



### ACT kids encouraged to join the 43<sup>rd</sup> Annual MS Readathon



Daisy, 5, and Elodie, nearly 3, Duffill, with some of their books. Picture: Keegan Carroll

The 43rd MS Readathon has opened registrations for 2021 - encouraging Australians to jump off social media and dive into a good book, all for a good cause.

Last year, sign-up numbers in the ACT more than doubled from 380 in 2019 to 889 in 2020. So, we are calling on ACT kids and families to get involved again to go even better.

The annual [MS Readathon](https://www.msreadathon.org.au) inspires kids to read as much as they can throughout August to raise vital funds for the 25,600 Australians living with multiple sclerosis and their family members. Simply visit [www.msreadathon.org.au](https://www.msreadathon.org.au) to register for free to take part in the campaign.

Showing everyone the way are Theodore sisters Daisy and Elodie Duffill. Daisy is only five and Elodie nearly three but, with the help of their parents, they have already raised \$3,300 participating in the last three MS Readathons. Last year, their parents Rebecca and Blake read the girls 100 books. <https://www.facebook.com/watch/?v=206959958015921>

They were the highest fundraisers in the ACT last year and are on a mission to read 103 books - Daisy's exact goal. Rebecca said losing a friend who had been diagnosed with MS has contributed to the family's commitment to the MS Readathon. "We thought it would be a good way to honour her and we just wanted to introduce the girls to fundraising and encourage them to help others," she said. "And they love to read."

Elodie's favourite book is Pingu Hides a Letter, while Daisy loves the Little People Big Dreams series, especially the one about Coco Chanel. Rebecca said they were focused on teaching Daisy to read this year. "All children love books and I think if you nurture that, it can really develop into a lifelong thing and encourage their learning as well," she said.

Elizabeth Dorizac, Senior Manager, Individual Giving at Multiple Sclerosis Ltd, said fundraising would contribute to supporting people living with MS and their families through funding services like MS family camps and fun days. The camps provide an opportunity for kids who have a parent living with MS to spend quality time with their family, learn more about the condition and bond with other kids who are sharing their journey.

Kids, adults, and schools are encouraged to register for the MS Readathon challenge today at [www.msreadathon.org.au](https://www.msreadathon.org.au).

See Daisy's video here: <https://www.facebook.com/watch/?v=206959958015921>



Applications now open



**MS Go for Gold Scholarships** provide one-off grants to follow a personal dream.

Applications for the **2021 MS Go for Gold Scholarships** are now open.

There are 25 scholarships available, each valued up to \$2,000 and applications close 15 September 2021.

This is your chance to kick-start that dream you have.

The MS Go for Gold Scholarships are made possible from the generous supporters of the MS Mega Challenge events.

To find out more information visit [www.ms.org.au/go-for-gold](http://www.ms.org.au/go-for-gold)

## Telegroups

**Under 30s Telegroup** [Click Here](#) First Thursday night of every month, 6.30pm – 7.30pm

**After hours group for working people** Second Wednesday night of the month, 6.30pm - 7.30pm

**Mums with MS support group** Second Tuesday of the month, 1.00pm - 2.00pm

### Men's support group

First Thursday of the month, 1.30pm - 2.30pm

Last Tuesday of the month, 12.00 noon - 1.00pm

### Women's support group

Fourth Monday of the month, 12.30pm - 1.30pm

### Women in 40 to 64 group

Third Tuesday of the month, 1.30pm - 2.30pm

### Over 65's group

First Tuesday of the month, 10.30am – 11.30am

Second Tuesday of the month, 10.30am – 11.30am

### General support groups

Second Monday of the month, 7.00pm - 8.00pm

Second Tuesday of the month, 7.00pm - 8.00pm



## Meditation Group

As we are all living in stressful times, some of us are stepping up our meditation practice and our online meditation sessions are proving popular.

The Mindfulness Meditation Group is meeting weekly on Fridays at 3.30 pm by Zoom for about an hour to chat and then to do a guided meditation.

(All suggestions welcome)

If you're not receiving alerts and an invitation for the online Meditation Group meetings at the moment and would like to be advised when sessions are being scheduled, please contact: Vanessa Fanning via email:

[vanessa.fanning@gmail.com](mailto:vanessa.fanning@gmail.com) or Richard Wilmott via email: [lisnrich@gmail.com](mailto:lisnrich@gmail.com)



## An opportunity to participate in research to improve health and wellbeing for people with multiple sclerosis

We are focusing on recruitment for the ACT MS Cohort Study in 2021, and now have over 50 participants enrolled! Our goal is to recruit 100 participants this year (50 people with MS and 50 people without MS), so we would love for you to consider if you would like to participate in this study.

