



Year in Review

the year to 30 June

2016

A world
without
Multiple
Sclerosis

Contents

Vision and Mission	3
Who we are	4
Our purpose	4
Our MS family structure	4
The MS Australia Board and senior staff	5
Co-convenors of the Parliamentary Friends of Multiple Sclerosis	5
What we do	6
National Advocacy	6
Election Commitments	7
World MS Day Employment Summit	8
National Advocacy Conference	9
National Disability Insurance Scheme (NDIS)	9
MSA Website refresh	10
Medicinal Cannabis	10
Autologous Haematopoietic Stem Cell Treatment (AHSCT)	10
Neurological Alliance Australia (NAA)	11
Submissions	12
John Studdy Award	13
About multiple sclerosis	14

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.

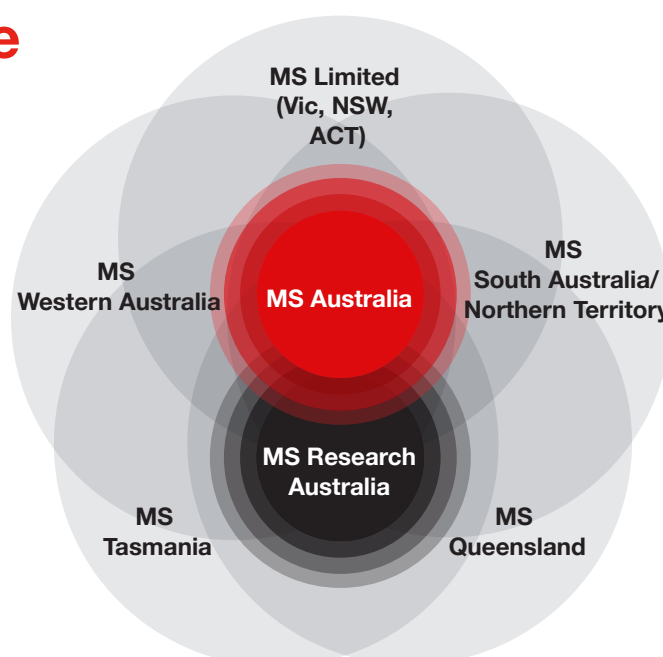
Support for our member organisations

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

MS Australia is the Australian representative member of the Multiple Sclerosis International Federation (MSIF), advancing the MS cause worldwide and promoting collaboration with our international partners.

Our MS family structure



The MS Australia Board MS Australia staff

(for the period 1 July 2015 - 30 June 2016)

Mr Anthony Abbott AM

Mr David Barnes AM (President)

Mr Roger Burrell

Professor William Carroll

Dr Annette Carruthers

Mr William Peter Day

Ms Sharon Eacott

Ms Christina Gillies

Major General Ian Gordon AO

Assoc Prof Desmond Graham

Mr William Hassell AM

Mr Robert Hubbard

Ms Sophie Langshaw

Mr Jonathan Loraine

Mr Paul Murnane

Mr Ian Pennell AM (Vice-President)

Mr Paul Stevens

Deidre Mackechnie

Chief Executive Officer

Mark Campbell

National Website and Social Media Editor

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

Co-convenors of the Parliamentary Friends of Multiple Sclerosis

Senator David Bushby

Senator Deborah O'Neill

What we do

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.

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 MSA annual priorities and reinforce our National Statement of Purpose.

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 MSA 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.



(L-R) Senator David Bushby, Mr Andrew Potter- National Advocacy Coordinator, Ms Deidre Mackechnie - CEO MSA, Mr Ian Pennell AM - Vice-President MSA, Senator Deborah O'Neill, Dr Matthew Miles - CEO MS Research Australia at Parliament House Canberra, May 2016

Election Commitments

On 4 May MSA, on behalf of the MS community in Australia, launched our submission seeking Election Commitments from all federal politicians and candidates, at a function at Parliament House attended by many MPs, Senators, their advisors and people from the MS community.

In this submission we stated our belief that people affected by MS have two fundamental needs:

- A cure for the disease
- Access to support from the first experience of symptoms, through diagnosis, treatment and ongoing management

We also stated that we believe a cure is within the grasp of this generation of political leaders and researchers, whereas access to support through welcome yet complicated Commonwealth and State arrangements, is an ongoing and sometimes unmet need.

