

annual report

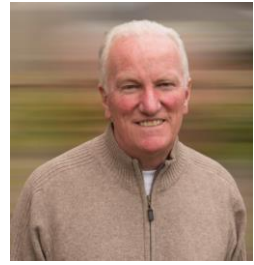


# CCSVI Australia Inc.

JUNE 2013

# contents

Insert your table of contents here.



# Message from the Chairman

Welcome to the inaugural Annual Report for CCSVI Australia. Since our inception in September 2012 we have made significant advances in creating a nationally recognised organisation that supports the thousands of Australians with Multiple Sclerosis who are seeking information about CCSVI and treatment options.

As Chairman of this volunteer-based organisation I am proud of our many outstanding achievements which include:

- Obtaining our Certificate of Incorporation and registering our Business Name
- Obtaining our Deductible Gift Recipient (DGR) status from the Australian Taxation Office which recognises us as a registered Charity with tax deductible donation authority
- The development of our new website and payment gateway to accept on-line donations
- Establishing a bank account and PayPal account to securely accept and process donations
- Conducting the launch of CCSVI Australia at the Nerve Centre, Blackburn, with guest speakers Laura Smyth (Local MP), Helen Kavnoudias (Researcher at the Alfred Hospital) and interventional Radiologist Manfred Spanger
- Securing office space at the Nerve Centre, Blackburn with a permanent postal address and listing in the White Pages
- Participation in a Parliamentary Briefing in Canberra concerning CCSVI treatment, research and Medicare issues
- Gaining significant media coverage of CCSVI through the Sunday Night Program on the Seven Network including an interview with Chrissy Amphlett and the 7.30 Report on the ABC.
- The commencement of the CCSVI research trial at the Alfred Hospital which now has 30 participants
- The development of a fundraising "tool kit" and new fundraising initiatives including "Come to My House"

To date we have raised over \$100,000 for the trial at the Alfred Hospital and our objective is to raise \$450,000 to ensure the trial achieves the objectives. I would like to take the opportunity to thank and acknowledge our inspirational CEO, Kerri Cassidy, for her commitment to our cause. I would also like to thank our Board members and their supportive partners for their time, effort, devotion and commitment; you are all outstanding people,

Yours sincerely,

Bill Younger

**Chairman, CCSVI Australia.**



# Message from the Chief Executive Officer

Welcome to our very first Annual Report for CCSVI Australia Inc. It is our intention in this report to provide an overview of the story so far, a document that essentially brings together our history, our present position and hopes for the future. Most of what you will read has been chronicled in more detail on our website and I encourage you to visit [ccsviaustralia.com.au](http://ccsviaustralia.com.au) to view related videos and articles.

Sincere thanks to members of the Multiple Sclerosis and CCSVI community who have supported us in many ways, through participating in and hosting events, sharing your story, writing to Members of Parliament, contributing to the Alfred study, being part of our online discussions and telling your friends about us.

Special thanks to our international partners such as the CCSVI Alliance, the National CCSVI Society of Canada and the world wide CCSVI Advocates network for your continued contributions to the further understanding of CCSVI globally. Finally to the team at CCSVI Australia, both our board and our online community who continue to persevere and remain a positive voice for people with CCSVI in Australia.

I look forward to working with you all towards our common goal of seeing CCSVI independently and thoroughly researched, for the best treatments to be accessible and available on Medicare and ultimately potentially unlocking further understanding of Multiple Sclerosis and other neurological conditions.

Yours sincerely,

Kerri Cassidy

## Definition

Chronic Cerebrospinal Venous Insufficiency (CCSVI) refers to a condition where blood flow is obstructed in the veins that drain the brain and/or spinal cord. This may involve stenosis or narrowing, abnormal valves, flaps, septums or membranes that disrupt flow as well as more serious problems of underdeveloped, partially closed or missing veins which contribute to insufficient drainage of the Central Nervous System. Research indicates that CCSVI is significantly correlated with Multiple Sclerosis.

## Background

CCSVI Australia, as we now know it, was birthed out of an online community of people with Multiple Sclerosis (MS) who were interested in discussing research relating to the role the vascular system plays in MS. This was prompted by the release of a study by Professor Paolo Zamboni in November 2009 where he hypothesised that Chronic Cerebrospinal Venous Insufficiency (CCSVI) was a factor in the development of Multiple Sclerosis. Whilst this opinion may have appeared to be novel in 2009 it was developed out of prior research pointing to a vascular component of MS. Rindfliesch's discovery of the central vessel in the MS lesion and Charcot's description of vascular obstructions in MS (1863) to Putnam's investigations of the effect of obstructing cerebral blood flow in animals (1934-53) to Franz Schelling's discovery of the high incidence of venous anomalies through the skulls of people with Multiple Sclerosis (1973-81) all inspired and complements Zamboni's research. CCSVI appears to be one piece of the large puzzle that comprises a diagnosis of Multiple Sclerosis and potentially other Neurological diseases such as Parkinsons and Alzheimers.



