



# Short Circuit

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People with Multiple Sclerosis Victoria Inc.

Autumn, 2019

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## **In This Issue**

**Page 1. Word from editor.**

**Page 2. President's letter.**

**Page 3. Step training for people with MS.**

**Page 5. New telecommunications resource for people with disability.**

**Page 6. Screening environmental chemicals which may influence MS.**

**Page 7. Conference registration form.**

**Page 8. Community Board.**

**G'day Everyone,**

I imagine that most of you have already given up on your 'New Year' resolutions such as more exercise, a better diet and drinking less 😊. So, to help you with maybe a bit of exercise, at least, we have a nice play and exercise research study option.

Also, I have noticed that many tech companies have started doing a lot of things to help people with many disabilities and help them live a safer more inclusive life. Especially when I investigated the USA market, I reckon we have a lot to catch up.

However, an unexpected recent USA finding is that there are many more people that have MS than earlier thought. Not a very positive one but there are hopes this will lead to more funds being provided for research to find more ways to prevent MS or even cure it, so in the end maybe not a bad outcome.

Enjoy the reading



*Editor*



*Happy new year to you all  
May 2019 be a great year, filled with  
good luck, good health and good fun  
May we live within our worldly means, and  
May world leaders learn to live as one*

*Over the festive season there have been several exciting announcements for people with MS; two recent news items from MS Research Australia were:*

*12 December 2018*

*A Sydney team has published results from an observational study of Autologous Haematopoietic Stem Cell Therapy (AH SCT) in 35 people with relapsing-remitting or secondary progressive MS. AH SCT aims to reset the immune system using chemotherapy to wipe out most or all the immune cells and then the individual's own blood stem cells are reinfused to rebuild the system. The hope is that the treatment puts MS into remission. It has been under investigation, worldwide, as a treatment option for MS using different protocols and in different types of MS. Good results have been seen for many people with relapsing MS however, it is also a treatment with high risks and international clinical trials and studies have shown that it is not effective or suitable for everyone with MS.*

*In this study, 60% showed no evidence of disease activity for three years after the treatment and 13 participants showed improvements in their disability whilst 8 people had continued disability progression during the follow-up period. This study showed that AH SCT can provide good outcomes for people with relapsing MS who do not respond to other types of MS treatments. But the results are similar to those seen in other international studies and confirm that people with relapsing-remitting MS respond better to AH SCT than those with secondary progressive MS.*

*17 January 2019*

*Historical studies have suggested that about 80% of people with relapsing remitting MS, if left untreated, were likely to enter the secondary progressive phase of the disease within 20 years. In more recent decades since the advent of effective disease modifying MS therapies, clinicians have observed an apparent decline or delay in people reaching the SPMS phase. But research to confirm this observation with clear data has been hard to come by. Now results from an international study led by Associate Professor Tomas Kalincik of the University of Melbourne, in partnership with UK researchers, have confirmed this and that this effect is heightened if treatment starts within 5 years of onset. For more information about either of these items go to [msra.org.au/news](http://msra.org.au/news).*

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*Do you have an interest in your family history? Have you thought about sending for a DNA test through someone like “AncestryDNA” or “23and Me”? It sounds very interesting to find out where your family came from. Millions of people think so and have sent their “spit-in-a-tube” samples to be analysed and opted in to share their DNA with Ancestry and for informed consent research. But have you wondered what the information might be used for? Well one of the big DNA testing companies “23and Me” has just announced a major deal with pharmaceutical giant Glaxo-Smith-Kline to use the data for research purposes.*

*So, if you are thinking of sending off for a DNA test you might want to bear in mind the privacy risks associated with opting-in to allowing your data to be shared.*

*Regards Nigel Caswell*

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## **Step training for people with MS RESEARCH STUDY**

**Neuroscience Research Australia**, is recruiting people to take part in a study to see if *Exercise can improve balance, stepping and thinking speed to reduce falls in MS*

### **What is the purpose of this study?**

To investigate whether a 6-month period of training using a stepping device can improve your balance, thinking skills and reduce your risk of falling.

### **What does the study involve?**

If you participate in this study you will attend our Melbourne study site at the Nerve Centre, Blackburn to undertake a falls risk assessment and step performance test. You are free to use mobility aids that you use in daily activities.

After the assessment you will be randomly allocated to one of two groups: exercise booklet or stepping exercise.

- If you are allocated to the exercise booklet group you, will be given a series of exercises to practice for 6 months.
- If you are allocated to the stepping exercise group, you will be provided with the smart step computerised step training system.

