Annual Report 2018



DECEMBER 2018

CCSVI Australia Inc.



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Chairperson Report

Bill Younger

Welcome to the FY2017/2018 CCSVI Australia Annual Report. This year the organisation has been mainly focused on the CCSVI trial at the Alfred Hospital Melbourne and the outstanding results from the latest phase. The lead researcher, Dr Helen Kavnoudias, is in the process of having the research findings, which have been peer reviewed, published in the Journal of Vascular & Interventional Radiology.

As reported last year, Dr Kavnoudias identified deficiencies and irregularities with the use of ultrasound to determine the presence of blockages or restrictions in the jugular vein. Her findings identified a significant number of false readings (as much as 50%) where the ultrasound results showed no blockages or restrictions in blood flow but, upon further investigation, the patient's veins were either completely blocked or had major restrictions. Dr Kavnoudias suggests that by incorporating Intravenous Ultrasound (IVUS) the variability and potential misdiagnosis of blockages can be significantly reduced. Her findings help explain why we have observed so many international CCSVI related research projects, all of which used a typical ultrasound technique, being abandoned despite the fact that they initially showed promising results.

"by incorporating IVUS the variability and potential misdiagnosis of blockages can be significantly reduced"

The only downside to this finding is the additional cost involved in screening people for CCSVI using IVUS. This improved technique costs approximately 4 times that of conventional ultrasound techniques. Our initial target of \$450,000 for the Alfred Hospital project has "ballooned" to \$800,000 due mainly to the increased cost associated with IVUS screening. Several leaders in the MS/CCSVI research community recently acknowledged and agreed that IVUS provides the most accurate and safest form of screening for CCSVI. It is imperative that we adopt the use of IVUS for the

repeat study at the Alfred to ensure that our findings and results are not compromised by false data.

In March, we were honoured to have Matt Embry visit Australia to premiere his movie 'Living Proof". Matt hired the cinema and provided complimentary passes to all attendees. The movie showed his personal journey with MS and the benefits that a healthy diet, exercise, the use of high dose vitamin D3 and CCSVI treatment have had on his life and on the lives of many other people living with MS.

The movie featured Dr George Ebers, a highly respected Neurologist and MS researcher who exposed the upsetting relationship between neurologists, the pharmaceutical industry and MS Societies and the lack of evidence to support the use or benefits of any MS drug. Not one MS drug has been shown to deliver any long-term benefit. To the contrary, some MS drugs have now been shown to cause serious health complications and/or death. The movie is now available to view free on Amazon Prime. It is thought provoking and definitely worth viewing.

I would like to take the opportunity to thank the Board Directors of CCSVI Australia for volunteering their time to not only fulfil their obligations as Directors but for also participating in various fundraising, awareness, advocacy and research events. Special thanks to Jennifer Robinson for her unwavering commitment to seek and secure much needed funding for the Alfred hospital trial and to Kerri Cassidy for her passion, commitment and courage to ensure all people living with MS will have access to this safe and effective angioplasty procedure.

Thank you to our many fundraisers, supporters and friends for your valued contributions throughout the year and thank you to everyone who has supported us, particularly our families, along this long but exciting journey and we hope that you will continue to provide your support as we move to the next phase of our journey,

Sincerely,

Bill Younger

CEO Report

Kerri Cassidy

I shall be telling this with a sigh Somewhere ages and ages hence: Two roads diverged in a wood, and I — I took the one less traveled by, And that has made all the difference.

Robert Frost

I think that the past year has been a time to reflect, consider where we have journeyed since the initial announcement of Chronic Cerebrospinal Venous Insufficiency (CCSVI) in September 2009, and what the possible future could look like. I don't pretend to understand what Robert Frost meant by this last verse in his famous poem, whether it is about treading an untested path and in hindsight realising you have discovered something life changing, or whether there is some ironic twist to the different life experienced by those who stayed in step with what was 'known' or mainstream.

There was no predictable result from seeking a vascular explanation for my symptoms that had been labelled Multiple Sclerosis. It, to me, was just an alternative path to the existing drug regime that I was ingesting, infusing and absorbing into my body with no positive benefit experienced. It seemed reasonable to take Zamboni's paper and commence a small study (n=1) and follow it through a series of if/then statements if the condition evaluates to 'true.'

Conduct neck ultrasound to diagnose possible abnormality. If 'no' then go home and forget about it.

If 'yes' then seek expert opinion. Ask expert whether further action is warranted. If 'no' then go home and forget about it.

