Annual Report 2019



DECEMBER 2019

CCSVI Australia Inc.



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Chairperson Report

Bill Younger

Welcome to the FY2018/2019 CCSVI Australia Annual Report. It has been a relatively quiet year for the organisation as we await the publication of the initial research findings from the Alfred Hospital trial in the Journal of Vascular and Interventional Radiology. The CCSVI Australia Board is confident that the research paper will bring further credibility to the connection between vascular health and the symptoms associated with Multiple Sclerosis.

As reported previously, the research team at the Alfred Hospital identified that it is imperative that Intravenous Ultrasound (IVUS) becomes the universal standard to screen and identify restrictions or blockages to avoid the variability found with previous testing methods that often led to misdiagnosis. One of our major challenges remains securing funding for the next phase of the trial due to the added expense of utilising IVUS as a screening method. An additional \$350,000 is required to complete the trial.

It is encouraging to see the significant increase in CCSVI research internationally with many of the studies complementing the work being conducted at the Alfred Hospital. Many international research organisations continue to follow CCSVI Australia's lead with interest and are eager to see our research findings published.

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,

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Bill Younger

CEO Report

Kerri Cassidy

I think that it would be remiss for me not to start this report by acknowledging that it has been a fairly stagnant year for CCSVI Australia. This is largely due to the slow moving of things with The Alfred and the reality that the first paper has not been published despite it having been finished two years ago. This is deeply disappointing and demotivating.

This time last year my report included a hopeful outlook that once the report was published we would be able to equip people with the evidence they need to take to their doctors and specialists and have the options to try treatment for CCSVI. Now I am a little reticent to suggest this to people as I cannot give my assurance that this will happen.

That said, there continues to be people who contact us through our email address to ask for information on testing and treatment for CCSVI and there are still people who are working through a couple of channels to seek treatment. It is very clear that people are still being diagnosed with abnormalities of the brain's venous drainage and that there are Vascular Interventionalists still willing to treat CCSVI in Melbourne. So there is a glimmer of light peeping through the slit in the door.

It has now been almost 10 years since CCSVI burst into public consciousness with the publishing of Zamboni's 'The Big Idea' paper. It is heartening to see that the International Society of Neurovascular Disease continues to meet annually and to discuss continuing research in the brain/heart connection. For me personally, I will always be thankful for the doctors and researchers who have stood up and identified with what has in neurological circles been a denigrated and maligned topic. It seems there is still much further to go.

I'd like to take this opportunity to thank all of you for sticking it out. Jenn for your strong resolve and for keeping us focused on the need to follow up on opportunities for research funding and keeping The Alfred Accountable as well as involving your friends and family in fund raising. Thanks Maree ensuring that the accounts and finance areas tick over. Thanks Kevin for your minute taking and your Tough Muddering to raise funds for us to keep going. Bill, thanks for your belief in us and rights of people with MS to have access to a treatment that has potential to help most people in some way. Glenn – thanks for keeping things going with the website, stepping in when things go awry as they do with technology and for being a rock in so many ways.

Reading back it sounds almost like a farewell speech. It is not. As I've said, as long as there are people who can be helped by what we do I am happy to keep going. I also do think in the future the vascular connection with MS will become mainstream and we will have been instrumental in having made it so.

Yours in solidarity,

Kerri Cassidy

Fundraising Officer Report

Jennifer Robinson

Once again we are at the end of the financial year for 2018/2019.

It is always a surprise to me just how quickly this comes around since we are continually on the search for funding for the Alfred Hospital trial.

This year has not been disappointing as we had two major events which raised over \$3500 between them.

The first was in October when Kevin and Emily Robinson, our long term friends and supporters, decided to tackle the infamous "Tough Mudder" 16 km run interspersed with 22 obstacles on Kevin's 60th birthday. Sounds easy enough! But when these obstacles include sheer walls, icewater, mud (surprisingly!) and mild electric shocks, it certainly takes its toll on the participants.

Together Kevin and Emily raised almost \$2000 for their heroic endeavours.

Kevin and a team will be competing again this October and raising funds (see below).

Our second event held in January when Chris and Nigel Hall organised an evening of cooking, drinking (naturally!), eating delicious food and fun.

This was the third time that our friends had organised a fundraising dinner to support our charity. This time the theme was Middle Eastern.

The idea of the dinner is that guests are divided into teams, given a recipe, all the ingredients and equipment and at specific times start their dishes, which, when completed, are handed round to the rest of the guests. There were a total of 27 diners who raised \$1630 for the Alfred trial.

