



Canberra Region Newsletter

February 2019

John Studdy Award

The late John Studdy was a tireless advocate for the multiple sclerosis community in Australia and was dedicated to advancing the wellbeing of people living with MS and the search for a cure. The John Studdy Award is Multiple Sclerosis Australia's most prestigious Award, given annually, This annual award recognises outstanding consistent and selfless provision of meritorious service to people living with MS, at either National or State/Territory level.



The standard of this service is to be of such high-status that 'the nominee has made, or is making, a tangible difference' for the benefit of people living with MS and/or their families or carers.

The Canberra region community is very proud that Dr Mary Webb has been awarded the John Studdy Award by MS Australia. Dr Webb has served the ACT and National MS Communities as a volunteer for 16 years in many capacities. The full citation of all Dr Webb's achievements and contributions on behalf of the MS Community can be found on the MS Australia website.

Dr Webb is pictured here with Sandra Walker, General Manager, Service Innovation .

Financial Assistance

While we have all enjoyed the Christmas break, we understand this this can put pressure on budgets. Through a number of donors, trusts, foundations and money raised from mega swims, across the organization

we are able to offer some one-off financial assistance to promote quality of life and assist with health-related concerns, where no other funding program is available.

If you have a need for assistance, whether it be for a small item such as a grocery voucher, gift card to buy some necessities, or petrol card to get you through or larger items such as assistance with cooling, aides or equipment please give **MS Connect on 1800 042 138** to discuss your need and how we can help.



The MS Dream Car Lottery was launched on Wednesday 9 January and is selling very fast.

The MS Dream Car Prize Package includes:

Grand Prize – Your choice of a Mercedes Benz AMG GLC 63S OR \$170,000 in Gold.

Early Bird Prize – Your choice of an amazing Canadian Holiday OR \$20,000 in Gold.

The link to the website is msdreamcarlottery.com.au

An information night for those who are newly diagnosed and their family and friends with Dr Ronak Patel



Maintaining health and wellness is vital for people living with chronic health conditions.

There are many aspects essential to living a healthy lifestyle including exercise, symptom management, medical management and education.

This information session is specifically for those who are recently diagnosed with MS their families and friends.

Join us for an informative evening focusing on what MS is, how it is diagnosed, disease process, symptoms and treatment. You will also have an opportunity to speak with one of our MS Nurse Advisors, Bridie Phillips and hear from Katie Malone from the MS Connect team, who will present on MS Services

**Tuesday 19 February 2019
6.00pm – 7.30pm**

Please arrive 5.30 to check in

Gloria McKerrow House
117 Denison Street, Deakin

[Click here to register online*](#)

Or call **MS Connect on 1800 042 138**
***Registrations close: 12 February 2019**



Free Movie Tickets

We have had a lovely donation of some Adult and Children's movie tickets for **Events Cinemas** that are valid until **31 March 2019**.

Should you like a free movie ticket or two (max 2), please contact Heather on 62347000 or email: ACTenquiries@ms.org.au to secure your tickets.

Taking Control Group Meeting – Guest Speaker

We are starting the year with a guest speaker who will be of interest to many of you. Jude King representing Pain Australia will be addressing the meeting on :
Saturday 9 February 2019 at 2.00 pm.

Jude is a specialist in pain management and in particular strategies for living with chronic pain.

It would be helpful for planning purposes if you could let me know if you plan to attend by emailing Vanessa.fanning@gmail.com .

Peer Support and Self Help Groups

Please find below the ACT Peer Support and Self-Help Groups currently meeting in and around the ACT. Telegroups, that run over the phone are also listed. To register your interest, please contact MS Connect™ Freecall 1800 042 138 or email msconnect@ms.org.au.

Peer Support Groups

My Safe Space (MSS) for young PwMS (under 35s)

Bi-monthly, first Saturday of the month. Next meeting is on Saturday 2 February 2019.

People with MS Support Group, Deakin

Last Friday of Every Month, except December

Batemans Bay - Eurobodalla MS Peer Support Group

1st Thurs of month, 11.30am–1.30pm

Cooma/Berridale Peer Support Group

1st Saturday of each month, time and venue varies



Self Help Groups

The MS Side Steppers Walking Group, Canberra

Weekly, every Wednesday morning, 9.30am in various locations across Canberra.

