



Victoria

# Short Circuit

*People with Multiple Sclerosis Victoria Inc.*

*September 2008*

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## *Editors Report*



Now remember you only have until 14 September 2008, to have your nominations Forms in, so remember to send them in.

You also have until 30 September 2008 to win the Bruce McCulloch Prize, which appeared in our earlier issue. **We would like more entries;** it is a very good prize and all we need is for you to tell us about you experience with MS.

In addition, do not forget about the second competition where you get to win vouchers of three different values. ***Put yourself on the email list and you will get the chance of winning one of three vouchers.***

This year we would like to see as many as possible at the AGM that way you get to have your say in person on any issue you may have, so hope to see you there.

*Anthony Virgona*

## *Presidential Message July 08*

It came as a shock when Fred, who has run the Committee since Adam was an egg, told me that he wished to stand down from the Committee. He has run everything for so many years – and supervised or trained so many eager young wannabees – plus the odd President, CEO and a few shrinking violets. He not only knew what the Rules said – he *knew* what they *meant!* He kept the whole game floating, with not-so-simple applications for that most necessary ingredient, Money. It was only some work with another ‘volunteer body’ - ADDE – which began to show me how much Fred has been quietly doing all these years. He not only knows where the bodies are buried, he probably knows how they got there.....

My first real encounter with him was when I interviewed him for Short Circuit. It certainly wasn't easy to ‘draw him out’, but I remember clearly that after half a lifetime in Baking, he has never worn a watch! He has developed iron-clad efficiency with completion of forms and procedures, and magical production of toys, fridge magnets and teasers for Conferences, but I may have tried his patience with this year's requirement for each Committee Member to Write A Piece for Publication in SC. He has absorbed and starred in the use of modern systems and computers to get the job done.

His Contribution over the years is visible everywhere – including a term as President – which he very sensibly limited to a single spell. He was prominent in negotiating, for Victorian PwMS, the Aircon Discount. He has been awarded virtually every honour the Society/MSL can bestow. I'm sure his wife, Helen, will get pretty tired of finding new spots to park him around the house. Mind you, my spies tell me that the Cranbourne Squad already have their Not-so-secret Agenda for him set to roll, so Helen should survive. As I'm sure Fred will confirm, Retirement is just a word – and not so useful when considering a Hyper-Active Volunteer. There again, some nervous President might wish to retain his services to organise the occasional Election. So it is with great sorrow and admiration we are compelled to bid Fred a Fond Farewell. It really has been a pleasure learning from you, and we'll be lucky to Give Half as Much as you have done for so long.

And now for a Special. You may have heard about the new MS Brain Bank, and wondered what it's for, and whether you can make a Contribution. (If you hate the idea of Organ Donation, better stop reading).

I'm delighted to be able to tell you that one of our number – the redoubtable Gail – has pursued the matter and found out how to make her Contribution (but only once she no longer needs the brain herself). Anyone who saw and appreciated the film ‘Jesus of Montreal’ may find the idea appealing. It certainly makes a Difference to be sure of doing something useful once the Game is Finally Over. If you're interested, their Website is [www.msbrainbank.org.au](http://www.msbrainbank.org.au). If you have other ways to Make a Difference – we'd be glad to hear about and publicise them.

Stay well.....

**David Sullivan**



## **Mobility Aids on Public Transport**

### **Before You Buy a Mobility Aid**

To ensure you have an enjoyable and safe journey, we highly recommend your mobility aid meets the specifications outlined in this brochure. Further detail is provided in the DDA Disability Standards for Accessible Public Transport 2002.

### **Dimensions**

Your mobility aid needs to:

- Fit within an allocated space of 1300mm by 800mm

- Be no more than 750mm wide at a height 300mm above the ground to fit between the wheels axles of a bus

- Be able to negotiate a taxi door height of 1400mm.

The total weight of yourself, your assistant and your mobility aid needs to be less than 300kg. This is to ensure you do not exceed the maximum weight capacity of a boarding device (for example, ramp) which is 300kg.

### **Stability**

Your mobility aid needs to:

- Be able to move in the direction determined by the transport operator

- Have effective braking systems to maintain stability

- Transfer to a seat in a taxi if required.

### **Maneuverability**

Your mobility aid should be able to:

- Turn 180 degrees within an area 2070mm by 1540mm

- Cross a horizontal gap up to 40mm wide

- Mount a vertical rise (bump) up to 12mm

- Cross grating gaps up to 13mm wide and 150mm long

- Negotiate a 1:14 grade unassisted (e.g. ramp)

- Negotiate up to a 1:8 grade where the ramp is less than 1520mm

- Negotiate a 1:4 grade with assistance (e.g. ramp).

