MS AUSTRALIA

Year in Review

the year to 30 June

2019

A world without multiple sclerosis

Contents

Vision

A world without multiple sclerosis.

Mission

Working with and representing our member organisations to meet the needs of people affected with Multiple Sclerosis (MS), their families and carers. To improve their well-being through leadership in advocacy, communication, brand and collaborative relationships and, in collaboration with, and support for, MS Research Australia, advancing research into the cause, prevention and a cure for MS.

Who we are

Our purpose

On behalf of our members and people with MS, our purpose is to develop:

Research

Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.

Advocacy and Awareness

Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with this disease.

Communication and Information

Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member societies and our key stakeholders.

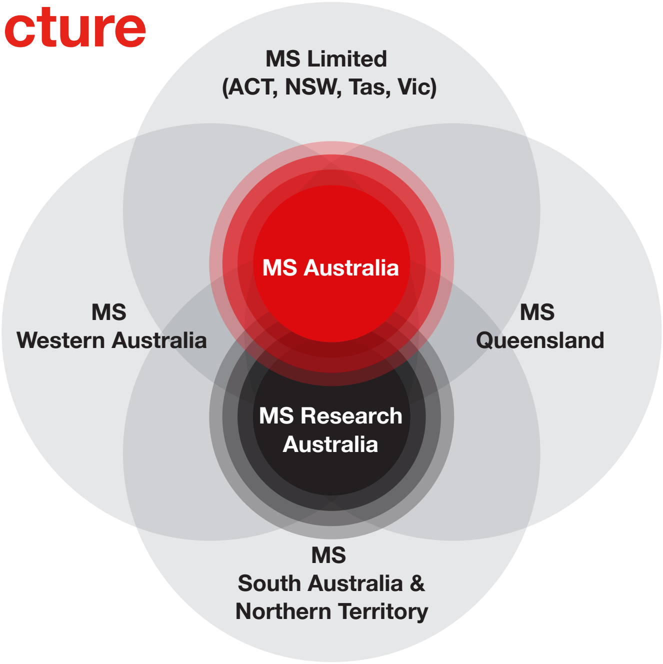
Support for our Member Organisations

As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.

International Collaboration

Representing the MS cause and promoting collaboration with our domestic and international partners.

Our MS family structure



The MS Australia Board

(for the period 1 July 2018 - 30 June 2019)

Mr Ron Brent

Mr Roger Burrell

Dr Annette Carruthers

Mr William Peter Day (President)

Ms Christina Gillies

Assoc Prof Desmond Graham (Vice-President)

Ms Christine Hahn

Ms Sophie Langshaw

Mr Paul Murnane

Mr George Pampacos

MS Australia staff

Deidre Mackechnie
Chief Executive Officer

Bea Beswick
Project Officer

Mark Campbell
National Digital Communications Officer

Patrick Foong
Finance Manager

Andrew Giles
National Policy Officer

Mary Michaliades
Executive Assistant

Lisa Montague
National Advocacy, Publications and Media Officer

Andrew Potter
National Advocacy Coordinator

Parliamentary Friends of Multiple Sclerosis

Purpose

The Parliamentary Friends of MS (PFMS) was established and is managed by MS Australia. It provides a non-partisan forum for MPs to meet and interact with volunteer advocates from the MS community and representatives from MS Australia, its member organisations in each state and MS Research Australia, on matters relating to raising awareness of the needs of people living with MS and opportunities to advance research into the cause, prevention and a cure for MS.

The Group is open to all Senators and Members and has no sponsorship from external organisations. It was formally registered with the 45th Australian Parliament in April 2017 and has ten members. The Group was re-registered with the 46th Australian Parliament, following the outcomes of the Federal Election held in May 2019.

The following Members of Parliament and Senators were members of the Group until the Federal Election was held in May 2019:

NAME	ELECTORATE/STATE
Senator Helen Polley	Tasmania
Senator Glenn Sterle	Western Australia
Senator Claire Moore	Queensland
Senator Rachel Siewert	Western Australia
Mr Andrew Laming MP	Bowman, Queensland
Ms Justine Keay MP	Braddon, Tasmania
Ms Amanda Rishworth MP	Kingston, South Australia
Senator Louise Pratt	Western Australia
Senator David Bushby	Tasmania
Senator Deborah O’Neill	New South Wales

Co-convenors

The PFMS was co-convened by Senator Deborah O’Neill (Labor, NSW) and Senator David Bushby (Liberal, Tasmania).


Senator Deborah O’Neill
(Labor, NSW)


Senator David Bushby
(Liberal, Tasmania)

Activities

Prime Minister, the Hon. Scott Morrison MP launched the MS Australia 2019 Election Commitments package at a Parliamentary Friends of Multiple Sclerosis event, in the Senate Alcove, Parliament House, Canberra, on Thursday 29 November, 2018.

