

MS My Story



MS Annual Report 2015

#### MS ANNUAL REPORT 2015

## Contents

Corporate Governance	02
Chairman's report	03
CEO's report	04
Executive team and supporters	06
Our Service Promise	07
MS My Story campaign	08
MS community works with Board	10
Workforce of engaged staff	11
Technology of the future	12
Services Innovation	
Positioning for the future	15
Focus on service	17
Professor Millard retires	22
Investment in facility upgrades	23
Keeping people at work	26
What does the NDIS mean?	27
MS Australia	29
Committed to diversity,	
inclusion and equality	30
Volunteers, we thank you!	31
Essential help at events	32
Focused on future success	35
MS Research Australia	37
Fundraising and events	38
Thanks to MS Mega Swim	43
Concise financials	46

### MS My Story

Jana Morgan	13
Tim Ryan	24
Nadine Spilsbury	33
Scott Bushell	44







1

# The Board of Directors

William Peter Day, Chairman

**Garry R. Whatley**, Deputy Chairman

**Christina Gillies** 

**Denise Cosgrove** 

**Don Ferguson** 

Ian Pennell, AM

Karen Hayes, AM

Major General Ian Gordon, AO, Retd

**Robert McEniry** 

Scott McCorkell

**Sophie Langshaw** 

## Our Corporate Governance Statement

- It contains the principles, policies and procedures that the Board adopts to ensure that the long-term health and prosperity of the Company are maintained for the benefit of Australians affected by multiple sclerosis.
- It provides an overall governance framework for the Company.
- It includes the roles and responsibilities of the Board and Executive in setting the strategy and direction of the Company and in managing and controlling the organisation.

Our full Corporate Governance Statement can be viewed at ms.org.au





# Chairman's report



On behalf of the Board, I am pleased to present the first Annual Report under our new name MS. The name change is part of our brand strategy in response to the National Disability Insurance Scheme (NDIS). TO MEET the challenge of the changing landscape under the NDIS, we will continue to build the profile and reach of the brand to engage the wider public in supporting people affected by multiple sclerosis.

People affected by multiple sclerosis need us more than ever. And we need the ongoing support of the community and volunteers more than ever. The NDIS is going to play a big part in helping to provide people with better supports, and where we can, we will continue to leverage our expertise on their behalf.

Throughout the year, the Board has continued to maintain adherence to sound governance and effective financial oversight of the activities of MS. The Board has been kept abreast of NDIS reforms and has been very involved in strategic planning, oversight of strategic initiatives and future opportunities. Board membership has been stable throughout the year and it has continued engagement with the MS community through the MS Advisory Councils and community engagement forums, wherever possible.

#### Year ends in surplus

The Board and I believe the surplus financial position helps ensure MS is as strong as it can be in preparation for the NDIS. My thanks go to the management team who have delivered significant change, exercised great discipline and provided operational leadership in a challenging environment to ensure the organisation is 'NDIS ready'. Management has successfully put us in a strong financial position and has built cash reserves.

Over the past 18 months we have also worked with other State societies to further the strength of the MS movement nationally. We have provided both financial and professional support. In particular, we acknowledge the great contribution made by our colleagues from MS Western Australia who stepped up to assist MS South Australia and Northern Territory reposition itself.

My thanks also go to my fellow Directors, whose astute governance has been appreciated. It's a great honour to continue my service and, hopefully, lead the organisation to even more exciting opportunities. Our MS team, volunteers, partner providers and the community we serve have also been instrumental through their generous support and encouragement.

W. Peter Day Chairman

## **CEO's report**



The year 2014–15 has been a demanding year. We are collectively going through massive change, and we acknowledge this is tough. We have been trying to give our staff and the MS community tools and information to move through this change in a positive way. We are also clear that we need to work hard to inspire and engage people. IT IS with these challenges in mind that we are committed to bring the Service Promise to life, in the hope that word gets around and we inspire our MS team to stay the course and the MS community to come to us for services. We have thousands of examples of how our dedicated team is doing small things with big impact. An example of this is the MS My Story campaign, which is a way of sharing such stories—a way of engaging donors and the public to support people affected by multiple sclerosis to do all the ordinary things the rest of us take for granted.

Our Service Promise sets the course of our strategy and identifies how by making changes we can ensure MS is a recognised, trusted service provider. We are making great progress. In year two of our five-year Strategic Plan, we have completed and embarked on a range of major initiatives. I thank the senior management and staff for their hard work and commitment to ensuring a successful year. We have been focused on how we work together, as it is clear the pace of change needs to be managed well.

#### Improving access

With upgrades to MS Connect, our new website and an increase in the number of webinars, we believe we are on track to improving access for people who live with multiple sclerosis.

We are making investments in new information communication technology foundations; embedding our refined service model; and building our engagement with service recipients, referrers and aligned partners. This work is to ensure that people affected by multiple sclerosis can get better access to supports when they have been diagnosed, and increase access to any other services we can help them with during their journey with the disease.

We are clear about our strategic objectives, and our value proposition, and we are continually focused on managing resources carefully.

We are not alone in having to plan for, and anticipate, changes in our external environment, given the complexity and scale of those changes. To this end, we have engaged with other like-minded, neurological organisations in order to improve our influence and capacity to provide supports on a more sustainable footing.

#### **Changing MS**

There is a growing demand for service. As a result of this, we need to invest in service innovation. Our new MS Advisor service is an example of a recent role redesign, to ensure people with multiple sclerosis have access to services in a timely way. It also enables staff members to spend time with service recipients when this is required.

## **CEO's report**

The NDIS shows great promise. Under the scheme there is the real prospect of growth in the scope and level of supports for people affected by multiple sclerosis who meet eligibility requirements. We can play a big part in helping people get better supports. We can also have more in-depth discussions and ask our service recipients if there are any other services with which we can help.

