Canberra Region Newsletter
August 2018

New Office Hours

Monday to Friday
9.00 am to 4.00 pm
(02) 6234 7000
MS Connect 1800 042 138

What’s in this newsletter?
- New Office Hours
- New Chief Executive Officer
- One-on-one NDIS Sessions
- Get Your ACT Together Tool
- Live Chat with MS Connect
- Upcoming MS Nurse Visits
- Community Consultation
- Volunteers Wanted for ANU Study
- Plus much more

Get Your ACT Together Tool

We are excited to announce that the three new symptoms of cognition, heat sensitivity and pain have been added to the Get Your ACT Together tool on the MS website.

The Get Your ACT Together tool is an interactive guide to help you manage some common symptoms of multiple sclerosis. The content of the tool was developed for people in the ACT, however it includes information that is helpful for anyone living with multiple sclerosis, wherever you live. This was developed in consultation with people in the ACT community, and feedback from the first stage of the project.

You can answer a few questions and then download your own personalised report filled with handy tips and tricks to help manage your symptoms. You can also select if you would like to receive a call or email from MS Connect after completing your report, to provide you with additional support and information.

We would love to hear your feedback, and you can find the Get Your ACT Together tool here: https://www.ms.org.au/living-well-with-multiple-sclerosis/wellbeing-support/get-your-act-together.aspx
On behalf of the MSL Board, I am pleased to announce the appointment of Mr John Blewonski as the new Chief Executive Officer (CEO) of MSL to commence on 5 November 2018.

John is a highly credentialed and respected leader in the community services and not-for-profit sector, bringing over 26 years’ experience.

John is currently CEO of VincentCare Victoria, where over the past eight years he has been responsible to the Board for the implementation of its strategic direction and operational delivery, with oversight of more than 400 FTE staff, including responsibility for Finance, Human Resource, Risk and broader corporate systems. John concurrently leads VincentCare Community Housing, an organisation which offers a range of accommodation options for people at risk of Primary Homelessness, managing housing properties, independent living units across regional Victoria; and rooming house properties. In 2016, John undertook a secondment as CEO of St Vincent de Paul Society in Victoria.

Before this John operated at Anglicare Victoria for eleven years, commencing as Executive Manager Corporate Services with accountability for operational leadership of key functional areas, and later moving into the role of Deputy Chief Executive Officer/Chief Operating Officer, managing the Agency’s corporate and community services. Earlier in his career John held the position of Director Community Relations & Development.

John’s current Board appointments include those with the Council to Homeless Persons (CHP) where he serves as Chairman; Catholic Social Services Victoria; DHHS Launch Site (Housing Access) Senior Leadership Group; and the Victorian Housing Minister’s Homelessness Advisory Committee.

Under John’s leadership VincentCare is also transitioning to the consumer directed environment including the delivery of Commonwealth Home Care Packages and a NDIS funded Disability Employment Program. “The NDIS and My Aged Care are significant social reforms which present wonderful opportunities for those in our community living with a disability. While offering consumers a greater say in terms of choice and self-direction, navigating these new systems present significant challenges.” said John Blewonski.

“I am very much looking forward to working with the team at MSL to ensure all those living with MS have access to the best advice and support appropriate to their needs and achieving their goals.”

MSL’s process for the selection of our new Chief Executive Officer has been extensive and we appreciate the level of input provided by all those involved in the process. The Board was delighted with the level of interest shown in the position by a large number of highly qualified candidates, which is an indication of the standing of MSL in the eyes of the community. We congratulate John on his appointment, and look forward to working with him as he takes up the challenges and opportunities that are ahead in the coming years.

W Peter Day
Chairman, on behalf of the Board of MS Limited
MS Peer Support Program: Dinner Peer Support Groups

MS peer support groups come in all shapes and sizes. Many peer support groups meet during the day however dinner groups are now becoming more popular to fit into our busy lifestyles. Dinner groups allow access to social support after hours as people who work or have commitments during business hours can attend. Kylie, who facilitates a group in NSW says “I find the dinner group has a very different feel to the more structured or large support groups. The smaller, intimate group feels more inclusionary”.

Dinner groups are a relaxed atmosphere where members can wind down after a long day and grab a glass of wine with dinner. If you are interested in starting a Dinner Peer Support Group in the ACT Region contact MS Connect on 1800 042 138 or email msconnect@ms.org.au and they can link you into the Peer Support team.

MS Education

These are the webinar programs running over August:

- **Webinar - Live Well with Multiple Sclerosis**
  Monday 13 August, 2.00pm – 3.00pm

- **Webinar - Get Active with MS: Falls Prevention**
  Tuesday 21 August, 10.30am – 11.30am

- **Webinar - Brain Wellness in Multiple Sclerosis**
  Thursday 30 August, 11.30am – 12.30pm

MS Nurse Advisor & MS Connect Information Specialist Visit 11 & 12 September 2018

Jane Bridgman MS Nurse Advisor will be offering clinic appointments at Gloria McKerrow House on the 11 & 12 September 2018.

Appointments can be organised through MS Connect 1800 042 138.