If 'yes' then proceed to recommended action – venogram. Conduct venogram to confirm possible abnormality. If 'no' then go home and forget about it.

If 'yes' then proceed to venoplasty treatment. Test and see if treatment improves symptoms. If 'no' then go home and forget about it.

If 'yes' then engage campaign action to enable all people with MS to have access to proceed through all of the above if/then statements for themselves. This narrative was conducted publicly, in almost real time, on YouTube.

It would take a book to relay everything that has happened since 2009 when myself and thousands of people around the world first considered the vascular connection to Multiple Sclerosis. The grassroots organisation of people was birthed online, possibly the first international patient movement of its kind, where information was openly shared and people's experiences were considered valuable and trusted evidence. The conversations through social media resulted in the forming of CCSVI Australia and other local groups around the world and it was these informal networks that raised awareness, engaged with medical experts and influenced research. For the first time we could use our corporate presence to effect real change.

"information was openly shared and people's experiences were considered valuable and trusted evidence"

The emergence of a combined patient voice was set to rattle those who had, for many decades, directed the funding, services and research of Multiple Sclerosis. It was perhaps the mutual discontent with these MS institutions who had co-opted the name 'MS' to further the interests of drug industries, closely connected Neurological Associations and to progress the careers of executives across the world. It raised to consciousness, when these groups denied the importance of a vascular connection to MS, that they did not entirely exist for the support and benefit for people with Multiple Sclerosis nor were people with MS central to the decision-making processes. Those with lived experience did not have majority status on boards with consultation occurring occasionally through token advisory councils of non-elected representatives.

The influence of media and creation of CCSVI medical tourism centres served to muddy the waters. Poorly designed research studies with biased reporting were rushed

through and held up as disproving the association with MS which stirred the confusion and left many of us disillusioned or exasperated.

Despite this, organisations like CCSVI Australia, the Canadian Neurovascular Health Society and the International Society of Neurovascular Diseases continued to focus on the complex issues, understanding that angioplasty for CCSVI was not the full story, but that science needed to continue to map out the different abnormalities that can occur in the venous system – an area of the human body that was poorly understood.

The Alfred Hospital had been developing knowledge of CCSVI out of scientific curiosity and their observations of the experiences of the patients they had treated both in their initial 'pretrial' in 2010 and then through their double blinded, clinically controlled, gold standard study. They also understood the value of co-design research, that measurable outcomes must include the functional and symptomatic factors that people with MS describe as being most important, rather than just lesions load or number of relapses which decreasingly has any predictable value on disease progression. That's why we are so pleased with the many endpoints that have been gathered such impact on fatigue, memory and thinking, as well as development of disability. Our only regret is the length of time a study such as this takes. But it must be said all of this time has been needed, including the opposition experienced, to create such robust and well-led research. We wait in anticipation for the first paper to be released and for everyone to have access to the findings thus far.

"Our only regret is the length of time a study such as this takes...
all this time has been needed, including the opposition
experienced, to create robust and well-let research."

CCSVI Australia uphold the Australian Charter of Healthcare Rights:

- The right to access health care
- The right to receive safe and high quality care
- The right to be shown respect, dignity and consideration
- The right to be informed about services, treatment, options and costs in a clear and open way

- The right to be included in decisions and choices about care
- The right to privacy and confidentiality of personal information
- The right to comment on care given and to have concerns addressed

All of these rights have been tested in relation to medical treatment of people with Multiple Sclerosis and many people have reported to us that several of these basic human rights have been infringed in relation to vascular symptoms. None of the least of which is right to access an approved treatment for vascular abnormalities.

"many people have reported to us that several of these basic human rights have been infringed"

The Alfred's soon to be published paper, will show that treating venous abnormalities can potentially lead to better quality of life for some people, and this will be evidence enough. Australians with MS, for whom no cause or cure is known, should have access to treatments as a matter of human rights if there is reasonable evidence that it may improve quality of life. It is that simple.

From early 2010 when Australians were first treated for CCSVI to where we are today, many hundreds of people have stories that form part of our epic-sized novel. Whilst it may appear that we have been quiet as an organisation over recent times, the condition continues to evaluate to 'true' – it is still not time to go home and forget about it and, I believe, the path less travelled will make all the difference.

Yours in solidarity,

Kerri Cassidy

Fundraising Officer Report

Jennifer Robinson

In the words of Dr. Paolo Zamboni:

"Being faithful to your dreams is the job I suggest. Do not be afraid of fighting, collecting defeats, biting the dust for them. It may also be that these dreams never come true. I don't think that matters. Because even if you have reached just one, you will understand what gives meaning to everything is the path you have taken to get there. Today, I'm sure of it."