The smart step training system has been designed to enable you to undertake training in your own home, by exercising whilst playing engaging and enjoyable computer games. The system connects to a TV or computer monitor and are played with a step mat. These games have been designed to train important balance and cognitive functions, while also being fun. You may recognise some of the games, such as Space Invaders and Tetris. During the 6 months of the study we ask that you try play the stepping games for 120 minutes per week.

### **Who can enrol?**

People who have confirmed diagnosis of MS, aged 18 years and over, living in the community.



To be included in the study, MS participants need to be:

- Mobile and able to walk at least 50 meters with or without mobility aid
- Able to understand and follow instructions
- Having stable MS (with or without disease modifying drugs) with no exacerbation in the past 30 days
- And currently not involved in any falls prevention programs.

**Will I be reimbursed?**

Your participation in the study is totally voluntary. If travel to the study site is a problem, please contact us as other arrangements can be made.

You will be able to contact us at any time throughout the study if you have any questions about the system. While participating in the study, whether you are in the normal or stepping exercise group, you can continue your routine exercises such as hydrotherapy, riding bicycle, yoga, tai chi, gym, etc.

If you have any questions, or if you are interested in participating, please contact a member of the research team:

**Melbourne: Ph (Ms Anna Butler, research assistant): 0408 368 244,  
email: [ifims.melbourne@neura.edu.au](mailto:ifims.melbourne@neura.edu.au)**

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### **New telecommunications resource for people with disability**

*Australian Communications Consumer Action Network (ACCAN) has launched a new website and call centre for people with disability.*

*The Accessible Telecoms project provides information about the accessibility features of telephone handsets and accessories so people with disability can use them as well as training and skill support. It was funded by a grant from the National Disability Insurance Agency (NDIA).*

*ACCAN director of inclusion, Wayne Hawkins, said there was an acknowledged lack of up-to-date, appropriate and independent information about telecommunications equipment and services available for Australians with disability.*

*“We’re pleased that the NDIA understands the significance of this project in assisting people with disability to be able to utilise telecommunications to enable greater participation in all aspects of life – economic, social, and cultural and community.”*

*ACCAN has enlisted IDEAS (Information on Disability Education and Awareness Service) to deliver the information via their website and call centre. Accessible Telecoms is available at **[www.IDEAS.org.au](http://www.IDEAS.org.au)**, or by phoning IDEAS on **1800 029 904**.*

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## SCREENING ENVIRONMENTAL CHEMICALS WHICH MAY INFLUENCE MS

It is known that MS is caused by a mixture of genetic and environmental risk factors. Now investigators in the US have developed an approach to systematically test the effects of hundreds of environmental factors on inflammation in the brain.

- MS is thought to develop through a complex interaction of genetic and environmental factors.
- Scientists have developed a novel way to screen hundreds of environmental chemicals at once.
- After screening 976 chemicals they identify two which potentially might contribute to MS.

MS is a complex disease which arises when the immune system mistakenly attacks the protective myelin sheath coating on nerve fibres. Exactly what triggers this autoimmune process in each individual is unclear. However, studies in identical twins have shown that genetics alone is not enough (as, if one identical twin has MS, the other twin only has a one in four chance of developing MS) and environmental factors must play an important role. Most epidemiological studies have failed to show any strong links between environmental chemicals and the development of MS, except for smoking. Identifying these environmental chemical risk factors is challenging given the sheer number of different chemicals and other factors we are exposed to each day of our lives.

As part of funding from the **International Progressive MS Alliance**, a group of scientists based at the Brigham and Women's Hospital in Boston USA have developed an innovative way to screen hundreds of chemicals to see whether they may play a role. They have recently published their findings in the prestigious scientific journal ***Cell***.

They started with a list of 976 chemicals provided by the United States Environmental Protection Agency (EPA), which included a broad collection of representative chemicals ranging from industrial and consumer products to food additives. Using bioinformatics, they identified a subset of 76 of these chemicals that might affect immune signals in the body. They found that five of the compounds increased the activity of *nos2a*, a zebrafish gene associated with inflammation. Once they had narrowed the list to five compounds, they tested these on mice cells grown in a laboratory. They found that two out of the five chemicals, a herbicide known as linuron and a chemical used by various industries called methyl carbamate, led to an increase in *Nos2*.

Linuron has recently been banned in Europe because of its risk to mammals. Both chemicals boosted *Nos2* and two other important signals in the immune system IL-1b and TNF-a, suggesting that these chemicals might create an environment in the brain that promotes disease.

**The scientists point out that further studies would need to be carried out to evaluate the impact of linuron in the environment on humans and see whether it does in fact contribute to MS.**

**Source: <https://msra.org.au/news/screening-environmental-chemicals/>**

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## Twice as Many People Have Multiple Sclerosis Than Previously Thought

The number of people living with multiple sclerosis (MS) is now estimated at nearly 1 million in the United States, more than twice the long-standing estimate of 400,000. The research confirmed more women than men have the disease, but now it's estimated that women outpace men 3 to 1. Earlier estimates suggested a 2-to-1 difference.

