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# Annual Report 2015-2016



# CCSVI Australia Inc.



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## Chairperson's Report



Welcome to the FY2015/2016 CCSVI Australia Annual Report. It has been pleasing to see a shift in thinking from segments of the Multiple Sclerosis (MS) research community with acceptance that MS might not be purely a neurological condition or an autoimmune disease. As global evidence mounts, it is becoming increasingly difficult for the research community to ignore the relationship between vascular health, in particular CCSVI, and MS and other neurological conditions. The volunteer team at CCSVI Australia are focused on raising funds to support the CCSVI trial at the Alfred hospital and to keeping abreast of any new developments from around the globe.

Preliminary results from the Alfred trial are encouraging but more funding is required to obtain a sufficient statistical base to confirm the findings. This trial has a significant amount of global interest as it is the only double-blinded, placebo controlled trial of its kind in the world.

As evidence of the trial's importance our CEO, Kerri Cassidy, accompanied the lead researcher from the Alfred hospital trial, Dr Helen Kavnoudias who spoke at the 6<sup>th</sup> Annual Meeting of the International Society of Neurovascular Disease, which was held in New York in April 2016. There were presentations from 49 scientists and doctors who are specifically looking at vascular aspects of neurological diseases. These presentations provided increasing evidence of a linkage between CCSVI and MS. Dr Kavnoudias's presentation showed that 80% of people tested suffer from CCSVI. Of those who have undergone the angioplasty procedure, to relieve venous blockages or restrictions, many have shown significant functional improvement.

Earlier this year, one of our founding Directors, Helen Webb, resigned from the Board to pursue her interest in other aspects of MS including the importance of diet and gut health in alleviating symptoms. Helen was a major contributor to the establishment of CCSVI Australia and became an important member of the team by providing regular scientific and research related updates to the CCSVI and MS communities. On behalf of the Board and the general MS community I would like to express my deep appreciation and gratitude to Helen for her commitment and dedication to CCSVI Australia over the past 6 years. We wouldn't be where we are today without your support.

I would also like to take the opportunity to thank the Board Directors of CCSVI Australia for volunteering their time to not only fulfill 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 also to our many fundraisers, supporters and friends for your valued contributions throughout the year,

Sincerely,

**Bill Younger**  
Chairman



# Chief Executive Officer's Report



We are pleased to be presenting our fourth annual report and to share some of the major stories of 2015-2016.

We participated in several events to inform and raise awareness of the vascular connections being discovered in Multiple Sclerosis and other Neurological diseases.

In September Jennifer Robinson featured on 3WBC radio sharing her own experience of MS and giving a strong explanation of what CCSVI is and why we do what we do.

I had the pleasure of speaking at Waverley Rotary and received much encouragement and helpful feedback to help progress the research.

Later in 2015 we were a finalist in the Melbourne Awards and Helen Webb and I attended the gala event in December. It was a tremendous opportunity to show video footage of our cause and to speak with others who are doing other community-led initiatives in Melbourne.



A highlight of the year was the opportunity to attend the International Society of Neurovascular Disease Annual Meeting with Dr Helen Kavnoudias in New York. It was inspiring to hear so many researchers are exploring vascular aspects of neurological disease, and the consensus between them that technology was

unearthing some new and exciting avenues. More of this is in my report on page 7.

The board of CCSVI Australia is undergoing some change in coming months as we farewell Helen Webb and welcome some new faces in the next year. I'm grateful for the support and friendship of Helen and wish her and Leo every future happiness.

The Alfred trial is ongoing with further analysis being done in partnership with Mark E Haacke's team in Detroit. It is pleasing to learn that many relationships have been forged between researchers at the Alfred and members of the ISNVD that will strengthen the study and contribute to some additional, objective endpoints. We look forward to further enrolments in the study over the next year.

There are so many people to thank, to all those who have continued to support us on social media, in practical fund raising and your ongoing belief in the importance of this work. Finally, sincere thanks to the team at CCSVI Australia, it is a pleasure to be part of something that is making a difference for people with MS and other neurological conditions and I look forward to an exciting 2016-2017!

