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# Annual Report 2020

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SEPTEMBER 2020

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CCSVI Australia Inc.



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# Chairperson Report

Bill Younger

Welcome to the FY2019/2020 CCSVI Australia Annual Report. It has been another relatively quiet year for the organisation due to the global COVID19 pandemic. With numerous Cardiovascular and Interventional Radiology conferences postponed or cancelled this year it has been a frustrating period for CCSVI Australia and the Alfred Hospital's Research team. Despite the many setbacks I am pleased to advise that key learnings from the research being conducted by the Alfred Hospital Melbourne will be presented at the 2020 Scientific Meeting of the Cardiovascular and Interventional Radiological Society of Europe (CIRSE) Conference from 12<sup>th</sup> -15<sup>th</sup> September.

A key learning from the study suggests improvements in the Expanded Disability Status Score (EDSS) only occurs after 24 months. The Alfred is also looking at the perivascular spaces of the brain, toxic clearance and pressure in the brain. 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 the MS Network stated recently, "Knowledge and expertise associated with what is being learnt at the Alfred Hospital positions Australia well for the diffusion of associated medical learnings across the broader (and International) medical professions. It brings with it realistic potential for significant relief for many MS associated disabilities and long term reduction in government outlays accompanied by broader economic benefits. What is being learnt needs to be appreciated in the context of global learnings regarding the chain reaction of factors influencing MS progression – including long standing concerns about the impact of (frequently undetected) cardiovascular disorders across global MS communities".

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.

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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.

I would also like to express my appreciation to the Alfred Hospital and its dedicated research team for continuing to support and drive this important research project. 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

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# CEO Report

Kerri Cassidy

January 2020 marked ten years since CCSVI Australia was first birthed on Facebook where Australians were able to gather and share information and experiences with each other and indeed with people with MS globally. It has also been ten years since the first Australian patients were treated with venoplasty to improve their venous brain drainage. In those early few years there was a great deal of momentum and subsequent developments in the worldwide understanding of Chronic CerebroSpinal Venous Insufficiency (CCSVI). Whilst things have been significantly quieter on this front, there are still people experiencing the benefits to their quality of life as a consequence of their treatments. CCSVI Australia still receives inquiries by people seeking information through our email and Facebook.

Due to COVID-19 our Board has, like so many organisations, been meeting over Zoom to discuss the latest in the vascular connections to Multiple Sclerosis and to keep abreast of research being conducted at The Alfred in Melbourne. CCSVI Australia has raised over \$320,000 for this research and we continue to seek ways to further understanding.

We were expecting the study of Venoplasty for CCSVI in people with Multiple Sclerosis to recommence on 1 July 2020, however this has been frustrated by the complications arising with COVID-19 here in Melbourne. As this has been such a long process the additional speed bump is deeply disappointing as delays for access to treatment for venous abnormalities is delays for people to have opportunity to be tested and treated.

We are thrilled however that our 2020 Annual General Meeting coincided with the CIRSE (Cardiovascular and Interventional Radiological Society of Europe) 2020 Summit at which Prof Ken Thompson and Helen Kavnoudias presented the results of the Alfred CCSVI in Multiple Sclerosis study (see abstract on page 7). The Summit is featuring the field's top experts giving their presentations on the latest scientific data and knowledge exchange. Due to COVID-19 this is being stage online. The results of this study show

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that improvement in Expanded Disability Score (EDSS), on average, is evident at the two year mark. For this reason, the conclusion is that further research should be conducted and that is certainly what we hope to see continue.

I'd like to thank the members of the CCSVI Australia team who I have the pleasure of saying have become good friends over the last ten years; Bill, Jennifer, Jim, Maree, Kevin and my husband Glenn (who has been around for a few more than ten years for me).

May this coming year see further understanding of the connection between our vasculature and neurology and the ultimate hope that people with MS in Australia will be able to discover for themselves whether CCSVI is a contributing factor with the removal of testing and treatment barriers.

Every strength to you each,

Kerri Cassidy

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**Title: A randomised, double-blind, sham-controlled study of percutaneous transluminal angioplasty for extracranial vein stenoses (CCSVI) in patients with multiple sclerosis**

**Abstract**

**Introduction**

Following controversy about CCSVI, an ethics approved randomised, double-blind, shamcontrolled cross-over study with two-year follow-up to assess the safety and efficacy of venoplasty for the treatment of extracranial vein stenosis in MS-patients.

**Methods**

Patients were randomised 1:1 to balloon or sham venoplasty. Imaging (US,MRV,DSA) was used to assess the extracranial veins. Outcomes were measured at 1,3,6,12,18 and 24mths. Crossover occurred at 12mths. Venoplasty was repeated if restenosis was noted. The primary safety-endpoint was number of AEs and the primary efficacy-endpoint was change in the EDSS. Other measures included MS-QoL-54, CogState, PASAT, Fatigue-Score, MRIbrain.

**Results**

36 patients consented. 4(11%) had normal DSA, two were MRI ineligible and two withdrew. 28 patients completed the study. There was no difference between the groups for gender, age, MS-type, disease-duration or types of abnormalities. More patients were on immunomodulators in the sham-arm (12:7). 12/62 AEs were trial related (2-haematoma, 4neck/groin/cannulation pain, 2-thrombus, 2-headache. Two patients relapsed, one at 6mths after a sham-procedure and the other 3mths after venoplasty. At 12 and 24mths, no significant difference was found for PASAT, FS, Cogstate or MRI lesion-volume. 26/28 patients had enlarged perivascular spaces (scores 1-4). At 12mths there was no significant difference in EDSS (p=0.229). There was a significant difference in the EDSS at 24mths (p=0.025).