The coming year will be an exciting one, and our commitment remains resolute. The strategy is in place; the organisation is geared to implement and embed new structures, new processes and a demanding program of major initiatives to ensure we have longstanding capacity to serve people affected by multiple sclerosis.

#### **NDIS** rollout

This is especially important now, when the timetable for the rollout of the NDIS has been released. The rollout commences on July 1 2016 to cover people living in North East Melbourne, Central Coast NSW, Northern Sydney, South Western Sydney, Western Sydney and Southern NSW, and the remaining populations of Hunter and New England, and Nepean and the Blue Mountains.

This will be life-changing for many people affected by multiple sclerosis, and will give them greater choice and control.

We have already seen more than 300 people living with the disease experience this fundamental social reform. The insights and feedback that we have had from the NDIS trial sites in Barwon in Victoria, the ACT, and the Hunter in NSW have been extremely positive.

This sets the framework for our role in supporting and preparing people in the new areas so they will be ready by July 2016. We will be there to assist them in accessing the scheme and understanding the benefits they might be eligible to receive.

We are geared up for this very busy period. We will be inviting people in these areas to contact us through our revitalised MS Connect service to be connected to a member of our MS team who can provide them with more detailed assistance and support explaining how they can access the scheme.

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Robyn Hunter Chief Executive Officer MS

## **Executive Team**

**Robyn Hunter** Chief Executive Officer

**Catherine Saint General Manager** Human Resources

## Sandra Walker **General Manager**

Services Innovation

#### **Jack Hanson**

General Manager Commercial Development/ **Company Secretary** 

#### **Dyranda Hortle**

**General Manager** Strategic Marketing and Sales

## We thank our generous supporters

#### **Our Patrons:**

Tim Ferguson Sarah Ryan OAM

#### **Our supporters: KPMG**

Clayton Utz The Profield Foundation Dooleys Lidcombe Catholic Club Transurban

#### Our media partners:

OMD media agency oOH! Outdoor Media Grey **Executive Channel** Media i Network Ten SBS SKY MCN Multi Channel Network Café Media APN News and Media

#### Our event partners:

Transport for NSW Scody Specialized Brooks Canon Penguin Books Australia RACV (Corporate Property Services) **Mitchelton Wines** Monjon **QBE** Insurance Bunnings Warehouse City of Melbourne Legends & Heroes Memorabilia Rotary Lend Lease Publican Group Australia

#### In particular, we would like to acknowledge:

#### The Australian Government:

- National Disability Insurance Agency
- Department of Social Services
- Department of Health and Ageing

#### The Australian Capital **Territory Government:**

- Disability ACT
- ACT Health

#### The New South Wales Government:

- Department of Family and Community Services -Ageing, Disability and Home Care
- NSW Health

#### The Victorian Government:

• Department of Health and Human Services

#### And

National Disability Services

#### All our donors, supporters and volunteers!

### Our Service Promise

These four guiding principles define our attitudes, behaviours and ultimately our reputation.



**First Contact** Being there from the beginning.

Think Yes Work out how things can be done.

Act Now Problems are addressed and solutions found.

#### **Push Ahead**

Find new ways to minimise the impact of multiple sclerosis and search for a cure.







7

**MY STORY** 

## MS My Story campaign thanks donors



## **Their stories**



#### Seeing MS wins award

THE Seeing MS campaign for 2013–14 won two prestigious Effie Awards, which celebrate great marketing ideas that achieve real results and the strategy that goes into creating them.

The Seeing MS campaign showcased nine people who live with multiple sclerosis and revealed the invisible symptoms which impact their lives.

The campaign was awarded a Silver for Most Original Thinking and a Bronze for Cause Related Marketing.

The Effie Awards are recognised by advertisers and agencies as the pre-eminent awards for the Australian advertising industry.



From left, Tim Ryan, Jana Morgan, Nadine Spilsbury, Robyn Hunter, CEO of MS, and Scott Bushell.

## The MS My Story campaign builds on the success of last year's Seeing MS campaign.

#### **MS means My Story**

THIS year's MS My Story campaign acknowledged the contributions made by donors and fundraisers and how their generosity enables people living with multiple sclerosis to improve their lives.

The campaign was launched at a reception held on 26 May 2014, the eve of World MS Day, and special guests included leading donors, fundraisers and volunteers. The reception was sponsored by Biogen Idec.

Around 150 people attended the event at the Cruising Yacht Club of Australia, which also welcomed the crew of the yacht Oceans of Hope to Sydney.

Oceans of Hope called into several Australian ports during its voyage around the world aimed at educating people about multiple sclerosis.

In welcoming guests, Robyn Hunter, the Chief Executive Officer of MS, said, "Tonight is about acknowledging and thanking the generosity of our donors. The people in this room represent a community who give of their time or money, and sometimes both, to make a difference."

Robyn explained that MS My Story was stage two of the Seeing MS campaign, which had been praised by people who have multiple sclerosis.

"Last year's Seeing MS campaign was about helping people see the invisible symptoms of multiple sclerosis. This year, we want to celebrate and acknowledge the people whose contributions enable people living with multiple sclerosis to face their challenges and retain their dreams."

MS My Story showcases the stories of four people who have multiple sclerosis—Tim Ryan, Nadine Spilsbury, Scott Bushell and Jana Morgan. They each explain how donors, fundraisers and volunteers have directly improved their quality of life, as well as the lives of their families, by enabling them to access MS services.

Robyn thanked Grey Advertising in Melbourne for the time and resources the company devoted to creating the MS My Story project; the team at Infinity Squared who produced the wonderful videos; Biogen Idec, for sponsoring the campaign launch event; and Amanda Duval, Network 10 weather presenter, who acted as Master of Ceremony for the evening.

Robyn also paid special tribute to Tim, Scott, Nadine and Jana for sharing their stories. "These honest and raw stories continue to inspire me to keep helping people affected by multiple sclerosis to face the challenges of a life with multiple sclerosis," she said.

