# Annual Report 2021

**SEPTEMBER 2021**

**CCSVI Australia Inc.**

## Contents

# Chairperson Report

## Bill Younger

Welcome to the FY2020/2021 CCSVI Australia Annual Report. Along with many other organisations and businesses, the COVID19 pandemic continues to have a negative effect on our activities including the study at the Alfred Hospital and fundraising.

I am pleased to advise that key learnings from the research study, being conducted by the Alfred Hospital Melbourne, were presented at the 2020 Scientific Meeting of the Cardiovascular and Interventional Radiological Society of Europe (CIRSE) Conference 12th -15th September 2020. As reported last year, a key learning from the study shows 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 results to date bring further credibility to the connection between vascular health and the symptoms associated with Multiple Sclerosis.

The Board is pleased to advise that CCSVI Australia has entered a relationship with the University of NSW to investigate venous sinus pressure and idiopathic intracranial hypertension using computational fluid dynamics. The specific focus of 20 male participants with Secondary Progressive Multiple Sclerosis (SPMS) and matched controls could provide an important comparison to the female Relapsing Remitting Multiple Sclerosis (RRMS) group which might contribute to the knowledge of venous abnormalities experienced by people with Multiple Sclerosis.

Our ongoing challenge remains securing an additional $350,000 in funding for the next phase of the trial at the Alfred Hospital. The funds are needed to support the added expense of utilising Intravenous Ultrasound (IVUS) as a reliable and accurate screening method to identify venous occlusions and blockages.

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,
Chairman,
CCSVI Australia

# CEO Report

## Kerri Cassidy

I'm very happy to contribute to the 8th Annual Report of CCSVI Australia.

Due to COVID-19 our Board continue to meet over Zoom to discuss the latest in the vascular connections to Multiple Sclerosis and to keep abreast of research being conducted both locally and overseas. Despite there being significant focus and resources being directed to COVID generally and in relation to Multiple Sclerosis specifically, there continues to be investigation and development of understanding of the vascular associations with MS.

It was very pleasing to learn that Australian researchers at the University of New South Wales (UNSW) have published two papers during this year relating to the vascular abnormalities that commonly exist for people with MS. In September a paper, The Incidence of Transverse Sinus Stenosis in Multiple Sclerosis: Further Evidence of Pulse Wave Encephalopathy (G. Bateman, J. Lechner-Scott, A. Bateman, J. Attia & R. Lea) was published in *Multiple Sclerosis and Related Disorders,* the researchers found that:

- Multiple Sclerosis is associated with narrowing of the transverse sinuses of the venous outflow.
- The findings indicate Multiple Sclerosis is on a continuum with idiopathic intracranial hypertension.
- Elevated venous pressure induces neuro-inflammation and blood brain barrier breakdown.
- Dilatation of the sagittal sinus cross-sectional area indicates a reduction in the pressure gradient across the sinus wall and is a point of distinction between Multiple Sclerosis and idiopathic intracranial hypertension.

More recently a second paper has been published, 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) which 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, upon request CCSVI Australia received an Expression of Interest from the research team at UNSW to investigate 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. Please see page 7 of this report for more details.

I'd like to again thank the members of CCSVI Australia who continue to hold fast to the importance of this research either for ourselves, our family and/or friends with MS; Bill, Jennifer, Jim, Maree, Kevin and Glenn.

Together we look forward to further investigations throughout 2021-22 contributing to the global puzzle that is the vascular connection to Multiple Sclerosis.

In solidarity,

Kerri Cassidy

# 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

No one thought at the end of last reporting year that yet again we would be in this situation of having spent almost 18 months in an on again off again lockdown state.

Our fundraising capacity has been severely restricted and 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.

| | |
|---|---|
| Shopnate | 34.08 |
| Good2Give | 748.80 |
| | **782.88** |

We will continue to work hard in seeing the trial at the Alfred Hospital and other similar research trials being fully funded. We also look to provide resources to extend knowledge and information on CCSVI and available treatments to the wider community. 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:

- 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

# 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 |

# Treasurer Report

## Maree Thomson

$782.88 was raised from Shopnate and Good2give between July 2020 and June 2021.

Expenses were $339.00 for the year which was lower than last financial year ($632.95).

A balance of $50,258.23 remains in the CCSVI Australia bank accounts. $40,000 will be distributed to the University of New South Wales research team investigating the Effect of Cerebral Venous Vasculature on Venous Pressure in Multiple Sclerosis (see page 7 for more details).

# Financial Statements 2020-21

## Balance Sheet

### CCSVI Australia Incorporated

### As at 30 June 2021

| | 30 June 2021 | 30 June 2020 |
|---|---|---|
| **Assets** | | |
| **Bank** | | |
| Cash Reserve Account | $44,318.55 | $43,555.53 |
| Cheque Account | $5,939.68 | $6,242.32 |
| **Total Bank** | **$50,258.23** | **$49,797.85** |
| **Total Assets** | **$50,258.23** | **$49,797.85** |
| **Liabilities** | | |
| **Total Current Liabilities** | **$0.00** | **$0.00** |
| **Total Liabilities** | **$0.00** | **$0.00** |
| **Net Assets** | **$50,258.23** | **$49,797.85** |
| **Equity** | | |
| Current Year Earnings | $460.38 | $1,722.76 |
| Retained Earnings | $49,797.85 | $48,075.09 |
| **Total Equity** | **$50,258.23** | **$49,797.85** |

# Profit & Loss

## CCSVI Australia Incorporated

## 1 July 2020 to 30 June 2021

| | 30 Jun 21 | 30 Jun 20 |
|---|---|---|
| **Income** | | |
| Events | $0.00 | $1,337.61 |
| Gifts and contributions | $782.88 | $965.44 |
| Interest Income | $16.50 | $52.66 |
| **Total Income** | **$799.38** | **$2,355.71** |
| **Gross Profit** | **$799.38** | **$2,355.71** |
| **Less Operating Expenses** | | |
| Internet Costs | $339.00 | $632.95 |
| **Total Operating Expenses** | **$339.00** | **$632.95** |
| **Net Profit** | **$460.38** | **$1,722.76** |

# Statement of Cash Flows

## CCSVI Australia Incorporated

## For the year ended 30 June 2021

| Account | 2021 | 2020 |
|---|---|---|
| **Operating Activities** | | |
| Receipts | $ 799.38 | $ 2,355.71 |
| Payments | -$ 339.00 | -$ 632.95 |
| **Net Cash Flows from Operating Activities** | **$ 460.38** | **$ 1,722.76** |
| **Net Cash Flows** | **$ 460.38** | **$ 1,722.76** |
| **Cash and Cash Equivalents** | | |
| Cash and cash equivalents at beginning of period | $ 49,797.85 | $ 48,075.09 |
| Cash and cash equivalents at end of period | $ 50,258.23 | $ 49,797.85 |
| **Net change in cash for period** | **$ 460.38** | **$ 1,722.76** |