The MS Australia 2019 Election Commitments package set out the **nine important ways our Federal politicians can help people affected by multiple sclerosis** (MS).

The package comprised the 2019 Election Commitments and three Roadmaps:

- A Roadmap to Defeat MS in Australia, with a focus on health and increased funding for research into MS
- A Roadmap to Support People with MS Living with Disability
- A Roadmap to Support People Ageing with MS.

(Note: Due to the formatting of these 3 PDF documents, please choose 'fit to page' or 'fit' when printing.)

MS Australia, on behalf of the broader MS community, sought commitments from all political parties and independents, to the nine initiatives in these Roadmaps that will each make significant improvements for people living with MS in Australia.

"There is no known cause or single cure, but there is now an opportunity for this generation of political leaders and decision-makers to consign MS to a foot-note in history," said MS Australia CEO, Deidre Mackechnie.

"We need a concerted effort to provide improved support for the management and care of MS, through systemic improvements to the health care, disability care and aged care sectors," added Ms Mackechnie.

Further details on how these improvements will be achieved are set out in the 2019 Election Commitments and the three Roadmaps.

MS Australia, with the support of those living with MS in Australia, pursued a commitment from all politicians to each of these improvements in the lead up to the 2019 Federal election.

L-R: Deidre Mackechnie (MSA CEO), Prime Minister, the Hon. Scott Morrison MP, Peter Day (MSA President) and Assoc Professor Des Graham (MSA Vice President).

Member of Multiple Sclerosis International Federation

The MS International Federation has 49 members and links to many other organisations.

The MS International Federation is the only global network of MS organisations. All of its members share a belief that the challenges in MS are worldwide, and the solutions must be too. It can be more effective and efficient by sharing its members' experiences and speaking with one voice.

MS Australia is an active member of the Multiple Sclerosis International Federation (MSIF).

MS Australia is pleased to be able to contribute to MSIF's planning for World MS Day each year and to make regular contributions to MSIF publications.

More details on our work with MSIF can be found under 'International Activities'.

MSIF member organisations:

What we do and Our achievements

National Advocacy

MS Australia is the national peak body for people living with MS in Australia. We work on behalf of all state and territory based member organisations to provide a voice for people living with MS to support the development of:

- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- Research through MS Research Australia
- International collaboration

MS Australia advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community, focusing on national issues.

MS Australia is an active member of other peak bodies in Australia such as the Consumers Health Forum, the Australian Council of Social Services, National Disability Services and the Neurological Alliance Australia, working collaboratively to advance the interests of people affected by MS.

National Advocates

Advocacy work is delivered through a range of activities including our National Advocates Program under the stewardship of our National Advocates Program Coordinator. The Program is delivered by a network of volunteer Advocates, who advance MS Australia annual priorities and reinforce our Mission and Purpose. Photos and bios of our current team of National Advocates can be found on the MS Australia website at https://www.msaustralia.org.au/about-MSA/who-we-are/advocates

The National Advocates Program recruits and trains people with MS, and carers, to be effective Advocates and participate in public policy debates. Mentoring, support and information sharing assists the MS Australia Advocates to participate in a wide range of activities. Through this Program, MS Australia makes regular representations to Federal parliamentarians, gains media exposure and makes submissions to Australian Government enquiries.

Make Our Stories Matter

In the weeks leading up to the 2019 Federal Election, we shared posts about each of the 9 ways our politicians could commit to helping improve the lives of people with MS.

We sent a copy of our 2019 Election Commitments package to all sitting parliamentarians and to the leaders of each of the major parties asking them to commit to our nine initiatives. We also sent the package to some high profile independent candidates asking them to commit too.

Our team of National Advocates met with candidates in their electorates to seek their commitment and support.

Prime Minister, the Hon Scott Morrison MP (centre) with MSA National Advocates (left-right); Mike Welsh, Lynda Whitton, Andrew Potter, Lynne Smith, Astrid Edwards, Dr Mary Webb, Bruce Frost and Suzanne Hadley.

National Advocate Lynne Smith (right) with ALP member for Dobell, Emma McBride MP.

National Advocate Astrid Edwards (left) with Greens MP for Melbourne, Adam Bandt MP.

National Advocate Dr Mary Webb (left) with Greens Candidate for Canberra, Tim Hollo.

National Advocate Jenny Wallis (second from right) with candidates for Braddon (left to right), Karen Spaulding (UAP), Phill Parsons (Greens), Craig Brakey (Independent) and Sally Milbourne (Nationals).

Living with Multiple Sclerosis in 2019

Nationwide research project

In March 2019, MS Australia conducted a landmark, nationwide 'Consumer Insights' investigation.

