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# Annual Report 2014-2015



# CCSVI Australia Inc.



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## Chairperson's Report



The past 12 months has seen a significant level of activity concerning CCSVI research and improved procedures both locally and internationally. There is mounting evidence that there is a strong connection between vascular health and the effects of Multiple Sclerosis and other neurological conditions. The volunteer team at CCSVI Australia is actively involved in being at the forefront of the latest research to ensure we are fully informed of any developments.

Our reputation continues to be recognised and enhanced through the work of all of the Board Directors and the broader support network. In October 2014 the National CCSVI Society of Canada (NCS) invited our CEO, Kerri Cassidy, to speak at their national conference in Saskatoon, Canada along with Helen Kavnoudias from the Alfred Hospital, Melbourne. Kerri delivered a touching presentation about her MS journey and the positive impact the simple angioplasty procedure has had on her life and the lives of many others. Helen presented the initial findings from the CCSVI trial at the Alfred Hospital which generated much discussion and excitement. The Alfred trial is the first double-blinded, placebo controlled trial of its kind in the world and the results continue to show significant promise.

We were fortunate to be recognised by the Annette Funicello Foundation for our work with CCSVI through a grant of US\$50,000 which will be applied to the trial at the Alfred Hospital to include more participants. CCSVI Australia continues to pursue other funding opportunities through philanthropists, community events, crowd funding and Government grants to further research into CCSVI and other neuro-vascular conditions.

We continue to face challenges with building a relationship with MS Australia (MSA) and MS Research Australia (MSRA) as both organisations seem to have little, if any, interest in supporting our research and fundraising efforts. This is particularly disappointing given the growing evidence that CCSVI and the effects of MS are closely linked.

I would like to take the opportunity to express my deep appreciation and thanks to the CCSVI Australia Board Directors and to our broader support network all of whom have contributed significantly to our cause over the past 12 months. Special thanks to Kerri, Jennifer and Helen for their tireless efforts in identifying and pursuing funding opportunities to support CCSVI Australia,

Sincerely,  
Bill Younger,



# Chief Executive Officer's Report



The 2014-2015 year saw CCSVI Australia elevated to a new level of, not only fundraising, but awareness and international exposure.

We have continued to be a presence online, predominantly on Facebook and Twitter, where the wider community keep updated on the latest Neurovascular news and research. Our number of followers has increased this year, and I believe people view CCSVI Australia as a place for the latest information that is not subject to industry bias. This was very obvious during the time of the Kipnis paper on the new discovery of the brain lymphatic system. Our following increased considerably over this time. The website continues to receive good traffic and our subscribers have stayed steady. Contact still occurs over email and telephone for those wanting more in depth information. Thanks to both Helen and Jennifer who have worked in this space.

Whilst we have been involved in the global conversation on CCSVI from the outset, this year was the first time we had attended one of the international conferences.



The opportunity to address the Canadian Neurovascular Health Society's Annual Convention was an important step in increasing visibility and placing us as part

of the international work. I was honoured to share our Australian story in my speech, 'The Collaboration Imperative' and meeting many online friends. Helen Kavnoudias presented on the Alfred study. Spending time with Dr Bill Code, Dr Mark Haacke and Dr Robert Zivadinov was incredible, learning how things can be improved in our research as well as influencing by our unique study in Melbourne.

Above the networking and knowledge formation, it was this time that cemented our success with the Annette Funicello Foundation. Following the conference we met with Joan Beal of the CCSVI Alliance, further strengthening ties between Australia and the United States. I look forward to joining Helen in New York next April to further these relationships at the International Society of Neurovascular Disease conference.

I'm excited as we enter into the new year. We are approaching our fundraising goal, Professor Zamboni's Brave Dreams is now completed and we look forward to he's published results, The Alfred continue in the CCSVI in Multiple Sclerosis study and we are closer to seeing testing and treatment available for all Australians.

We're getting there!

Kerri Cassidy

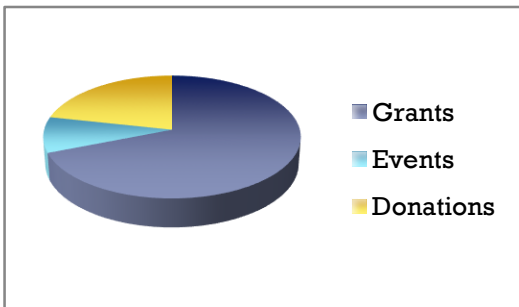
# Fundraising Report



It is with great pleasure, that we are able to announce our fundraising efforts for this year have brought us to a total of almost a quarter of \$1 million. We would not have been able to achieve this amazing amount without the support of all our CCSVI friends and families not only in Australia, but throughout the entire world. Our thanks go to each and every one of you.

The sources of funds were grants, events and donations totaling \$72,447.