These words are so true of our continuing struggle to raise enough funding to complete the trial at the Alfred Hospital, Melbourne. Our dream is to see its completion and results published.

"our dream is to see its completion and results published"

We constantly talk of us working in the background, but anything we do can take years to see any results. We are certainly not defeated, even though we do not have those results yet. We continue to apply to various philanthropic organisations, as we have had some success to date from this avenue. These can take time and effort to come to fruition.

Our main fundraising for the year was the July RunMelbourne when seven walkers: Kerri, Glenn, Bill, Maree, Linda, Michael and myself and four runners: Kevin, Sam, his daughter and Steve completed the course on a cold, but dry Melbourne morning. Between us we raised a little under \$5000. We are very grateful to all of our friends and supporters especially Linda and Michael Drew who not only held a delicious afternoon tea prior, raising \$1000, but also braved the cold to walk on the day. Our thanks to everyone who supported us.

We will continue to work hard in seeing the trial at the Alfred Hospital being fully funded and as always we rely on the help and support of all our friends at CCSVI Australia.

To this end there are many ways to participate in generating funds. For example you can host an event at "Come to my House" not necessarily in September, but that is a good starting point.

You can join another event, for example "Tough Mudder" and fund raise through 'everydayhero': https://www.everydayhero.com/au/fundraising-events-to-participate-in/

Or simply raise funds and donate via our website: http://ccsviaustralia.com.au/donate/

Lastly don't forget that your place of work may also do 'workplace giving' where they make a contribution to the funds that you are raising.

Here's to the next fantastic year of fundraising!

Yours sincerely,

Jennifer Robinson

CCSVI Australia Board

Bill Younger	Chairperson
Kerri Cassidy	Chief Executive Officer
Maree Thomson	Treasurer
Jennifer Robinson	Fund Raising Officer
Kevin Robinson	Secretary
Glenn Cassidy	General Member
Jim Lewis	General Member

Treasurer Report

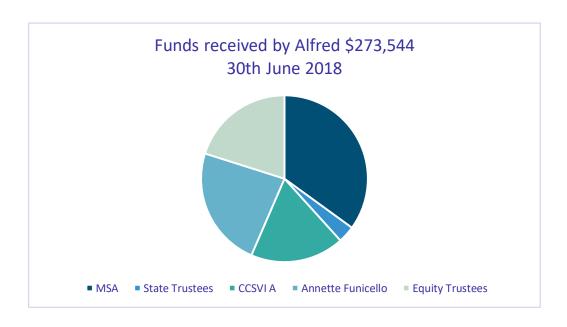
Maree Thomson

In total \$2,404 was received from fund raising and donations between July 2017 and June 2018. Operating expenses were \$3,619 for the year which was lower than last financial year (\$7,996.06) due to no travel expenses. Whilst we did not do a great deal of fund raising in this financial year there were still expenses to be paid such as insurance, maintaining our website and financial recording.

We are very pleased to confirm that we disbursed \$34,800 to the Alfred Study in June 2018 to contribute to the purchase of IVUS catheters for the study's next phase.

In total \$319,199 has been raised for the Alfred CCSVI in Multiple Sclerosis study as at 30th June 2018 of which \$49,800 has been transferred from CCSVI Australia Inc.

A balance of \$45,655 remains in the CCSVI Australia bank accounts after \$34,800 was donated to the Alfred study as it commences its second phase.





Auditors Report

The accounts were audited by the Field Group who have confirmed that the financial reports fairly represent the financial position of CCSVI Australia Inc. as at 30 June 2018.

Copies of audited Financial Statements follow.

CCSVI AUSTRALIA INC.
A.B.N. 15 107 843 012
FINANCIAL REPORT
FOR THE YEAR ENDED 30 JUNE 2018

CCSVI AUSTRALIA INC. A.B.N. 15 107 843 012 BOARD'S REPORT

Your board members submit the financial report of CCSVI Australia Inc. for the financial year ended 30 June 2018.

Board Members

The names of board members throughout the year and at the date of this report are:

William Younger - Chair

Glenn Cassidy

Maree Thomson - Treasurer

Jennifer Robinson

Kerri Cassidy - Secretary and CEO

Kevin Robinson

lan James Lewis

Principal Activities

The principal activities of the association during the financial year were to raise funds to support, facilitate or seek funding for medical research into Multiple Sclerosis (MS) and Chronic Cerebrospinal Venous Insufficiency (CCSVI).