This project consisted of two online surveys designed to understand the needs of both people living with MS and carers in Australia. KPMG *was commissioned to undertake this research*.

We sought the MS community's involvement to help us describe what the future will look like for services, focusing on the needs and demands of people with MS. We were looking to reach as many people as possible.

MS Australia released findings of national research study: *Living with Multiple Sclerosis in 2019.*

The multiple sclerosis (MS) journey has changed significantly over the past decade with regard to diagnosis, treatment and management options and cost of the disease. These changes, coupled with the social, technological, policy and economic trends in Australia and overseas, have had a dramatic impact on the service landscape.

In some cases these changes and trends present challenges for the sustainability of existing business models and also provide the opportunity to redesign services to ensure people with MS, their families and carers receive the right support at the right time in the right place.

The MS family of organisations recognises the need to respond to these challenges using evidence about the specific and emerging needs of people affected by MS to support decisions about what, when and how to offer services.

To this end, MS Australia on behalf of its four State/territory member organisations (MSWA, MS Queensland, MS Limited [ACT/NSW/TAS/VIC] and MS Society of SA/NT) engaged KPMG to conduct independent research with people living with MS, their families and carers to better understand:

- The experience of people living with MS, their families and carers,
- The extent to which they are satisfied with current supports, services and information and any unmet demand, and
- The emerging services that are likely to meet their needs into the future.

The Report of these research findings has now been released. Incorporating well over 2,000 responses from a broad cross-section of the MS community across the nation, the Report provides a rich source of insight into the lives of people with MS, their families and carers and their needs at the various stages of their MS journey.

Among the key findings:

- 64% reported an effect on employment and ability to earn an income
- 27% (1 in 4 people) had an unmet service need
- 79% of people diagnosed with MS were taking a disease-modifying therapy (medication that modifies the activity of the immune system to slow the frequency and severity of attacks to the central nervous system)
- 69% of carers reported that caring has an impact on family and relationships.

Marcus Stafford, CEO, MSWA said,

> *"We've always known that the time of diagnosis is a 'ground zero' moment for people with MS and other neurological conditions. Knowing the specific information that newly diagnosed people are seeking at this incredibly emotional stage of their journey, helps ensure we provide the right services and support at the right level at the right time".*

Gerard Menses, CEO, MS Qld said,

> *"Carers play a vital role in supporting people living with MS. The research will help us provide better assistance to the thousands of unpaid carers who require the same first-hand advice, information and connection to supports, as people living with MS".*

Christine Hahn, Acting CEO, MS Society of SA/NT said,

> *"The MS community, like the broader community, are increasingly using technology to access information and in many cases, to monitor their disease journey. The Report tells us that for those not already using it, there are strong levels of interest (61%) in using technology to increase connectivity with service advice and support and to connect with peers. This helps us to build and expand these channels".*

John Blewonski, CEO, MS Limited (Vic, NSW, ACT and Tas) said,

> *"We know that MS has a huge impact on employment and incomes, and the finding of a 36% drop in full time employment for those still of working age (under 55 years) is significant. The impact on carer's capacity for employment (a drop of 30% in carers employed full time) is also significant. That's why we are committed to keep expanding our MS Employment Support Service, so people with MS can stay employed longer. Our team provides a range of support especially assisting with workplace arrangements and fatigue management."*

Deidre Mackechnie, CEO, MS Australia said,

> *"The Report will provide MS Australia with valuable evidence for its ongoing advocacy at the national level, with a particular focus on advocating for systemic improvements in the health, aged care and disability sectors. I would like to take this opportunity to thank all those people living with MS and carers who participated in this study – their insights will help us shape how we meet their needs into the future."*

Submissions

MS Australia seeks to develop strong networks and build relationships of influence with federal parliamentarians and other government and departmental thought leaders and decision-makers to raise awareness of MS, particularly systemic issues at the national level. To this end MS Australia makes submissions to national enquiries on issues that affect our member organisations and people living with MS.

In the year to 30 June 2019, MS Australia made submissions to the:

- Joint Standing Committee on the NDIS inquiry into the provision of assistive technology (a joint submission with MS Limited)
- Senate Select Committee Inquiry on Charity Fundraising in the 21st Century regarding the current framework of fundraising regulation for charities and options for reform
- Senate Standing Committee on Community Affairs inquiry into the My Health Record system
- NSW Parliamentary enquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales (a joint submission with MS Limited)
- Victorian Department of Health and Human Services Draft Disability Action Plan 2018-2020 – Consultation (a joint submission with MS Limited)
- NDIS Thin Markets Project
- Royal Commission into Aged Care Quality and Safety
- Queensland Government's Inquiry into the Health and Other Legislation Amendment Bill 2018 – Queensland Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (a joint submission with MS Research Australia)

Therapeutic Goods Administration (TGA) and Pharmaceutical Benefits Advisory Committee (PBAC)

MS Australia is particularly passionate about the provision of safe, affordable and accessible treatments that can improve the lives of people with MS. As with all MS medications, the efficacy, side-effect profiles and tolerability of a drug can vary greatly between individuals, and it is for this reason that a range of affordable treatment options is necessary to increase the chance of every individual finding an effective and well tolerated treatment that suits their individual circumstances.