To see their videos visit: ms.org.au/get-involved/ms-my-story.aspx

### MS community works with Board



Rob de Ridder, Chair, MSAC NSW, with Sarah Ryan OAM, a former Olympic Swimmer who is a Patron of MS. Since 2009, Rob has raised over \$115,000 for the Mega Swim.

THE MS Advisory Councils of NSW and Victoria have been active during the year, providing regular feedback to the MS Board and leadership team. Some of the topics under discussion include:

- Feedback on the content and functionality of the new MS website. The new site is a substantial improvement, and ongoing feedback on content and design is offered and positively received.
- Feedback on the upgrade to the MS Connect service, including the fact that it is greatly improved.
- Exploring the emergency preparedness needs of people affected by multiple sclerosis.
- Understanding the impact of the National Disability Insurance Scheme for people affected by multiple sclerosis, and encouraging people to stay informed.
- Working to better understand the needs of specific groups, including those people who come from



Kate Cherry, Chair, MSAC Victoria, is pictured in the centre of two friends who ran with her in this year's MS Walk and Fun Run in Melbourne.

culturally and linguistically diverse backgrounds; carers; and people with multiple sclerosis who live in residential care, and in rural and regional areas.

- Looking at information resources to help employers support people with multiple sclerosis to stay in work.
- Gathering input and identifying emerging themes via direct contact and emails from people affected by multiple sclerosis. We also monitor MS-relevant social media and MSAC's Facebook page and pass concerns onto the Board. In addition, MSAC Victoria and NSW are seeking contact with facilitators of MS Peer Support Groups.
- MSAC NSW has been working closely with the MS Board and the Executive in a consultative role regarding the future of the Lidcombe site.

Many of these projects are ongoing and work will continue during the coming year.

#### ACT and Southern NSW Advisory Board

THE ACT and Southern NSW Advisory Board has continued to represent the interests of people affected by multiple sclerosis in the ACT and Southern NSW.

The Advisory Board meets six times each year to receive reports from the management of MS and the MS support groups that meet in the ACT and southern NSW region.

Members of the Advisory Board come from a variety of backgrounds and include people with multiple sclerosis, as well as carers of people affected by the disease. Two members of the Advisory Board are members of the MS Board and represent the views presented to the ACT Advisory Board at the MS Board.

Advisory Board members support MS management at MS fundraising activities in the ACT including the MS 24 Hour Mega Swim, the MS Walk and Fun Run, and the MS Go for Gold presentations.

A highlight of the year involved the MS Executive recently proposing a new Service Model for the region. This has been agreed by the ACT Advisory Board and the MS Board. As part of the new Service Model, MS will:

- Register as a provider with the National Disability Insurance Agency in Canberra and trial the provision of National Disability Insurance Scheme Coordination Supports.
- Strengthen the relationship with the ACT Primary Health Network, including up-skilling GP Practice nurses in immunotherapy and multiple sclerosis.
- Strengthen the relationship with neurologists via the Canberra Hospital MS Nurse.

# Workforce of engaged staff

The focus for the year was on leadership and commitment to the transformation agenda.



ONE of our main achievements has been to improve employee commitment, and to increase the engagement of staff and volunteers.

#### Our key objectives are to:

- build an inspired and engaged workforce; and
- focus on our culture and values.

With this in mind, we conducted an Employee Engagement survey and led focus groups in each area of the business. This enabled us to drill down into the priorities of our staff.

It confirmed our understanding that employees wanted strong leadership underpinned by robust performance processes, which enable them to be challenged and to thrive.

Our response was to revamp the performance management process, which enabled us to better cascade our strategy throughout the departments and to provide objectives that showed a clear 'line of sight' of contribution to the employees. We also renewed the recognition and reward program.

In order to understand the workforce capability we created a profile of the current skills within the organisation.

This is foundation work for the Learning and Development system, and we will link this with our performance management by identifying our talented and high-performing employees, with a view to future needs.

One of our major successes for the year was the development of a cultural change program called Seeing Ourselves, Seeing MS. It enabled us to co-design foundation and leadership behaviours with staff in a series of workshops run in Sydney and Melbourne.

These behaviours were rolled out across MS by Robyn Hunter, Chief Executive Officer, who is leading the way to a constructive culture built on a shared understanding of how our behaviour contributes to the success of the organisation.

These behaviours are now being embedded as part of human resource management processes, from recruitment and selection, to induction and performance management, and more.

Our continued focus is to provide MS with the workforce of the future to ensure delivery of our transformation strategy. We have established a very high target for leadership and for increased employee commitment.

Our ultimate goal is be a recognised leader in the MS community through our team of truly inspired and engaged people.

#### **Catherine Saint**

General Manager Human Resources

## Technology of the future

Updating and investing in technology to support fundraising and service delivery has been a key focus during 2014–15.



WE are proud of what has been accomplished this year to establish a strong foundation for the future, but moving forward there remains much to do.

Our new website was launched on World MS Day on 27 May 2015. This website has been completely redeveloped with a new look and feel, new functionality and optimised for viewing on all screen sizes such as PC, tablets and phones.

There was a focus on consultation with the MS community via design reviews, updating of content and testing.

The new website provides us with an excellent platform for further development and innovation. Behind the scenes, it will link to Salesforce, our new customer relationship management system (CRM) and financial systems.

Over the years our internal IT systems have become complex and isolated from each other, so we have invested in Salesforce to centralise all business processes and customer records into one CRM system. Salesforce captures all contacts and transactions in one place to better coordinate marketing campaigns, communications and service delivery.

This year we have migrated all fundraising and events participants, representing 80 per cent of all contacts, into Salesforce. The remaining 20 per cent comprises service recipient contacts and volunteers. These will be moved into Salesforce next, so that all of our donor, service recipients and volunteer contacts are recorded in the one CRM system.