Our Election Commitments submission set out 10 important ways to address these fundamental needs, and MSA asked the major parties for their support (see below).

We received responses to our submission from the Coalition, the ALP and the Greens, and our National Advocates met with many local members, senators and candidates during the election campaign to reinforce our request for these election commitments.

We also received wonderful support for these 10 commitments at meetings with independent MP Andrew Wilkie and Senator Jacqui Lambie.



MSA - 10 Election Commitments for the 2016 Federal Election:

1.	Supporting and assisting to prioritise a \$25 million allocation from the Medical Research Future Fund to MS Research Australia to explore promising areas of MS research underway in Australia.
2.	Providing \$15 million for the Brain Health Project, a world class therapeutic strategy driven by Australian researchers intended to maximise lifelong brain health for people with MS and minimise the cost to the health and disability sectors.
3.	Establishing a MS Stem Cell Research Working Group for discussions with key decision-makers on how to alleviate the need for people with MS to travel overseas for AHSCT ('stem cell') treatment.
4.	The full and timely roll out of the NDIS.
5.	Improving the Aged Care/Disability care interface, including services for people with MS 65 and over.
6.	Improving employment options and workplace flexibility.
7.	Improving early intervention processes for people with MS.
8.	Preventing more young people entering residential care.
9.	Introducing a single, national, medical energy concession.
10.	Implementing Australia's Liveable Housing Design Guidelines by 2020.

World MS Day Employment Summit

World MS Day is a fantastic chance to raise awareness about MS and to strengthen the network of people living with MS across the world. The 2016 international theme was 'independence'. Global MS organisations celebrated how people living with MS maintain independence and get on with their lives. This includes support from family and friends, home and workplace adjustments and flexibility, support from MS organisations, effective treatment and lifestyle choices, a steady income, or even just an attitude shift.

MSA marked World MS Day on 25 May 2016 with an Employment Summit.

Most people diagnosed with MS are in the prime of their working lives, with valuable experience and expertise to contribute to the workplace, and for many people, a supportive employer is what enables them to remain in employment.

A global employment report from the MS International Federation, shared at the Summit, revealed that significant numbers of people with MS leave employment earlier than necessary; highlighting the need for employers to incorporate reasonable adjustments to help people continue working. The report, based on survey data from over 12,200 people living with MS, shows that 43% of people with MS who weren't working had left employment within three years of diagnosis. This rose to 70% within 10 years of diagnosis.

Summit participants included representatives from employer organisations, universities, researchers, other peak bodies, senior public servants and the MS community.



The major focus of the Summit was to acknowledge and address the stigma associated with MS in the workplace. MSA launched a new 'Guide for Employees' and 'Guide for Employers'; both located on the MSA website: <https://www.msaustralia.org.au/living-with-ms/workplace>

The Summit featured presentations by Stephen Jolly, Manager of the MS Employment Service and MSA Advocate Mike Welsh alongside his manager, Claire Rogers, Head of Digital Banking at ANZ Bank. In addition, presentations from four people with MS who shared their experiences of dealing with the stigma of MS in their workplace.

MSA also launched four new employment videos, in which four women living with MS talk about their employment experiences.

To view the videos visit: <https://www.msaustralia.org.au/living-with-ms/workplace> under the heading '**How does it feel to tell your employer you have MS?**'



National Advocacy Conference

At the October 2015 MSA Advocacy Conference in Canberra, the National Advocates learnt how to integrate their work with the service directors and communications managers from the state and territory MS organisations. The conference was also a chance to interact with Federal politicians and their advisors at a Parliamentary Friends of MS event at Parliament House.



(L-R) National Advocates Mike Welsh and Lynne Smith with Co-Chair of the Parliamentary Friends of MS, Senator Deborah O'Neill

National Disability Insurance Scheme (NDIS)

MSA continues to work with our State and Territory Member organisations to closely monitor NDIS implementation, to enable early identification of issues that require advocacy. For example, we have prepared a paper on the implications of the NDIS for people with MS over the age of 65, who are precluded from entering the NDIS and have to rely on the aged care sector to have their needs met. This work has been the result of collaboration with the National Services Leadership Group and was finalised for discussion at the National Advocacy Conference and to underpin the subsequent work of the National Advocates.