MS Australia works with MS Research Australia and relevant pharmaceutical companies to make submissions to the TGA regarding the regulation of therapeutic goods including prescription medicines and PBAC for listing of MS medications on the Pharmaceutical Benefits Scheme (PBS) to ensure they are accessible and affordable.

One submission was made to the TGA during the year:

- TGA consultation: referral of proposed amendments to the current Poisons Standard to the ACMS, Joint ACCS-ACMS or ACCS meeting, November 2018, regarding Nabiximols

Two submissions were made to the PBAC during the year:

- Gilenya® (fingolimod) for Relapsing Remitting MS (RRMS) for patients who weigh 40kg or less including paediatric patients
- Tysabri® (natalizumab) for Relapsing Remitting MS (RRMS) for all ages

Neurological Alliance Australia (NAA)

The Neurological Alliance Australia is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or muscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and funding to support research. Members of the Alliance include Alzheimer's Australia, Brain Injury Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia and Spinal Muscular Atrophy Australia.

MS Australia plays a leading role in the Neurological Alliance Australia, with CEO Deidre Mackechnie chairing the NAA and National Policy Officer Andrew Giles providing secretariat support.

During this year, new members Leukodystrophy Australia and Polio Australia were welcomed to the Alliance, increasing the overall number of people represented by the member organisations. The members of the NAA continued to work collectively on a number of issues relevant to the work of each member organisation, and to the communities they serve.

John Studdy Award

The John Studdy Award is Multiple Sclerosis Australia's most prestigious Award, given annually, in recognition of outstanding consistent and selfless provision of meritorious service to people living with MS, at either National or State/Territory level, preferably over a period in excess of ten years or for other factors considered by the committee as worthy of the award. The standard of this service is to be of such high-status that 'the nominee has made, or is making, a tangible difference' for the benefit of people living with MS and/or their families or carers.

The late John Studdy was a tireless advocate for the multiple sclerosis community in Australia and was dedicated to advancing the wellbeing of people living with MS and the search for a cure. MS Australia's John Studdy award is for individuals who, like John Studdy, have made a significant contribution to the MS movement in Australia.

PREVIOUS JOHN STUDDY AWARD RECIPIENTS	
1999	Inaugural Winner – Yvonne Smith
2000	Mrs Thonad AM
2001	Elizabeth Ann Zanna Barron
2002	Ann Langley
2003	Jim Conway
2004	Graham Tribe
2005	Michael Stewart OAM
2006	David Conry
2007	Dr Leslie Sedal M.B, B.S., FRACP, M Ed
2008	Zona Tripp OAM
2009	Carol Cooke
2009	David Barnes
2010	Simon McKeon
2011	Bill Carroll
2012	Andrew White
2013	Carol and Roy Langsford
2014	Katrina and Mike Hemingway
2015	Lina Marrocco
2016	Therese Burke
2017	Dr Rex Simmons

We were delighted to announce that there are two recipients of the John Studdy award for this year: Ros Harman and Dr. Mary Webb.

Ros Harman

Ros Harman was first diagnosed with MS at the age of 26. Her early career included being a school teacher and a Human Resources and Training Manager for a medium-sized company. Many years ago Ros initiated and pioneered a parents' support group, and is widely felt to be an inspirational role model for people with MS and for women in particular.

She has served on the MSWA Board since 2004, and is an ambassador for MSWA, representing the organisation on all forms of electronic media and an active ambassador within political circles. Ros is the Vice President of the Board and the Chair of Member (Client) Services Committee and the Chair of the Research Committee. Her stewardship has led MSWA's position as the leading funder of MS research. Her past roles within MSWA have also included Editor of the MS Bulletin magazine and Director roles that included Fundraising.

Ros is a regular public speaker at events and functions, promoting the involvement and participation of people with disabilities.

Ros was unable to attend the announcement so her award was accepted by Marcus Stafford (MSWA CEO) George Pampacos (MSWA President) in her absence.

Dr Mary Webb

Mary was diagnosed with MS over twenty years ago, when her two children were babies. Since then, she has been actively involved with her local MS society and the wider MS community.