Another of our main achievements during 2014–15 was the rebuild of our data and communications network and our server/data store infrastructure. This project has included:

replacing all our data and communication networks

- migration of data and applications to a cloud-based environment
- replacing our old (and at some sites, not working) phone and video conferencing systems with online communications
- implementation of a cloud-based version of Microsoft software to replace email and local data storage.

Although the main driver for this change has been to save costs by using cloud-based technologies, there are a number of benefits to staff including:

- web-based data and application access
- improved video conferencing from each computer and the ability to link meeting rooms into Skype
- instant messaging between staff members
- improved audio conferencing
- increased email inbox from 3GB to 50GB
- cloud-based individual data storage
- improved network speed and stability.

We have capital investment planned for the coming year to ensure we have the necessary business systems and technology infrastructure. We see continued IT investment as a priority to streamline our internal business processes and improve the communications and marketing capability necessary to provide sustainable and cost-effective services to the MS community.

#### **Jack Hanson**

General Manager Commercial Development

## Exercise helps Jana to walk



## Exercise helps Jana to walk



Jana Morgan says encouragement from Dr Phu Hoang, an MS Consultant, gave her the confidence to attempt to walk again.





A GRAPHIC designer before multiple sclerosis forced her to retire, Jana, 54, was diagnosed with the disease in 1997. By 2010, ongoing dizziness and balance problems left her dependent on a walking frame when she was inside her Sydney home and a scooter when she was outside.

In 2013, when she was using her walking frame, she tripped, hit her head and ended up getting six stitches. The fall left her afraid. She stopped walking, only used the scooter, gave up driving and became increasingly isolated. "After several months I realised that if I didn't do something I'd be on the scooter for life," she says.

She contacted MS and, as a result, she asked her husband to drive her to the Studdy MS Centre at Lidcombe, to attend the gym that specialises in exercise for people with mobility problems.

When Dr Phu Hoang, an MS Physiotherapist, watched Jana move from the scooter to the examination table he remarked, "If you can do that, I think we can get you moving". That observation gave Jana confidence that if she put in the effort she could use the walker again.

Back home, her husband rescued her walker from the garage. "Each day I'd walk a few metres further and each day my confidence increased." She combined this with regular visits to the MS gym and the day came when she left her scooter at home. "The MS staff in the gym cheered when they saw me walk in using my walker."

She now only uses the scooter for travelling distances outside her home and she has returned to driving her car.

"Going to the Studdy MS Centre gave me friendship and people who understand how I was feeling. That helped me to start demolishing the wall I'd built around myself, brick by brick."

# Positioning for the future

We're in the midst of huge reforms in health, disability and aged care. This requires innovation, investment and commitment to ensure the best outcomes possible for people living with multiple sclerosis. AT MS, we embrace the ethos that people who have multiple sclerosis have choice over the services they require and control of who provides those services. We are working to make sure our services match this. Our Service Promise sets the course of our overall strategy and identifies how we can ensure MS is a recognised, trusted service provider. We also have thousands of examples of the positive impacts those services have made on the lives of people who have multiple sclerosis.

To meet the challenges of our changing environment, we are extending ways to access our services and our capacity to provide a sustainable and relevant suite of services. We have implemented many changes in 2014–15, and we'll continue to make more changes in the future.

#### **MS Connect**

We have upgraded our MS Connect information and advice service. This year we've tripled our capacity to enable people affected by multiple sclerosis to access phone or online support from our MS experts. We've upgraded our technology and our team is constantly expanding their knowledge and skills.

#### **MS** Advisor

We launched our brand new MS Advisor service on 1 July 2015. The MS Advisor role, accessed through the MS Connect team, is a free, specialised consultation with an MS health professional. The service is provided in more accessible ways, such as over the phone or face-to-face via Skype—so it's more convenient, flexible and can reach many people. We'll be evaluating this new service to make sure it's responsive to the needs of the MS community.

#### **MS Wellbeing**

Our MS Wellbeing suite of services remain focused on ensuring people living with multiple sclerosis have control over their symptoms and lives. This year we:

- expanded our MS Employment Support Service in NSW
- refreshed our MS Peer Support Program, making it easier to train new facilitators using online training modules
- launched our very successful MS Education webinar series an instant hit, with thousands of people logging in to learn from home
- refined what we offer through our MS Social Support Day Program, which is stronger than ever.

We will continue to refine our MS Wellbeing services and invest in service innovation.



# Positioning for the future

#### MS@Home

Our vision for MS@Home is that people living with multiple sclerosis will be able to remain living at home for as long as possible. We have launched the Gift of Time, partnering with our subsidiary Australian Homecare Services, and we're looking to partner with a range of organisations in local communities, and to inform them about the needs of people living with multiple sclerosis. This year we also launched a partnership with the National Home Doctor Service, which provides GP services in the home in metropolitan areas—and it's expanding, including into regional areas.



#### **MS Respite and Residential**

We continue to provide full care around the clock for the times when life gets challenging. We provide respite and specialist disability accommodation in NSW and Victoria, and this year we've upgraded several of our facilities, improving gardens, kitchens and linen—thanks to our generous donors. Next year we'll focus on providing new respite retreat packages, which will provide a chance for the person in respite and their carer to properly recharge.

#### **Innovative services**

We are adapting and improving so we can do what it takes to ensure that people living with multiple sclerosis do not undertake their journey alone—and to ensure that we're here, now and in the future.

Sandra Walker General Manager Services Innovation

The year 2014–15 was a time of ongoing preparation for the National Disability Insurance Scheme and subsequent opportunities to innovate.

AS a result of the changes the NDIS brings we need to be responsive to a new 'lifecycle' of services. These include new referral pathways and changes in patterns of delivery such as demand for out-of-hours services and services delivered at different locations. To rise to the challenge we need to invest to stimulate innovation and change in how we work.

As we become informed of key changes in the policy environment, we are making considered changes. We have changed the way we record service data as we need robust evidence of costs of providing services. Where we are not able to generate revenues we will need to make staffing changes.