To value add to this important area of work on the NDIS, MSA implemented a regular NDIS blog for people with MS to provide information as it comes to light, and to enable engagement with MSA and with each other.

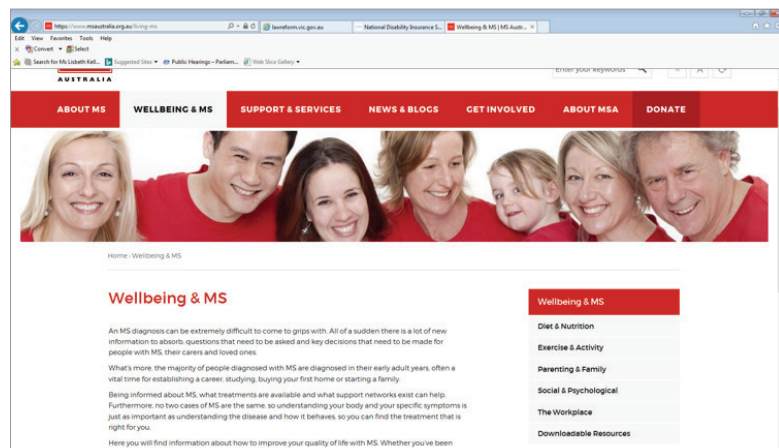


MSA Website refresh

A review and refresh of the MSA website achieved a contemporary look and content. For example, a new 'Wellness Hub' facilitates a broader focus on managing MS and includes other key inputs such as diet and exercise.

We 'soft launched' the site in October 2015 to iron out any teething problems and incorporate feedback from the MS community, prior to the full launch in February 2016.

On our growing '*Uninterrupted*' blog site, guest bloggers share their stories and to date this has been a successful engagement platform for people with MS.



Medicinal Cannabis

In December 2014 the Victorian Attorney-General, the Hon. Martin Pakula MP, referred to the Victorian Law Reform Commission for review and report, options for changes to the law to allow people to be treated with medicinal cannabis in exceptional circumstances. The reference was not in relation to legalisation of cannabis generally, nor in relation to legalisation of cannabis for medical purposes generally; but rather, for treatment with medicinal cannabis in exceptional circumstances.

MSA Response

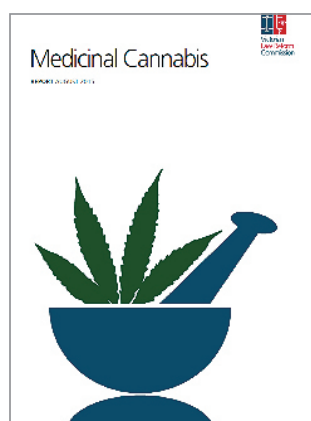
The terms of reference for this inquiry asked the Commission to appoint expert panels specifically to examine prescribing practices and the regulation of the manufacture and distribution of medicinal cannabis. Former MSA CEO, Debra Cerasa, and former MS Medical Director, Dr Liz McDonald, each served on one of these expert panels.

MSA and MS Research Australia made a joint submission to the review and MSA was represented at the public hearings.

Outcome

The review report was completed in August 2015 and released by the Victorian Government in October 2015. The report quotes extensively from our joint submission and the 42 recommendations in the report are in keeping with the approach of MSA to this issue. In short, people with MS head the list of those in exceptional circumstances, for whom medicinal cannabis will be allowed.

We were very pleased that the Victorian Government responded in this way and welcomed the Australian Government's announcements regarding action to ensure medicinal cannabis is available to people living with MS across the nation.



Autologous Haematopoietic Stem Cell Treatment (AHSCT)

BBC program *Panorama's story* on Autologous Haematopoietic Stem Cell Treatment (AHSCT) in MS ignited an increase in interest in the MS community. In January 2016, MS Research Australia and MSA contributed to subsequent media stories on SBS and Channel 7.

Whilst it is noted that AHSCT remains a high risk procedure that has variable applicability and efficacy, one of the main sources of frustration often raised is the perceived lack of access of treatment of this kind in Australia and the need for people living with MS to travel overseas for the treatment.