## Community driven research

From early 2010 scores of Australians with Multiple Sclerosis began to access Doppler Ultrasound testing and angioplasty treatment for CCSVI with a variety of results. Some experienced a complete resolution of symptoms following treatment, some more modest improvements with others receiving no benefit at all. It was clear from the outset that there was a great deal to be understood about the

**"It was clear from the outset that there was a great deal to be understood..."**

best methods of testing for venous abnormalities. It was also recognised that there could be a variety of causes and therefore treatments requiring investigation. This is research that will take many years to complete.

From March to July 2010 the Alfred Hospital in Melbourne investigated 44 patients by venogram and balloon angioplasty was performed on 42 people with MS. Patients were asked to complete a validated Quality of Life Form one month after the procedure and these initial cases were the pilot study for the current randomised, blinded, placebo controlled study currently being conducted.

The informal, grassroots, community group known as CCSVI Australia began raising awareness, lobbying for research and assisting people interested in investigating CCSVI for themselves. In April 2011 people with MS were invited to attend a patient forum as part of the Australasian College of Phlebology Conference where Professor Zamboni was presenting.

This was a pivotal event where the medical profession allowed the patients they serve to participate and learn direct from the experts. We had opportunity to share our perspective and be heard as well as ask Professor Zamboni many of our burning questions. Sincere thanks goes to Dr Paul Thibault for allowing us that opportunity.



That same weekend we hosted a CCSVI Forum at the Nerve Centre in Blackburn with MS Australia. Video link up with people in Sydney and Canberra enabled us to facilitate a discussion with over 120 people with MS and their supporters. Our panel included the then Chairman of MS Research Australia, Jeremy Wright, Dr Paul Thibault (Phlebologist), Dr Olga Skibina (Neurologists) and Helen Webb

"this showed our heart to have open and informed discussions about CCSVI... honouring the voice and experience of people living with Multiple Sclerosis."

(CCSVI advocate). Again, this was an amazing opportunity to come together and talk about CCSVI and hear stories of a number of people's experience. I believe this showed our heart to have open and informed discussions about CCSVI to move understanding forward whilst honouring the voice and experience of people with MS.

## Advocacy

Since early 2010 our focus has been on sharing information and raising awareness with people living with MS in the hope that we could help as many people as possible. This was primarily through Facebook (now with over 2,600 'likes' in June 2013) and our website. We also sought public interest through events such as the MS Walks, a Bourke Street Mall Flash Mob and hosting informational sessions such as the CCSVI Forum in April 2011.



"...people with MS deserve to know if treating CCSVI could bring improvements in quality of life and if so that treatment should be accessible..."

Throughout we have instigated conversations with institutions mandated to represent people with MS, politicians and medical specialists. In June 2012 we had opportunity to bring all three groups together and present CCSVI to the Parliamentary Friends of MS group in Canberra. In collaboration with MS Australia we presented both the patient's perspective as well as the views of a representative vascular specialist and that of MS Australia. The basic message being that people with MS deserve to know if treating CCSVI could bring improvements in quality of life and if so that treatment should be accessible on Medicare as it is for other Australians with venous abnormalities.

## Media

In 2011 our story piqued the interest of Australian National Radio's Norman Swan who interviewed Dr Ziv Haskall from the United States and Kerri Cassidy bringing CCSVI into a more public arena. Lisa Whitehead presented CCSVI on ABC's 7.30 report in December 2011 portraying the two perspectives. interviewing a Neurologist as well as a representative group of people from CCSVI Australia.



In April 2012 the Seven Network's Sunday Night programme aired that year's National Press Club's *Best Documentary for a Health, Health Science or Innovation* called "MS Hope" by Rahni Sadler and Penelope Cross. This featured the much loved late Chrissy Amphlett who shared her journey with Multiple Sclerosis and her positive outcomes being treated for CCSVI along with Professor Paolo Zamboni and how his wife inspired him to research Multiple Sclerosis. The personal experiences of Vicki Costa and Kerri Cassidy were also presented.