We have improved the capacity of MS Connect which is handling substantially more calls as a result of the hiring of more staff. Being able to respond more effectively through MS Connect has seen a shift in the utilisation of our services. As a result we have focused on providing information, monitoring and coordinating supports which are unmet by mainstream services. This is reflected in the data.

The promise of the NDIS is great and we have dedicated resources to increase our understanding of the services required by people with multiple sclerosis within the new landscape of the NDIS to ensure we are best able to prepare for the future.

During 2014–15, we delivered wraparound specialty services to address health needs as well as traditional disability support for 'invisible' symptom management, and 'tune up' health needs to maximise function.

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#### **MS** Connect

12,042 contacts for year

1,004 per month on average

4,744 people accessed an education session

1,000 enquiries to MS Library



#### MS Wellbeing hours of service:

MS Consultants 26,873 Exercise classes 8,778

MS Employment Support Service 48,228 customer contacts

#### MS @ Home

985 hours of help given via Gift of Time

Partnered with National Home Doctor Service

#### **MS Respite and Residential**

33 residents live in our facilities

3,750 days of respite provided

#### **MS Advisor role**

I took my 16-year-old son to the GP. As usual, we had to wait for more than an hour. Why do we wait? Because she delves deeper than she might need to. Perhaps she should refer him to the practice nurse or a specialist. Waiting made me think of MS Connect because when we spend too much time with one person, they get great service, but others have to wait. This means the phone may not get answered in a timely manner. We are trialling the MS Advisor role because it will give an opportunity for the deeper dive if required, and free MS Connect up to be more responsive to calls and email.

Jo Whitehouse Senior Manager MS Connect

#### **MS Connect grows**

During the year 2014–15, we successfully completed a major redesign of MS Connect, our information and advice service.

This redesign increased its capacity and simplified registration and other processes to enable a person's enquiry to be handled quickly and efficiently.

The focus on improving effectiveness and efficiency can be seen in the following statistics.

During 2014–15, MS Connect delivered 12,042 contacts, an average of 1,004 per month.

People who have multiple sclerosis accounted for an estimated 6,485, or 54 per cent, of total contacts with MS Connect. People who were 'not-yet-diagnosed' or 'newly diagnosed' accounted for a further three per cent of contacts.



#### **MS Peer Support**

More than 200 people with multiple sclerosis or their carers accessed our phone peer support program, while over 800 people regularly attended our 80 local peer support groups across NSW, Victoria and the ACT. There was also a surge of interest in the Facebook and online peer support groups with more than 930 people joining and communicating with each other during the year.



## **MS Education**

WHEN a person is diagnosed with multiple sclerosis they seek information on what they can expect during their journey with the disease and how to manage symptoms.

The need to keep abreast of up-to-date and trusted information is essential as their symptoms or circumstances change. Using the expertise of our MS Consultants and also drawing on expertise from the wider health and disability sectors, we have delivered a stellar program of educational sessions in the past year.

The introduction of webinars has enabled people to participate in an education session from the comfort of their home or their work desk.

The growing interest and participation in webinars has been encouraging and has enabled people who have restricted mobility, those living in regional areas or in other States, to participate in an education session.

#### In 2014–15:



#### **MS Social Support**

There are 11 funded social support day programs in Victoria, located around metropolitan Melbourne and Geelong. They support 145 people living with multiple sclerosis. The groups provide a range of social and physical activities that are determined by the people who attend.



## **MS Library**

The MS Library has provided a trusted source of research, news and information which builds confidence and disseminates knowledge. It also plays a key role in supporting MS Connect.

Each fortnight we email our MS Library Update containing the latest research information to MS staff members, and once a month we email the newsletter to 1,021 people who live with multiple sclerosis and 644 external health professionals.

#### In 2014–15, the MS Library also:



## Intouch expands



THE AMOUNT of information offered to readers of *Intouch* expanded when the production of the magazine was reduced from four times a year to three times a year to allow for the introduction of a monthly *Intouch* eNewsletter.

*Intouch* provides the latest news, research and wellbeing information for people who are affected by multiple sclerosis.

Around 3,500 people have elected to receive the magazine when it is posted out in March, July and November.

Since the monthly *Intouch* eNewsletter was introduced in September 2014, the number of people requesting to join the email list has steadily grown.

The September 2014 *Intouch* eNewsletter was requested by 2,450 people and nearly 60 per cent of them opened it in order to read items. This opening rate is impressive as the average open rate for eNewsletters is around 20 per cent.

Over the months the open rate has decreased but the number of people requesting the eNewsletter has increased.

For example, the June 2015 *Intouch* eNewsletter was emailed to 3,370 people and the open rate was 48 per cent.

The continued above average open rate underscores the strong connection readers have with *Intouch*.

## Studdy MS Centre Gym

During 2014–15, the number of exercise sessions offered in the gym at our Studdy MS Centre at Lidcombe expanded and demand continued to grow.

## Here is a summary of visits to the gym:

- independent exercisers made 1,341 visits
- members of the Stretch and Strength program made 1,856 visits

The expanded floor space offers greater capacity, and plans are in place to further increase the physiotherapy– directed exercise programs on offer. In addition, the gym continues to be improved, and thanks to generous donations it will be repainted.



## Professor Millard retires



AFTER 34 years of working with people with multiple sclerosis out of urology clinics based in Chatswood and Lidcombe, Professor Richard Millard retired in early 2015.

The affable Associate Professor of the Prince of Wales Clinical School estimates he has seen thousands of people facing bladder challenges and incontinence issues during the past three decades.

"I have enjoyed assisting people along their journey with the disease," Professor Millard says. "As their multiple sclerosis changes so their requirements change and helping them has given me a sense of achievement."

English-born, Professor Millard graduated in London in 1969 and moved to Sydney in 1978. In Sydney during this period, Dr Robert Barnesworth oversaw a urology clinic at the R.A. Phillips Centre in Chatswood. "In 1980, he wanted to stop so he asked me to take over," Professor Millard says.