**Kerri Cassidy**  
Chief Executive Officer

# Fundraising Report



## Run Melbourne

Our fundraising year kicked off to a fabulous start with our team of 10 participating in Run Melbourne in July. We had Gavin and Kevin both completing the 10-km run and the rest of us walkers and rollers completing the 5 km walk. It was a gorgeous morning; the sun came out early and the rain stayed away.

The day was a tremendous success and with the help of our supporters we raised over \$8,000 for The Alfred CCSVI in Multiple Sclerosis research study.

Thank you to everyone who contributed and we look forward to more people joining our team in coming years.



## Come to my House

Nadine and her family hosted a garden party on a sunny afternoon in September, in her beautifully decorated backyard.

There were over 100 people who visited and each received a cuppa or cool drink and a cake. Hours had been spent sourcing items for the silent auction which included massages, bath salts, bed and breakfast stays, kitchen items amongst other fabulous things.

Nadine has chosen to contribute all monies raised to CCSVI Australia, an amazing total of \$4,000! Sincere thanks to everyone who participated, baked, served and played music to make it such a pleasurable afternoon for all for, what we believe, is a very important cause.

## Melbourne Marathon

Our sincerest thanks to Simone for choosing CCSVI Australia to support. A tremendous effort both running and raising just over \$1,500. Thank you for your continued support.



## Grants

Although we have not received any large grants this year, a lot of work has gone into groundwork and we are hopeful of seeing some of these come to fruition next year. We will continue to work hard in seeing the trial at the Alfred Hospital 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:

- 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 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 another amazing year of fundraising!

Jennifer Robinson  
Fundraising Coordinator



## ISNVD 29-30<sup>th</sup> April 2016

### DAY ONE:

49 scientists and doctors presented on vascular aspects of neurological diseases including Multiple Sclerosis, Alzheimer's, Parkinson's, Ménière's disease. One frustration that was mentioned several times was that current theories of MS have tunnelled vision – that MS is purely an auto-immune disease. Increasingly we see that MS has multiple factors with many unanswered questions. Certainly, over the weekend we heard that people with MS have a higher incidence of cerebral microbleeds and that cardiovascular co-morbidities are associated with neurological disease progression. This was not believed to be due to a sedentary lifestyle as **Dr Robert Zivandinov** mentioned, these are seen in people with clinically isolated syndrome.

There was discussion about the impact of impaired venous flow on the endothelium and how shear stress is required to keep the veins healthy. Perhaps this is what makes the blood brain barrier permeable to immune cells? Several researchers are using the latest MR technology to study both the arterial and venous micro vessels in the brain, their density and flow. Never have we had such a clear picture of oxygen concentration within the vessels of the brain. There was an incredible image shown of areas of hypo-perfusion, or low levels of oxygen in the blood, in the areas of the brain where MS lesions are seen. There's interest in **Dr Mark Haacke's** group of imaging the venous walls and getting a better understanding of what they look like in people with MS compared with healthy controls.

Keynote speaker was **Dr Jonathon Kipnis** from Virginia University. His first comment was that the belief that there should not be any immune cells present in the brain is bad and needs to change. He discussed how immune cells move in and out of the brain and the role of lymphatics. Dr Kipnis explained that arteries are like water pipes bringing in blood, veins act like the sewerage system and the lymphatics cleanse waste products from the tissue and drains them to the lymph nodes. Cerebrospinal fluid is constantly cleansing and being replaced. Any disruption to this process, called glymphatics, is bad news for brain health. Kipnis was able to image the pathways of lymphatics by injecting two different coloured dyes into the blood vessels and the lymph of mice to show quite nicely that the T cells move in a vessel like structure next to the sinus and nowhere else. Incidentally It is not new news that the brain has lymphatic vessels as there were papers in 1966 and 1979, however, this is the first time they have been able to image them. A deeply encouraging statement from Kipnis was that he is moving to study MS specifically as in his words, "MS is a condition close to his heart."

# + ISNVD 29-30<sup>th</sup> April 2016 cont...



## DAY TWO:

Some interesting discussion from **Zamboni's** lab on imaging, models of the mechanical system to measure jugular blood flow including venous pressure in both the brain and the heart, the velocity of blood flow and movement of pressure waves in the jugular veins. Interestingly they found that 22% of people with MS studied showed reflux, reversal of flow in the jugular vein and that the amount of time blood remains in the brain (wash out rate) is correlated to EDSS. They have also found that in sections of the jugular vein where there is increased pressure (like behind a narrowed valve) there is reduced endothelial cells. This endothelial layer is damaged in people with CCSVI because veins are exposed to turbulent flow. They have also been studying situations where there is a muscle compressing the vein and open vein surgery as angioplasty is not successful for these abnormalities.

