

# ANNUAL REPORT

JUNE 2017

*“We are seeing an association between Multiple Sclerosis & venous drainage abnormalities across many research centres around the globe.”*

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# CHAIRPERSON REPORT

Welcome to the FY2016/2017 CCSVI Australia Annual Report. It has been another rewarding and busy year for everyone involved. From my perspective, the highlight was the recognition of our CEO's dedication to the rights of people with MS when she received a National Disability Award from the Federal Government. On 7th December 2016, in The Great Hall at Parliament House, Kerri Cassidy received the award for Excellence in Justice and Rights Protection for People with a Disability. The award was in recognition for her striving for Medicare access for angioplasty treatment for CCSVI, initiating a clinical trial into its effectiveness and working to raise over \$320,000 for this research. The National Disability Awards recognise the achievements of people and organisations that have improved the lives of people with disability.



Kerri's reputation within the global CCSVI community resulted in her being invited to the 2017 International Society of Neurovascular Diseases Annual Scientific Meeting in Taormina, Sicily on 4-6th May. Over 20 countries were represented at this year's conference. Another CCSVI Board member, Maree Thomson, was holidaying in Europe at the time and joined Kerri at the conference.

The lead researcher involved in the CCSVI trial at the Alfred Hospital, Dr Helen Kavnoudias, has made a major breakthrough in understanding the discrepancies that have appeared in previous trials when diagnosing patients for CCSVI. Dr Kavnoudias found that there were many variables when using typical ultrasound techniques i.e. patients were reported as normal at one time point and significantly abnormal (stenosis/flow) at a different time point. Her findings identified that incorporating Intravenous Ultrasound (IVUS) would be beneficial and significantly reduce the variability and potential misdiagnosis. Results from the Alfred trial after 24 months show that there was a significant difference in EDSS (disability scale) at 24 months. This EDSS significance gives momentum to continue with further enrolments, which will commence later this year.

In November 2016, Multiple Sclerosis Research Australia (MSRA) produced an Executive Summary of a survey which included one qualitative question, "Did we miss anything?" to which some participants raised questions regarding CCSVI. MSRA responded by saying "Chronic Cerebrospinal Venous Insufficiency (CCSVI) has also received funding from MS Research Australia in the past. However, following a considerable level of international attention in this area, there is now a global consensus that abnormalities in venous drainage of the spinal cord and brain are unlikely to contribute to the development of MS and further investment into this area is not currently warranted". This is despite their own finding that identified "abnormal internal jugular vein valves in 7 people with MS and one control" which, they say, "warrants further investigation" (MSRA 2012). What we now know is that Doppler Ultrasound is not an externally validated method for diagnosing CCSVI.

What we are seeing is an association between MS & venous drainage abnormalities across many research centres around the globe. The Alfred study identified CCSVI in 80% of participants using venogram (an invasive technology where a catheter wire is inserted into the vein) who then received angioplasty treatment for these abnormalities. We would encourage MSRA to reconsider their position and review the mounting global evidence that CCSVI deserves further investigation.

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. Thank you also to our many fundraisers, supporters and friends for your valued contributions throughout the year,

Sincerely,

Bill Younger  
Chairperson

## CEO REPORT

We've had another successful year progressing our statement of purpose to supply accurate information of CCSVI, lobby for treatment to be accessible to all Australians with MS, raising funds for research, ensuring that the interests of people with CCSVI have representation and that the understanding of CCSVI continues to advance.



Jason Wood MP and Kerri

It was fantastic to raise awareness federally through the National Disability Awards in November. To receive the award for Excellence in Justice and Rights Protection was deeply appreciated and the opportunity to speak at Parliament House about the importance of our work and research meant that many key decision makers in health were informed. Thank you to those who nominated me for this award, to Bill and Glenn for accompanying me and for everyone who has been involved with CCSVI Australia and have contributed over the past seven years – this award truly reflects a team effort.

