



# Canberra Region Newsletter

## October 2018

### MSL Annual General Meeting 2018



Will be held in Melbourne on 24 October @ 5.00pm at the Nerve Centre 54 Railway Road, Blackburn and papers have been mailed out to financial members

### What's in this newsletter?

- Annual General meeting
- National Gallery Visit
- Go For Gold Celebration
- Peer Support Dates
- Grand Challenge
- The Health Economic Impact of Multiple Sclerosis

**Save the Date...**  
**WEDNESDAY**  
**5th December 2018...**  
**more information soon**

### Mindfulness Meditation Practice Group

A mindfulness Meditation Practice Group meets at Gloria McKerrow House on the last Friday of every month from 10.30 am to 12 noon.

It is an informal group and attendees can bring along their favourite guided meditations or the group may engage in silent meditation depending on the mood of the group on the day.

Newcomers who are interested in practicing meditation with a group or who want to know more about meditation are always welcome.

Contact [Vanessa.fanning@gmail.com](mailto:Vanessa.fanning@gmail.com) or Richard Wilmott at [lisrich@gmail.com](mailto:lisrich@gmail.com) to register to be on the mailing list for this group

### National Gallery of Australia

The upcoming assisted tour dates for people of all abilities and their carers:

- ◆ Spring Program Thursday 25 October 2018, 10.30 am — 11.30 am.
- ◆ International Day of People with Disability Wednesday 28 November 2018, 10.30am –11.30am

These tours are free and bookings are recommended by phoning 02 62406519 or email [access@nga.gov.au](mailto:access@nga.gov.au)

## Go For Gold



Congratulations to our 2018 Go For Gold Scholarship Winners Jo (left) who won a Scholarship in the Employment category and Nerida who won a scholarship in the travel category. The award ceremony was held at Gloria McKerrow House on 4 September

The Go for Gold Scholarship Program is funded by the MS 24 Hour Mega Swim, which is a fun team relay swimming event established by MS Ambassador and gold-winning Paralympian Carol Cooke. The first swim was held in 2001 at the Fitzroy Pool in Victoria and raised \$22,000.

Thank you to the Canberra community of 19 teams (300 participants) who swam over the 24 hour, to raise \$67,485. After the Go for Gold scholarships are awarded the residual money is allocated to the Financial Assistance program.

## Financial Assistance Program

The program aims to provide one-off financial assistance to promote quality of life and help with health-related concerns where no other funding program is available. Funding is available for MSL registered clients only. Applications can be submitted directly by the applicant or by Health Professionals on behalf of the MSL client. Ring MS Connect for more information on 1800 042 138

## i-FIMS Research Study September Update



The i-FIMS research study in the region has now reached the half way mark with 50 participants taking part in the study in the Canberra region. Thank you to all who have expressed interest and are taking part. We are hoping to reach 100 people in the region. The i-FIMS study is recruiting 500 people living with MS across Sydney, Canberra, Melbourne and Tasmania.

The i-FIMS research study is investigating whether using a home based step training program for six months can reduce the risk of falling and improve balance and cognitive abilities. The interactive stepping games are fun and engaging and participants report enjoying playing them. We are looking for more participants if you would like more information about taking part please contact Sophie Robinson at [ifims.canberra@neura.edu.au](mailto:ifims.canberra@neura.edu.au), 0400 988 531 or drop by office Eleven at Gloria McKerrow House

### Webinars and other Education Events

Webinar Topic	Day	Date	Time
Working with Multiple Sclerosis	Tuesday	9 October	6.30pm-7.45pm
Grief and Loss	Wednesday	24 October	11.00am-12.00pm
My Aged Care – Services & Support for people over 65	Tuesday	30 October	2.00pm-3.00pm
NDIS Information Sessions	Various dates via Webinar		

For more information please email [education@ms.org.au](mailto:education@ms.org.au) or call MS Connect on 1800 042 138.

<b>MS Peer Support Groups</b>		
<b>Group</b>	<b>Meets</b>	<b>Location</b>
<b>MSS Group (previously Canberra under 30s)</b>	3rd or 4th Saturday of each Month	Various
<b>People with MS Support Group</b>	Last Friday of Each Month, except December, 12.30 pm – 2 pm	Gloria McKerrow House
<b>Batemans Bay – Eurobodalla MS Peer Support Group</b>	1 <sup>st</sup> Thursday of month 11.30 am – 1.30 pm	Various
<b>Cooma/Berridale Peer</b>	1 <sup>st</sup> Saturday of each	Various
<b>MS Peer Support Groups</b>		
<b>MS Side Steppers Walk-</b>	Wednesdays, weekly	Various
<b>HSCT For Ms Support</b>	1 <sup>st</sup> Friday of month	Gloria McKerrow House
<b>MS Café Group</b>	2 <sup>nd</sup> Friday of Month 10.30 am	Various
<b>Ms Art &amp; Craft Group</b>	Fortnightly on Fridays 12.30 pm – 2.30 pm	Gloria McKerrow House
<b>Taking Control of MS</b>	2 <sup>nd</sup> Saturday of month	Gloria McKerrow House
<b>Mindfulness / Meditation Practice Group</b>	Last Friday of Each Month, except December, 10.30 pm – 12.00 pm	Gloria McKerrow House
<b>Tele Groups</b>		
<b>Men's Support Group</b>	1 <sup>st</sup> Thursday of month 1.30 pm – 2.30 pm	Telephone
<b>Women's Support</b>	4 <sup>th</sup> Monday of month	Telephone
<b>Women in 40 – 64 Group</b>	3 <sup>rd</sup> Tuesday of month 10.00 am- 11.00 am	Telephone
<b>Over 65's Group</b>	1 <sup>st</sup> Tuesday of month 10.30am – 11.30 am	Telephone
<b>After hours group for</b>	2 <sup>nd</sup> Wednesday of month	Telephone
<b>Family and friends</b>	1 <sup>st</sup> Tuesday of Month	Telephone
<b>Mum's with MS Support</b>	2 <sup>nd</sup> Tuesday of month	Telephone
<b>General Support Group</b>	1 <sup>st</sup> Monday of month 11.00 am to 12.00 pm	Telephone
	2 <sup>nd</sup> Monday of month 7.00 pm – 8.00 pm	
	2 <sup>nd</sup> Tuesday of month 7.00 pm – 8.00 pm	
To register your interest, please contact MS Connect™ Free call 1800 042 138 or email <a href="mailto:msconnect@ms.org.au">msconnect@ms.org.au</a> .		