Given the level of interest by mainstream media and on social media, and the increasing level of activity by special interest groups, MS Research Australia and MSA collaborated on a number of concurrent advocacy and communications initiatives around AHSCT, as we remain committed to the provision of high quality, contemporary information to facilitate informed choice and options for people with MS.

For information about AHSCT visit:

<https://www.msaustralia.org.au/about-ms/medications-treatments/stem-cell-treatments>

For further detailed information, including a position statement and clinical trial information visit the MS Research Australia website:

<http://www.msra.org.au/autologous-haematopoietic-stem-cell-transplant-ahsct-ms>

Autologous haematopoietic stem cell transplant (AHSCT, also known as bone marrow transplant) is an immunosuppressive chemotherapy treatment combined with reinfusion of blood stem cells to help re-build the immune system.

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.

The NAA met on 24 May 2016 to discuss the future of the Alliance, with consideration of NDIS implementation, balanced against opportunities for collaborative Advocacy work. The Alliance members agreed to continue to work together at a national level focussing on collaborative advocacy opportunities. Furthermore, the Alliance appointed MSA CEO, Deidre Mackechnie, as Chair.

**FIGHT ALZHEIMER'S
SAVE AUSTRALIA**
FIGHTALZHEIMER'S.ORG.AU

brain injury AUSTRALIA
www.braininjuryaustralia.org.au

**Huntington's
Australia**

**parkinson's
AUSTRALIA**

**IN THIS TOGETHER
parkinson's
AUSTRALIA**

**MND
AUSTRALIA**

**MJD
FOUNDATION**

**MUSCULAR DYSTROPHY
FOUNDATION • AUSTRALIA**

**MS
AUSTRALIA**

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 2016, MS Australia made submissions to:

- National Disability Insurance Scheme inquiry into accommodation for people with disabilities and the NDIS
- Therapeutic Goods Administration Proposed amendments to the Poisons Standard for medicinal cannabis*
- Australian Human Rights Commission
- Willing to Work: National Inquiry into Employment Discrimination against Australians with Disability
- Department of Social Services New Aged Care Short-Term Restorative Care Programme Policy Consultation Paper
- Department of Social Services Increasing Choice in Home Care – Stage 1 Discussion Paper
- Department of Social Services Review of the National Disability Framework
- Ernst & Young who conducted an independent review of the NDIS Act (2013), for the Australian Government.
- National Disability Services (NDS) who conducted a consultation with their member organisations (including MSA) regarding the commissioning of the Information, Linkages and Capacity-building (ILC) component of the NDIS, for the NDIA.

*Joint submissions with MS Research Australia

John Studdy Award

The most prestigious Award of MSA, the annual John Studdy Award recognises outstanding consistent and selfless provision of meritorious service to people living with MS.

This service may be 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 the 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.

2015 Recipient Lina Marrocco

At its November 2015 Board meeting, Lina Marrocco was recognised with the 2015 John Studdy Award for her tireless work as Chair of Charityworks for MS.

The not-for-profit organisation was set up in 2002 after Lina was diagnosed with MS and has since raised over \$1 million to support people living with MS through funding vital research projects at leading Australian MS laboratories and long-term care and respite support services.

Lina can be affected by fatigue and nerve pain caused by her MS but considers herself to be one of the lucky ones as her symptoms don't get in the way of her living an active life. When she isn't working on Charityworks for MS events or busy with her family, she volunteers her time at the MS Community Shop near her home. She has even made time for a cameo appearance on the television show 'Neighbours' as an inspiring mentor to a regular series character who has been diagnosed with MS.

On receiving the award Lina said *"I am humbled to receive the John Studdy Award and am honoured to be in the company of previous winners including Carol Cooke, Simon McKeon and Carol and Roy Langsford – some of my MS heroes."*

"Some say that what I do is extraordinary. It isn't extraordinary. It would be extraordinary if I did nothing. I choose to do something. Thank you to my Charityworks for MS team and my family, without whose support I could not do half of what I do."



MS Australia CEO Deidre Mackechnie said: "We'd like to thank Lina for her outstanding commitment and passion to the MS cause over the past 13 years. She is making a tangible difference to thousands of people living with MS. It is people like Lina whose dedication to funding research will help us to eventually find a cure for MS."

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	Mike and Katrina Hemingway



A U S T R A L I A

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