### **Frequently Asked Questions**

**Q. Is all public transport accessible to passengers using mobility aids?**

**A.** Not yet, but Melbourne's public transport operators are working hard to improve access to all modes. All trains, low floor buses with on-board ramps, and low floor trams at platform stops are accessible. Please seek further details from Metlink via the website or call centre. Plan your trip ahead as much as possible.

**Q. How can I have a safer journey on public transport?**

**A.** By ensuring your mobility aid meets the specifications in this brochure and by planning your journey in advance.



**Q. If I use a wheelchair or mobility aid where should I wait on a train platform to obtain driver assistance and ramp access?**

**A.** On a metropolitan platform, wait near where the front of the train stops to help ensure the driver can see you. This is marked with a yellow or white rectangle on the pavement. Note that sometimes a shorter train is used so the front would be more towards the middle of the platform. On a regional platform, wait in a prominent location as the conductor will assist you to board.

**Q. How should I let the train driver (or V/Line Conductor?) know where I am going?**

**A.** To assist the driver in helping you get off where you need to, it is best to write your destination on a note which you can collect from the station office before you travel. If you are at an unstaffed station, you can use your own note. If you are travelling in a group, please call ahead to the station.

**Q. How can I become confident with getting on and off public transport?**

**A.** You will feel more confident the more you practice getting on and off public transport. Contact Metlink to discuss your transport needs.

**Q. Does my mobility aid need to be anchored when travelling on public transport?**

**A.** Most trains, trams and buses do not have specific anchoring points; however they do have allocated spaces for people using mobility aids which are marked with signage. You should ensure that your mobility aid has suitable braking that you can apply while traveling.

**Q. Are there any weight limitations when using a boarding device?**

**A.** If you require assistance to access public transport, you must ensure that the total weight of yourself, your assistant and your mobility aid is less than 300kg. For further information, contact



Metlink or your public transport provider.

### **C.O.M.S. (CARERS OF MULTIPLE SCLEROSIS)** **SOCIAL SUPPORT GROUP**

We are a support group with both men and women members ages ranging from 30 to 80.

There are **NO** lectures it is simply a get together with other carers who know what you are going through.

We meet the 2<sup>nd</sup> Wednesday night of each month 6.30pm – 8.30pm

We have two meetings at the Footscray Centre and the third is a social evening out at a venue that is local.

A fee of \$6 is paid to cover the cost of a meal when we are at Footscray.

**Contact Michelle Casey on 9449 2524 or 0433 093 260**

Natalizumab, also known by the trade name Tysabri and formally known as Antegren, is the latest drug to be approved by the Pharmaceutical Benefits Advisory Committee, PBAC, for listing on the Pharmaceutical Benefits Schedule, PBS, in Australia. Tysabri is an antibody and was developed to attach to the surface of the white blood cells of the immune system, the T cells, and prevent them from crossing the blood- brain barrier and entering the brain, which is thought to be one of the first occurrences in MS.

The initial clinical trial of Tysabri, known as the AFFIRM study, began in 2001 and included study centre's in Australia. The trial was double blinded and placebo controlled with 942 subjects enrolled. The active drug or the placebo was given every 4 weeks by intravenous infusion for up to 116 weeks. The primary end point of the trial at the end of one year was the rate of clinical relapses. Secondary endpoints were the number of new or enlarging lesions seen on MRI. At the end of two years, the primary end was related to sustained progression of disability.

A second trial of Tysabri, known as the Sentinel study, began in 2002 with 1196 subjects in Europe and USA. This trial compared subjects on Tysabri alone to subjects taking a combination of Tysabri and Avonex an immunomodulating treatment already being used in MS. The results of these two clinical trials showed that Tysabri reduced both the rate of MS relapses over twelve months as well as the number of new lesions seen on MRI. Tysabri was passed by the American Food and Drug Authority, the FDA, as a treatment for relapsing remitting MS in the USA in 2004.

In February 2005 Biogen Idec the pharmaceutical company marketing Tysabri voluntarily suspended sales as there were two reported cases of a rare but serious brain condition, progressive multifocal leucoencephalopathy or PML, in those who had been taking the combination of Avonex and Tysabri. There have been no further cases of PML reported and Tysabri was again approved by the FDA in 2006 as a monotherapy for MS that is it cannot be used in combination with any of the currently available immunomodulating drugs. Tysabri is now widely marketed in North America and Europe.

In Australia Tysabri was passed by the Therapeutic Goods Administration TGA in November 2006 as a monotherapy for the treatment of relapsing remitting MS to delay the progression of physical disability and reduce the frequency of relapses. Tysabri is a first line treatment option. It will be available on the PBS on 1<sup>st</sup> July 2008 and a special program, the Tysabri Australian Prescribing Program, has been established to closely monitor those on the drug and watch for any serious side effects, in particular the development of PML. All those taking part in the prescription and provision of Tysabri are to be trained including neurologists, pharmacists and nurses and patients will be closely monitored.

