 2018

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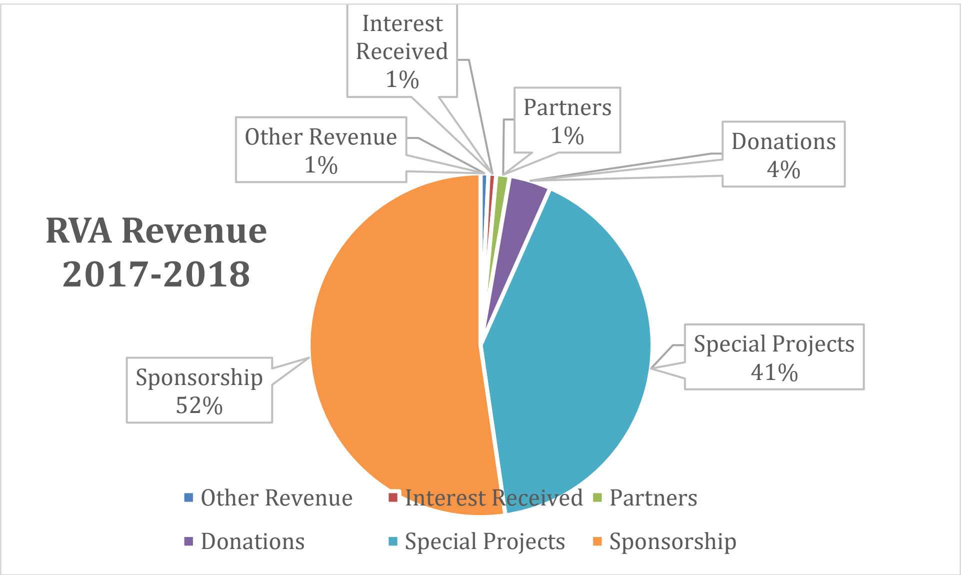
INSTITUTE OF PUBLIC ACCOUNTANTS

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

FINANCIAL REPORT

Funding of RVA

RVA actively seeks funding by direct grants and partnerships with the State governments, 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 2018 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 2018

	Note	2018 $	2017 $
CURRENT ASSETS			
Cash and cash equivalents	3	459,205	349,553
Trade and other receivables	4	50,261	34,992
TOTAL CURRENT ASSETS		509,466	384,545
NON-CURRENT ASSETS			
Property, plant and equipment	5	3,439	1,296
TOTAL NON-CURRENT ASSETS		3,439	1,296
TOTAL ASSETS		512,905	385,841
CURRENT LIABILITIES			
Trade and other payables	6	201,936	111,968
Provisions	7	10,370	6,700
TOTAL CURRENT LIABILITIES		212,306	118,668
TOTAL LIABILITIES		212,306	118,668
NET ASSETS		300,599	267,173
EQUITY			
Retained earnings		300,599	267,173
TOTAL EQUITY		300,599	267,173

STATEMENT OF INCOME AND EXPENDITURE AND OTHER COMPREHENSIVE INCOME

For the year ended 30 June 2018

	Note	2018 $	2017 $
CLASSIFICATION OF EXPENSES BY NATURE			
Revenue	2	277,202	300,539
Other income		-	-
Employee benefits expense		(3,670)	(5,463)
Depreciation and amortisation expenses		(1,105)	(2,442)
Other expenses		(239,001)	(230,852)
Profit / (loss) before income tax		33,426	61,782
Income tax expense		-	-
Profit / (loss) attributable to members of the company		33,426	61,782
Other comprehensive income		-	-

STATEMENT OF CHANGES IN EQUITY

For the year ended 30 June 2018

	Other Reserves $	Retained Earnings $	Total $
Balance at 1 July 2016	-	205,391	205,391
Profit (loss) attributable to members	-	61,782	61,782
Balance at 30 June 2017	-	267,173	267,173
Profit (loss) attributable to members	-	33,426	33,426
Balance at 30 June 2018	-	300,599	300,599

ACKNOWLEDGEMENTS

RVA highly values our relationship with our RVA Partner organisations, rare disease patient groups that not only provide support to the patient 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 Australia rare disease community through this collaboration.

RVA’s 2017-18 Not for Profit Partner Organisations:

Alagille Syndrome Alliance
Australian Mitochondrial Foundation Australia
ausEE Inc
Australia Alopecia Areata Foundation Inc. (AAAF)
Australian Kabuki Syndrome Association Inc.
Australian Pituitary Foundation
Australian Pompe Association Inc
Batten Disease Support & Research Association
Congenital Diaphragmatic Hernia Australia
Charles Bonnet Syndrome
Dyskeratosis Congenita Outreach Pacific
Fabry Australia
Fibrodysplasia Ossificans Progressiva Australia
Foundation for Angelman Syndrome Therapeutics Australia
HAE Australasia Ltd
Haemochromatosis Australia
Haemophilia Foundation Australia
HCU Network Australia
Immune Deficiencies Foundation Australia
Jack's Butterflies Rachel Gates
Leukodystrophy Resource & Research Org Inc
MDDSA
Metabolic Dietary Disorders Association
MPN AA
Multiple Sclerosis Australia
Muscular Dyst WA
Muscular Dystrophy Foundation Ltd
Muscular Dystrophy Qld
Myositis Association of Aust
PNDU
Porphyria Association Inc
Prader-Willi Syndrome Association of Aust. (PWSA)
Pseudomyxoma Survivor
Retroperitoneal Fibrosis Group
Rett Syndrome Association of Australia Inc.

Sanfilippo Children's Foundation
Spinal Muscular Atrophy Australia Inc
The Australian Dercums Disease Support Group
Tuberous Sclerosis Australia

In 2017-18 RVA was also supported by 38 Individual Partners.