Our grateful thanks go to Chris and Nigel and all their friends, for their unwavering support. It is because of such people that we are able to continue the work that we do.

We are always looking for ways to apply for funds from philanthropic organisations. If anyone has any contacts in this area, please do contact 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. We have now partnered with several fundraising organisations:

- One is "Shopnate". All you need to do is install their app on whatever device you do your Internet shopping and the donation will be automatically given to CCSVI Australia at no extra cost to you: https://www.shopnate.com.au/cause/ccsvi-australia-inc
- You can join an event, or sponsor someone, for example: "Tough Mudder" and fund raise through "everydayhero":

https://toughmudder-melbourne-19.everydayhero.com/au/kevin

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.

https://good2give.ngo/services/workplace-giving/

- We continue to promote "Come to My House" where the premise is that it is difficult for a person who has walking issues to go to visit their friends, so we invite them to our house sharing the meal they would have made.
- Or simply raise funds and donate via our website: http://ccsviaustralia.com.au/donate/

Here's to the next fantastic year of fundraising!

Yours sincerely,

Jennifer Robinson

CCSVI Australia Statement of Purpose

To remain abreast of international advances in Chronic Cerebrospinal Venous Insufficiency (CCSVI) and the Vascular connection to Multiple Sclerosis.

To supply accurate information to all interested parties including, but not limited to;

- Those seeking testing for treating CCSVI,
- Medical researchers and practioners,
- Government at all levels, and
- Related community-support organisations

To lobby for treatment of CCSVI to be readily available to all Australians on Medicare.

To ensure the interest of people with CCSVI have continued representation and that the understanding and treatment of CCSVI continues to advance.

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

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. \$3,989.13 was received from fund raising and donations between July 2018 and June 2019.

Expenses were \$2,403.97 for the year which was lower than last financial year (\$3,619.71) due to functions expenses dropping.

In total \$322,198 has been raised for the Alfred CCSVI in Multiple Sclerosis study as at 30th June 2019 of which \$49,800 has been transferred from CCSVI Inc.

A balance of \$48,075 remains in the CCSVI Australia bank accounts.

Financial Statements 2018-2019

Balance Sheet CCSVI Australia Incorporated As at 30 June 2019

	30 Jun 2019	30 Jun 2018
Assets		
Bank		
Cash Reserve Account	\$42,571.56	\$42,388.11
Cheque Account	\$5,503.53	\$3,913.48
Paypal	-\$647.48	\$2,157.18
Total Bank	\$47,427.61	\$48,458.77
Total Assets	\$47,427.61	\$48,458.77
Liabilities		
Current Liabilities		
Rounding	\$0.04	\$0.04
Total Current Liabilities	\$0.04	\$0.04
Total Liabilities	\$0.04	\$0.04
Net Assets	\$47,427.57	\$48,458.73
Equity		
Current Year Earnings	\$1,773.50	-\$32,593.28
Retained Earnings	\$45,654.07	\$81,247.35
Total Equity	\$47,427.57	\$48,654.07

Profit and Loss

CCSVI Australia Incorporated

1 July 2018 to 30 June 2019

	30 Jun 19	30 Jun 18
Income		
Events	\$3,989.13	\$2,154.03
Gifts and contributions	\$0.00	\$250.00
Interest Income	\$188.34	\$422.40
Total Income	\$4,177.47	\$2,826.43
Gross Profit	\$4,177.47	\$2,826.43
Less Operating Expenses		
Consulting & Accounting	\$75.00	\$450.00
Functions & Events	\$608.52	\$1,582.30
Fundraising Processing Fees	\$0.00	\$55.76
Grant distribution	\$0.00	\$34,800.00
Insurance	\$960.00	\$925.00
Internet Costs	\$760.45	\$308.95
Office Expenses	\$0.00	\$127.00
Regulatory Fees	\$0.00	\$170.70
Total Operating Expenses	\$2,403.97	\$38,419.71
Net Profit	\$1,773.50	-\$35,593.28

Statement of Cash Flows

CCSVI Australia Incorporated

For the year ended 30 June 2019

Account	2019	2018
Operating Activities		
Receipts from customers	4,177.47	2,826.43
Payments to suppliers and employees	(2,403.97)	(38,419.71)
Net Cash Flows from Operating Activities	1,773.50	(35,593.28)
Net Cash Flows	1,773.50	(35,593.28)
Cash and Cash Equivalents		
Cash and cash equivalents at beginning of period	45,654.11	81,247.39
Cash and cash equivalents at end of period	47,427.61	45,654.11
Net change in cash for period	1,773.50	(35,593.28)