The development of Tysabri offers another treatment option for those with relapsing remitting MS and as such is a welcome addition to the current armamentarium of neurologists in managing MS the disease.



**For Sale**

Motorized scooter offered for sale by Mrs. Sylvia HOFFMAN  
The make is a PRIDE 5000; CELEBRITY 3WHEELER red in  
Colour it is in mint condition and has had a regular service.

**Contact Andrea Dorey (daughter) on 85089329 or  
0418394342.**

**The location is North Caulfield.**



**Save on Gas & Electricity in 4 easy steps. "Go Switch lets you go figure best deal on domestic power" [www.goswitch.com.au](http://www.goswitch.com.au) Have your power bills handy so that you can enter in relevant details to compare what you are paying. If leaving your existing supplier make sure there are no EXIT fees.**

**[MS internet access at Blackburn](#)**

The MS Society offers people with MS internet access at Blackburn. They have a small number of public access computers that are available for use and they do have internet connections.

For further information, contact the Librarian **Jacqui Harvey on 98452809**

**Anthony's Kitchen**



**Audrey's chocolate truffles ..... Sent in by Audrey Scott**

**You need:**

- 125 grams coconut
- 50 grams cocoa powder
- 1 pack Marie Biscuits
- 375 mls condensed milk
- Extra coconut for dusting

**Method:**

Firstly, crush the Marie biscuits in the bag until they are down to a fine crumble texture. Then mix the cocoa, coconut and crushed Marie biscuits together.

Open and add the condensed milk and stir all the ingredients together until a thick chocolate mixture is formed.

Using your hands, roll the mixture into truffles (the smaller the size, the more you can make).

Dust with extra coconut and enjoy. You can put the truffles in the fridge to harden them.

**A lovely sweet treat from Rob Scott's daughter Audrey (school holidays, so the kids get to come into the studio).**

# Eight-letter Words

Every word in this puzzle is eight letters long –  
how long will it take you to spot them all?

V	S	B	P	P	Y	J	O	T	S	E	L	T	N	E	G	Z
J	S	O	F	R	M	D	R	A	Y	K	N	U	J	I	H	E
E	E	L	I	N	E	V	U	J	B	A	I	K	C	J	S	P
Y	L	I	T	A	D	S	Y	H	R	Q	C	P	O	D	I	P
Q	E	N	F	O	E	M	I	G	R	A	T	E	M	E	L	E
I	V	E	U	T	P	Q	A	D	S	R	X	V	P	I	R	L
N	O	S	L	A	W	L	I	P	E	E	O	L	L	F	U	I
S	L	M	L	K	F	M	A	Z	L	D	G	O	E	I	H	N
U	D	A	Y	A	P	N	M	U	M	N	K	S	T	D	C	C
O	Q	N	M	R	K	O	F	I	J	E	E	S	E	O	O	A
M	F	N	I	K	O	E	S	O	N	G	A	I	D	M	D	V
A	M	S	O	R	T	T	K	F	A	N	D	D	P	N	D	U
F	O	J	H	A	A	I	I	K	L	E	X	O	E	G	P	Z
N	A	S	R	K	N	E	A	D	H	M	S	I	P	B	W	Z
I	U	G	E	G	T	E	H	S	U	E	C	S	X	Y	O	R
M	M	N	L	K	R	A	V	D	R	A	A	O	F	J	J	Z
N	R	Y	L	B	V	W	L	V	H	O	M	E	L	E	S	S

AARDVARK	FITFULLY	JUVENILE
AUDITORY	FLAGRANT	KNAPSACK
BREAKAGE	GENTLEST	KRAKATOA
CHURLISH	GRATEFUL	LINESMAN
COMPLETE	HACIENDA	LOVELESS
COMPOSER	HOMELESS	MISTAKEN
DIAGNOSE	IMPRISON	MODIFIED
DISSOLVE	INFAMOUS	MUSHROOM
EMIGRATE	JOKINGLY	PRESIDED
ENGENDER	JUNKYARD	ZEPPELIN

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**PEOPLE WITH MULTIPLE SCLEROSIS VIC. INC**

**ABN 73 104 198 752**

**ABSENTEE VOTING FORM FOR AGM 2008**

**Positions**

**Nominations**

**Ordinary Committee Member (3) Positions**

1.....

2.....

3.....

**PwMS-V Members Name.....**

**Address.....**

**.....Post Code.....**

**Signature.....**

**Email address.....**

**Return to the Secretary  
PwMS-V Inc. by 14/09/2008  
19 Edgbaston Parade  
Caroline Springs 3023  
Email: [mike\\_dalli@yahoo.com.au](mailto:mike_dalli@yahoo.com.au)**