HSCT for MS Support Group, Deakin

1st Friday of each month, 5.30pm-7pm

MS Café Group

3rd Friday of each month, 10.30 am

Taking Control of MS Group, Deakin

2nd Saturday of each month, 2pm–4pm

Art Group, Deakin

Weekly, Every Second Friday Afternoon, 12.30pm – 2.30pm

Mindfulness Practice Meeting, Deakin

Monthly, Last Friday of Each Month, 10.30am – 12pm.



Telegroups

Current Telegroups:

- **Men's support group** First Thursday of the month – 1.30pm to 2.30pm
- **Women's support group** Fourth Monday of the month – 12.30pm to 1.30pm
- **Women in 40 to 64 group** Third Tuesday of the month – 10am to 11am
- **Over 65's group** First Tuesday of the month – 10.30am – 11.30am
- **After hours group for working people** Second Wednesday night of the month – 7.00pm to 8.00pm
- **Family and friends telegroup** First Tuesday of the month – 7.30pm to 8.30pm
- **General support groups** First Monday of the month – 11am to 12pm Second Monday of the month – 7pm to 8pm Second Tuesday of the month – 7pm to 8pm
- **Mums with MS support group** Second Tuesday of the month – 1pm to 2pm

Upcoming Telegroups:

[Greek Speaking Telegroups for People living with multiple sclerosis](#)

Fourth Monday of the month – 11am to 12pm. Telegroup is starting in February 2019.

Coming to Canberra 19 & 20 February 2019

Meet MS Nurse Advisor, Bridie Phillips and MS Connect Specialist, Katie Malone
Book an appointment via MS Connect on 1800 042 138

MS Connect Specialist
Katie Malone



Hi everyone,
I have been working in the disability and healthcare industry for 4 years with a background in Speech Pathology and most recently experience working for the National Disability Insurance Agency (NDIA) as a planner.

I have a passion for working with Neurological conditions and was honoured to be able to come and work with Multiple Sclerosis and join the MS Connect Team.

I will be joining Bridie on the 19 and 20 of February where I can discuss with you MS supports and services, queries around the NDIS, navigating resources and any other MS related matters you would like to speak about.

Please call MS Connect on 1800 042 138 if you would like to book in for an appointment with me.

I look forward to meeting you all for my first visit to Canberra.

MS Nurse Advisor
Bridie Phillips



Hi everyone
I have been a Registered Nurse since 1983 and have committed the last 12 years to community health, predominantly in palliative care, pain management and within the MS community

Currently, Jane Bridgman and I work as the MS Nurse Advisors in MS Connect and one of us is available to speak to Monday-Friday during business hours on 1800 042 138.

Jane and I are available for phone support, skype or facetime, and we offer face to face clinics in rural NSW, Vic and in ACT through the Nurse Advisor @ program in the community.

I enjoy sharing my knowledge and experiences within the community and showing compassion for all age groups. It is a privilege to be invited into an individuals personal story, to listen, support and advise to the best of my knowledge.

If you would like to come and meet me while I am in Canberra and discuss anything MS i.e. medications, symptoms, and general health and well being, please call MS Connect to book an appointment.

Weekly Restorative Dru Yoga Classes at Gloria McKerrow House

Mondays: 11.00 am—12.30 pm with Barb

Wednesdays: 5.45pm – 7.15pm with Karen

Dru Yoga Term 1 of 2019 will commence on Monday 4 February 2019 (11.00 am – 12.30 pm) and

Wednesday 6 February 2019 (5.45 – 7.15 pm)

The cost for these classes is \$20.00 per session.



Do you get hungry but are too fatigued to prepare food, here are some healthy snack ideas

- ◆ Rice crackers and hummus dip
- ◆ Protein/ bliss balls
- ◆ Seaweed snacks
- ◆ Nuts, especially walnuts and almonds
- ◆ Pumpkin and sunflower seeds 4



Education Update

Sharing the MS Health Professional Program with Your Health Care Team

Did you know that MS also delivers education programs and provides resources for your health care team?

Webinars

We have a range of webinars designed to improve the knowledge and clinical skills of your team. Your team may include one or more of the following professionals: Occupational Therapists, Doctors, nurses, exercise physiologists, speech pathologists, dietitians, physiotherapists, allied health practitioners and personal care assistants.

The 2019 Health Professional Calendar has a superb range of webinar based programs presented by subject matter experts. Everything from MS101, Managing Your Client's Fatigue, Neurophysiotherapy and Self Care for Health Professionals – there really is something for every practitioner. Our programs add to their Continuing Professional development and accreditation.

