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Australians living with MS asked to tell their story

Australia's largest multiple sclerosis (MS) longitudinal study is looking for new participants.

The Australian MS Longitudinal Study (AMSLS) is a national collaborative survey platform run by the University of Tasmania's Menzies Institute for Medical Research and MS Research Australia.

The AMSLS started in 2001, and around 10% of people diagnosed with MS in Australia are currently taking part.

Longitudinal research involves following people over time, and the AMSLS tracks areas such as lifestyle, employment, other medical conditions, current treatments, medical costs and overall quality of life.

People at all stages of their MS journey are encouraged to help us make change by joining the thousands of Australians already telling their story through the AMSLS.

"It's vital that we have as many people as possible providing us with data, because that helps to ensure the most complete picture of what it is like to live in Australia with MS," Associate Professor Ingrid van der Mei, Project Manager of the AMSLS, said.

"People living with MS can have a positive impact by contributing just a few hours a year from the comfort of their own home.

"The study enhances our understanding of MS, which helps provide better services and support for people living with MS. It also provides the evidence we need to advocate for positive change for everyone living with the disease."

Since 2001, the AMSLS has revealed important information about MS in Australia, including an increase in the number of people living with MS from 21,283 in 2010 to 25,607 in 2017 (more than 20%), and that the

total costs for all people with MS have increased substantially over time from \$1.24 billion in 2010 to \$1.75 billion in 2017 (an increase of 41%).

Head of Research at MS Research Australia Dr Julia Morahan said, “the AMSLS has produced tangible benefits for people living with MS since its inception and with more people taking part, this will boost our ability to use the information to improve lives”.

If you or someone you know is over 18 years old and living with MS in Australia, please visit this website for more information: www.msra.org.au/AMSLS.

About multiple sclerosis (MS)

MS is the most common acquired neurological disease affecting young Australian adults, often diagnosed between the ages of 20 to 40, and affects three times more women than men. As yet, there is no cure.

MS is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged, this interferes with messages between the brain and other parts of the body. The symptoms of MS are different for each person; sometimes, they even vary within the same person. For some, MS is characterised by periods of relapse and remission, while for others, it has a progressive pattern. For everyone, it makes life unpredictable.

About MS Research Australia

MS Research Australia is the largest national not-for-profit organisation dedicated to funding, coordinating, educating and advocating for MS research as part of the worldwide effort to solve MS. Its goal is to accelerate research: into the cause, better treatments and prevention, with the aim of ultimately finding a cure for MS. MS Research Australia is the national research arm of the Australian peak body MS Australia. For further information visit www.msra.org.au

About the Menzies Institute for Medical Research

The University of Tasmania’s Menzies Institute for Medical Research exists to improve human health and well-being by performing excellent basic, clinical and population health research that focuses on the major diseases affecting the Tasmanian community. Our research takes a bench-to-bedside and disease prevention approach and is aimed at improving patient care and clinical outcomes for the community by translating knowledge into clinical and policy actions.

In 2017, the Menzies Institute established the MS Research Flagship, a hub of interdisciplinary MS research, knowledge, knowledge translation and support within the Menzies Institute, which builds momentum across the wider MS community, nationally and internationally, towards improving outcomes for people living with MS and ultimately curing MS.

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