We will also have a team member from MS Connect joining Jane.
‘Live Chat’ to a MS Connect Team Member

Have you seen this red box pop up when you’ve been looking at the [www.ms.org.au](http://www.ms.org.au) website?

Did you know that when you click on the box and type your question this goes straight to a MS Connect Team member who will answer your query straight away in ‘real time’?

Jess says that Live Chat is a great way for people to contact MS Connect. ‘It can feel less rushed than a phone call and as you are typing questions and replies there is more time for people to think about what they want to ask. People can often engage in a ‘Live Chat’ when they are at work or doing something else on the computer, so they are not having to stop everything as you often need to for a phone call.’ Live Chat is available from our website during MS Connect business hours Mon – Fri 8.30am to 5pm. Ms Connect can also be contacted during this time on 1800 042 138.

You can also email anytime at msconnect@ms.org.au

MSS Group (previously Canberra under 30s)

**Event:** Mind and Body Relaxation and Yoga Session  
**Location:** Illeso Studio, 68 Bandjalang Cres, Aranda ACT 2614  
**Date:** Sunday 26 August 2018 at 1:00pm - 2:30pm

Join the newly named MSS Group for a free Yoga and mindfulness session.

Jayne has offered our group a wonderful opportunity to learn mindfulness techniques that can be used to reduce stress, anxiety and promote relaxation.

Jayne will briefly talk with us about mindfulness and teach a few techniques that can be used every day to reduce stress and anxiety. This will be followed by a beginner’s mind and body yoga class and relaxation.

If you have a yoga mat, bring it along. The session will go for 1.5 hours and we will aim to go for coffee after for those that are interested in staying later. Hope to see you all there,

RSVP to [www.facebook.com/mysafe.ms.space/](http://www.facebook.com/mysafe.ms.space/) or email mysafe.ms.space@gmail.com
FREE ASSISTED TOUR
at the National Gallery of Australia

American Masters 1940 – 1980
A Tour of American Masters for people of all abilities and their carers.
When: August 28 (Tues) 10.30am – 11.30am
Venue: Meet at information desk
Price: Free (bookings recommended) Phone: (02) 6240 6519


An opportunity to have your NDIS questions answered by Robyn Lang face to face and one on one at Gloria McKerrow House!

Are you under 65?
Do you want to learn more about the NDIS and whether you might be eligible for supports under the Scheme?
Do you want to get ready for a possible planning conversation?

Do you already have an NDIS plan?
Are you struggling to understand or activate the funding in your plan?
Do you know what to do if your needs have changed or if the funds in your plan don’t reflect your needs?
Do you want to know how to be well prepared for your annual review?

30-minute appointments available
Monday 27th August from 3.30 pm
Tuesday 28th August from 9.00 am

Please contact MS Connect on 1800 042 138 or email msconnect@ms.org.au by 17th August 2018. Places are limited so please RSVP as soon as possible. Please note if there are Insufficient numbers the sessions will be cancelled with seven days’ notice.
If you require personal care please ensure that you are accompanied by a carer.

Introducing Tulene McCabe

The MS Employment Support Service is now up and running in the ACT, with our first clients accessing the ACT service in July. Tulene McCabe, the Employment Support Consultant, is here to help people living and working with multiple sclerosis to maintain their employment. The service also helps people seeking new employment. Tulene will be out and about visiting people at their workplaces or wherever else they would like to meet. If you see Tulene, please say hello and have a chat if you’d like to know more. You can also find out more by calling MS Connect on 1800 042 138.
# Peer Support Group Meetings

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<tr>
<th>Group</th>
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<th>Contact</th>
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<tr>
<td>Cooma MS Group – Meet for informal lunch get-togethers</td>
<td>First Wednesday of the month</td>
<td>Jacqueline on <a href="mailto:snowymount.ms@gmail.com">snowymount.ms@gmail.com</a></td>
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<tr>
<td>People with MS</td>
<td>Last Friday of each month</td>
<td>Mary Webb on <a href="mailto:denmar@netspeed.com.au">denmar@netspeed.com.au</a></td>
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<td>Taking Control</td>
<td>Meets: Second Saturday of the month at Gloria McKerrow House 2pm to 4 pm</td>
<td>Contact: Vanessa Fanning <a href="mailto:vanessa.fanning@gmail.com">vanessa.fanning@gmail.com</a></td>
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<tr>
<td>Canberra Café Group</td>
<td>Meets: Second Friday of the month at 10 am</td>
<td>Contact: Virginia on <a href="mailto:vjfergus@iinet.net.au">vjfergus@iinet.net.au</a></td>
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<tr>
<td>MS Side Steppers</td>
<td>10am (30 to 60-minute walk), differing locations around the ACT</td>
<td>Jenn on 0403 759 188 to find out where the walk will be starting from</td>
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<td>MSS Group Weekend MS Café Group (Formally Canberra under 30s) Group for younger people living with multiple sclerosis</td>
<td>Email <a href="mailto:mysafe.ms.space@gmail.com">mysafe.ms.space@gmail.com</a> or join us on Facebook <a href="https://www.facebook.com/mysafe.ms.space">https://www.facebook.com/mysafe.ms.space</a></td>
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<td>Canberra HSCT for MS Support Group People who have had stem cell treatment for MS are sharing their experiences with those wishing to learn more</td>
<td>First Friday of the month 5-7pm at Gloria McKerrow House</td>
<td>Nicola 0448 138 381 or Facebook page: Canberra HSCT for MS Support Group</td>
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<tr>
<td>Batemans Bay/Moruya</td>
<td>Eurobodalla Support Group – call Peter Glen on 0411 597 133</td>
<td><a href="http://msact.freeforums.net">http://msact.freeforums.net</a></td>
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<td>Anywhere</td>
<td>Local ms online forum</td>
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# Seeking Volunteers with Primary Progressive Multiple Sclerosis

