
Annual Report 2022

SEPTEMBER 2022

CCSVI Australia Inc.



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Chairperson Report

Bill Younger

Welcome to the FY2021/2022 CCSVI Australia Annual Report. Having been through 2 very difficult years caused by the COVID19 pandemic it is a relief to be able to return to some level of normalcy in our lives. Despite the disruption the organisation has been active in pursuing new opportunities and maintaining a close watch on global research in the area of CCSVI and related fields.

The trial at the Alfred Hospital Melbourne, which was funded by CCSVI Australia, came to a conclusion due to lack of resources. The findings and results from the Alfred trial will be transferred to the University of NSW (UNSW) to assist them in their endeavours to study venous sinus pressure and idiopathic intracranial hypertension using computational fluid dynamics. The UNSW research team has been able to utilise dynamic MRI scans to study blood flow through the brain and spinal region in people with MS and control groups which has yielded many interesting findings. The preliminary results show unusual blood flow in people with MS which causes “turbulence” and poor circulation. The team has also created 3D models of the vascular system in people with MS to further test their theories on blood flow and possible remediation.

Funding for the ongoing research studies remains our biggest challenge but we are hopeful that the results from the Alfred trial and the work being conducted by UNSW will be of interest to the philanthropic community. There is no denying that these studies are providing compelling evidence that there is a link between vascular health/blood circulation and the symptoms/possible cause of Multiple Sclerosis.

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 the work being conducted by the UNSW.

I would like to express my appreciation to the Alfred Hospital for taking on the CCSVI trial and for their support over the past 10 years. As we “pass the baton” to the University of NSW for the next phase of our journey, I would also like to thank their knowledgeable and dedicated research team for driving 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.

Sincerely,

Bill Younger,
Chairman,
CCSVI Australia

Australian Research Update

In August 2021 a second paper was published by an Australian research team in NSW. Possible Markers of Venous Sinus Pressure Elevation in Multiple Sclerosis: Correlations with Gender and Disease Progression (G. Bateman, J. Lechner-Scott, M. Carey, A. Bateman & R. Lea) found there was significant gender differences and for those with progressive MS in grey matter volume, venous system and pressures of the brain. In particular:

- Males with MS and those with progressive forms of MS showed greater grey matter volume loss and larger EDSS scores compared to females with MS and those with RRMS.
- In patients with MS, worse outcomes in both males and progressive forms of MS were associated with larger sagittal sinus cross-sectional areas suggesting altered sinus pressure
- Females with MS have narrower transverse sinuses than males but males have higher jugular bulbs.

In July 2021, CCSVI Australia received an Expression of Interest from the research team at UNSW to investigate further the effect of Cerebral Venous Vasculature on Venous Pressure in Multiple Sclerosis. Upon review and satisfactory response to our questions, CCSVI Australia confirmed the grant for this study of \$40,000. The study will be conducted over 2022-23 with two journal articles to be written.

Alex Bateman joined us on Zoom on 8th March to give us a detailed presentation of the study. It was fascinating to see the Computational Flow Dynamic modelling of the cerebral venous system and the variation of venous structures between different people with MS.

Following ethics approval in March this year the study has now commenced.

The study hypotheses are that:

- There is a higher cerebral venous pressure in participants with MS compared to controls
- The five year following up study will show the development of MS and how this affects venous pressure
- The inclusion of male participants with MS will highlight the differences between male and female anatomy regarding areas of pressure increase

More details of this study is found on page 7.

The Alfred Hospital

\$28,500 of unspent funds that had been distributed to The Alfred were returned in June 2022. Details of this will be recorded in the Financial Statements.

CCSVI Australia is thankful for the research conducted at The Alfred by Kenneth R Thomson and Helen Kavnoudias and the discoveries they have contributed to the global knowledge of CCSVI and the vascular connection to MS.

****** Invitation for Expressions of Interest ******

Due the return of funds, CCSVI Australia is now seeking expressions of interest for additional research relating to the Vascular connection to Multiple Sclerosis.

Enquiries can be directed to admin@ccsviaustralia.com.au

CCSVI Australia \$40,000 Research Grant

Investigating the effect of Cerebral Venous Vasculature on Venous Pressure in Multiple Sclerosis

Background

A study undertaken in 2020, demonstrated that transverse sinus venous outflow stenoses caused a reduction in the venous compliance of multiple sclerosis (MS) patients. The findings indicated similarities between MS and idiopathic intracranial hypertension [1]. This year, a study was published by members of this team that used computational fluid dynamics (CFD), to investigate venous sinus pressure and idiopathic intracranial hypertension [2]. The application of this engineering software (CFD) allowed for new insights into the venous system and helped establish the relationship between cerebral blood flow and pressure in the cerebral venous system.

