



Canberra Region Newsletter

May 2019

Have your say! Nationwide research project launched

MS Australia is conducting a landmark, nationwide 'Consumer Insights' investigation. This project consists of two online surveys designed to understand the needs of both people living with MS and carers in Australia.

We need your involvement to help us describe what the future will look like for services, focusing on the needs and demands of people with MS.

We're looking to reach as many people as possible. You may also hear about this project via the state/territory MS organisations who are working with us.

Your insights will help to plan appropriate services going forward.

HOW TO PARTICIPATE:

We invite you to participate in this research by completing one of the two surveys, which ask about your views and experiences as a person living with MS, or as a carer for a person living with MS.

Each survey takes around 20 minutes to complete and will be open for at least six (6) weeks from Wednesday 27 March 2019.

Please also share these 'Consumer Insights' surveys with your carers and networks to help us get a full picture.

If you have queries please email: info@msaustralia.org.au with 'Consumer Insights' in the subject line.



24 Hour Mega Swim This Weekend 4-5 May

The **Canberra MS 24 Hour Mega Swim**, hosted by Australian Institute of Sport (AIS) is happening on 4 – 5 May.

The MS 24 Hour Mega Swim is a fun team relay event, suitable for any level of swimmer. You can set yourself a challenge or simply get involved with a few laps, in support of people living with multiple sclerosis across Australia.

Each team has a swimmer in the water for the entire 24 hours and competes for laps swum and money raised for MS.

You still have time to sign up for this awesome day out! Are you with us?

Register, donate or volunteer today at www.msmegaswim.org.au or contact us on 1300 733 690.

Thank you!

**MS WALK
+ FUN RUN**

ACT | NSW | TAS | VIC | 2019

The **Canberra MS Walk + Fun Run** was held on 31 March and was a fantastic day out for all involved! Families, kids (and don't forget pooches) ran or walked for MS in the most successful event yet. Our incredible participants **raised nearly \$114,000** to provide vital support services for people living with MS – surpassing our fundraising goal by over **\$40,000!** We look forward to seeing you next year.



To celebrate World MS Day on May 30 we have plenty in store to support the global campaign which this year is focused raising awareness of the invisible symptoms of multiple sclerosis. The

hashtag #MyInvisibleMS is your ticket to finding people and content on sites such as Facebook, Twitter and Instagram so you are up-to-date with what is happening around the world on World MS Day.

We are encouraging all the community to 'Wear Red' on World MS Day and if you need to jazz up your outfit don't forget to check out our MS lapel pins and ribbons which you can purchase at www://shop.ms.org.au/collections/doitforms

Let us help YOU to celebrate World MS Day

If you're interested in putting together your own activity, big or small, get in contact with Erin via communityfundraising@ms.org.au or on 03 9845 2825 and she'll help you make something magic happen for this big occasion.

We need you

The MS Ambassador program is on the lookout for new applications in Canberra.

To be a successful MS Ambassador, you need to be a person living with multiple sclerosis who is interested in sharing their personal story and experiences with the wider community.

The role of an MS Ambassador includes public speaking engagements, media appearances and event appearances on behalf of MS.

You should be comfortable with public speaking, confident in presenting to large groups of people and passionate about educating people about multiple sclerosis.

You can learn more about the program [here](#), and take a look at our current ambassadors [here](#).

If this sounds like something you'd like to do, we want to hear from you! Please [email](#) us a small paragraph about why you are interested in being part of the program, along with your contact details. Applications will be open until all spots are filled.

Webinars For May

Managing Spasticity in MS

Monday 13 May
11.00 am—12.00 pm

“Let’s Think about Your Thinking - An Interactive Session with Dr Luke Smith”

Wednesday 15 May
11.00 am - 12.00 pm

Fatigue Management in MS - General Strategies

Friday 17 May
11.00 am - 12.00 pm

Speech and Swallowing in MS

Tuesday 21 May
11.00 am - 12.00 pm

Mindfulness by Webinar - Focus on Pain

Mondays 14 October to 2 December
1.00 pm - 2.00 pm

NDIS Information Sessions

Various Webinars and workshops

To register your interest, please contact MS Connect™ Freecall 1800 042 138 or email msconnect@ms.org.au.



2019/20 Entertainment Membership

To support MS please visit our page <https://www.entertainmentbook.com.au/2321u5>

PLEASE NOTE: These books are not available from our Deakin Office



Do you know about our Employment Support Service in ACT

If you are currently working but feel as though multiple sclerosis is impacting on your ability to work, we can provide assistance and advice that will help you maintain your employment. Our MS Employment Support Service team are Leanne Neasey and Gillian Kennedy

Whatever your symptom(s) may be, Leanne will be able to assist you to identify the individual barriers you are experiencing at work and develop strategies to help you to remain at work. She can also prescribe adaptive equipment to reduce the impact of your symptoms and help you stay in the work force.

If you are currently not working and would like support in seeking new employment, Gillian may be able to assist you to identify suitable jobs, support you to write a resume and practice interview techniques. Once you have found a job we also provide ongoing support to help you maintain your employment.



Leanne is an Occupational Therapist and has worked in a number of hospitals and organisations throughout ACT and NSW. She has worked in both the Health sector as well as the Occupational Rehabilitation sector giving her a wealth of understanding about how to assess a work role and implement strategies to support a person to maintain their role.



Gillian has over 25 years of experience in the Employment Services Industry as well as her extensive experience background in disability employment services, community development, counselling and education. Gillian's role is to offer support and practical advice to clients living with a diagnosis of multiple sclerosis who are looking to return to the workforce.