It was also a crazy experience being involved in the media promotions for the Disability Awards which included a detailed story in the December edition of the Australian Women's Weekly as well as appearing on ABC News. We landed in Canberra that day with only ten minutes to find a quiet place for me to be interviewed by Clare Bowditch on ABC774 radio. What the public didn't know was that my 'quiet place' quickly became filled with tradesman trying to get some noisy work done!

We continue to provide information largely through our Facebook page, Twitter and website. This gives the public opportunity to participate in open discussion or to request information privately via email. There remains strong interest in people obtaining testing and treatment as well as volunteering to participate in The Alfred Trial and donating.

CCSVI Australia made a contribution to providing the latest information on international CCSVI research by investing in my attendance at the 2017 Scientific Meeting of the International Society of Neurovascular Disease (ISNVD) conference. It was a pleasure to attend this conference with Dr Helen Kavnoudias from the Alfred who presented on the most recent findings from the Melbourne study as well as with fellow board member Maree Thomson. Building connections with researchers and other patient organisations ensures that Australia remains a valuable member of the global effort. More about the ISNVD on page 7.



Funding has steadily increased this past year with The Alfred receiving over \$85,000 in grants for CCSVI research. We expect there will be several new funding applications made in the next financial year.

I am thrilled that The Alfred have commenced stage two of their study and will now include Intravenous Ultrasound (IVUS) in their protocols for the next group. There has been new energy injected into this research since preliminary data revealed that people in the treatment arm, on average, are experiencing improvement in disability level. I'm looking forward to seeing the second group enter the study and, I believe, more people with MS will have the opportunity to find out whether they have CCSVI and if angioplasty treatment can help their symptoms.

Unending gratitude goes to each member of CCSVI Australia who remain steadfast in upholding the importance of vascular issues in neurological diseases. This year our board has welcomed Maree Thomson, a long-term MS Ambassador and a woman who felt strongly to contribute to CCSVI Australia after her very successful treatment early in 2016. Maree has certainly injected some fresh blood into our team (pun intended). We also officially welcomed Kevin Robinson, who has been involved with Jennifer since CCSVI Australia was first incorporated, and he has generously taken on the additional role of documenting our meetings.

I am greatly encouraged by the continued work relating to CCSVI both here in Australia and around the globe. More research is published every year about the importance of a properly functioning vasculature and its relationship to the brain in not only Multiple Sclerosis but Meniere's Disease, Parkinson's Disease, Alzheimers and other neurological conditions. I believe that the results of the Brave Dreams trial from Zamboni's team in Italy will further confirm the necessity of continuing to better understand CCSVI and I feel so proud that CCSVI Australia is playing a significant role in ensuring this happens.

Thank you,

Kerri Cassidy  
Chief Executive Officer

# FUNDRAISING REPORT

I am very proud that our fundraising total has reached almost \$320,000. This is an amazing total and getting



closer to our goal each year. This was achieved by substantial ground work over the past few years.

Firstly, we received the second instalment of our two-year grant from the Annette Funicello

Research Fund from the USA.

Secondly, following many applications, presentations and a rigorous review process, we were very pleased to receive a grant of \$55,000 from Equity Trustees. We are extremely grateful that Equity Trustees have seen merit in our story and the need for this research to be completed. This endorsement is a reflection of the great work being undertaken at The Alfred Radiology department and the grant applications and presentations from CCSVI Australia's Kerri Cassidy and Dr Helen Kavnoudias.



In July we entered our second RunMelbourne event with a team for CCSVI Australia. We had lovely weather albeit a little cold. Kevin Robinson ran the 10 kms whilst Lisa and John Hills ran 5 km. The rest of us choosing to walk 5 km, with the merry group of Kerri Cassidy, Ellen Hills, Henry and Leonie Brockman, Anne Geddes and Jennifer Robinson sporting blue wigs or headbands to stand out from the crowd. We raised a little over \$3,000 for the Alfred research trial. Thank you to everyone that supported us. As our team continues to grow, perhaps next year you might like to join us?