A recent review article completed by this group (currently in review) was conducted to critically summarise the literature available concerning the venous system in multiple sclerosis, primarily concerning specific data on the venous pressure and blood flow in this system. The findings included that the internal jugular vein (IJV) flow was not significantly different between MS patients and controls [3], but there was a variance between stenotic and non-stenotic MS patients [4]. There was limited data on venous pressure and intracranial flow, which indicated a lack of knowledge in this area requiring further investigation.

Current Work

The findings of the review article have led to the development of a new study, whereby CFD is to be used to investigate the venous pressure in MS patients. The MRI scans of 21 patients that have previously been captured will be used to investigate if the transverse sinus stenoses can cause a significant increase in venous pressure. The contrast in the MRI scans allows for a model of the patient's venous vasculature to be created. This is then used in the CFD model to simulate blood flow through the veins, enabling the venous pressure and blood flow features to be determined. The use of CFD will also allow for other potential causes of venous pressure increase to be investigated, should they become evident in this study. This provides information that would only otherwise be accessible through invasive surgical procedures.

Proposed Research

The research currently being undertaken is limited to MRI scans which have been previously completed with the protocols required for the CFD program. The funding provided by CCSVI Australia Inc would be used to perform MRI scans on a wider demographic of MS patients, as currently it is primarily comprised of female relapsing-remitting MS patients. This would fund MRI scans of up to 20 male control subjects and 20 people with secondary progressive MS (pw-SPMS). Novel MRI protocols would also be included to enable information to be captured which will increase the accuracy of the CFD models. This would be developed through industry collaborations with Siemens. The study hypothesises that male pw-SPMS will yield elevated venous pressures compared to male HC. A study by members of this group (currently in review) discovered evidence of venous vasculature variations between these male and female MS patient sub-groups. A CFD study would confirm how this impacts the venous pressures. These findings would

enable potential treatments to be proposed which could reduce the venous pressure and improve MS patient outcomes.

In addition, the funding would allow for 5 year follow up MRI scans to be performed on the subjects of the current study. Based on previous studies, it is likely that approximately 85% of patients would return for a follow up MRI. This would enable a longitudinal study to be completed, which will allow further insight into the cause and effect of the transverse sinus stenosis development and venous pressure changes over time and potential effects of disease modifying therapies. This study hypothesises that stenosis in venous vasculature causes an elevated pressure, contributing to the development of MS. The ability to use CFD in a longitudinal study will enable us to quantify the hemodynamic changes in the cerebral venous system and measure the effect it has on disease course and activity, in particular, if it correlates with the progression of the disease.

Research Team

Alexander Bateman is a first-year mechanical engineering PhD student at the University of New South Wales, in which the current research outlined in this expression of interest is being completed as part of his PhD work.

Jeannette Lechner-Scott is a senior staff specialist in the Department of Neurology and Conjoint Professor at the University of Newcastle. She has a multidisciplinary Multiple Sclerosis Clinic at the John Hunter Hospital (JHH) servicing over 1200 pwMS and has extensive experience in basic research as well as clinical trials.

Saadallah Ramadan is the Director of Magnetic Resonance Research and National Imaging Facility Node Director at the HMRI Imaging Centre and Associate Professor at the University of Newcastle. He is an expert in MRI protocols and techniques relating to MS and his research has included using MRI as a tool to detect markers associated with fatigue and depression in MS.

Grant Bateman is a senior staff specialist in the Department of Medical Imaging and Conjoint Associate Professor at the University of Newcastle. He is a Neuroradiologist and an expert in measurements of venous flow on MRI.

Tracie Barber is a mechanical engineering Professor at the University of New South Wales, specialising in vascular fluid dynamics. She is an expert in modelling vascular blood flow and leads a research group (Vision Fluid Dynamics) with various projects in the area of vascular fluid dynamics.

References

- [1] G. A. Bateman, J. Lechner-Scott, A. R. Bateman, J. Attia, and R. A. Lea, "The Incidence of Transverse Sinus Stenosis in Multiple Sclerosis: Further Evidence of Pulse Wave Encephalopathy," *Multiple Sclerosis and Related Disorders*, p. 102524, 2020.
- [2] A. R. Bateman, G. A. Bateman, and T. Barber, "The relationship between cerebral blood flow and venous sinus pressure: can hyperemia induce idiopathic intracranial hypertension?," *Fluids and Barriers of the CNS*, vol. 18, no. 1, pp. 1-10, 2021.
- [3] M. Blinkenberg *et al.*, "Chronic cerebrospinal venous insufficiency and venous stenoses in multiple sclerosis," *Acta neurologica scandinavica*, vol. 126, no. 6, pp. 421-427, 2012.
- [4] W. Feng *et al.*, "Characteristics of flow through the internal jugular veins at cervical C2/C3 and C5/C6 levels for multiple sclerosis patients using MR phase contrast imaging," *Neurological research*, vol. 34, no. 8, pp. 802-809, 2012.