## Our Health in Our Hands

### The Australian National University's Grand Challenge to investigate how personalised medicine can address major global health challenges

#### From Dr Jane Desborough

In 2017 our team of clinicians and researchers from five ANU Colleges was selected from approximately 40 highly competitive and diverse applications to be funded for its highly innovative research. Our aim is to investigate and demonstrate how personalised medicine can address major global health challenges, focusing on multiple sclerosis and diabetes as case studies. Global health challenges include: rising costs, inequality in access to health care, an increasing prevalence of chronic disease, and issues associated with the health system's 'one-size-fits all' approach.

Our Health in Our Hands aims to focus on these health challenges by:

- Creating actionable personalised genomic and phenotypic datasets that provide the information to drive decision making in the clinic, and promote discovery of disease mechanisms;
- Effective data sets that will drive the development of portable and / or wearable technologies that can assist with diagnosis and / or disease management; and
- Using a co-design research implementation approach, collaborating with patients, clinicians and health services, to investigate and develop person-focused digital medical technology solutions for diseases, focusing on diabetes and multiple sclerosis (MS).

The research group consists of four teams: 1. Genomics; 2. Technologies; 3. Big data (machine learning); and 4. Patient Experience and Implementation. These teams will work closely with cohorts of people with MS and diabetes.

#### *The Patient Experience and Implementation Team*

Our team will use a collaboration and co-design approach to incorporate patients' perspectives and leadership, health services and policy engagement from inception to implementation. In addition, it will investigate ethical and cybersecurity issues associated with data, explore decision-making between clinicians and patients, identify ideal devices from a user / patient perspective. Mapping the landscapes of care for patients and the ACT's current health system ecosystem will inform change management initiatives.

#### *We need your help!*

Your knowledge of your illness is essential for us to get the research right for our project. With this in mind, we have set up a variety of ways in which you can be involved, which is outlined in the table below. In the first instance we are keen to hear your stories.

**Focus groups:** We will be starting our focus groups in November and December 2018.

**Filmed vignettes:** We would love to hear your stories, whether they are about your diagnosis, experiences of access and communication with clinicians, what symptoms bother you the most, what you would like to see come out of this research.

**Brains trust:** If you would like to advise on research or our findings, but are not sure of your ongoing capacity, this may be the role for you. Members of the Brains Trust will provide advice on research and its interpretation, and may be able to come and go from this role through the life of the program. If we come up with unusual challenges, we will contact members of the Brains Trust to help us solve them. This will be a virtual group - that is, will communicate by email and/ or Skype or Zoom at times.

Participation	Details
<b>1. Patient Advisory Committee</b> - comprised of members from the following organisations:  The Consumers' Health Forum The Health Care Consumer Association ACT MS Society Diabetes Australia ACT Health	Approximately six meetings per year  Two MS members
<b>2. Research Team</b>  a) MS research partners x2  b) Brains trust (large number of people required)	a) Meet with research team to plan/ discuss research  b) Brains trust – virtual group of PwMS to consider specific issues. Communication mostly by email.
<b>3. Research Participants</b>	a) Focus groups <ul style="list-style-type: none"> <li>- developing a model of research collaboration for PwMS and researchers</li> <li>- ethics and cybersecurity of personalised medicine;</li> <li>- health knowledge – use of websites/ Apps</li> </ul> b) Navigating care journal/ storytelling workshops  c) Interviews – use of current devices/ technologies  d) Co-design of technologies with scientists  e) Filmed interviews and discussions for the OHIOH website – filmed by us or by you.

If you would like to be a part of our project, please contact:

Dr Jane Desborough Email: <a href="mailto:jane.desborough@anu.edu.au">jane.desborough@anu.edu.au</a>  Phone: 02 6125 6545	or	Dr Anne Parkinson Email: <a href="mailto:anne.parkinson@anu.edu.au">anne.parkinson@anu.edu.au</a>  Phone: 02 6125 1908
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## The Health Economic Impact of Multiple Sclerosis in Australia 2017 report

The report commissioned by MS Research Australia and prepared by the Menzies Institute for Medical Research, University of Tasmania, was launched on the 28 August and can be found on the MS Research Australia site:

<https://msra.org.au/news/ms-economic-impact-report-launch/>

Major points were:



The number of people living with **MS in Australia** increased by **just over 20%** from 21,283 in 2010 to 25,607 in 2017.



**103.7 people per 100,000** have MS in Australia.



The percentage of people using disease modifying therapies (DMTs) in 2017 **increased by 40%** compared to 2010.



The latitude gradient of MS prevalence continues to persist with the prevalence of **MS highest in Tasmania (TAS)** at **138.7 per 100,000 people**, almost double that of Queensland (QLD) at 74.6 per 100,000 and Western Australia (WA) 87.7 per 100,000.