MS AUSTRALIA

Year in Review

the year to 30 June

2015

A world without Multiple Sclerosis

Contents

AUSTRALIA

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.

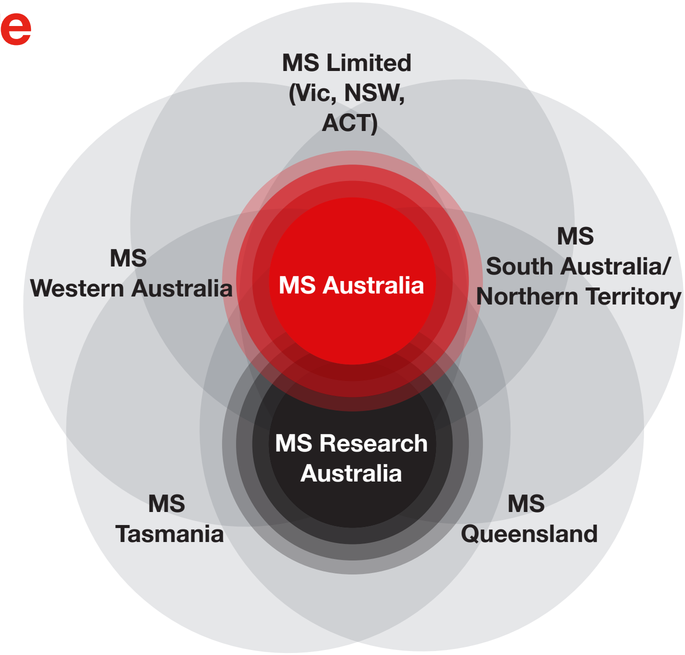
Support for our member organisations

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

(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

MS Australia staff

Debra Cerasa
Chief Executive Officer

Deidre Mackechnie
Executive Officer

Lauren Connors
National Communications Manager

Andrew Giles
National Policy Officer

Andrew Potter
National Advocacy Coordinator

Co-convenors of the Parliamentary Friends of Multiple Sclerosis

Senator The Hon Kate Lundy

Senator David Bushby

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.

National Advocates team celebrating World MS Day at Darling Harbour Sydney

Launch of the joint position statement from Palliative Care Australia (PCA) **and the Neurological Alliance Australia** (NAA)

On 24 November 2014, Palliative Care Australia and the Neurological Alliance Australia (NAA) released a new position statement on Palliative Care and Neurological Conditions.

The main focus of adopting a palliative approach to neurological conditions was described as *to maintain dignity and increase hope through the disease process by adequately managing physical, psychological and existential suffering while assisting with decision making processes.*

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australia and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care for all at the end of life.

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.

In addition to MS Australia, members of the Alliance include Alzheimer's Australia, Brain Injury Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia and Spinal Muscular Atrophy Australia.

As set out in the Joint Position Statement, PCA and the NAA believe:

- Palliative care should be available to all people with neurological conditions who need and want it.
- Palliative care for people living with neurological conditions should be person centred, be integrated with other services and supports, recognise people's individual needs and treat people with dignity and respect.
- Palliative care for people living with neurological conditions can improve quality of life, symptom control, end of life care, and support for the person, their family and carer/s at all stages.
- People with more rapidly progressing conditions will benefit from early referral to palliative care services so that they can express, and be engaged in discussions about their future care wishes and preferences.
- Advance care planning and advance care directives should be a standard part of the care plan for people living with neurological conditions.
- All parts of the health, disability and aged care systems that provide care to people living with neurological conditions should be informed and aware of both neurological conditions and palliative care.
- People living with neurological conditions, their family and carer/s need to be provided with accurate information about palliative care.

Palliative Care and Neurological Conditions

Position Statement

PCA and the NAA call for:

- Improved access to palliative care services for people living with neurological conditions, their family and carer/s based on their needs and wants.
- Education for neurologists and health professionals involved in the care of people with neurological conditions about the benefits of palliative care to improve access and information provision to people with neurological conditions, their family and carer/s.
- Education for palliative care staff about neurological conditions to improve their knowledge and understanding of neurological conditions, and their confidence in providing care to people with neurological conditions.
- Early, comprehensive and accessible information on palliative care for people with neurological conditions, their family and carer/s, particularly for people with more rapid onset conditions such as MND.
- Neurology and palliative care teams to work together and provide coordinated care for people living with long-term neurological conditions.
- The development of a national framework for people living with neurological conditions outlining a pathway for palliative care service provision. It should adopt an interdisciplinary approach and outline triggers for when palliative care and end of life discussions should occur between people living with neurological conditions, their family and carer/s, health and community services. The framework must recognise the varied symptoms and needs of different neurological conditions.
- The high care needs associated with neurological conditions be considered in future policy decisions about funding and access to inpatient and community palliative care services.