She has served the ACT and National MS communities as a volunteer for 16 years in many capacities.

Her official roles have included:

- Director of the MS Society of ACT (2002-2008)
- Vice President of MS Society of ACT (2003-2008)
- Member of the MSL ACT S/NSW Regional Advisory Board (2008-2017)
- Convenor of the ACT PwMS Group since 2008.

In 2006 she also began running the PwMS Group at Gloria McKerrow House, and continues to run it once a month; also providing some informal social support for several PwMS, and as Peer support volunteer (phone support.)

Other achievements in this area include being awarded the 2012 ACT Volunteer of the Year (through nomination by Mirimba Kovner/MSL), being made the ACT Disability Advisory Council member (requested to nominate by MSL) from 2011–2014, and as ACT Medicare Local Board (Consumer Director) (requested to nominate by MSL) from 2012–2014.

Mary is also a strong supporter of the role of MS Research Australia and is a member of the Steering Committee of the Australian Multiple Sclerosis Longitudinal Study which she joined in July 2014. In 2017, she also served as an Observer on Social and Applied Research (SAR) panel of the Research Management Council (RMC), and in 2018 as a Voting member of SAR panel of RMC.

Mary has been an active MS National Advocate for MS Australia since 2004. In this role, she has attended many MS Advocacy meetings at Parliament House Canberra and on occasions been a spokesperson, including media interviews, on behalf the MS Advocates Group.

As a person with MS, Mary has always and continues, in all her capacities, to support and share her wide knowledge and experience of MS with others affected by MS. She has willingly mentored, by telephone, other people living with MS who have sought support and advice, although they have not met face to face.

Pictured here on the right, receiving The John Studdy Award from MS Australia President, Dr. Annette Carruthers, on the left.

Mary has a background in biological research and science education, and currently works as a freelance editor. With this professional background, she feels strongly about educating people about MS, and also closely follows the progress being made in MS research.

Key Facts and Figures update

The launch of the Health Economic Impact of Multiple Sclerosis in Australia 2017 report, in August 2018 (commissioned by MS Research Australia and prepared by the Menzies Institute for Medical Research, University of Tasmania) enabled MS Australia to update its Key Facts and Figures fact sheet. The report is the first in nearly eight years to provide a comprehensive landscape analysis of MS in Australia. It shows how many Australians are now living with MS, the costs of the disease from an individual and societal perspective, and the quality of life indices for individuals living with MS.

Some highlights:

- There are now over 25,600 people living with MS in Australia
- MS is estimated to have cost the Australian community $1.75 billion in 2017
- In 2017, the average cost of MS per person was $68,382
- On average, in 2017, the quality of life of people in Australia is 31% less than that of the overall Australian population
- 64% of people with MS are using a disease modifying therapy, an increase of 40% since 2010
- The prevalence of MS in Australia in 2017 was 103.7 people with MS per 100,000 compare to 95.5 in 2010 (this increase reflects global trends and likely reflects the increased survival of people with MS)

To see the full, downloadable Key Facts and Figures document, please visit: www.msaustralia.org.au/about-ms/information-sheets

International activities

Multiple Sclerosis International Federation (MSIF)

MSIF is a unique global network of MS organisations with 49 members from around the world, with links to many others. Protecting and advocating for the rights of people with MS is at the heart of MSIF's work.

MSIF's advocacy objectives are:

- Increased global awareness of MS amongst the public and policy makers
- Increased policy impact and opportunities for MS organisations through international epidemiological and socioeconomic comparative research and action.

MSIF's approach to advocacy has these components:

- To provide member organisations with research reports, films and other resources to advocate for changes that benefit people with MS in their country.
- To take part in advocacy initiatives as part of networks and collaborations such as the International Alliance of Patients' Organisations and the International Pediatric Multiple Sclerosis Study Group.
- To help raise awareness of MS to create an enabling environment for members' advocacy and other work.
- To support advocacy through capacity building/ training in development of emerging national organisations.

Where and when appropriate, MSIF works with, or advocates to, global and international, bilateral/ multilateral bodies directly.

One of MSIF's strategic priorities is to support and encourage the development of new, emerging and existing MS organisations and groups through capacity building activities.

MSIF World Conference 2018 Report

As the Australian member of the Multiple Sclerosis International Federation (MSIF), we were honoured to be invited to participate and present at the recent MSIF World Conference in Rome.

Co-hosted by the Italian Multiple Sclerosis Society and MSIF, this six-day key event in the global MS calendar brought together top researchers, leaders from the international MS movement and people living with MS from all corners of the globe.

The 2018 conference was a chance to exchange skills, experiences and best practice, and to discuss the latest innovations in MS research, treatments and issues affecting quality of life for people living with MS, both in Australia and globally.