A big thank you to our friend and long-time supporter, Leonie Brockman, for organising a very successful fundraising film night in August. We all enjoyed watching the fast pace of "Bourne"! and \$1,090 was received for the Alfred Hospital trial. Leonie also received \$354.80 in "Workplace Giving" from her workplace at Maroondah Council to add to our total.

Also in August our friend and supporter Brent, ran in Brisbane for "Turn on the Tap". Thank you to everyone who supported him and of course Brent for choosing to support our charity.

In February, once again our friends and supporters, Chris and Nigel Hall outdid themselves by opening their lovely home to 23 friends and hosting a fundraising dinner. This was a dinner with their usual twist: we all paid for the privilege of bringing a bottle of wine and cooking our own meal! The evening's theme this time was Greek. A fabulous evening of sipping, cooking, eating, conversing, puzzling and pondering the real meaning of the instructions ensued. All up we had 10 courses from saganaki to baklava! Chris and Nigel have now hosted two of these events for for us. They are a wonderfully creative way to combine fun, dining with friends, meeting new friends and charitable giving. The evening raised \$1,350.

We 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 in generating funds:

- 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’ as our film night showed, where they make a contribution to the funds that you are raising.

Here’s to the next amazing year of fundraising!

Jennifer Robinson, Fundraising Officer

## ISNVD SCIENTIFIC MEETING 2017

### Official Opening

Paolo Zamboni, Stephen Alexander and Pierfrancesco Veroux conducted the opening ceremony. The ISNVD is at an all-time high for membership with over twenty countries represented. Zamboni reflected that the soul of the society is the interdisciplinary team working together to solve various unknowns in neurovascular conditions.



### Alfred Study Update – Dr Helen Kavnoudias

We were able to quantify limitations of the different imaging modalities to measure abnormalities of the Internal Jugular Vein and confirm that multimodal imaging is required. Agreement between all modalities was only 50%. Agreement between Angiography and Ultrasound was 60%, Angioplasty and MRV was 64% and Ultrasound and MRV was 70%. This confirms that incorporating IVUS would be beneficial.

Ultrasound imaging for the control arm was obtained before, and in approximately half of patients there were significant differences in the result over the twelve months - high variability within individual patients. Patients were reported as normal at one time point and significantly abnormal (stenosis/flow) at a different time point.

Some comparative analysis has been completed between the treatment and sham to 24 months. There was no significant difference in two parameters: cerebral arterial flow and between the groups the EDSS was reported and found not to be significant at 12 months. However, there was a significant difference in EDSS (disability scale) at 24 months ( $p=0.016$ ). This EDSS significance gives momentum to continue with further enrolments which will recommence this year.

Patients were provided a second treatment for restenosis. There were two relapses recorded over the 24 month period. Studies that don’t follow patients for at least 24 months may fail to appreciate improvement over a longer period. Dr Kavnoudias gave special thanks to Prof Ken Thomson for taking on the initial research.

### Brave Dreams Update

Regrettably the Brave Dream (BRAIn Venous Drainage Exploited Against Multiple Sclerosis) results are still under embargo awaiting completion of peer review. The release of this information will be important considering the large variability in prevalence of CCSVI in Multiple Sclerosis across several

# ISNVD SCIENTIFIC MEETING 2017

studies. Brave Dreams is a multi-centre trial across Italy that includes a sham arm. Inclusion criteria is patients with either RRMS or SPMS experiencing an EDSS between 2-5.5 and a disease duration less than 15y years (in contrast to Canadian Study). A total of 204 patients were initially identified for the trial, RRMS (177). 74 were ineligible due to clinical criteria. 130 were enrolled and randomised and 127 completed the protocol. Neurologist assessors are blinded and quality of life measured. One key point is that quality training was given to effectively diagnose and treat CCSVI and certification was required. There were several functional endpoint measures; new MRI lesions, Cog State, memory, attention, fatigue, bladder, anxiety and depression. Prof Zamboni's closing statement was that he believes something important will be reported.