If you think that a practitioner in your team would appreciate some further information about multiple sclerosis then please give them the following link and they can see what is available to them in 2019 to book into:

<https://www.ms.org.au/support-services/ms-education-programs/health-professionals.aspx>

InForm Health Professional Newsletter

Your health team may also be very interested to know of the monthly Health Practitioner e-newsletter called InForm. InForm has details of all upcoming health professional webinars, useful research links, e-book recommendations and resources for Health Practitioners. They can subscribe to InForm, by clicking on the link below, and that way they will stay informed about all things multiple sclerosis.

<https://www.ms.org.au/support-services/education/publications-resources/inform-eneewsletter.aspx>

MS Shop

If your Health care professional would like to purchase a recording of a webinar they can head to our shop:

<https://shop.ms.org.au/collections/professional-development>

Coming in March 2019
Go For Gold Scholarshipmore
information in the next newsletter.



My Safe Space (MSS)

The **My Safe Space (MSS) for Young PwMS Peer Support Group** is social in nature. It's a safe space for young people living with MS to connect with and support each other, share experiences, discuss challenges, ask questions and talk non-MS things.

"We're a friendly and supportive bunch!"



When	Bi-monthly, First Saturday of every month Next Meeting Saturday 2 February 2019
Where	Different Coffee shops/venues in ACT
Register	By calling MS Connect, 1800 042 138 or msconnect@ms.org.au

Have you had a Fall or a Near Fall?

You may be surprised to learn that approximately 50 to 60% of people living with multiple sclerosis will have one or more falls in a 12 month period. Research shows, perhaps surprisingly, that the majority of falls actually occur inside the home.

The fear of falling can also lead people to severely restrict their day-to-day activities. We want to equip you with the information you need to manage and prevent this.


As you may know, many of your symptoms can contribute to the risk of falling, such as balance and mobility impairments, ankle joint contractures, muscle weakness, poor concentration and forgetfulness, urinary urgency and fatigue. **Understanding exactly which combination of symptoms poses the greatest risk is absolutely crucial to designing effective interventions to prevent falls.**

We recommend both aerobic and strengthening exercises, at least two times a week, to reduce fatigue, improve mobility, and reduce the frequency and possibility of falling. There is also evidence that balance can be improved by functional exercises both individually prescribed or in a group exercise class. Exercises that improve balance, leg and core muscle strength and also incorporating stretching have been found to reduce your risk of falling.

If you would like to know more about preventing falls please contact MS Connect on 1800 042 138 or msconnect@ms.org.au. There is plenty you can do to help prevent falls. MS has recently added some resources to the website. www.ms.org.au

Learn more: publications and resources

[Practical, everyday advice: Falls](#) 

[Poster: What to do if you fall](#) 

[Home Safety Check List](#) 

[Home Safety Action Plan](#) 





“Our Health in Our Hands - Health Experience Team wins an MS Research Australia Incubator grant”

The Our Health in Our Hands (OHIOH) – Health Experience Team received a prestigious MS Research Australia Incubator grant, announced on Wednesday 23 January. This grant enables the OHIOH Health Experience Team to begin their MS health experience project next month. The MS Health Experience Team is unique, in that People with MS (PwMS) are actively involved within the project as researchers.

It will combine the medical expertise of scientists with the real-life experience of people who live with MS, in the hope of finding better, more personalised treatment. It is also aimed at breaking down communication barriers between scientists and patients.

Vanessa Fanning and Katrina Chisholm who both live with MS are active members of the MS Health Experience Team that includes Dr Jane Desborough, Associate Professor Christine Phillips, Professor Robyn Lucas, and Dr Anne Parkinson.

Dr Desborough and Associate Professor Phillips spoke to the “Taking control group” in September 2018, inviting PwMS to participate in focus groups, become a member of the Advisory Board, and participate in a “Brains Trust”, to share their knowledge and experiences of living with MS. Dr Desborough and Associate Professor Phillips will be attending the Taking Control Group meeting on the 9th February.

The announcement of the grant generated a great deal of media interest including three television interviews, an in depth interview for the ABC’s AM program on Wednesday morning and other radio interviews throughout Wednesday, as well as an article in The Australian. Dr Desborough, who leads the project, has invited PwMS to participate and has since received a number of calls from PwMS willing to participate. It is heartening to see such interest in MS research that actively involves PwMS. More information can be found at <https://science.anu.edu.au/news-events/news/ms-patients-produce-ms-research-anu>