L-R: MS Australia CEO Deidre Mackechnie and National Advocate, Astrid Edwards about to present!

MS Australia at the MSIF World Conference October 2018

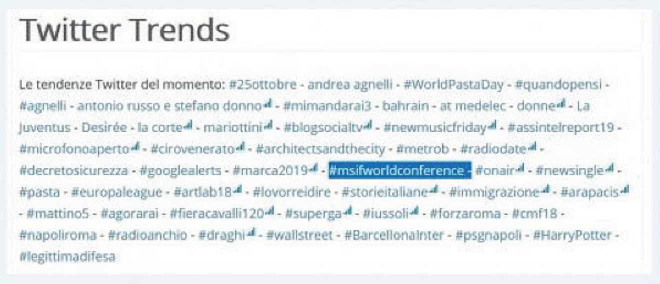
DAY 1: Young People with MS Workshop

At a day workshop dedicated to young people with MS, MS Australia was represented by our National Advocate Astrid Edwards. Peppered throughout the dynamic presentations and discussions led by young people representing global MS organisations, Astrid's tweet reports covered topics such as disclosure, accessibility, new ideas, messaging, services, the needs of young people and the changing nature of MS over the years.

To read Astrid's summary visit https://bit.ly/2TBdjrS or https://bit.ly/2Fccbro.

DAY 2: Research and Treatments Updates

This day focussed on the latest research and therapy that impacts the lives of people with MS. Astrid again live tweeted her personal perspectives on the various updates, which you can view on the October 25, MS Australia Twitter and Facebook pages.



Twitter Trends

Le tendenze Twitter del momento: #25ottobre - andrea agnelli - #WorldPastaDay - #quandopensi - #agnelli - antonio russo e stefano donno - #mimandarai3 - bahrain - at medelec - donne - La Juventus - Desirée - la corte - mariottini - #blogsocialtv - #newmusicfriday - #assintelreport19 - #microfonoaperto - #cirovenerato - #architectsandthecity - #metrob - #radiodate - #decretosicurezza - #googlealerts - #marca2019 - #msifworldconference - #onair - #newsingle - #pasta - #europaleague - #artlab18 - #lovorreidire - #storieitaliane - #immigrazione - #arapacis - #mattino5 - #agorarai - #fieracavalli120 - #superga - #iussoli - #forzaroma - #cmf18 - #napoliroma - #radioanchio - #draghi - #wallstreet - #BarcellonaInter - #psgnapoli - #HarryPotter - #legittimadifesa

#msifworldconference trending in Italy and globally!

DAY 3: MSIF Movement - Sharing Skills And Best Practice

With the focus of the day on 'Innovative programme initiatives being carried out around the world', MS Australia was delighted to present in two sessions.

During the Raising awareness with impact session, MSA CEO Deidre Mackechnie spoke about our approach to government lobbying, with a focus on the Roadmap to Defeat MS initiative (also visit here), developed in association with our partner organisation, MS Research Australia and launched by the Federal Health Minister on World MS Day 2018. The presentation included the importance of collaboration, learnings, key achievements, teamwork and next steps.

Later in the day, in the Volunteers at the heart of MS organisations session, Deidre discussed the MSA National Advocates Program and introduced Astrid Edwards, who provided a lively overview of her experience as a volunteer national advocate.

MSIF World Conference
October 2018 - Rome, Italy

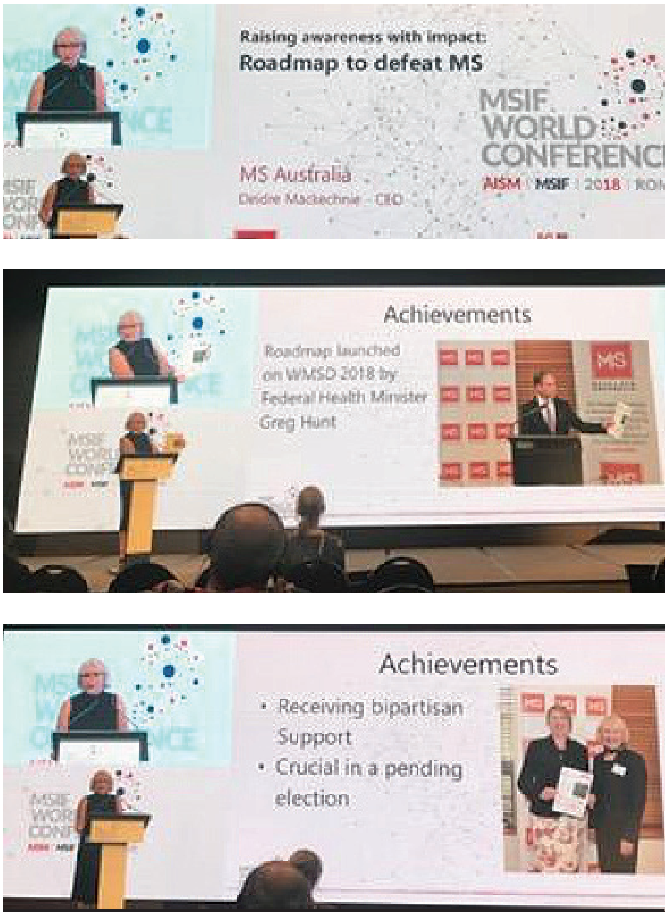
VOLUNTEERS AT THE HEART
OF MS ORGANISATIONS