Our story has appeared in an article in Australian Doctor called "Vein Hope" informing General Practitioners of CCSVI research and the work at the Alfred Hospital as well as by interview with Helen Webb on Triple R's Einstein a Go Go program. In August 2012 ABC Catalyst's Maryanne Demasi investigated Zamboni's CCSVI theory along with the potential role of Chlamydia Pneumoniae in affecting the lining of veins as hypothesised by Dr Paul Thibault. Vicki Robinson openly shared her experience with both.

## **CCSVI Australia Inc. established**

In August 2012 we learnt that an application for funding to MS Research Australia for the Alfred study was unsuccessful. It became clear that private and/or government investment would be required to see this trial completed. CCSVI Australia Inc. was established in order for us to have capacity to raise funds as well as being recognised as a legitimate entity. The invitation was extended to core people within the community to help found CCSVI Australia and our first board meeting was in September 2012. CCSVI Australia Inc. was registered as a Health Promotion Charity from January 2013 and granted Deductible Gift Recipient Status in June 2013.

Early in 2013 CCSVI Australia established an office at the Nerve Centre in Blackburn, Victoria. We appreciate the opportunity to be situated at the Head office of MS Australia with access to telephone and meeting rooms enabling us to be readily available to field queries on CCSVI from people living with MS.

In numerous ways this past year has seen us laying some very important foundations to ensure adequate governance and procedures are in place. We believe we are now well positioned to fulfil our Statement of Purposes (outlined on page \_\_\_\_).

## **CCSVI Australia Launch**

Our official Launch was held at The Nerve Centre on Sunday 14<sup>th</sup> April 2013. This was a tremendous celebration of the journey so far and inspiration for future developments in the understanding of CCSVI. We had the privilege of hearing from MP Laura Smyth who spoke of her admiration of our patient advocacy and encouraged our future efforts. Dr Manfred Spanger, who had completed over 500 angioplasty procedures for people with CCSVI, described some case studies and made a strong stance that "CCSVI is real." Dr Helen Kavnoudias updated us on the status of the Alfred Study, congratulated CCSVI Australia on our "resilience, resistance and resolve" and explained what our trial participants would experience. Chairman Bill Younger shared his perspective and what has inspired him to be involved with supporting CCSVI research - an encouraging and warm address.

Finally we proudly revealed our new logo – a product of months of collaborating between many people. We believe we have captured a great image projecting the basic definition of CCSVI.

"The fierce debate that has been raised in response to Zamboni's CCSVI research raises far more than the issue of obstructed blood flow and it's relationship to Multiple Sclerosis. Our story has been about removing obstructions to the flow of information, the flow of communication and the flow of access to treatments and, we hope, influencing the culture of health ownership in Australia." Kerri Cassidy

# Testimonials

## Jill Hendy

It's hard to know where to begin. How do you explain to someone that you've been given a 2<sup>nd</sup> chance. But I have.... Since having my venoplasty last November I have been able to rejoin the human race.

With improved mobility, cognitive function and loss of fatigue my life has become considerably better. Don't get me wrong I still tire and am ready for the nana nap after lunch, but at 51 and with 4 grand-kids I think that's ok.

Words cannot explain my gratitude to CCSVI Australia & Manfred Spanger for giving me my health and well being back. Having PPMS for 17 years and being told by neurologists that there was no treatment/medicine available to me I thought I should give it a go. I had nothing to lose and quite possibly something to gain.

Research done and with a lot of prayer I embarked on the journey. What a ride! Improvements were noticed immediately, I could walk in bare feet, carry a cup of tea without spilling it (provided it's not too full) and I looked better once again my eyes were clear not glazed over, colour in my cheeks and my husband even commented the first time he saw me after the procedure that I looked better. Slowly but surely more improvements became evident.

I realize that this is no cure but a huge relief from the rotten symptoms that quite literally rob us of any quality of life. I can only encourage you to give it a go. Best of luck!



### Jill's friend Marilyn Maddern:

The diagnosis of MS sent shivers down my spine when my neighbour and best friend, Jill, told me she was suffering PPMS seventeen years ago. For quite a while, nothing was different, she was the same cheerful person she'd always been.

Then small things started to become obvious; her balance wasn't so good, coordination was off, carrying a cup of coffee became difficult, she was so tired all the time. It was horrendous seeing someone who had been so vibrant and full of life on a downhill slide, knowing there was very little to be done to stop MS's miserable progression.