There were complex presentations on cerebral spinal fluid and how it moves through the brain and that if jugular flow is impeded there is a rise in venous pressure. There were mathematical models of flow for fluids in the brain, discussion on intra-cranial compliance – what the brain does to adjust to pulsation of cerebrospinal fluid.

Several researchers are looking specifically at angioplasty treatment of CCSVI. **Petrov** in Bulgaria is utterly convinced after seeing over 1300 people with MS that venous abnormalities precede MS and he is seeing on average an improvement in EDSS and that 62% had functional improvements in those successfully treated.

**Dr Helen Kavnoudias** presented on **Australia's** venous angioplasty treatment of CCSVI in Multiple Sclerosis study. They have not disproved CCSVI, it does exist and was found in 80% of people tested. These 80% (n=30) went on to the treatment arm, half to placebo group and half to treatment group. Those in the placebo group crossed over to treatment group at the one year point giving 30 people treated. Some people have shown considerable functional improvement and on average the increase in EDSS is approaching significance. More participants would need to be studied to find statistical significance. Interestingly, no placebo effect has been detected, in other words, no one who received placebo have shown any improvements. We look forward to seeing further enrolment of people with MS in this study in the near future.

It appears people with MS have a higher incidence of cardiovascular issues than healthy controls. It would be beneficial for people with MS to have cardiovascular assessment when they are first diagnosed and throughout their lives as these appear to be associated with disease progression.

# Statement of Purpose



1. To remain abreast of international advances in Chronic Cerebrospinal Venous Insufficiency (CCSVI).
2. 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
3. To lobby for treatment of CCSVI to be readily available to all Australians on Medicare.
4. To ensure the interest of people with CCSVI have continued representation and that the understanding and treatment of CCSVI continues to advance



# +Board Members



## **Bill Younger, Chairman**

Bill has enjoyed a wide-ranging career encompassing engineering, business development and executive management roles across the information technology, telecommunications and not-for-profit sectors. Bill has also worked in business and consumer product development, service delivery, marketing and cultural change in major national and international organisations. Most recently, Bill worked as a Director of St Vincent's Foundation, following five years as CEO at Multiple Sclerosis Australia. He has a strong interest in the health and community sectors, and champions the causes for people with Multiple Sclerosis.

## **Kerri Cassidy – Chief Executive Officer**

Kerri is a gifted public speaker communicating to patient groups, medical professionals and parliamentarians. She holds as sacred the responsibility of speaking on behalf of people who are struggling to be heard and respected – in particular people with Multiple Sclerosis and those with CCSVI. In her early career, Kerri operated an Accounting practice in which she trained and employed new mums to be work-from-home bookkeepers. Kerri is currently expanding her knowledge by studying a Bachelor of Social Science.

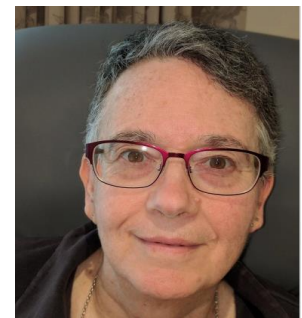


## **Jim Lewis, Treasurer**

Jim brings experience to our board as a former President of a local branch of the Liberal Party (Waverley North) and also a Director of the Victorian Billiard and Snooker Association. He has had a successful career in financial services and currently operates his own business as a Financial Adviser.

## **Jennifer Robinson, Fund Raising Coordinator**

Diagnosed with Primary Progressive Multiple Sclerosis in 2000, Jennifer stands firm when told that treatment for CCSVI cannot help people with Progressive forms of MS citing her long-lasting benefit (now over five years) to her fatigue levels and heat tolerance. Jennifer's former career was as a Cartographer and in recent times felt that there was little she could do due to her MS, however, has risen up with renewed rigor filling the role of Fund Raising Coordinator.