MSA's National Advocacy Co-ordinator, Mr Andrew Potter, shared his experiences from the consumer perspective at the event to launch the joint statement at Parliament House Canberra on 24 November 2014.

World MS Day

On 27 May 2015, we marked World MS Day by joining with the MS community at Darling Harbour, Sydney, to welcome the 67-foot yacht, *Oceans of Hope*, to Australia. This flagship vessel of the Sailing Sclerosis Foundation, sponsored by Biogen, is undertaking a global circumnavigation with a working crew of people living with MS. The 33,000 nautical mile voyage aims to change perceptions of MS by showing what is possible when people with a chronic condition are empowered to conquer their individual challenges.

The voyage began in Copenhagen, Denmark, in June 2014 stopping over in numerous port cities in Europe, crossing the North Atlantic and the Pacific oceans and arriving in Sydney for World MS Day 2015, before heading up the east coast of Australia to Newcastle, Brisbane, Cairns and Darwin before sailing on to Singapore.

MS Australia was especially delighted to have Andrew Potter on board as he is not only a person who has lived with MS for 25 years, and a keen sailor, but he also works as MS Australia's National Advocacy Program Co-ordinator. Andrew spent nine weeks on board and managed the VIP visits from politicians and business people and the taster sailing experiences offered to people with MS, their families and carers at each Australian port that Oceans of Hope visited.

Many people in Australia and overseas have followed the Oceans of Hope journey, creating a significant level of awareness-raising and media attention at the national and international level.

National Advocacy Conference

From 27-29 October 2014, MS Australia held its annual National Advocacy Conference in Canberra. All 12 Advocates from across Australia came together for the two day event to discuss key priorities for people with multiple sclerosis and to meet with key policy makers to profile issues currently facing more than 23,000 Australians living with MS.

Participants were able to hone their advocacy and campaign skills in a workshop delivered by political adviser, John Whelan. A media workshop followed from MSA Communications Manager Lee Davelaar, preparing Advocates for media interviews. Three industry guest speakers also attended to provide insight into what makes a successful advocacy campaign.

A productive workshop concluded the first day, with Advocates agreeing on future priorities and opportunities for advocacy and campaigning. In summary, these include aged care/ disability care age cut off at 65, young people in nursing homes and early intervention.

A highlight of the conference was the Parliamentary Friends of MS (PFMS) morning tea, held in Parliament House. The event was hosted by Co-chair of the PFMS, Senator Kate Lundy and was well attended by Senators, MPs, and their staff. The Advocates had an opportunity to meet key policy and decision-makers and their local MPs and arrange separate meetings to further discuss current issues affecting those with MS.

Andrew Potter, MSA National Advocates Coordinator said the advocacy program is unique and helps to bring about change.

National Advocates visit Parliament House for a Parliamentary Friends of MS event, part of the National Advocacy Conference held in October 2014

"All National Advocates are volunteers who have MS, or care for someone who does. They know first-hand the challenges of living with MS and it can be powerful meeting with politicians and policy makes and sharing these perspectives," said Andrew.

The conference gave the Advocates a chance to establish and renew friendships, and an energised and cohesive team of Advocates has emerged, excited about advancing MSA's advocacy priorities for the upcoming year.

Special thanks to Genzyme and Novartis for their sponsorship of the 2014 National Advocates Conference.

Senator Kate Lundy (far left), MSA CEO Debra Cerasa (second from left) and the National Advocates team at the Parliamentary Friends of MS event at Parliament House, Canberra

(L-R) Simone Rutherford, Karen Costa, Lee Davelaar, Nigel Caswell and Jesse Frick at the National Advocates Conference

Submissions


Oceans of Hope arrives in Sydney on World MS Day

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 2015, MS Australia made submissions to the:

- National Disability Insurance Scheme proposal for a Quality and Safeguarding Framework
- Victorian Law Reform Commission's Medicinal Cannabis Issues Paper*
- NDIS Information, Linkages and Capacity Building (ILC) Policy Framework online consultation by the MS organisations
- Senate Legal and Constitutional Affairs Legislation Committee Inquiry into the Regulator of Medicinal Cannabis Bill 2014*
- Community Affairs Reference Committee inquiry into residential care for young people with disability
- ACT Legislative Assembly Health, Ageing, Community and Social Services Inquiry into the exposure draft of the Drugs of Dependence (Cannabis Use for Medical Purposes) Amendment Bill 2014 and related discussion paper
- Therapeutic Goods Administration regarding the regulation of autologous stem cell therapies.

*These submissions were made jointly with MS Research Australia

International activities

The Joint ACTRIMS ECTRIMS Meeting in Boston, USA

10-13 September 2014

ECTRIMS is an independent representative European-wide organisation devoted to multiple sclerosis (MS). Its mission is to facilitate communication, create synergies, and promote and enhance research and learning among professionals for the ultimate benefit of people affected by MS.