Paolo Zamboni will be presenting Brave Dreams at the Australasian College of Phlebology in Melbourne, February 2018. We are hopeful that the peer review process will be complete so that Prof Zamboni can give the full results of this essential study.

## **International Patient Associations Meeting**

Over 50 patients representing various CCSVI patient groups around the globe attended the meeting chaired by Professor Zamboni and Carol Schumacher from the Annette Funicello Research Fund for Neurological Diseases. The heart-warming keynote testimonial was given by Nicoletta Mantovani, International Patient Spokesperson for CCSVI and wife of the late Luciano Pavarotti. Nicoletta echoed the experiences of many people with Multiple Sclerosis as she shared her story of learning she had MS at aged 23 when she was told to expect that she would require a wheelchair. She felt that doctors treated her like a number, giving her lots of medication which changed nothing. She decided to cease taking medication and seek elsewhere for answers. Nicoletta stated, "My husband taught me to see MS as an opportunity. I went to listen to Zamboni and I heard answers I'd never had before." After she had the vein procedure she says she, "saw another world. Like I had been behind glass and now I sensed that everything was real." Since then she has had no more MS attacks. Nicoletta concluded her speech by saying:

"We need to work so that everyone has the possibility to see if this can help, research to make this available from a moral point of view. We need to make known to government that whilst it is not for everyone, it can help people."

Zamboni acknowledged the important work on CCSVI at Melbourne's Alfred Hospital where significant improvements are being seen in Multiple Sclerosis. He hopes to see the paper soon! He thanks Kerri Cassidy and the ongoing work of Australians for CCSVI in MS.

The microphone was given for individual groups to provide updates including Kerri Cassidy from CCSVI Australia, Sharon Richardson from the CCSVI Alliance and Linda from the Canadian CCSVI Coalition. Linda called on the international community to help complete funding for the Australian CCSVI research.



Kerri, Paulo Zamboni & Maree

## **Scientific Presentations**

There were close to 100 presentations over the three days including more accurate ultrasound techniques for CCSVI, Venous stent trial, genetic studies, the significance of the Central Vein Sign in MS and many more. You can read a more comprehensive summary on the CCSVI Australia website. ([link](#))

Report compiled by Kerri Cassidy, 22<sup>nd</sup> June 2017



# STATEMENT OF PURPOSE

- To remain abreast of international advances in the understanding and treatment of Chronic Cerebrospinal Venous Insufficiency (CCSVI) and associated discoveries.
- To supply accurate information to all interested parties including, but not limited to,
  - a. those seeking testing for, and treatment of, CCSVI
  - b. medical researchers and practitioners
  - c. government at all levels
  - d. related community-support organisations.
- To lobby for treatment of CCSVI to be readily available to all Australians and for the costs to be covered by Medicare.
- To raise funds for CCSVI research.
- To ensure the interests of people with CCSVI have continued representation and that the understanding and treatment of CCSVI continues to advance.

# BOARD MEMBERS



## **Bill Younger, Chairperson**

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 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 an interest in the health and community sectors, and champions the causes for people with Multiple Sclerosis.



## **Kerri Cassidy, Chief Executive Officer**

In 2017 Kerri successfully completed a Bachelor of Social Science (Psychology) with an interest in Health Sociology, an achievement she attributes to her passion for upholding the rights of people living with illness and disability and the grit she possesses despite MS. A gifted public speaker, Kerri has presented to patient groups, medical professionals, parliamentarians and this year, academics at Edinburgh University. Kerri was the 2016 winner of the National Disability Award for Justice and Rights Protection. Prior to CCSVI, Kerri operated an Accounting practice in which she trained and employed work-from-home bookkeepers.



## **Maree Thomson, Treasurer**

Maree involves herself in a variety of activities and groups. Having been diagnosed with MS since 1990, she has worked in a voluntary capacity as an ambassador educating people about Multiple Sclerosis. In addition, she is the treasurer for CCSVI Australia, and volunteers rescuing Golden Retrievers. She enjoys working in her garden, planning a trip to Africa for next year and enjoying things like Pilates she finds helpful for her MS.