The study was conducted by the National Multiple Sclerosis Society and published this month in *Neurology*, the medical journal of the American Academy of Neurology.

### Why the increase?

Nick LaRocca, PhD, vice president of healthcare delivery and policy research for the National Multiple Sclerosis Society, says there's no evidence yet that there's an actual increase in MS. There're just now more people who have a diagnosis. LaRocca discussed several possible reasons for this increase in diagnoses. "The diagnosis process has become more refined," LaRocca told Healthline. "People are diagnosed better, sooner, and more readily."

The increase could partially be contributed to the large number of treatments today. The data also spotlights the need for more and better care. "MS is a more challenging disorder than we realize, and there is a greater need than we realized," LaRocca explained. "We need to work hard and redouble our efforts to make sure that everyone diagnosed with MS has access to quality medical care and access to treatments that can help with MS."

"We have to do a better job at not only making sure they have access to quality care, but they are using the quality care," he said. "It can make a difference in their lives with MS to take care."

"And we need to build the MS clinical workforce, which is strained or not available, especially in rural areas," he added.

The study also highlights the need for a cure.

"We have a mission to find a cure," Tim Coetzee, PhD, chief advocacy, services, and research officer at the National Multiple Sclerosis Society, told Healthline. "This information will help with advocating for more funds."

This new data helps researchers have a better understanding of MS and provides tools to do more studies to look at environmental triggers. "How can we cure MS? By preventing it from starting at all is part of the answer," LaRocca said. "If we can find environmental triggers, then we could reduce risk and maybe prevent it."

### Data mining

The study involved 125 million health records. Coetzee calls the study "remarkable" and a tour de force.

Coetzee explains how epidemiologists came together to create an algorithm that collected a lot of data in a statistically valid way. Researchers in this study used three major groups of records that encompassed private healthcare, government-funded healthcare, and veterans' healthcare. "Without a national health system, or government-funded registry, this is a powerful tool," he said. "Others can learn from and adapt".

Researchers can't segment the data to define types of MS. There's only one administrative code used for MS that's not broken up by subtype.

"I'm excited that in this era of big data that we can come up with a way that really builds on bringing all these health records together," Coetzee said. "We solved a challenging problem for people with MS and set us on a path for even more progress."

**Source:** <https://www.healthline.com/health-news/twice-as-many-people-have-ms-than-previously-thought#Data-mining>



**People with MS Victoria Inc**  
**2019 “Living with MS” Annual Conference**  
**Saturday 4<sup>th</sup> May 10.00am – 3.00pm**  
**The Nerve Centre, 54 Railway Road, Blackburn**

This conference proudly brought to you by **People with MS Victoria Inc**;  
 with support from **Multiple Sclerosis Limited, City of Whitehorse** and the **National Disability Conference Initiative**

Enquiries; rogerreece@optusnet.com.au    PH: (03) 9878 5768    Mobile: 0419 365 140

**Opening Presentation by John Blewonski**

*The New CEO of MSLtd*

**“A New Vision and a Strong Future for MSL”**

**A/Prof Anneke van der Walt**

*Head of MS and Neuro-ophthalmology, Alfred Health*

**“Current MS Treatments and Research”**

**Associate Professor Catherine (Kate) Cherry**

*Person with MS; & Infectious Diseases Physician at Alfred Health*

**“A Good Life with MS.”**

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 The cost is only \$15 per person including morning tea and a light lunch.

Coffee & tea can also be purchased from a mobile van.

Some assistance with transport & accommodation costs may be available on request

**To make a booking fill in and return the form below by Wednesday, April 24th.**

**Numbers limited bookings essential**

PwMS Conference 2019 Registration Form  
 Return form to: PwMS Conference,  
 PO Box 1035, CRAIGIEBURN NORTH VIC. 3064

<b>Names of attendees</b>				
<b>Phone:</b>		<b>Email:</b>		
<b>Special dietary needs [if any]</b>		Vegetarian	Vegan	Gluten Free
<b>Access needs [if any]</b>		Wheelchair	Walker	Scooter
<b>Do you need information about transport, or assistance?</b>				
<b>Mob: 0435 085 827</b>		<b>PH: (03) 8351 9780</b>		

Enclose payment of \$15 per attendee (Please tick payment method)

Cheque payable to PwMS Victoria, Inc.; or

Direct payment to PwMS Vic Inc, BSB 083-004, Acct 04-636-6841 (include name)

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**PO Box 1035**

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**(include your name in the bank transfer)**

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