From 1980 until December 2014, Professor Millard ran a urology clinic every two weeks, first at Chatswood and then at the Studdy MS Centre at Lidcombe. He saw 14 people with multiple sclerosis during each clinic.

Professor Millard handed the clinic over to Dr Tom Jarvis who also replaced him at the Prince of Wales Hospital.

During 2014–15, the urology clinic delivered 369 hours of service.

## Investment in facility upgrades

#### We continued our ongoing program to revitalise and improve our residential and respite facilities.

TO THIS end, we used money generously donated by trusts and foundations to refurbish units at Watsonia and also to improve all pathways around the facility.

At Lidcombe, a \$90,000 grant from Community Building Partnerships paid for the installation of three accessible kitchenettes.

The kitchenettes were installed in the residents unit, the respite unit and the family lounge. The lounge is an area that enables residents and people in respite to spend time privately with family members and friends who visit them.

The kitchenettes now have accessible features such as sinks, cupboards and a bench that move up and down to enable easy use by a person in a wheelchair.

This means that residents and respite guests can prepare snacks or make a cup of tea independently. Previously these were tasks the residents and respite guests would have required staff to help them with.

Another grant from trusts and foundations paid for four accessible garden beds to be installed in the outdoor area of the Lidcombe residence, enabling residents to create a vegetable garden.







#### Victoria

- Watsonia Shared Supported Accommodation: 12 residents
- Williamstown Shared Supported Accommodation: 10 residents
- McKinnon Shared Supported Accommodation: 6 residents
- Respite is offered at our Watsonia facility and at four other facilities, which are operated by external providers and are located in Bundoora, Leopold, Beaumaris and Bellfield.
- In total, 2,128 respite days were provided in the facilities, a slight increase, using a total of 10 beds.
- In-home respite is offered under a State Government agreement and 4,380 episodes of care were delivered resulting in 8,153 hours being provided, which is up on the 2,661 hours delivered last year.

#### NSW

- Lidcombe Shared Supported Accommodation: 5 residents, following the sad passing of Naji Magdalawi who had resided there since 2007.
- Respite is offered under a State Government agreement and 76 people accessed respite, staying for an average of 24.5 days per customer. We are operating respite at full capacity.
- In total, 1,622 respite days were provided, up from the 964 respite days that were delivered last year.

## ESS keeps Tim working



## **ESS** keeps Tim working



In 2008, about six months after Tim Ryan was diagnosed with multiple sclerosis, he was running around the oval when he couldn't feel his feet touching the ground.







THE SYMPTOM appeared soon after the champion Aussie Rules player had proposed to his wife, Leanne, and was enjoying his football career.

"Over a month, I got worse," Tim, 30 and now father of daughter, Quinn, says. "My legs were so badly affected that my father-in-law had to drive me to work and I kept falling over in the office."

After a few months, Tim recovered but he had to accept that he needed a stick and he couldn't walk further than a couple of hundred metres. He never ran again.

Trying to hide symptoms at work became increasingly hard for Tim. Because providing for his family is a priority, Tim contacted the MS Employment Support Service (ESS) for advice. An ESS consultant arranged for supports including occupational therapy, physiotherapy and myotherapy, which assist Tim in staying at work. Support was also provided to obtain a wheelchair to combat his impaired balance and fatigue.

Our ESS consultant talked to Tim's employer and they worked together to modify Tim's work practices, enabling him to maintain his full potential. At home, the ESS arranged for assistance with household duties in order to ease his fatigue. And, there is one more thing for which Tim is grateful.

"I missed playing sport and the ESS consultant suggested I look at wheelchair basketball. It was a great idea. My sense of joy and excitement and my competitive instincts came back," he says.

# Keeping people at work



A growing number of people who have multiple sclerosis are assisted to stay in the workforce for longer thanks to the MS Employment Support Service (ESS).

THE ESS is able to do this under a sub-contracting arrangement with CoAct, formally known as Job Futures. The promise of this service, aimed at improving employment and economic participation, has faced set backs in NSW but we remain committed to expansion of the ESS in that State. In Victoria, the ESS has increased capacity in the Geelong office.

We are actively engaged with the current Disability Employment Taskforce established by Senator the Hon Mitch Fifield to develop a new National Disability Employment Framework.

The ESS response to the National Disability Employment Framework – Issues Paper will be published on the Department of Social Security DSS Engage website, (www.engage.dss.gov.au), along with our other written submissions selected for publication.

#### In 2014–15:





# What does the NDIS mean?



The National Disability Insurance Scheme (NDIS) is touted as the biggest generational reform since Medicare. Yet many people do not know what the NDIS stands for.

During the two years since the NDIS was launched, we have been relentless in our focus on people affected by multiple sclerosis to:

- Raise awareness of the NDIS and share information to assist people in understanding what the NDIS may mean, now or in the future.
- 2. Increase interest through sharing stories and experiences from people living with multiple sclerosis who have become an NDIS participant.
- **3.** Engage and support people in exploring their individual circumstances and what the NDIS may mean for them.
- **4.** Support people in accessing the NDIS and receiving a plan with funded supports.

#### Is the NDIS for me?

Sue has been living with multiple sclerosis since 2001. Here, she explains how her needs have changed.

I WAS contacted by an MS Consultant in June 2014 to discuss my potential interest and eligibility for the NDIS. The conversation helped me to understand the process and the consultant provided me with the information and support I required.

At the time I was living well with my multiple sclerosis. I worked full time and I was well supported by my family and friends. I didn't feel that I required any supports or services. But I kept the information and tools provided.

Over the course of the year I began to experience some physical difficulties and, because my job requires me to stand for considerable lengths of time, this became more challenging.

I made the decision to reduce my working hours but as I love my job it was important for me to continue to work.

After a conversation with an MS NDIS project officer, who worked through the MS checklist with me, I decided it was time to get started. I needed to determine if I was eligible for funded supports to assist me to maintain and build my strength, which would enable me to continue to work and participate fully in family life.