Significant Changes

No significant change in the nature of these activities occurred during the year.

Operating Result

The deficit after providing for income tax for the 2018 financial year amounted to \$35,593 (2017: deficit \$930).

Signed in accordance with a resolution of the members of the board.

Maree Thomson			(Kasay Keri Cassidy	
	Treasurer		Secretary and CEO	
Dated this	15th	day of	Noumber	2018

CCSVI AUSTRALIA INC. A.B.N. 15 107 843 012 INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 30 JUNE 2018

Note INCOME	2018 \$	2017 \$
Functions and events	2.154	F 730
Gifts and donations	2,154 250	5,720 804
Interest received	422	542
interest received	2,826	7,066
	2,820	7,000
EXPENDITURE		
Accounting and consultancy	(450)	(487)
Advertising	-	(100)
Bank fees and charges	-	(46)
Grant distribution	(34,800)	-
Functions and events	(1,582)	(660)
Fundraising processing fees	(56)	(308)
Insurance	(925)	(890)
Internet & Telephone fees	(308)	(400)
Office supplies and printing	(127)	(184)
Regulatory Fees	(171)	-
Travel		(4,921)
	(38,419)	(7,996)
Current year (deficit before income tax	(35,593)	(930)
Income tax expense 1a.		
Net current year (deficit)	(35,593)	(930)
RETAINED SURPLUS AT THE BEGINNING OF THE FINANCIAL YEAR	81,248	82,178
RETAINED SURPLUS AT THE END OF THE FINANCIAL YEAR	45,655	81,248

CCSVI AUSTRALIA INC. A.B.N. 15 107 843 012 ASSET AND LIABILITIES STATEMENT AS AT 30 JUNE 2018

ACCUTE	Note	2018 \$	2017 \$
ASSETS CURRENT ASSETS			
Cash and cash equivalents	2	45,655	81,248
TOTAL CURRENT ASSETS		45,655	81,248
TOTAL ASSETS		45,655	81,248
NET ASSETS		45,655	81,248
MEMBERS' FUNDS			
Retained surplus		81,248	82,178
Current year (deficit)		(35,593)	(930)
TOTAL MEMBERS' FUNDS		45,655	81,248

CCSVI AUSTRALIA INC. A.B.N. 15 107 843 012 CASH FLOW STATEMENT FOR THE YEAR ENDED 30 JUNE 2018

	Note	2018 \$	2017 \$
CASH FLOWS FROM OPERATING ACTIVITIES			-
Receipts from members and donors		2,404	6,524
Payments to suppliers		(38,419)	(7,996)
Interest received		422	542
Net cash (used) by operating activities	3	(35,593)	(930)
Net (decrease) in cash held		(35,593)	(930)
Cash and cash equivalents at the beginning of the financial year	_	81,248	82,178
Cash and cash equivalents at the end of the financial year	2	45,655	81,248

CCSVI AUSTRALIA INC. A.B.N. 15 107 843 012 NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2018

NOTE 1. STATEMENT OF SIGNIFICANT ACCOUNTING POLICIES

The financial statements are special purpose financial statements prepared in order to satisfy the financial reporting requirements of the Australian Charities and Not-for-profits Commission Act 2012 (ACNC Act) and the Associations Incorporation Reform Act 2012 Victoria. The board has determined that the association is not a reporting entity.

The financial statements have been prepared on an accruals basis and are based on historic costs and do not take into account changing money values or, except where stated specifically, current valuations of non-current assets.

The following significant accounting policies, which are consistent with the previous period unless stated otherwise, have been adopted in the preparation of these financial statements.

a. Income Tax

No provision for income tax has been raised as the association is exempt from income tax under Division 50 of the Income Tax Assessment Act 1997, being an endorsed Health Promotion Charity.

b. Impairment of Assets

At the end of each reporting period, the board reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have been impaired. If such an indication exists, an impairment test is carried out on the asset by comparing the recoverable amount of the asset, being the higher of the asset's fair value less costs to sell and value in use, to the asset's carrying amount. Any excess of the asset's carrying amount over its recoverable amount is recognised in the income and expenditure statement.

c. Cash and Cash Equivalents

Cash and cash equivalents include cash on hand, deposits held at call with banks, and other short-term highly liquid investments with original maturities of three months or less.

d. Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable after taking into account any trade discounts and volume rebates allowed. For this purpose, deferred consideration is not discounted to present values when recognising revenue.