We are a research group based at the John Curtin School of Medical Research (JCSMR). We are investigating immune responses in people with multiple sclerosis (MS), in particular primary progressive MS. In collaboration with The Canberra Hospital we are looking at the function of white blood cells (neutrophil granulocytes). We believe that these cells may play a part in the development of the disease and our aim is to understand this better with a view to informing future studies.

**What do we need?** Study participants will be asked to attend a research clinic appointment at JCSMR or Canberra Hospital. This will involve finding out about clinical details and performing a physical examination of the nervous system. We will also ask for a blood sample which will allow us to perform a DNA analysis as well as to determine neutrophil activity.

If you are potentially interested or would like further information, please email: [netsmsresearch@anu.edu.au](mailto:netsmsresearch@anu.edu.au) or phone Dr Anne Brustle on 02 612 59009. The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (protocol 2015/079), and by ACT Health Human Research Ethics Committee (protocol ETH.1.15.015)
Taking Control of MS Group.

The next meeting of the Taking Control of MS Group is on Saturday 8 September 2018. From 2pm to 4pm at the MS Society, Gloria McKerrow House.

The guest speaker will be Dr Jane Desborough from the ANU MS Grand Challenge Research Project.

Jane will talk about the arrangements that are being put in place to enhance and embed communication between the project’s researchers and people with MS. She will also be telling us about the plans for case studies and research projects that will be seeking voluntary participation from PwMS.

Contact: takingcontrolgroup@hotmail.com

Community Consultation Forum

We would like to thank all the members who attended the first of our Community Consultation Forums.

You provided us with some valuable feedback and we are currently in the process of collating all the information that was discussed and we will publish more information in our September issue of this newsletter.

New Faces in the Office

For these members who have not met me yet, I though as part of the next few newsletters I would include a photo to introduce you to our staff here at Gloria McKerrow house so I have started with myself.

I am Heather Perry and I am the new Business Support Officer and I work Monday to Friday from 9.00 am to 4.00pm, you can find me in office 7. Please drop by and say hello when you are at Gloria McKerrow House.
"Dance For Wellbeing - come and try a free class!!"

- @ Belconnen Arts Centre, Fridays, 12 – 1pm

You've probably heard of it, "Dance for Wellbeing". In fact, last year the Belconnen Art Centre ran a couple of dance sessions at Gloria McKerrow house on which this program is based. The event was very well attended and enjoyed by people with MS. What you may not know is that the Belconnen Arts Centre has developed the concept in to a yearlong program tailored specifically to people with neurological and immunological conditions such as MS. What's particularly great about the program is it gives you the opportunity to get some exercise, connect your mind with your body and have fun socially, all at the same time.

It doesn't matter whether you use a wheel chair or not, whether you have good balance or not and you don't even need to have danced before. Things happen at your own pace, all that's needed is a desire for a little fun.

I reckon this is such a good idea that I am going to do it myself. And the Belconnen Art Centre have made a very generous offer. Normally the sessions cost $5 each, but for a limited time, anyone who is eligible to join in can have 1 session for free as long as they accompany me. All you have to do is email me at cti@iinet.net.au saying you want to attend on any of the following dates 10 & 24 August 2018 and 7 & 21 September 2018

If you have difficulty getting there let me know. If you can get to my house or even to Gloria McKerrow house I may be able to give you a lift.

Ricochet – Dance for All (Dance for Wellbeing ACT)

Ricochet is the focus of a weekly dance class at Belconnen and Tuggeranong Arts Centres, designed for adults with physical challenges. People who experience Multiple Sclerosis, Chronic Pain, Chronic Fatigue, RSI, Arthritis or other various physical challenges are especially welcome to attend, with carers if required. Please note this is not a social dance class and it does not require you to come with a partner.

Term 3 – 23 July to 28 September 2018
Cost: $5.00 per person, per class pay on the day. Companion Card holders receive free admission for a support companion
Contact
Locations and Times:
Belconnen Arts Centre - 118 Emu Bank, Belconnen on Fridays 12 pm – 1 pm
Tuggeranong Arts Centre – 137 Reed Street, Greenway on Wednesdays 10 am – 11 am

New Activities for Gloria McKerrow House
New Groups: Is anyone interested in having a Book Club, video afternoon or bridge afternoon? Any other suggestions? We would love to hear from you.
What would you like to see more of in our monthly newsletter? You can contact Katrina via email: Katrina.chisholm@bigpond.com we look forward to hearing from you with your views and suggestions.