## Grants



We have been pleased to receive several donations from grant applications the State Trustees Australia Foundation, the Rotary Club of Balywn and in April we learned that an application to the Annette Funicello Research Fund for Neurological Disease (AFRFND) was successful. We are delighted that The Alfred Hospital trial is receiving the international focus it deserves. The selection committee consisted of expert members of the International Society of Neurovascular Disease (ISNVD).

There are more details of these grants on page 7.

## CCSVI Australia Events

October and May had our volunteers at Bunnings and Masters for their sausage sizzle, raising a total of \$2300. Thanks to our ever faithful band.

“Come to My House” this year was supported by an Indian Dinner, when a group of 16 friends had a candlelit meal raising \$1,200. Also a Grand Final Fever Fundraiser took place in September. Whilst in November our friends at the Karibu Fairtrade market (Brunswick) invited us to fund raise at their monthly market. Over \$200 was raised.

## Community Donations

There have been many individual fundraising efforts. On Saturday 20<sup>th</sup> December, Matt Elser, and his mate Joe, took the personal challenge to climb Mt Kilimanjaro, 5895 metres above sea level. This involved climbing for five days from the tropical jungle below up to the freezing summit. Matt was inspired to support CCSVI Australia’s own climb – to research venous abnormalities for those with neurological conditions. We are pleased that over \$1,500 was raised. Sincere thanks to Matt for believing in us and carrying our cause to one of the highest mountains in the world! We are inspired.

In March, one hundred entrepreneurs came together at “10x10” to hear pitches from three Not For Profits. Kerri Cassidy spoke and received an encouraging endorsement of \$4,400 of the \$10,000 on offer. Even more important was the opportunity to raise awareness and network with those who can help us make a difference. Sincere thanks to the organisers.

We were touched and privileged to receive a Christmas dinner invitation the Melbourne (82) Ionians. These generous ladies chose to forgo their Kris Kringle tradition in exchange for supporting CCSVI Australia and neurovascular research by raising \$900.



## +Fundraising Report continued...

Does your employer have an Employee Giving Program? CCSVI Australia received a donation of \$900 from BHP Billiton who doubled a contribution made by our generous local sponsors, Nadine and George.

In October Grill'd and the people of Knox voted CCSVI Australia as their preferred charity.

Throughout the year we have also received many individual donations from people the world over, through our website. Once again, we would like to extend our thanks to each and every one of you. We could not do any of this without your support.

Jennifer Robinson

## Ways you can help

CCSVI Australia is now a registered charity with GoFundraise and Everyday Hero. You can join a number of different events across the country to raise funds, including the very popular Colour Run. If you are planning your own personal challenge and would like to contribute in this way you can set up your own fundraising page on GoFundraise, [www.gofundraise.com.au/beneficiary/mshope](http://www.gofundraise.com.au/beneficiary/mshope) and <https://nfp.everydayhero.com/au/ccsvi-australia-inc>

Our team are making a commitment to participate each July in the Run Melbourne. Consider joining us in July 2016, buy a t-shirt and help us raise awareness and funds for neurovascular research. It is also a great opportunity to meet with others. There will be more details closer to the date.



# Major Research Supporters



## Balwyn Rotary Club

Members of the CCSVI Australia team shared a meal with Balwyn Rotary in July. Kerri spoke with clarity about CCSVI Australia, our goals and her own story. The questions flowed and comments such as “this is a no-brainer” and “what an inspirational story” confirmed their enthusiasm.

Later in the year it was announced that Balwyn Rotary Club had awarded CCSVI Australia with a grant for \$50,000 to be directed into Neurovascular research in Multiple Sclerosis. A dinner was held where Dr Helen Kavnoudias was guest speaker. Helen shared her experience of the Alfred trial to date and the challenges they have overcome to further the research.

Grateful thanks to President Henry and the Balwyn Rotary Club.

## Annette Funicello Research Fund for Neurological Disease

In April The Alfred was awarded a US\$50,000 grant by the Annette Funicello Research Fund for Neurological Disease (AFRFND). The scientific review panel comprised members of the International Society of Neurovascular Diseases (ISNVD). This grant is acknowledgement of the international importance of The Alfred’s clinical angioplasty treatment trial for CCSVI in MS.

This funding will be received directly by The Alfred in two instalments one year apart. Dr Helen Kavnoudias has been invited to speak at the 6<sup>th</sup> annual scientific meeting of the ISNVD in April 2016 and we look forward to her latest report.

The AFRFND are currently funding several clinical and science research into neurovascular disease with a specific interest in Multiple Sclerosis and neurodegeneration.

Sincere thanks to Carol Schmacher and the wider Annette Funicello family.

## State Trustees Australia Foundation

CCSVI Australia submit several grant applications to various funding bodies each year. We were pleased that in November, CCSVI Australia was successful with a submission to State Trustess and \$9,000 was awarded to The Alfred’s CCSVI in Multiple Sclerosis study.

This funding was received directly by the Alfred Hospital and immediately applied to the ongoing study.

Special thanks to Jennifer for her perseverance and commitment to pursuing grant funding on behalf of CCSVI Australia and The Alfred research

# 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. Bill currently works 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.