Interest revenue is recognised using the effective interest method, which for floating rate financial assets is the rate inherent in the instrument.

Grant and donation income is recognised when the association obtains control over the funds, which is generally at the time of receipt.

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

e. Goods and Services Tax (GST)

The association is not currently registered for GST. All expenses, assets and liabilities are recognised inclusive of the amount of GST as the amount of GST incurred is not recoverable from the Australian Taxation Office (ATO).

f. Comparative Figures

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

CCSVI AUSTRALIA INC. A.B.N. 15 107 843 012 NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2018

	2018	2017
	\$	\$
NOTE 2. CASH AND CASH EQUIVALENTS		
Cheque account	3,914	3,627
Cash reserve account	42,388	75,464
Paypal	(647)	2,157
Total cash and cash equivalents as stated in the asset and liabilities statement	45,655	81,248
Total cash and cash equivalents as stated in the cash flow statement	45,655	81,248
NOTE 3. CASH FLOW INFORMATION		
Reconciliation of cash flow from operations with (deficit)/surplus after income tax		
Net (deficit)	(35,593)	(930)
Cash flows excluded from (deficit) attributable to operating activities		
Non-cash flows in (deficit)	-	-
Changes in assets and liabilities		
	(35,593)	(930)

NOTE 4. ASSOCIATION DETAILS

The registered office and principal place of business of the association is:

CCSVI Australia Inc.

414 Glenfern Road

Upwey VIC 3158

CCSVI AUSTRALIA INC. A.B.N. 15 107 843 012 ANNUAL STATEMENTS GIVE TRUE AND FAIR VIEW OF FINANCIAL POSITION AND PERFORMANCE OF INCORPORATED ASSOCIATION

ASSOCIATIONS INCORPORATION REFORM ACT 2012 SS 94(2)(B), 97(2)(B) AND 100(2)(B)

We, Maree Thomson and Kerri Cassidy, being members of the board of CCSVI Australia Inc., certify that:

The statements attached to this certificate give a true and fair view of the financial position and performance of CCSVI Australia Inc. during and at the end of the financial year of the association ending on 30 June 2018.

Mareo Thomas		Considy
M ar ee Thomson Treasurer		Kerri assidy Secretary and CEO
Dated this 15th	day of	November 2018

CCSVI AUSTRALIA INC. A.B.N. 15 107 843 012 CERTIFICATE BY MEMBERS OF THE BOARD

I, Maree Thomson of Greensborough, Victoria, certify that:

a.	I attended the annual general meeting of the association held on August 18 2018
b.	The financial statements for the year ended 30 June 2018 were submitted to the members of the association at its annual general meeting.
	Maree Thomson Treasurer
Dated this	15th day of November 2018



INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF CCSVI AUSTRALIA INC.

Report on the Audit of the Financial Report

Opinion

We have audited the accompanying financial report of CCSVI Australia Inc. (the association), which comprises the balance sheet as at 30 June 2018, the statement of profit or loss for the year then ended, notes to the financial statements including the certification by members of the committee on the annual statements giving a true and fair view of the financial position and performance of the association.

In our opinion, the accompanying financial report presents fairly, in all material respects, the financial position of the association as at 30 June 2018 and its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements and the requirements of the *Associations Incorporation Act Victoria*.

Basis for Opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the *Auditor's Responsibilities for the Audit of the Financial Report* section of our report. We are independent of the association in accordance with the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110: Code of Ethics for Professional Accountants (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Emphasis of Matter – Basis of Accounting

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist the association to meet the requirements of the Associations Incorporations Act Victoria. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

Responsibilities of the Committee for the Financial Report

The committee is responsible for the preparation and fair presentation of the financial report in accordance with the financial reporting requirements of the Associations Incorporation Act Victoria and for such internal control as the committee determines is necessary to enable the preparation and fair presentation of the financial report that is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the committee is responsible for assessing the association's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless the committee either intend to liquidate the association or to cease operations, or has no realistic alternative but to do so.

Auditor's Responsibilities for the Audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with Australian Auditing Standards, we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures
 that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the
 effectiveness of the association's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the association's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the association to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial report, including the
 disclosures, and whether the financial report represents the underlying transactions and events in a
 manner that achieves fair presentation.

We communicate with the committee regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

The Field Group - Audit
Chirnside Park, Victoria

Gavin Fraser CA

Partner

Dated this

-10

day of

Novembe

2018

The Field Group.