SESSION 5 | Giunone 1

"Young" programme
volunteer engagement and motivation
Anna Zaghi, AISM Italy

National Advocates Programme
Deidre Mackechnie & Astrid Edwards,
MS Australia

DAY 3: *Innovative Programs around the globe.*



DAY 3: Sharing Skills and Best Practice: MS Australia CEO Deidre Mackechnie presents on the *Roadmap to Defeat MS* initiative.

European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS)

In October 2018, the 34th Congress of the European Committee for Treatment and Research in MS (ECTRIMS), was held in Berlin. This is the largest global conference on MS, encompassing:

- 9800 participants
- over 260 presentations delivered over 3 days
- more than 1,500 posters presented either in person or via an e-poster

Proceedings commenced on Day 1 with the opening lecture by distinguished neurologist Professor Alistair Compston, University of Cambridge UK, on the history of MS research, where we have come from and then into the future, in the digital age of big data and machine learning.

The theme of 'digital MS' continued throughout the conference with topics such as *Digital; MS: improving data acquisition and analysis*, *How real world data can inform treatment decisions*, *Robotic and telehealth supported rehabilitation and exercise training in MS* and other papers that were based on analyses of 'big MS data'. There was also an emphasis on patients taking control of their own health monitoring through various apps and devices and also digital tools for clinicians to use in diagnosing, treating and monitoring people with MS. The potential for this digital focus is fascinating and clearly increasing use of technology is making an incredible impact though there did seem to be a lack of evidence for efforts to join up this data to improve treatment and management.

Other presentations included an interesting debate on whether the new McDonald diagnostic criteria are too difficult and complex to use in clinical practice – the audience decided that they were not!

In addition to the scientific program, ECTRIMS also provided the opportunity to attend:

- an Multiple Sclerosis International Federation (MSIF) function celebrating the recipients of Fellowships from ECTRIMS and the MSIF. These fellowships allow young researchers from different parts of the world to work with international centres of excellence in MS research advancing MS research and clinical care for people with MS and providing opportunities for discoveries to occur.
- a meeting of the MSIF International Scientific and Medical Advisory Board, a focus of which was a report on the work of the Access Working Group about its application to the World Health Organisation to get certain MS treatments listed on the WHO Essentials Medicine List so that people with MS can receive the best care no matter where in the world they live (especially those in developing countries).
- a launch event hosted by pharma company Merck of a new documentary *Seeing MS from the inside out*, which seeks to interpret the experiences and perspectives of those impacted by MS through art and also a new report, *Living with MS: the Carer's Perspective*, developed in collaboration with the International Alliance of Carer Organisations and reports on the experience of carers across seven countries (not including Australia, but provides useful benchmark data for us to examine).
- a meeting of representatives from around the world involved in the MS Brain Health: Time Matters in MS initiative with a focus on the newly published International consensus on quality standards for brain health-focused care in multiple sclerosis. These standards outline a practical timeline for brain health-focused MS care and provide MS teams with a framework for service evaluation, benchmarking and improvement. MS Australia is heavily involved in the Australian Brain Health working party and is working on the application of these standards in Australia.

ECTRIMS
EUROPEAN COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS

World MS Day - 30 May 2019

World MS Day each year is a fantastic chance to raise awareness about MS and to strengthen the network of people living with MS across the world.

A day to celebrate global solidarity and hope for the future.

This year World MS Day was officially marked on Thursday 30 May, 2019.

The theme and campaign for World MS Day each year is led by MSIF.

This year's theme, **Visibility** aimed to (both) **spotlight the invisible symptoms of MS** (#MyInvisibleMS) and their unseen impact on quality of life; and **increase the visibility of MS**. People with MS often hear, "but you look so well!" when in reality, they are experiencing severe invisible or hidden symptoms.

MSIF released their WORLD MS DAY 2019 video and we were proud that Ivan, a young man from Australia, was included in this year's campaign (see Ivan's full video.)

