

# THE MS COMMUNITY'S RACE AGAINST THE CLOCK

## EXPERTS BRING TO LIGHT CRITICAL EVIDENCE ON TIME AND SPEED IN MS

For the first time, MS Motion – a collaboration between the Australian multiple sclerosis (MS) community and world-leading clinicians, are urging those in early stages of MS to make 'time' a critical priority in the management of their disease, and to act as quickly as possible to help avoid likely irreversible brain damage.<sup>1</sup>

Influential members of the MS community including the Brain Foundation, global and local **MS experts Professor Gavin Giovannoni** (Chair of Neurology, Barts and The London School of Medicine and Dentistry) and **Dr. Chris Dwyer** (Neurologist, The Royal Melbourne Hospital), along with people across Australia living with MS, have come together to translate the confronting realities of the latest scientific research into practical, constructive resources for the MS community, particularly those in their twenties and thirties to motivate them to act quickly to protect their brain health. Brain volume loss can progress much more rapidly in MS patients than in healthy individuals – up to five times the rate.<sup>2</sup>

Initiative participant, 28-year-old Queensland primary school teacher, [Elise Osmand](#), states: "Waking up on my European holiday blind in one eye was actually a blessing in disguise. A terrifying experience – but it forced me to act – resulting in my MS diagnosis. I do however consider myself one of the lucky ones with a quick diagnosis – which is very unusual with MS<sup>1</sup> – and can sometimes take years. That's why the MS Motion campaign is critical – not everyone is so lucky and we need to ensure everyone with MS understands the need for speed to protect their brain from further damage."

The MS Motion social resources aim to expose the hidden side of MS, with emerging evidence showing that by the time a diagnosis of MS is reached – permanent brain damage has already taken place and therefore time is critical to have the best chance to stabilise the disease.<sup>1,3</sup>



The resources are based on the latest scientific research and equip Australians with the knowledge and understanding to protect their brain health in relation to MS.

10 Australians are diagnosed with MS every week<sup>4</sup> and they are usually young adults (75% are women)<sup>4</sup> in the prime of their lives (average age 20 to 40 years old)<sup>4</sup> with decades of employment and important decisions ahead of them, such as starting

families. Acting fast is therefore crucial to maximise their chances of successfully managing the disease and going on to enjoy a good quality of life.<sup>1,6,7</sup>

"Great to be involved with this initiative and group of such well-informed and socially-connected people with MS who are clearly taking the message of "Brain Health: Time Matters in Multiple Sclerosis" to hear," said Professor Gavin Giovannoni. "It is clear that the true change agents in the MS space will be people with the disease and not necessarily us healthcare professionals or our politicians. This initiative reiterates to me that if I had MS I would want to live and have my MS managed in Australia."

Neurologist Dr. Chris Dwyer, stresses: "Presenting the MS community with the latest science in MS – which at times can be often challenging and scary – was a difficult task. But the incredible participants understood that it is crucial that the message 'time is brain in MS' is circulating, particularly with young Australians, in an effort to maximise their brain health and maintain a good quality of life as they age. For these people – every day, week and month is crucial in their ongoing fight against this crippling disease."<sup>8</sup>

Trevor Thompson, Brain Foundation CEO added: "It's crucial we get the word out there that people with MS should actively protect their brain health as much as possible. Our brains are unequivocally imperative to normal functioning in our lives – which is why as an organisation like the Brain Foundation is so supportive of the MS Motion campaign. With one in six people being affected by brain disease and related disorders in their lifetime – this touches the lives of far too many Australians. We must act swiftly."

To find out more information or to access the MS Motion resources visit:

[www.MSMotion.com.au](http://www.MSMotion.com.au)

The MS Motion campaign is funded by Biogen and supported by The Brain Foundation.

### **More about multiple sclerosis**

- MS currently affects over 25,600 Australians and there is no known cause or cure<sup>5</sup>
- Three out of four diagnosed with MS are women, with an average age of just 20 to 40 years old<sup>5</sup>
- It affects more young people than any other acquired chronic neurological disease in Australia<sup>5</sup>
- The annual per person cost for people living with MS with severe disability is incredibly high at \$114,813<sup>9</sup>
- The impact on the quality of life for people living with severe MS is comparable to, or even lower than, the reported impact on quality of life for terminal metastatic cancer, chronic kidney disease and severe heart disease<sup>9</sup>

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*For media enquiries, please contact Cameron Donald, Cube Public Relations, via [cameron@cube.com.au](mailto:cameron@cube.com.au) or 0424 785 063.*

## About Biogen

At Biogen, our mission is clear: we are pioneers in neuroscience. Biogen discovers, develops, and delivers worldwide innovative therapies for people living with serious neurological and neurodegenerative diseases as well as related therapeutic adjacencies. One of the world's first global biotechnology companies, Biogen was founded in 1978 by Charles Weissmann, Heinz Schaller, Kenneth Murray, and Nobel Prize winners Walter Gilbert and Phillip Sharp, and today has the leading portfolio of medicines to treat multiple sclerosis (MS), has introduced the first and only approved treatment for spinal muscular atrophy, and is focused on advancing neuroscience research programs in MS and neuroimmunology, Alzheimer's disease and dementia, movement disorders, neuromuscular disorders, acute neurology, neurocognitive disorders, pain and ophthalmology.

## About the Brain Foundation

The Brain Foundation is a nationally registered charity dedicated to funding world-class research Australia-wide into neurological disorders, brain disease and brain injuries.

Established in 1970 by neurologists and neurosurgeons, the Brain Foundation funds groundbreaking projects that aim to advance diagnoses, treatment and patient outcomes. The Brain Foundation annually provides research grants to candidates who are selected by eminent neurological practitioners.

## References

1. Giovannoni G, et al. Brain health: Time matters in multiple sclerosis. 2015 Available at: [www.msbrainhealth.org](http://www.msbrainhealth.org). Last accessed November 2020.
2. De Stefano N et al. Clinical relevance of brain volume measures in multiple sclerosis. *CNS Drugs*. 2014;28:147-156.
3. Sinay V, Perez Akly M, Zanga G et al. School performance as a marker of cognitive decline prior to diagnosis of multiple sclerosis. *Mult Scler* 2015;21:945–52.
4. Better Health Victoria. Multiple Sclerosis. Available at: <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/multiple-sclerosis-ms>. Last accessed November 2020.
5. MS Australia. Key facts and figures about multiple sclerosis. Available at: <https://www.msaustralia.org.au/about-ms/information-sheets>. Last accessed November 2020.
6. Kobelt G, Berg J, Lindgren P et al. Costs and quality of life of patients with multiple sclerosis in Europe. *J Neurol Neurosurg Psychiatry* 2006;77:918–26
7. Kobelt G et al. New insights into the burden and costs of multiple sclerosis in Europe. *Mult Scler*. 2017 Jul;23(8):1123-1136.
8. Doesburg D, Vennegoor A, Uidehaag BMJ, van Oosten BW et al. High work absence around time of diagnosis of multiple sclerosis is associated with fatigue and relapse rate. *Mult Scler Relat Disord* 2019;631:32-37
9. MS Research Australia. Health Economic Impact of Multiple Sclerosis in Australia in 2017. Available at: [https://msra.org.au/wp-content/uploads/2018/08/executive-summary\\_health-economic-impact-of-ms-in-australia-in-2017-report\\_ms-research-australia.pdf](https://msra.org.au/wp-content/uploads/2018/08/executive-summary_health-economic-impact-of-ms-in-australia-in-2017-report_ms-research-australia.pdf). Last accessed November 2020.