



Our Vision Find a cure, minimise the impact

2019 MS Art Exhibition



Expressions of Interest and entries for the **2019 MS Art Exhibition** are now open.

This year we will be inviting entries from NSW, ACT, Tasmania and Victoria. People with multiple sclerosis and/or other progressive neurological conditions are welcome to apply.

Art forms can include **paintings, illustration, photography, textiles, digital, jewelry, pottery, sculptures and more!**

The entry form with the terms and conditions can be downloaded from www.ms.org.au/art.

Entries will close at 5pm 7 June 2019.

The Barry Allen Art Award and other awards will be announced at the launch on 8 August.

For more information contact MS Connect on 1800 042 138 or email msart@ms.org.au



Our CEO John Blewonski officially launched the Understanding MS Massive Open Online Course (MOOC) in Hobart at the beginning of May.

MOOC is an innovative way to help anybody with an interest in MS understand the disease.

The MOOC is part of the Menzies MS Flagship Program, which recently was awarded \$10 million in federal government funding for its collaborative research working with the wider MS community, nationally and internationally, towards better prevention, treatment and ultimately a cure for multiple sclerosis.

You can head over to Understanding Multiple Sclerosis - MS to learn more about the course.

Congratulations to our friends and partners at the UTAS Menzies Institute on the successful launch of the MOOC!

Canberra Wellness Dinner—13 June 2019

Maintaining health and wellness is vital for people living with chronic health conditions. MS endorses a holistic approach to living a healthy lifestyle that includes a focus on exercise, fatigue and stress management and nutrition. We have invited nutritionist Ms Nicola Graham, to present the latest nutritional research in a fun, easy to follow and direct manner, busting myths and providing clear information.



Thanks to generous sponsorship come and join us for a fun, interactive and informative session and enjoy a healthy dinner while learning the latest about nutrition.

When: Thursday 13 June 2019 6.30 pm - 8.30 pm. Please arrive at 6.00 pm to check in.

Where: Raiders Belconnen, Hardwick Crescent, Holt ACT 2615 (Venue is wheelchair friendly)

To book: [Register Online](#) or call MS Connect on 1800 042 138 for more information. Places are limited and registrations close: Monday 10th June 2019. Proudly supported by Merck.



MS is now delivering the Community Visitors Scheme in the ACT

It is wonderful to see this program up and running with the appointment of Kerri Marie, as the Program Coordinator for the ACT. Kerri brings with her a warm presence and genuine enthusiasm for the program.

For older people many issues can impact on community involvement, sense of value and wellbeing. Loneliness and a sense of isolation are common issues for older people. The Community Visitors Scheme helps to address loneliness and social isolation by bringing together volunteers who want to spend time with a lonely member of the community as a friend. They may go for a walk, go out for a cuppa and generally enjoy each other's company. Visits are fortnightly however they can be weekly too.

We are very pleased that our funding has been increased to include the ACT. If you have a family member or friend living in an aged care home that would benefit from our program, please submit a referral either online <https://www.ms.org.au/get-involved/volunteer/community-visitors-scheme/recipient-online-referral-form.aspx> or contact via MS Connect 1800 042 138.

If you are interested in becoming a Community Visitor, please send an application either online <http://www.ms.org.au/get-involved/volunteer/apply-to-volunteer/cvs.aspx> or contact via MS Connect 1800 042 138.

Did you know that exercise is a great way to maintain your mobility, improve your balance and understand you body better?

Exercise is proven to be one of the best things you can do for yourself to manage your MS symptoms.

Every Thursday morning there are 2 classes available to you at Gloria McKerrow House.

Be Better Balanced is a chair base class for people still able to walk but struggling with balance, stamina, and general movement difficulties. The classes are well rounded and paced, making them fun and accessible. We currently have a wonderful group of people attending and have made some more space for new members to join in.

This is followed by **Wheels In Motion** which is a class designed for people in wheel chairs or who are having difficulty walking. In this class the focus on upper body mobility as well as making use as of motorised exercise bikes for those it suits. This is a small group and where possible individual work is done on each person to mobilise leg movement.

Eli Haski has been teaching these classes for the past few years and for more information please contact Heather at Gloria McKerrow on 6234 7000.

Dream Home Lottery Update

Following on from the success of last years raffle in April we launched the Dream Home Lottery in Victoria and it has had a great response.