Thanks to the hard work of our Communications team, MS Australia had a huge media presence during this year's World MS Day. Among many other items, our media coverage included:

- Tim Ferguson featured on Channel 7's The Morning Show, Channel 10's The Project, and in an article by WA Today.
- National Advocate Astrid Edwards and CEO Deidre Mackechnie on ABC News Breakfast
- National Advocates, Mike Welsh and Astrid Edwards, featured on 10 Daily's website.

We were also very excited to launch an invisible symptoms animation on the day.

When MSIF and our fellow WMSD working group members chose 'invisible symptoms' as the 2019 theme, the MS Australia team identified that animation would be a great medium to illustrate something so elusive and esoteric.

We produced and project managed an animation depicting Sonia, a young woman living with MS, talking the audience through different symptoms that are 'invisible, or hard to notice'.

As well as being someone with MS in real life, Sonia lives with MS and, being a professional actor, was the perfect choice to evoke the emotion and sensitivity required for the material.

We endeavoured to include as many of the invisible symptoms in the WMSD campaign as the social-media-friendly two minute time length would allow, making sure to consult with people with MS and MS professionals to establish which symptoms were most commonly experienced yet misunderstood by the public.

We crafted the script to include as many direct quotes from Sonia, our MS advocate, and the other people with MS we spoke to, to ensure it was as accurate and empathetic to their lives as possible. Likewise, at every stage of production; concept, sound and music, animation style, etc., we closely consulted with people with MS, incorporating their own words and experiences. It is this strategy which we believe has led to the animation's effectiveness and reach.

Andrew Giles, Tim Ferguson, Deidre Mackechnie, Lisa Montague and Mark Campbell

worldMSday 30 MAY

International activities continued

Our video has been viewed over **338,608 times** across the various platforms. It has so far been shared over **10,518 times** by International MS organisations, pharmacies and medical centres, health professionals, researchers and medical research centres, MS bloggers and advocates, and others across **over 40 countries**. It has also been shared by other organisations and people to raise awareness of similar conditions.

With the helpful collaboration of many international MS societies, we are now able to present the video with **18 different language translations**. Further to this, the animation has now been **dubbed into Spanish** thanks to Esclerosis Múltiple España (EME), and a Dutch dubbing is currently in development by Multiple Sclerose Vereniging Nederland.

The animation has not only raised awareness and brought to light symptoms that are invisible, but it has provided a chance for parents wanting to educate their children, sons wanting to educate their mothers, and friends wanting better understanding amongst friends. People with MS are using it to help gain some reconnection, and they have left countless glowing comments extolling its accuracy.

Screenshots from *Invisible Symptoms* animation

About MS

Multiple Sclerosis is a chronic disease that attacks the central nervous system. There is overwhelming evidence that MS is primarily caused by an autoimmune process where the body attacks its own myelin, a fatty sheath that covers our spinal tissues and nerves, although the exact mechanism remains unclear. There is no known cause or cure.

The physical impact of MS varies as no two cases of MS are identical. The visible and hidden symptoms of MS are unpredictable and vary from person to person and from time to time in the same person. Common symptoms include:

- Extreme tiredness
- Visual disturbance, such as blurred or double vision
- Difficulties with walking, balance and coordination
- Altered muscle tone, such as muscle weakness, tremor, stiffness or spasms
- Dizziness and vertigo
- Altered sensation, such as tingling, numbness, and pins and needles
- Extreme sensitivity to temperature, usually heat
- Pain
- Bladder and bowel changes
- Emotional and mood changes
- Sexual changes
- Changes in memory, concentration and reasoning
- Slurring or slowing of speech.

The economic and personal cost of MS cannot be overestimated:

- MS is estimated to cost Australia over $1 billion per year
- Loss of productivity $494 million per year
- Australians with MS spend $78 million per year in out of pocket health care expenses
- The informal care provided by family and others to Australians with MS would cost $145M per year to replace.

Impact on employment

- 50-80% of people with MS cease to work full-time within 10 years of diagnosis
- Of the 20,400 people with MS aged 15-64, an estimated 9,800 were employed, with 5,900 being part-time
- People with MS have a 30% higher representation in part-time employment compared to the average Australian and a lower annual income
- People with MS are less likely to be in paid employment compared to those with other chronic diseases.

About MS Australia

MS Australia (MSA) is the national peak body for people living with MS in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration.

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with the disease, their carers and the broader MS community.

MSA works closely with partner organisation, MS Research Australia – the largest not-for-profit funder and coordinator of MS research in Australia.

Contact us:

MS Australia
Level 19 Northpoint Building,
100 Miller St
NORTH SYDNEY NSW 2060
T: 02 8413 7977
F: 02 8413 7988
E: info@msaustralia.org.au
W: www.msaustralia.org.au