When Jill first heard of CCSVI, everything changed. It was as though a life buoy had been thrown to her, it offered hope and she grabbed it with both hands. But it wasn't going to be easy, with her doctor and neurologist dismissing the idea completely and warning her not to undergo this 'untested, experimental' treatment.

Jill soldiered on, believing this was going to help her symptoms, she underwent venoplasty at the end of 2012. Improvements came immediately and the sparkle came back in her eyes. People she met in the street noticed how much better she looked and moved. The change in her was undeniable.

Jill has been blessed to be a blessing to others. She is so eager to share her story, just ask her. To MS sufferers and the medical fraternity I say – open your mind, listen and please, have ears to hear.



Robyn Ellis

My CCSVI journey began at the MS Walk in 2010 and I came home with a CCSVI pamphlet. It wasn't until just before the MS Walk in 2011 that I had gone for a Doppler Ultrasound on May 9th to discover my Right Jugular vein had distal stenosis and refluxing blood flow in the right vertebral vein & my Left Internal Jugular vein had distal stenosis. CCSVI.

On the 18th of August 2011, Dr. Manfred Spanger performed my first venography and venoplasty. My Right Jugular did not appear to have stenosis but showed signs of having been compensating for the Left Side and was dilated easily with a 14mm balloon. My Left Jugular had distal stenosis, reflux & collaterals. When 14mm venoplasty was performed it was quite tight and I could feel it "pop" as the balloon inflated in my vein. As soon as the flow patterns were returned to normal, the cloud in my head that had been there so long – evaporated!

I have had two CCSVI procedures so far and the first had the most dramatic effects on my life. First was the cloud vanishing from my head, the MS fog that affected my ability to be at a party or in a crowd and focus, concentrate or even enjoy myself!

I also felt sensation come back to my hands and could feel temperature better. After about 6 to 8 weeks Tingling in my legs improved, fatigue and energy improved, heat intolerance wasn't so much of an issue for me anymore. Basically, life improved. Yes, I still have MS and I still have to pace myself and avoid stress as best I can etc... I just got a bit of the old Robyn back!

Some MS things started to return about this time last year in 2012. Fatigue, brain fog, moods, tingling. In October I had another Doppler and it showed my left jugular was pinched in two places so the blood was not flowing so well. Venogram and Venoplasty #2 happened on 8th November 2012. Only the Left Jugular had a tight stenosis at the top and needed a high pressure balloon to "pop" it open. The lower end required a 14mm balloon. The second time round hurt more and the symptom relief was not so immediate. 6 to 8 weeks and I started feeling the benefits with fatigue, energy & sensations, mood etc.

Every December I go for my MRI checks and both in 2011 and 12 have had "glowing" reports. No new lesions, no active existing lesions. In fact, my spinal lesions have seen improvement and faded!

I was diagnosed in November 2007 with relapsing remitting MS and started Copaxone in January 2008. I stopped Copaxone in May 2009 to have a baby and re-started Copaxone in October 2010 when my daughter was almost 7 months old. Copaxone started to hurt. I scar easily and most of my injections went to my tummy as was easier to self-inject there. I stopped Copaxone in July 2012 as was having issues with injection sites, didn't want to travel overseas with my injections and at the time was thinking we might try for another baby.



After returning from overseas my symptoms were not great and I had my second CCSVI procedure. In this time we decided no more babies and I decided to see what the MRI was going to say after no Copaxone for almost 6 months. The MRI was as good as the MRI the previous year, no different to when I was on Copaxone to when I wasn't. I haven't ruled out other MS therapies, I'm just trying what is working for me right now. A healthy dose of better, cleaner eating, lots more exercise, self-hypnosis & working on a lesser stress lifestyle.

I haven't even mentioned I now go to the gym at least 3 times a week, have lost 17kg since Feb 2012 and am probably in the best shape I have ever been! I lift weights, I can run/jog if I want to. I do a lot more than I did before. I am slowly learning how to deal with the depression, fatigue, cognitive issues and sensory issues that are still there – particularly if I overdo life and forget I still have MS and need to pace & rest.

CCSVI is not a cure, it is a treatment that I believe gives people with MS a relief from some of our pain and symptoms and I am guessing it is also slowing down progression. The Procedure doesn't come without pain. It isn't comfortable and it does hurt a little bit. You do feel sore in the neck for a little bit afterwards which lasted a few weeks for me. It is also expensive. It is money well spent but really, does something that can keep us active and functioning as well as it does have to cost so much? It is out of reach for so many yet could have these people back in the workforce and kicking



# Statement of Purpose 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;
  - a. those seeking testing for and treating of CCSVI,
  - b. medical researchers and practitioners,
  - c. government at all levels, and
  - d. related community-support organisations
3. To lobby for treatment of CCSVI to be readily available to all Australians on Medicare
4. To raise funds for CCSVI research.
5. To ensure the interests of people with CCSVI have continued representation and that the understanding and treatment of CCSVI continues to advance.