## **Jennifer Robinson, Fund Raising Officer**

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 seven years) to her fatigue levels and heat intolerance. Jennifer's former career was as a Cartographer and in recent years she has experienced great success in grant writing and recruiting for fund raising events.

## BOARD MEMBERS



### **Kevin Robinson, Secretary**

Kevin is Jennifer’s husband and primary carer. He has had a varied career which has taken him through the oil and gas, IT and investment services industries. This included roles in technical support, software development and financial advice, both in Australia and overseas. As well as his role as Jennifer’s primary carer, Kevin now works as an investor and has two other non-executive directorships in commercial businesses. Kevin is keenly interested in having evidence used to guide health policy and medical treatment as well as health outcomes



### **Glenn Cassidy, Board Member**

Glenn is a senior business 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, provide 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 lived experience of disability and its impact on individuals, family and community.



### **Jim Lewis, Board Member**

Jim brings experience to our board as President of the Waverley North branch of the Liberal Party 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 lists the number of board meetings during the year ended 30<sup>th</sup> June 2017 and the number of meeting attended by each member.

<b>Director</b>	<b>Eligible to attend</b>	<b>Meetings attended</b>
Glenn Cassidy	7	3
Kerri Cassidy	7	7
Jim Lewis	7	6
Jennifer Robinson	7	6
Kevin Robinson	7	7
Maree Thomson	7	6
Bill Younger	7	7

# TREASURER REPORT

\$7066 was received from fund raising and donations between July 2016 and June 2017. In addition to this, the second 50% instalment from the Annette Funicello Research Fund for Neurological Diseases of \$31,769 was paid directly to the Alfred. \$55,000 was also received from Equity Trustees. This brought the total raised for The Alfred study to \$86,769 for this financial year. A very pleasing result.

Expenses were \$7,996 for the year which was only marginally higher than the previous year (\$7,678). In total, \$316,364 has been raised for the Alfred CCSVI in Multiple Sclerosis study as at 30th June 2017 (see fig. 1). \$238,940 has been distributed directly to the Alfred (see Fig 2). A balance of \$77,620 remains in the CCSVI Australia Trust account until the Alfred study commences its second phase.