Fundraising Officer Report

Jennifer Robinson

It has been another tough year for fundraising. After 10 years of raising funds for CCSVI Australia, it is hard to raise enthusiasm. We are constantly looking at new ways to raise funds, but little has come to fruition.

At present our only source of donations has been 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 \$12.20 this year.

Our focus now is on seeing that the work being done in Newcastle is fully support as the trial at the Alfred Hospital has come to a close. 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 at admin@ccsviaustralia.com.au.

How you can partner with us:

There are many opportunities for you to contribute to further research into the vascular connection to Multiple Sclerosis. We have registered with several fundraising organisations:

- **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>

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- **EVERYDAY HERO** You can join an event, or sponsor someone, for example: “Tough Mudder” and fund raise through “everydayhero”
 - **WORKPLACE GIVING** 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/>
 - **DONATE DIRECTLY TO CCSVI AUSTRALIA** Simply raise funds and donate via our website: <http://ccsviaustralia.com.au/donate/>

Here’s to the next fantastic year of fundraising!

Jennifer Robinson

Vale Peter Sullivan

Acknowledging the life of Peter Sullivan who we sadly lost in November 2021. This brief reflection cannot possibly portray the depth of Peter's contribution to our community over many years.

Peter was a friend of CCSVI Australia from its inception in 2010 and was involved in disseminating the unfolding CCSVI research and real world experiences of people with MS through the MS Network of Care. His warmth, honesty, generosity, integrity and quiet strength is what we will remember as he championed the work of people with MS and open-minded MS researchers both here in Australia and across the world who were investigating the vascular connection to Multiple Sclerosis. He spent the last decade or more documenting and providing commentary as well as directly challenging the status quo and existing dogma held by our MS institutions, neurologists and government. He also shared the extensive knowledge that he had gathered and provided insight into how to make real impact when advocating for people with MS.

Peter held the value that people with MS deserve to have their experiences and perspectives heard, understood and respected and their rights upheld - anything less is simply unacceptable. He lived this value into his last days sharing his work right up until August 2021.

The world has lost a true gentleman and our sympathies go out to Peter's family and friends.

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
Maree Thomson	Treasurer
Jennifer Robinson	Fund Raising Officer
Kevin Robinson	Secretary
Kerri Cassidy	General Member
Glenn Cassidy	General Member
Jim Lewis	General Member

Treasurer Report

Maree Thomson

\$12.22 was raised from Shopnate between July 2020 and June 2021.

\$28,500 was refunded from the Alfred Hospital.

Expenses were \$275 for the year which was lower than last financial year (\$339).

A balance of \$78,506 remains in the CCSVI Australia bank accounts.

Financial Statements 2021-22

Balance Sheet CCSVI Australia Incorporated As at 30 June 2022

	30 June 2022	30 June 2021
	\$	\$
Assets		
Bank		
Cash Reserve Account	72,829	44,318
Cheque Account	5,677	5,940
Total Bank	78,506	50,258
Total Assets	78,506	50,258
Liabilities		
Total Current Liabilities	0	0
Total Liabilities	0	0
Net Assets	78,506	50,258
Equity		
Current Year Earnings	28,248	460
Retained Earnings	50,258	49,798
Total Equity	78,506	50,258

Profit & Loss
CCSVI Australia Incorporated
1 July 2021 to 30 June 2022

	30 June 22	30 June 21
	\$	\$
Income		
Gifts and contributions	28,512	783
Interest Income	11	16
Total Income	28,523	799
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Gross Profit	28,523	799
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Less Operating Expenses		
Internet Costs	0	339
University of NSW	275	
Total Operating Expenses	275	339
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Net Profit	28,248	460
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Statement of Cash Flows
CCSVI Australia Incorporated
For the year ended 30 June 2022

Account	2022 \$	2021 \$
Operating Activities		
Receipts	28,523	799
Payments	- 275	- 339
Net Cash Flows from Operating Activities	28,248	460
Net Cash Flows	28,248	460
Cash and Cash Equivalents		
Cash and cash equivalents at beginning of period	50,258	49,798
Cash and cash equivalents at end of period	78,506	50,258
Net change in cash for period	28,248	460

Contact Details

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Facebook: [@ccsviaustralia](https://www.facebook.com/ccsviaustralia)