We have already had some very happy winners with the early bird and bonus prizes. The grand prize is again the choice of a house or gold bullion, more information is on our website www.ms.org.au

The Neuro Carers Network

In conjunction with Carers ACT, we have started a new support group, The Neuro Carers Network, for family and friends who are carers of people with multiple sclerosis, motor neurone disease or other conditions that effect the nervous system and are sharing some similar experiences.

For more information please contact support.groups@carersact.org.au or phone 6296 9975.

Next Meeting

Monday 3 June 6.00 pm - 8.00 pm
Gloria McKerrow House, 117 Denison St, Deakin



Your GP & You

Keeping an eye on your general health is important

“MS is not exclusive, don't forget all the normal health checks such as:

- ◇ Mammograms
- ◇ Pap smears,
- ◇ Prostate checks
- ◇ Skin checks.
- ◇ Vaccinations
- ◇ Bowel checks

Speak with your GP at your next appointment to make sure you are up to date and to discuss your options for maintaining your health.



Webinars For June

Talking to your Kids about MS

Thursday 13 June 11.00 am - 2.00 pm

Disease Modifying Medication in MS

Wednesday 19 June - 1.00 pm - 2.00 pm

Sleep Well with Multiple Sclerosis

Wednesday 17 July - 11.00 am - 12.00 pm

Mindfulness by Webinar focusing on pain

(8 Weeks) 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.



NDIS Update

Did you know that we can support you to prepare for accessing the NDIS?

This includes helping you source evidence, pre-planning and meeting with the NDIS for your planning meeting. In addition, we provide support coordination to people with plans.

We are currently calling out to all of our registered clients under 65 to discuss what the NDIS is and how to access it.

If you need any assistance, or have any questions, please call MS Connect on 1800 042 138

MS 24 HOUR MEGA SWIM

The **Canberra MS 24 Hour Mega Swim** was held on 4-5 May on our Mega Weekend, where we had Swim and Squash events also running in Melbourne at the same time! Over 200 superstar swimmers took on the team relay challenge of swimming for a 24-hour period, raising \$47,056 and counting.

Thank you to everyone involved in making this epic event possible, from volunteers, fundraisers, donors, participants and the amazing MS Events Team! We couldn't do it without you and look forward to everyone getting involved again in 2020.

You still have time to donate to the MS 24 Hour Mega Swim at www.msmegaswim.org.au

Research Update



First Disease Modifying Therapy approved for use In Children With Multiple Sclerosis.

On the 1 May it was announced that Gilenya (fingolimod) has been approved by the TGA (Therapeutic Goods Administration) for younger people with multiple sclerosis. 5% of multiple sclerosis diagnoses occur in children, some as young as two years of age.

Until now they have been treated with adult MS medications in an 'off-label' way with little information about the safety and side effects relating specifically to children. New evidence about good outcomes in use of Gilenya in children through multicentre trials, has led to the TGA approval and is the first licensed treatment for children and adolescents in Australia.

Gilenya (fingolimod) in children is not currently approved by the (PBAC) Pharmaceutical Benefits Advisory Committee for listing on the Pharmaceutical Benefits Scheme (PBS) for subsidy, it is hoped that after the July meeting of the PBAC that this will be the case.

MSRA has explained the criteria the PBAC considers and how members of the MS community can make submissions in support of the application for Gilenya (fingolimod) and another multiple sclerosis treatment, Tysabri to be subsidised through the PBS to provide safer treatment choices for children, as is accessible for adults with multiple sclerosis.

<https://msra.org.au/news/gilenya-approved-for-children/>

https://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form

Tai Chi by Webinar



The education team regularly run six week programs of Tai Chi by webinar.

The program has enabled people from across the country to attend in the comfort of their own homes, or wherever they have a working internet connection.

Tai Chi is a centuries-old mind-body practice that involves performing sequences of slow, flowing motions. It's usually done standing, but many of the movements can also be done while sitting.

There are many benefits of Tai Chi including improving balance, lowering blood pressure and improving cardiovascular health.

If you are interested in attending one of these six week programs, please contact MS Connect on 1800 042 138 to register to receive our education updates by email or keep an eye out on our "coming events" on our website - www.ms.org.au - and search upcoming programs. We also have an introductory webinar on tai chi which is available in our webinar library.

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.