Total Funds raised \$316,364  
30th June 2017

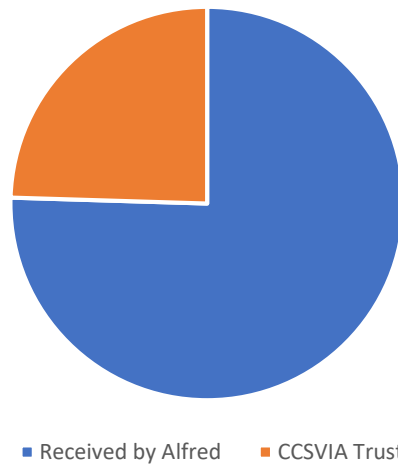


Figure 1

Funds received by Alfred \$238,940  
30th June 2017

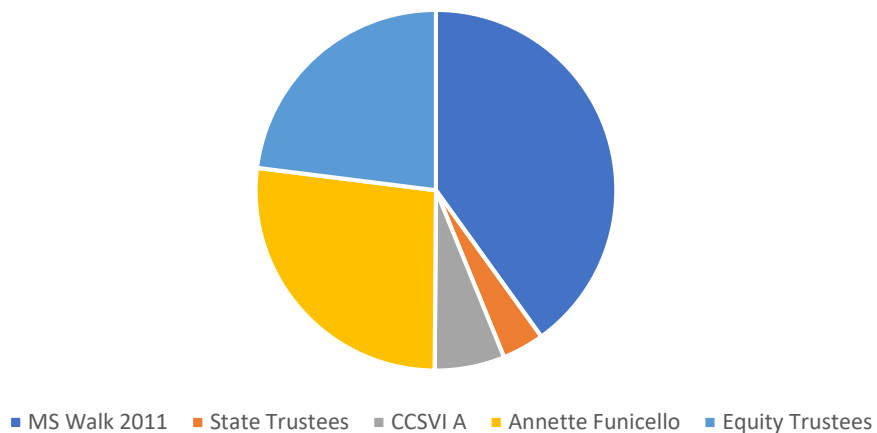


Figure 2

# TREASURER REPORT

We are fortunate to have many skills and talents available from those on our board and within the committed Multiple Sclerosis and CCSVI community which enables us to achieve so much without financial expense. These include but are not limited to website maintenance, administration, grant writing, printing, design, collating research and receiving queries.

Maree Thomson  
Treasurer



A 3-year review of the Deductible Gift Recipient status was conducted in late 2016 with the Australian Charities and Not-for-profits Commission. We are pleased that CCSVI Australia can continue to provide fully tax-deductible receipts to Australian donors.

# AUDITED FINANCIAL REPORTS

CCSVI AUSTRALIA INC.  
A.B.N. 15 107 843 012  
**INCOME AND EXPENDITURE STATEMENT**  
FOR THE YEAR ENDED 30 JUNE 2017

	Note	2017 \$	2016 \$
<b>INCOME</b>			
Functions and events		5,720	7,541
Gifts and donations		804	7,817
Grants received		-	-
Interest received		542	987
		<u>7,066</u>	<u>16,345</u>
<b>EXPENDITURE</b>			
Accounting and consultancy		(487)	(562)
Advertising		(100)	0
Bank fees and charges		(46)	(130)
Functions and events		(660)	(744)
Fundraising processing fees		(308)	(805)
General expenses		-	(103)
Insurance		(890)	(858)
Internet & Telephone fees		(400)	(316)
Office supplies and printing		(184)	(126)
Subscriptions		-	(271)
Travel		(4,921)	(3,762)
		<u>(7,996)</u>	<u>(7,677)</u>
Current year surplus before income tax		(930)	8,668
Income tax expense	1a.	-	-
Net current year surplus		<u>(930)</u>	<u>8,668</u>
RETAINED SURPLUS AT THE BEGINNING OF THE FINANCIAL YEAR		<u>82,178</u>	<u>73,510</u>
RETAINED SURPLUS AT THE END OF THE FINANCIAL YEAR		<u>81,248</u>	<u>82,178</u>

# AUDITED FINANCIAL REPORTS

CCSVI AUSTRALIA INC.  
A.B.N. 15 107 843 012  
CASH FLOW STATEMENT  
FOR THE YEAR ENDED 30 JUNE 2017

	Note	2017 \$	2016 \$
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>			
Receipts from members and donors		6,524	15,358
Payments to suppliers		(7,996)	(7,677)
Interest received		542	987
Net cash generated by operating activities	3	<u>(930)</u>	<u>8,668</u>
Net increase in cash held		(930)	8,668
Cash and cash equivalents at the beginning of the financial year		82,178	73,510
Cash and cash equivalents at the end of the financial year	2	<u>81,248</u>	<u>82,178</u>

CCSVI AUSTRALIA INC.  
A.B.N. 15 107 843 012  
ASSET AND LIABILITIES STATEMENT  
AS AT 30 JUNE 2017

	Note	2017 \$	2016 \$
<b>ASSETS</b>			
<b>CURRENT ASSETS</b>			
Cash and cash equivalents	2	<u>81,248</u>	<u>82,178</u>
<b>TOTAL CURRENT ASSETS</b>		<u>81,248</u>	<u>82,178</u>
<b>TOTAL ASSETS</b>		<b>81,248</b>	<b>82,178</b>
<b>NET ASSETS</b>		<u>81,248</u>	<u>82,178</u>
<b>MEMBERS' FUNDS</b>			
Retained surplus		82,178	73,510
Current year surplus		(930)	8,668
<b>TOTAL MEMBERS' FUNDS</b>		<u>81,248</u>	<u>82,178</u>

# CONTACT US

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