For further information please contact us at MS Connect on 1800 042 138 or pop into the office to say hello.



Have you heard of Podcasts well welcome to our Podcast series
“Not Alone – brought to you by MS”

In each episode we will be exploring some common multiple sclerosis symptoms and wellness topics and importantly providing you with some practical strategies to improve your overall health and wellbeing.

You can find these on the MS website under Support & Service, Education & Wellbeing tab. The great thing is you can download them and listen to them when it suits you. If you require any assistance accessing or listening to the podcasts. please email the team at: education@ms.org.au.

2019 MS Go for Gold Scholarship Program Applications Now Open



What is Go for Gold?

MS Go for Gold Scholarships are open to people living with multiple sclerosis who wish to achieve a dream. The program is funded by our MS 24 Hour Mega Events, with each scholarship being up to \$3000 in value.

This is an opportunity to kickstart whatever dream it is you'd like to achieve, under categories including employment, the arts, lifestyle & wellbeing, sport, travel, music and education. Go for Gold dreams can be big or small and anything in between.

Applications closing date Friday 31 May 2019:

Visit our website www.ms.org.au and search for Go for Gold
Email goforgold@ms.org.au or Call MS Connect 1800 042 138

Our Health In Our Hands Research Update

Thank you to everyone who was able to take part in the focus groups we conducted in March this year. We held a third focus group in Cowra with the MS peer support group there. The information generously provided in these focus groups has been valuable in helping us to understand what people value in relation to collecting and sharing their health data.

We are preparing for our next body of research, which has been funded by MS Research Australia. This research will help us to develop a model of collaboration for people with and affected by MS, and researchers. There will be five opportunities for participation in this research.

The first workshop is on **Saturday 1 June, 2019, 10.15 am - 2.15 pm at the ANU in Acton.**

This workshop is an innovative exercise in sense-making. We want to understand what the key challenges are for people affected by MS in engaging with researchers as equal partners. The fun part is getting a cartoonist to draw your ideas and you are welcome to keep the cartoons afterwards.

If you are interested and would like more information, please call Anne on 02 6125 1908 during work hours or email anne.parkinson@anu.edu.au.



2019 MS Symposium –Newcastle Live Streaming World MS Day 30 May

While the event being held in Newcastle has sold out you don't need to miss out, it will be live streamed! The Newcastle Symposium brings together a range of expert speakers to inform, educate and inspire you. Speakers include Prof Jeannette Lechner-Scott: Neurologist and Researcher, Dr Luke Smith: Neuropsychologist Dr Cassie Nesbit: Neurologist and MS lifestyle expert.

You will hear about the latest treatments and approaches to managing MS, be inspired to consider the benefits of lifestyle changes and good nutrition, be empowered by some of the thinking and memory strategies presented to improve your performance.

If you would like to join the Event via live streaming go to the **MS Website for more information.**

Watercolour Course For People With MS (6 classes) Wednesdays, 8 May to 12 June 2019

About the course

We will explore the wonderful technique of water colour as well as studying some Australian artists to produce a small painting at the end of each class. Every week we will look at an Australian artist and study their use of colour and what devices they used to create. Students are invited to bring a photo, either on their phones, or a print, to explore the weeks artist. No experience necessary and all levels of experience catered for. There is a limit of 10 people in this series, so book in fast!

About the Artist

Nicolette Black is a visual artist and educator, whose art practice bridges sculpture, textiles, painting and drawing using recycled objects, often in repeated, exploring memory and place, every so often from an aeroplane's viewpoint. Nicolette trained at the Australian National University and has a BA Visual Arts. Having taught at many institutions, Nicolette's main tenure includes Belconnen Art Gallery, Goulburn Regional Gallery and as a guest tutor in the papermaking department at the Australian National University. Nicolette has exhibited nationally and internationally including in New York, USA and Bologna, Italy.

Location: Gloria McKerrow House, 117 Denison Street, Deakin
Time: 10.00 am to 12.00 pm
Cost: \$30 for the 6-week program (*All materials provided*)
Contact Details: MS Connect (Freecall) 1800 042 138 or email msconnect@ms.org.au



Did you know that peer support is scientifically proven?

“Much evidence supports that peer support is a critical and effective strategy for ongoing health care and sustained behaviour change for people with chronic diseases and other conditions, and its benefits can be extended to community, organizational and societal levels.” (extract from UNC School of Medicine). It is great to learn from others that have been where you are or sharing the same journey. A person that truly ‘gets you’. Peer supports comes in many forms, for MS we have one to one phone support with a matched peer volunteer, peer support groups that meet face to face and groups that connect over the phone, and the benefits extend to everyone involved, these include:

- increased knowledge of multiple sclerosis and ways to cope with the challenges
- Empowerment to become more self sufficient
- Improved self-reported health care and outcomes, becoming more proactive
- Improved mental health and improved life expectancy.

If you would like to get involved or more information about the Peer Support Program including Face to Face groups that are located more rurally please contact MS Connect on 1800 042 138 or email msconnect@ms.org.au

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.

MS Peer Support Groups

Young People Living With MS (under 35s)

Bi-monthly, first Saturday of the month.

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 Wednesday of each month, time and venue varies

Self Help Groups

The MS Side Steppers Walking Group, Canberra (Please note - updated meeting place)

Weekly, every Wednesday Morning, 10 am at Carpark in Bowen Park on Bowen Drive, Kingston ACT

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.

MS Peer Support 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
- **Greek Speaking Telegroups for People living with multiple sclerosis** Fourth Monday of the month – 11am to 12pm. Telegroup start date to be advised, please register interest with MS Connect.