As part of the Our Health in Our Hands (OHIOH) project, researchers at the Australian National University are working together to improve the clinical management and overall health and wellbeing of people living with multiple sclerosis (MS).

A foundational part of the OHIOH project is establishing the ACT MS Cohort Study. In this study we will recruit people with MS as well as people who do not have MS. We aim to have a similar distribution of age and sex across the two groups, and collect new data each year to see changes over time. By collecting data over time in people with MS and people who do not have MS, we will be able to compare the two groups to answer questions about health and wellbeing, how that changes over time, and whether and how having MS affects health and how this changes over time.

### What does participation involve?

You need to be 18 years old or over either with MS or without a diagnosis or any known signs of MS. For people living with MS, participation will occur within one month of your appointment with your treating doctor/neurologist. Once you provide consent, all participants will be asked to:

- Complete online questionnaires that include information about background, medical history, psychological health and wellbeing and diet.
- Complete measures of current health including blood pressure, height, weight and functioning e.g., rating muscle weakness, limb mobility, balance, speech, body sensations and visual function.
- Provide a blood sample.

Once the baseline appointment has been completed, participants will be asked to attend an annual follow-up appointment that is similar to the baseline appointment. If a person living with MS experiences a relapse between their annual appointment, they will be asked to attend a follow-up appointment.

### Find out more!

Contact **Dr Jo Lane** on **02 6125 1485**

Or email: [jo.lane@anu.edu.au](mailto:jo.lane@anu.edu.au) Or go to the Our Health in Our Hands website at:  
<https://www.anu.edu.au/research/research-initiatives/our-health-in-our-hands>

This study has been approved by ACT Health and ANU Human Research Ethics Committees (ETH.2019.00081 and 2020/047 respectively).

# Let's make your work life ...work better for you!



- Get strategies to make work more manageable
- Support through exercise, healthy eating, pain, mental health, mobility and work station setup
- Free for you and your employer

We're here to make your work life better. We can support you to decide if, when and how to disclose MS to your employer.

Before you make a decision it's important to understand your rights, obligations, and also the impacts on your working life and environment.

For more information on the MS Employment Support Service call **MS Connect** on **1800 042 138** or email [msconnect@ms.org.au](mailto:msconnect@ms.org.au).



# People with MS (PwMS) Taking Control Group

Our group seeks to facilitate connections, sharing information and companionship among people living with MS in the Canberra region with the focus being on living well with MS. We host regular meetings twice a month. On the second Friday of each month we meet via Zoom. On the last Friday of each month we meet at Gloria McKerrow House (GMH). Meetings are at 12.30. We are doing our best to enable a Zoom link at the last Friday GMH meetings to allow our members, especially those who join us from rural and other interstate locations to fully participate and join the conversation from their homes. From time to time we also arrange coffee mornings or lunches for PwMS in various cafes around town.

In addition to our scheduled Friday meetings, we plan to arrange further meetings on a Saturday afternoon every 4 to 8 weeks to allow our members who are unable to join us on a weekday to join us. On Saturday July 17, we enjoyed a presentation from a Canberra Clinical Psychologist on cognitive assessments and cognitive rehabilitation for PwMS. We connected via Zoom as well as in person. If you would like to get timely updates on future gatherings and presentations and share news, information and feedback with us please subscribe to our mailing list by emailing your contact details to Mary Webb ([denmar@netspeed.com.au](mailto:denmar@netspeed.com.au)) or Vanessa Fanning ([vanessa.fanning@gmail.com](mailto:vanessa.fanning@gmail.com)). Or look for our page on Facebook: Canberra Region MSers.

We know that many people with MS do not necessarily wish to disclose their diagnosis, hence the names and email addresses of people who subscribe to our mailing list are strictly confidential and are not visible to any other recipients. In line with privacy principles, you can unsubscribe at any time.

## WEBINARS

### Art Demonstration - Painting my Journey with Multiple Sclerosis with Justine Martin

Monday 2 August, 11.00am – 12.30pm

Join MS Ambassador and successful artist Justine Martin to get all inspired and creative. Justine will take us on a journey by painting the story of when she was diagnosed with multiple sclerosis. She will demonstrate how a painting is created through each stage; from concept, to canvas, to paint and to finished product. All while sharing the story of being told she would never be able to work again to becoming a professional artist and successful business owner. You are welcome to stretch your artistic muscles during this program, so please have your blank paper, pencils or paint at the ready!