## **Glenn Cassidy, Board Member**

Glenn is a senior business and IT professional with experience in complex corporate organisations such as Coles Myer Ltd. This breadth, with his mix of Accounting, IT, operational and senior leadership skills, provides him with unique insight of how different functions within an organisation can work together to help achieve their mission. Glenn was previously Chief Information Officer of World Vision Australia and more recently, Director of Global Service Management for World Vision International. He has a strong understanding of the role of health and disability and its impact on individuals, their family and community.

## + Board Meetings

The following table sets out the number of Board Meetings held during the year ended 30 June 2016 and the number of meetings attended by each member.

<b>Director</b>	<b>Eligible to attend</b>	<b>Meetings attended</b>
Glenn Cassidy	5	4
Kerri Cassidy	5	5
Ian James Lewis	5	5
Jennifer Robinson	5	5
Helen Webb	2	2
William Younger	5	4

# Finance Report

\$15,358 was received from fund raising and donations between July 2015 and June 2016. Additional to this, the first 50% instalment from the Annette Funicello Research Fund for Neurological Diseases of \$32,427 was paid directly to the Alfred. This brought the total raised for The Alfred study to \$47,785 for this financial year. A very pleasing result.

Expenses were \$7,677 for the year which was only marginally higher than the previous year (\$7,487).

In total \$230,070 has been raised for the Alfred CCSVI in Multiple Sclerosis study as at 30<sup>th</sup> June 2016 (figure 1). \$152,171 has been distributed directly to the Alfred and a breakdown of contributions is presented in figure 2. A balance of \$77,899 remains in the CCSVI Australia Trust account until the Alfred study commences it's second phase.

More details can be seen in the audited reports on pages 13 and 14.