**Conclusion**

This study suggests improvement in EDSS occurs only after 24mths. RCTs by other groups were for  $\leq 1$ yr and did not include EDSS as a primary-endpoint. A vascular/endothelial cell component in the pathogenesis of MS warrants further investigation.

(Venoplasty of CCSVI in patients with Multiple Sclerosis study, The Alfred Hospital, Melbourne, 2020)

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# Fundraising Officer Report

Jennifer Robinson

The world beginning July 2019 is a completely different world ending June 2020.

Our fundraising year has been curtailed to 9 months, however during that time we were able to experience one fundraising opportunity and that was “Tough Mudder” 2019. We are, once again indebted to our friend and supporter Kevin Robinson, who, despite the torrential rain and hail ran through the 16 km track and 20 obstacles to raise \$1337.61. This is the second year he has completed the gruelling race to raise funds for CCSVI Australia. We are grateful for his dedication and tenacity!

Throughout the year we have also been raising funds through Shopnate and Good2give workplace donations. Shopnate is an online donations platform, where participating online shops will donate a percentage of the goods to your designated charity, all at no cost to you. In this new age of increased online shopping this is something well worth following up.

Good2give is a workplace donations platform where employee donations as well as company matched donations are sent to your chosen charity. In total, from both platforms, we received \$965.44.

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.

Please consider our suggestions below, as unfortunately, many of our previous activities will be curtailed for the foreseeable future.

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.

To this end there are many ways to participate in generating funds. We have now partnered with several fundraising organisations:

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

Here’s to the next fantastic year of fundraising!

Jennifer Robinson

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# 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 practitioners,
- 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

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# Treasurer Report

Maree Thomson

\$1337.61 (thanks Kevin) was raised from events and \$965.44 from Shopnate and Good2give between July 2019 and June 2020.

Expenses were \$632.95 for the year which was lower than last financial year (\$2403.97) due to cancelling our insurance policy and discontinuing Xero.

In total \$322,198 has been raised for the Alfred CCSVI in Multiple Sclerosis study as at 30th June 2020 of which \$49,800 has been transferred from CCSVI Inc.

A balance of \$49,797.85 remains in the CCSVI Australia bank accounts.

# Financial Statements 2019-2020

## Balance Sheet CCSVI Australia Incorporated As at 30 June 2020

	30 June, 2020	30 Jun 2019
<b>Assets</b>		
<b>Bank</b>		
Cash Reserve Account	\$43,555.53	\$42,571.56
Cheque Account	\$6,242.32	\$5,503.53
Paypal		
<b>Total Bank</b>	<b>\$49,797.85</b>	<b>\$48,075.09</b>
<b>Total Assets</b>	<b>\$49,797.85</b>	<b>\$48,075.09</b>
<b>Liabilities</b>		
<b>Current Liabilities</b>		
Rounding		\$0.04
<b>Total Current Liabilities</b>		<b>\$0.04</b>
<b>Total Liabilities</b>		<b>\$0.04</b>
<b>Net Assets</b>	<b>\$49,797.85</b>	<b>\$48,075.05</b>
<b>Equity</b>		
Current Year Earnings	\$1,722.76	\$1,773.50
Retained Earnings	\$48,075.09	\$45,654.07
<b>Total Equity</b>	<b>\$49,797.85</b>	<b>\$47,427.57</b>

**Profit and Loss**  
**CCSVI Australia Incorporated**  
**1 July 2019 to 30 June 2020**

	<b>2020</b>	<b>2019</b>
<b>Income</b>		
Events	\$1,337.61	\$3,989.13
Gifts and contributions	\$965.44	\$0.00
Interest Income	\$52.66	\$188.34
<b>Total Income</b>	<b>\$2,355.71</b>	<b>\$4,177.47</b>
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<b>Gross Profit</b>	<b>\$2,355.71</b>	<b>\$4,177.47</b>
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<b>Less Operating Expenses</b>		
Consulting & Accounting	\$0.00	\$75.00
Functions & Events	\$0.00	\$608.52
Fundraising Processing Fees	\$0.00	\$0.00
Grant distribution	\$0.00	\$0.00
Insurance	\$0.00	\$960.00
Internet Costs	\$632.95	\$760.45
Office Expenses	\$0.00	\$0.00
Regulatory Fees	\$0.00	\$0.00
<b>Total Operating Expenses</b>	<b>\$632.95</b>	<b>\$2,403.97</b>
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<b>Net Profit</b>	<b>\$1,722.76</b>	<b>\$1,773.50</b>
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**Statement of Cash Flows**  
**CCSVI Australia Incorporated**  
**For the year ended 30 June 2020**

Account	2020	2019
<b>Operating Activities</b>		
Receipts from customers	\$ 2,355.71	\$ 4,177.47
Payments to suppliers and employees	-\$ 632.95	-\$ 2,403.97
<b>Net Cash Flows from Operating Activities</b>	<b>\$ 1,722.76</b>	<b>\$ 1,773.50</b>
<b>Net Cash Flows</b>	<b>\$ 1,722.76</b>	<b>\$ 1,773.50</b>
<b>Cash and Cash Equivalents</b>		
Cash and cash equivalents at beginning of period	\$ 48,075.09	\$ 45,654.11
Cash and cash equivalents at end of period	\$ 49,797.85	\$ 47,427.61
<b>Net change in cash for period</b>	<b>\$ 1,722.76</b>	<b>\$ 1,773.50</b>