**Helen Webb, Secretary**

Helen has worked as a scientist and then an IT professional across a range of industries. Her career spans the academic, chemical, energy, healthcare and financial services industries. She has a particular interest in regulatory issues. Helen has a strong sense of justice and devotes her spare time to patient advocacy enjoying seeing the impact her work has on the lives of people and the wider community. She is a founding member of CCSVI Australia.



**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 Delivery 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 2015 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	5	4
William Younger	5	4

# Treasurer's Report



The audited reports for CCSVI Australia Inc. can be viewed on page 12. To summarise:

Net Receipts for financial year ending 30 June 2015:

Total Receipts	\$73,514
Total Payments	<u>\$ 6,922</u>
<b>Net Receipts</b>	<b>\$66,592</b>

Additional to these receipts, a grant from State Trustees was distributed direct to the Alfred for \$9,000, bringing our total funds raised to \$82,514 for year ending 30<sup>th</sup> June 2015. The grant from the Annette Funicello Research Fund of US\$50,000 will be paid in two installments in the next accounting period.

CCSVI Australia transferred \$15,000 to The Alfred research study in June 2015. The CCSVI Australia research trust account has a balance of \$72,108 at 30<sup>th</sup> June 2015 and it is expected that additional funds will be transferred in the next accounting period.

Operating costs are kept to such a minimum thanks to the contribution of talent, skills and personal resources of our board and community. This includes, but is not limited to, administration, information services, web design and maintenance, auditing, printing, collating research, grant writing and local travel expenses.

Jim Lewis

Treasurer

**CCSVI AUSTRALIA INC.**  
**A.B.N. 15 107 843 012**  
**INCOME AND EXPENDITURE STATEMENT**  
**FOR THE YEAR ENDED 30 JUNE 2015**

	Note	2015 \$	2014 \$
<b>INCOME</b>			
Functions and events		6,795	815
Gifts and donations		16,216	20,413
Grants received		50,000	-
Interest received		1,068	305
Membership fees		-	50
		<u>74,079</u>	<u>21,583</u>
<b>EXPENDITURE</b>			
Accounting and consultancy		(223)	-
Advertising		(510)	(435)
Bank fees and charges		(105)	(108)
Functions and events		(747)	(850)
Fundraising processing fees		(564)	-
Grants awarded		(15,000)	-
Insurance		(875)	-
Internet fees		(532)	(150)
Office supplies and printing		(329)	(96)
Postage		(120)	(107)
Regulatory fees		(131)	-
Travel		(3,351)	-
		<u>(22,487)</u>	<u>(1,746)</u>
Current year surplus before income tax		51,592	19,837
Income tax expense	1a.	-	-
Net current year surplus after income tax		<u>51,592</u>	<u>19,837</u>
RETAINED SURPLUS AT THE BEGINNING OF THE FINANCIAL YEAR		<u>21,918</u>	<u>2,081</u>
RETAINED SURPLUS AT THE END OF THE FINANCIAL YEAR		<u>73,510</u>	<u>21,918</u>

**CCSVI AUSTRALIA INC.**  
**A.B.N. 15 107 843 012**  
**ASSET AND LIABILITIES STATEMENT**  
**AS AT 30 JUNE 2015**

	Note	2015 \$	2014 \$
<b>ASSETS</b>			
<b>CURRENT ASSETS</b>			
Cash and cash equivalents	2	<u>73,510</u>	<u>21,918</u>
<b>TOTAL CURRENT ASSETS</b>		<u><b>73,510</b></u>	<u><b>21,918</b></u>
<b>TOTAL ASSETS</b>		<b>73,510</b>	21,918
<b>NET ASSETS</b>		<u><b>73,510</b></u>	<u><b>21,918</b></u>
<b>MEMBERS' FUNDS</b>			
Retained surplus		21,918	2,081
Current year surplus		<u>51,592</u>	<u>19,837</u>
<b>TOTAL MEMBERS' FUNDS</b>		<u><b>73,510</b></u>	<u><b>21,918</b></u>

**CCSVI AUSTRALIA INC.**  
**A.B.N. 15 107 843 012**  
**CASH FLOW STATEMENT**  
**FOR THE YEAR ENDED 30 JUNE 2015**

	Note	2015 \$	2014 \$
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>			
Receipts from members and donors		73,011	21,278
Payments to suppliers		(22,487)	(1,746)
Interest received		<u>1,068</u>	<u>305</u>
<b>Net cash generated by operating activities</b>	3	<u><b>51,592</b></u>	<u><b>19,837</b></u>
<b>Net increase in cash held</b>		51,592	19,837
Cash and cash equivalents at the beginning of the financial year		<u>21,918</u>	<u>2,081</u>
<b>Cash and cash equivalents at the end of the financial year</b>	2	<u><b>73,510</b></u>	<u><b>21,918</b></u>



# CCSVI Australia Inc.

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