Its vision is to work with the researchers and clinicians of its member countries and with other organisations that share similar missions and objectives on a worldwide scale, creating networking and collaboration opportunities. The ultimate goal of ECTRIMS is to improve basic and clinical research and clinical outcomes in MS.

The annual ECTRIMS Congress is the biggest MS conference in the world, reporting to attract greater numbers each year as research continue to make ground.

All of the major pharmaceutical companies are represented and they provide facilities for information gathering, information technology lounges and hospitality on a grand scale.

America's committee for treatment and research in Multiple Sclerosis is **ACTRIMS**. ACTRIMS® mission is to provide provides leadership in the field of multiple sclerosis and other demyelinating diseases.

In 1995, Dr. Kenneth Johnson and a group of like-minded MS clinicians and researchers founded ACTRIMS to serve as the US and Canadian counterpart to ECTRIMS, the European Committee on Treatment and Research in Multiple Sclerosis. The National Multiple Sclerosis Society (USA) agreed to serve as ACTRIMS' organizing body and, in collaboration with the MS Society of Canada, provide logistical support for its annual meetings.

The annual ACTRIMS meeting provides a forum to exchange information, debate current issues, and discuss advances related to basic and clinical issues in MS research. ACTRIMS seeks to encourage young clinicians and researchers to continue their careers in multiple sclerosis and other demyelinating diseases.

In 2009, ACTRIMS was incorporated as a non-profit organization in the State of Wisconsin and was recognized by the IRS as a tax exempt organization under section 501(c)(3) of the Internal Revenue Code. The National MS Society (USA) and the MS Society of Canada continue to serve as collaborative partners to ACTRIMS, providing organizational and logistical support.

At this joint meeting, attended by MSA CEO Debra Cerasa, over 9000 delegates attended and over 700 abstracts were accepted.

The BiogenIdec sponsored yacht Oceans of Hope sailed into the Boston Bay as a significant feature of the Conference opening. The captain and crew were welcomed and greeted at the official opening of the Conference.

MSA was invited to several meetings to discuss Advocacy and international work in Advocacy. Early access to diagnosis and choice of appropriate choice of treatment remains a constant theme in advocacy conversations, as is the case in Australia. Considerable interest in the introduction of the NDIS in Australia was demonstrated at the Advocacy meetings attended.

In line with contemporary thinking, key benefits of the use of SoMe to support, enhance and contribute to the Advocacy agenda on behalf of PaMS remained a strong feature at the conference. Debra Cerasa, MSA CEO attended two sessions where debates were streamed across numerous SoMe platforms.

MSA CEO, Debra Cerasa, marking World MS Day 2015 at Darling Harbour

John Studdy Award

The John Studdy Award is MSA's most prestigious Award, given annually, in recognition of 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.

2014 Recipients Mike and Katrina Hemingway

Two dedicated fundraisers and advocates have been formally recognised for their years of commitment to helping those in the MS community.

Mike and Katrina Hemingway, founding members of Foundation 5 Million were awarded the 2014 John Studdy Award, MS Australia's most prestigious honour, in recognition of their ongoing contribution to MS research at MSA's Board meeting in November 2014.

"It is an incredible honour to be mentioned in the same breath as previous winners such as Carol and Roy Langsford, Simon McKeon and Andrew White," Mike said. *"People with MS and their families are depending on MS Research Australia and MS Australia to keep driving for a cure. That is what motivates Katrina and me to keep working hard with the MS team."*

Mike was diagnosed with MS 10 years ago and the couple became determined to do whatever they could to help find a cure. Their efforts with Foundation 5 Million, a tight-knit community fundraising group, have already raised more than $5 million. This remarkable effort is helping to strengthen the research sector and raising awareness through fundraising events and initiatives.

Mike's dedication to the cause has led to him speaking at many MS research and community events, consulting with the MS Research Australia Research Management Council, and becoming the Chairman of the MS Advisory Council NSW.

Mike and Katrina Hemingway (right) receive the 2014 John Studdy Award from Board President, Mr David Barnes AM (left)

This year the couple joined 20 fellow fundraisers and walked more than 300km across England, raising over $200,000 for MS research. The Hemingway's planned the 'Coast2Coast Walk' event in their spare time.

MS Australia Chief Executive Officer Debra Cerasa congratulated the pair on their extraordinary achievement.

"The Hemingway's dedication and commitment to the MS community is purely admirable," Ms Cerasa said. *"Their relentless pursuit for a cure and determination to see the best research funded is a true asset to our community and it is dedicated and passionate people like Katrina and Mike that 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

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.

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