I was accepted into the scheme and my funded supports include a physio assessment and personalised plan to assist me to maintain strength, as well as domestic support.

This has been a great outcome as I can maintain my current level of employment and enjoy time with my family now that I don't have to expend precious energy on housework.

# What does the NDIS mean?



#### What MS has done

DURING this transition period, MS has focused on the following areas:

- 1. Raise awareness of the NDIS by sharing information relevant to eligibility and access to the scheme to assist people in understanding what the NDIS is about.
- 2. Increase internal and external engagement through regular communication activities and engagement forums.
- **3.** Learn from user and participant experiences to advance our readiness by understanding the impact of the scheme.
- **4.** Adopt practice change, transitioning systems and processes in a shifting environment.





#### Staff adjust to the NDIS

Michelle is one of our MS Consultants and she outlines the impact the NDIS has had on her work.

FOR ME the change has been about adapting to new terms such as calling the person with multiple sclerosis the 'participant' rather than client. There has also been an opportunity to develop new working relationships and this has assisted with getting things done more quickly and smoothly.

The transition to the National Disability Insurance Scheme has meant there has been a timely response for people with multiple sclerosis, in most instances.

While we are all still learning, I work in partnership with the National Disability Insurance Agency (NDIA) and I feel valued for the role I provide in implementing participant plans and troubleshooting along the way. I am also more aware of, and accountable for, how I spend my time, and of the participant being able to choose providers. It's great to see the outcomes we are helping people to achieve.

## **MS** Australia

MS provides financial support to MS Australia (MSA) as the national peak body for people living with multiple sclerosis. MSA works on behalf of state- and territory-based member organisations to support the development of advocacy and awareness combined with communication and information.



MS Australia National Advocates

IT IS the role of MSA to manage national issues and run the National Advocates Program across government stakeholders. The organisation is an active member of the Multiple Sclerosis International Federation (MSIF) and peak bodies in Australia, such as the Consumers Health Forum, the Australian Council of Social Services, National Disability Services and the Neurological Alliance Australia, to advance the interests of people affected by multiple sclerosis.

Advocacy work is included across a range of initiatives including the National Advocates Program that is delivered by a network of volunteer Advocates under the stewardship of Andrew Potter, National Advocates Program Coordinator. The National Advocates Program supports people with multiple sclerosis, and carers, to participate in public policy debates. For example, to mark World MS Day in May 2015, several Advocates gained exposure in local and national media on health and disability issues and the progress made in multiple sclerosis treatments.

Mentoring and information sharing is provided to Advocates who make regular representations to Federal parliamentarians, gain media exposure and make submissions to Australian Government inquiries. In May, Advocates formulated a response to the Federal Budget. They also provided input into submissions such as the Senate Inquiry into Young People in Residential Care, the McClure Welfare Review and a review into Disability Standards for Accessible Public Transport. MSA has also worked closely with State organisations to develop nationally consistent communications about the National Disability Insurance Scheme.

In early 2015, Andrew Potter sailed on Oceans of Hope, the vessel of the Sailing Sclerosis Foundation, sponsored by Biogen, and crewed by people who have multiple sclerosis. Greg Pugh, an MS Go for Gold Scholarship recipient, also undertook part of the global voyage. Oceans of Hope's voyage resulted in substantial international awareness and media coverage.

For information about MS Australia, visit msaustralia.org.au

#### **Deidre Mackechnie**

Interim Chief Executive Officer MS Australia

# Committed to diversity, inclusion and equality

As part of our commitment to recognising and appreciating cultural differences, and encouraging participation by all, we have a Cultural and Linguistic Diversity Committee (CALD) and a Reconciliation Working Group.

ONE of the highlights of the year was the commissioning of a significant original painting by Aboriginal artist, Auntie Marice Henare, photographed below with Robyn Hunter, CEO of MS. Marice, 75, has endured many struggles with multiple sclerosis since she was diagnosed in 1999. She was commissioned to paint a picture of what it is like to live with the disease. When Marice sought inspiration for the artwork, she realised she needed the strength displayed by an ant because each day it carries objects weighing more than it does. That work now hangs in the foyer of The Nerve Centre at Blackburn.







## Other achievements during the year include:

- Translation into Arabic, Vietnamese, Italian and Greek of the key MS publication *Understanding MS*, made available on the website and in print. (See photograph, at left.)
- Provision of flags and symbols to welcome Aboriginal people to MS offices.
- Development of acknowledgement of Aboriginal and Torres Strait Islander country, and protocol around its use.
- Raising of staff awareness of annual celebrations and events of significance to Aboriginal people.
- Collection of data about services for people from culturally diverse backgrounds to contribute to MS planning.

## We thank you!









THE HUGE contribution made by volunteers will still be required when the National Disability Insurance Scheme is fully implemented. The hours generously donated by volunteers enabled us to provide many programs to assist people living with multiple sclerosis and their family members and carers.

## Volunteers, we thank you now, and we hope you will continue to work with us in the future.

During 2014–15, here is how volunteers helped:

4,256 individuals volunteered a total of 139,062 hours.

**162** MS Peer Support Volunteers supported people living with multiple sclerosis by making phone calls, moderating online forums and their Facebook page, and organising face-to-face support and carers' groups. They contributed 26,824 hours.

**190** volunteers contributed more than 10,960 hours visiting a person with multiple sclerosis, supporting MS staff with administrative tasks, assisting MS social programs or visiting an MS facility to support its activities.

**57** MS Ambassadors contributed 808 hours to attend 195 events to help educate the community about multiple sclerosis.

**500** volunteers gave up their time before Christmas to wrap gifts in Federation shopping centres and raised \$45,000.



#### **MS Community Visitors Scheme**

In the past year our 478 Community Visitors Scheme volunteers made more than 11,365 visits to socially isolated older people in NSW and Victoria. Our volunteers visit people for companionship and friendship built on mutual interests. This simple philosophy has added genuine value to the lives of many people. In 2014, our program was expanded to include people living in their own homes who receive a home care package. In the words of one of the recipients, for many people, the program is a 'lifeline'.