### Mindfulness and Relaxation by Webinar (Six-week program)

Thursdays from 19 August to 23 September, 10.00am – 10.45am

Mindfulness has roots in Buddhism, utilising a meditation technique that helps shift your thoughts away from your usual preoccupations and toward an appreciation of the present moment – facilitating a feeling of calmness and relaxation within yourself and a larger perspective on life. Join Nicola Graham, MS Education and Wellbeing Program Coordinator as she steps us through the practice of Mindfulness and Relaxation.

During this 6-week series, Nicola will take us through a little theory, lots of practice and opportunities for connection and for building resilience during these trying times.

### NDIS Hot Tips and Q&A - A Recording with Lauren Houlder

On demand – watch anytime!

Join MS NDIS Service Delivery Manager, Lauren Houlder for this informative NDIS Hot Tips and Q&A session.

Lauren will address all your NDIS related questions. Lauren will also give you her top NDIS tips to help you progress through your NDIS journey ensuring you get the maximum out of your NDIS plan.

### Minimising Stress and Maximising Mindfulness - A Recording with Nicola Graham

On demand – watch anytime!

Join MS Education and Wellbeing Programs Coordinator, Nicola Graham as she discusses the negative impact stress can have and encourage you to consider ways of minimising stress. She will introduce mindfulness as a way of helping to manage stress and lead a short session which we're sure you'll enjoy.



## MS GIFT PLANNING

*“Generous Janis leaves her loving mark on the world”*

Janis Salisbury  
MS Callistemon League

The MS community lost a good friend when philanthropist Janis Salisbury died in 2017. But the memory of her generous spirit and sparkling personality live on, thanks to a gift she left in her Will to Multiple Sclerosis Limited (MSL).

The Balmoral resident had a lifelong enthusiasm for giving — whether it was caring for patients through her nursing work or donating to her favourite causes helping people, animals and the arts. Janis inherited the generosity gene from her parents, successful businesspeople who believed in giving back. For Janis, giving was essential and personal. She wanted to help whenever she saw a need.

Even though Janis didn't need to work, she wanted to. She trained as a registered nurse and practiced for many years. She also had a busy social life but always made time to help those less fortunate than herself.

Stories of her generosity abound. One year, Janis and her mother drove to an area devastated by bushfires to comfort people whose homes had been destroyed. They provided cash to those who had lost everything. Another time, Janis helped a teenage girl whose parents could no longer afford her private school tuition. Janis paid the fees for the rest of the girl's secondary education.

“Multiple sclerosis particularly interested Janis. As a nurse, she understood the challenges ahead for people diagnosed with the disease. She wanted to be a caring friend and helping hand to people with MS, even beyond her own lifetime,” said Laura Henschke, strategic future planning manager, MSL.

Over the years, Janis frequently visited the MS Studdy Centre in Lidcombe to chat with staff and patients. She wanted to help MSL, a charity she regarded highly for its excellent support and services. Sadly, Janis died at the age of 75 after a brief illness.

“Janis is greatly missed and people with multiple sclerosis will always remember her with love. She left an indelible mark on our organisation. The generous gift in her Will has enabled MSL to transform many lives, and her legacy will benefit others for years to come,” said Ms Henschke.

**Your Will says a lot about you and how you can leave your mark on the world.** Could you be like Janis and be a caring friend, and helping hand, so people with multiple sclerosis lead better lives? Any gift, big or small, can make a difference.

Contact MS Limited for more information. You will discover how easy it is to leave a gift in your Will and what a difference it can make to your life and for those living with MS.

You could also become a member of the **MS Callistemon League**. This is a group of remarkable people committed to ensuring that those living with multiple sclerosis are not alone.

**Want to know more? MSL has a Gift Planning Program. Talk to Laura or Nikita on 1800 443 867, email [Futureplanning@ms.org.au](mailto:Futureplanning@ms.org.au) or visit [www.mymslegacy.org.au](http://www.mymslegacy.org.au)**

*We are here, so no one needs to face MS alone, now or in the future*

### Future Redevelopment of Gloria McKerrow House Update

Members of the ACT Community will be aware that the MSL Board has made an in-principle decision to undertake a future redevelopment of Gloria McKerrow House.

Updates will be provided to the ACT Community when planning for the project commences.