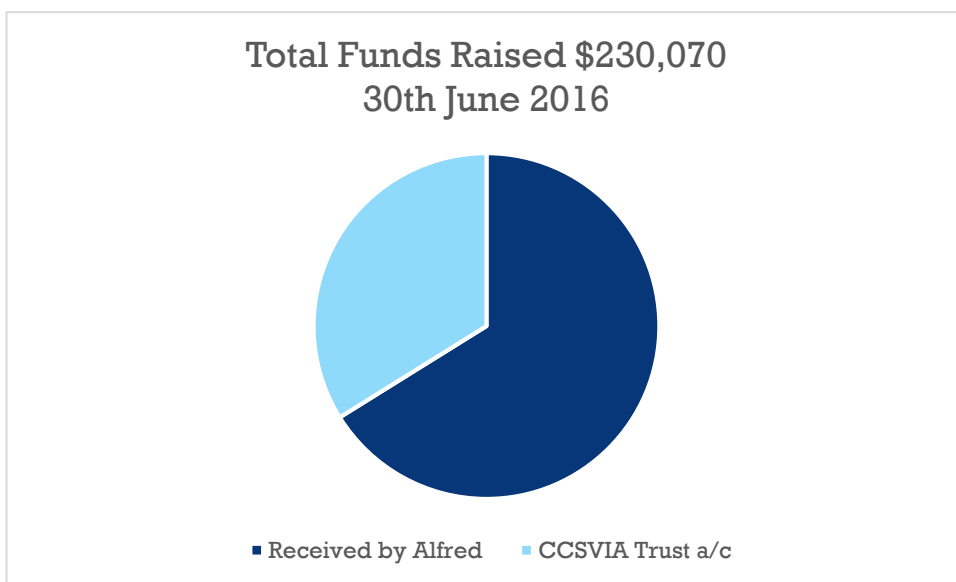


Fig.1

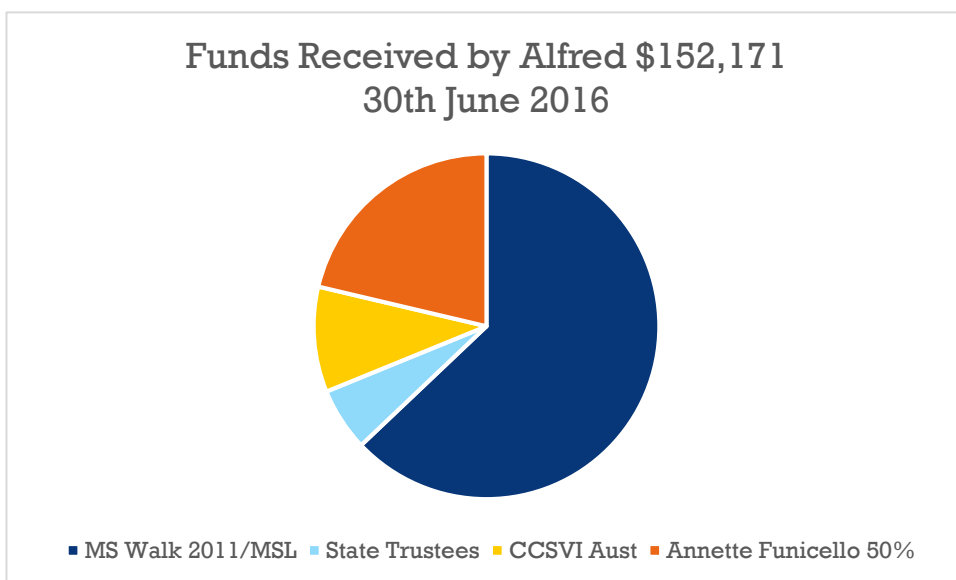


Fig.2

**CCSVI AUSTRALIA INC.**  
**A.B.N. 15 107 843 012**  
**ASSET AND LIABILITIES STATEMENT**  
**AS AT 30 JUNE 2016**

	Note	2016 \$	2015 \$
<b>ASSETS</b>			
<b>CURRENT ASSETS</b>			
Cash and cash equivalents	2	82,178	73,510
<b>TOTAL CURRENT ASSETS</b>		<b>82,178</b>	<b>73,510</b>
<b>TOTAL ASSETS</b>		<b>82,178</b>	73,510
<b>NET ASSETS</b>		<b>82,178</b>	73,510
<b>MEMBERS' FUNDS</b>			
Retained surplus		73,510	21,918
Current year surplus		8,668	51,592
<b>TOTAL MEMBERS' FUNDS</b>		<b>82,178</b>	<b>73,510</b>

**CCSVI AUSTRALIA INC.**  
**A.B.N. 15 107 843 012**  
**CASH FLOW STATEMENT**  
**FOR THE YEAR ENDED 30 JUNE 2016**

	Note	2016 \$	2015 \$
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>			
Receipts from members and donors		15,358	73,011
Payments to suppliers		(7,677)	(22,487)
Interest received		987	1,068
<b>Net cash generated by operating activities</b>	3	<b>8,668</b>	<b>51,592</b>
Net increase in cash held		8,668	51,592
Cash and cash equivalents at the beginning of the financial year		73,510	21,918
<b>Cash and cash equivalents at the end of the financial year</b>	2	<b>82,178</b>	<b>73,510</b>

**CCSVI AUSTRALIA INC.**  
**A.B.N. 15 107 843 012**  
**INCOME AND EXPENDITURE STATEMENT**  
**FOR THE YEAR ENDED 30 JUNE 2016**

	<b>Note</b>	<b>2016</b>	<b>2015</b>
		<b>\$</b>	<b>\$</b>
<b>INCOME</b>			
Functions and events		7,541	6,795
Gifts and donations		7,817	16,216
Grants received		-	50,000
Interest received		987	1,068
		<u>16,345</u>	<u>74,079</u>
<b>EXPENDITURE</b>			
Accounting and consultancy		(562)	(223)
Advertising		-	(510)
Bank fees and charges		(130)	(105)
Functions and events		(744)	(747)
Fundraising processing fees		(805)	(564)
General expenses		(103)	-
Grants awarded		-	(15,000)
Insurance		(858)	(875)
Internet fees		(316)	(532)
Office supplies and printing		(126)	(329)
Postage		-	(120)
Regulatory fees		-	(131)
Subscriptions		(271)	-
Travel		(3,762)	(3,351)
		<u>(7,677)</u>	<u>(22,487)</u>
Current year surplus before income tax		8,668	51,592
Income tax expense	1a.	-	-
Net current year surplus		<u>8,668</u>	<u>51,592</u>
RETAINED SURPLUS AT THE BEGINNING OF THE FINANCIAL YEAR		<u>73,510</u>	<u>21,918</u>
RETAINED SURPLUS AT THE END OF THE FINANCIAL YEAR		<u>82,178</u>	<u>73,510</u>



# CCSVI Australia Inc.

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