For Chronic Cerebrospinal Venous Insufficiency (CCSVI) to be fairly researched and treatment available of Medicare.

# Board of Directors

## 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 & Treasurer

As a founding member of CCSVI Australia, 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 the vascular condition Chronic Cerebrospinal Venous Insufficiency (CCSVI). In her early career, Kerri operated her own 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 with particular interest in health and ethics.



## Dr 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.

## Jennifer Robinson – Fund Raising Coordinator

Diagnosed with Primary Progressive Multiple Sclerosis (PPMS) in 2000, Jennifer has taken responsibility for the future of her health by keeping informed and connected with others on similar journeys. She stands firm when told that treatment for CCSVI cannot help people with Progressive forms of MS citing her long-lasting benefit (now over three 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 for CCSVI Australia with passion and resolve.



## Glenn Cassidy – Board Member



Glenn is a senior business and IT professional with experience in complex corporate organisations such as Coles Myer Ltd (now part of Wesfarmers) as well as large NGOs in a global capacity. This breadth, coupled 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 in recent years has moved to World Vision International as Director of Global Service Delivery. He has a strong understanding of the role of health and disability and it's impact on individuals, their family and community.

## Jim Lewis – Board Member

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.



## Board Meetings

The following table sets out the number of Board Meetings held during the year ended 30 June 2013 and the number of meetings attended by each member.

Director	Eligible to attend	Meetings attended	Status
Glenn Cassidy	7	7	
Kerri Cassidy	7	7	
Kylie Holmes*	3	3	
Jim Lewis	1	1	
Leonardo Mampusti*	3	2	
Jennifer Robinson	1	1	
Helen Webb	7	7	
Bill Younger	7	7	

\* The resignation of both Kylie Holmes (January 2013) and Leonardo Mampusti (June 2013) was regrettably accepted. Sincere thanks for assisting the initial formation of the systems and processes for CCSVI Australia.

# financial report

## Overview

In October 2012 our first bank accounts were opened and the member fees of our board were deposited. Our application fee for incorporation is the only expense during the 2012-2013 financial year.

We are fortunate to have many skills, talents and contacts available by those on our board and within the committed Multiple Sclerosis and CCSVI community and has enabled a large amount of work to be completed without financial expense. These include but are not limited to the hosting and development of our website, administration, service delivery, auditing, fundraising costs, printing, design and collating research. We are grateful to all who freely volunteer their time and resources.

## Charitable Donations Policy

In June 2013 CCSVI Australia was granted Deductible Gift Recipient status allowing donations to be fully tax deductible and will assist us greatly in raising financial support into the 2012-2013 financial year and beyond. The board of directors agreed in November 2012 that no less than 95% of all donations received would be allocated to CCSVI research.

In the period April to June 2013 net donations of \$2,015 was received and is held in a trust for The Alfred Hospital study of CCSVI in Multiple Sclerosis.

## Audit

An audit of our accounts was performed in November 2012 by independent auditor \_\_\_\_\_

## Financial Statements

**CCSVI AUSTRALIA INC.**

**INCOME STATEMENT**  
**for the year ending 30 June 2013**

**REVENUE**

Donations	2,026.15
Member Fees	125.00
Bank Interest	2.55
Other	0.74
<b>Total Revenue</b>	<b>2,154.44</b>

**EXPENSES**

Consumer Affairs	62.70
Paypal Fees	11.09
<b>Total Expenses</b>	<b>73.79</b>

<b>NET PROFIT</b>	<b>2,080.65</b>
-------------------	-----------------

**CCSVI AUSTRALIA INC.**

**BALANCE SHEET**  
**as at 30 June 2013**

**ASSETS**

**Current Assets**

Cheque Account	452.12
Cash Reserve Account	1,286.20
Paypal	342.33

<b>Total Current Assests</b>	<b>2,080.65</b>
------------------------------	-----------------

<b>TOTAL NET ASSETS</b>	<b>2,080.65</b>
-------------------------	-----------------

Note:

This financial report is presented in Australian dollars using the Cash Basis method of Accounting.

## Independent Auditor's Report