# Essential help at events







PEOPLE volunteer to work at MS fundraising events and in the MS Community Shops for a variety of reasons.

In fact, Kerry Reiter-Lynch, MS Retail Shops Support Manager who oversees volunteers, points out that the nature of volunteering is changing.

"People are staying in the workforce longer and when they retire they balance volunteering with other obligations such as looking after grandchildren, or they may volunteer for a while and then go travelling for a year."

These days in the MS Community Shops and at MS fundraising events, many people volunteer to improve their English skills. There is also a portion of people who volunteer so they can add the activity to their curriculum vitae or who want to get out into the community and meet new people.

While this can mean less people who volunteer regularly, Kerry says no matter the reason for people helping out at MS shops or events, she is grateful they do. "Volunteers are essential in helping us raise funds in order to provide services for people who have multiple sclerosis. We can't do it without them.

"As well, we always have folk who volunteer because they have a family member, friend or colleague who has multiple sclerosis. That connection is truly special and it is wonderful that they want to help out."



3,025 volunteers supported our fundraising events by giving 10,066 hours

95 Community Fundraising events were held raising \$408,825



#### **MS Community Shops**

We have 12 MS Community Shops that are staffed by volunteers. This year, their service helped us to raise \$405,649, up from \$267,278 in 2013–14, making a year-on-year increase of 52 per cent. The 335 volunteers donated 70,734 hours, helping to generate a total annual gross income of \$1.745 million, up from \$1.575 million in 2013–14; that's a year-on-year increase of 10.7 per cent.

## MS advice helps recovery



## MS advice helps recovery



Nadine Spilsbury was at the high point of her career when the onset of multiple sclerosis, in April 2012, cut her working life short.







"I WAS the Accounting Manager at Random House Australia," says the Melbourne mother of three who is married to George, a 'fly-in, fly-out' BHP employee who is away for two weeks out of three.

As the symptoms of vertigo, numbress and debilitating fatigue worsened, Nadine relied on her children and local church members for help. Even when her health improved, balance issues left her confined to home.

When she was diagnosed, Nadine had registered with MS and received an information pack. "Some months later, I was at a low point and I phoned MS Connect. I explained I wasn't driving and I couldn't leave the house to do the shopping."

MS Connect arranged for Neti Caird, MS Consultant Occupational Therapist, to visit. "Neti explained the things I could put in place, like managing my fatigue and seeing a physiotherapist, which I did."

During a second visit, Neti and Nadine set goals for the next stage of Nadine's journey. "One goal was to do something social with my husband. Neti outlined how I could explain my limitations to him, such as my loss of confidence and lack of energy."

With this in mind, George planned a relaxing getaway to celebrate their wedding anniversary and it was a great success. But even though her home situation had improved, Nadine remained grief stricken over the loss of her career.

She began volunteering at The Nerve Centre in Blackburn, and this turned into a paid position, three mornings a week. "I still need to rest for at least 90 minutes each afternoon."

While the work she now does "is only a small slice of what I might have done in my previous position," it makes Nadine happy.

"It's a return of part of my identity. I'm okay with having multiple sclerosis. I'm not okay with not working," she says.

## Focused on future success

The focus this year in Marketing and Fundraising centred on putting in place the fundamentals for our future success. These include a revitalised brand, a new website and a redeveloped 2020 fundraising strategy, which will underpin the future aspirations of the MS organisation.

#### **MS** brand

FOLLOWING the success of last year's Seeing MS Campaign, stage two, entitled MS My Story, was designed to acknowledge our donors and create a framework for people who use MS services to directly recognise the support given by donors and fundraisers.

MS My Story captures the inspiring journeys of people affected by multiple sclerosis in achieving the ordinary, everyday things people without the disease take for granted. In the initial four stories we hear how our services enable recipients to improve their mobility, get connected and continue their employment.



#### Website revamp

The new ms.org.au website was launched following significant market research and a user-testing program. The new website increases the profile and accessibility of information for people affected by multiple sclerosis, and provides a new and improved architecture for fundraising.

#### **Innovative approach**

A key focus of the year was commencing the rollout of a new customer satisfaction tool, the Net Promoter Score (NPS). The tool invites donors, fundraisers and users of our services to rate on a scale of one to 10 how likely they would be to recommend the service or fundraising event. They can also provide a suggestion on how we could improve their score. The NPS is now active across the volunteer and event fundraisers space. It is scheduled for roll out in MS Connect in late 2015.
# Focused on future success



#### Inspired to fundraise

Donors and fundraisers are at the very heart of our brand. They enable people affected by multiple sclerosis to access our services while we search for a cure. To acknowledge these people, we launched *Inspire*, a new eNewsletter that celebrates the contribution of our donors and fundraisers.

More than 12,000 Australians made a direct donation to MS this year through one of four direct mail appeals, while a further 20,000 bought tickets in one or more of our art union lotteries.

A huge range of fundraising activities filled the financial year, starting with the 35th MS Readathon, which attracted more than 3,500 readers and some 826 schools.

The MS Sydney to Gong Ride attracted more than 9,000 keen cyclists and fundraisers. We were lucky to have Carol Cooke, Paralympian Gold Medallist and World Champion, head up Team MS. Also, Olympic Gold Medallist Brad McGee and Commonwealth Games Gold Medallist Ben Kersten led the fastest riders at the start. Also on a cycling note, in April, the Melbourne Cycle attracted almost 3,000 riders for what is only one of two cycling events to cross the West Gate Bridge.

The MS Walk and Fun Run was held on 31 May in Canberra, Sydney and Melbourne with almost 11,500 people participating and raising funds.

The MS Mega Swim celebrated its 15 year anniversary, bringing the total of funds raised since inception to more than \$7 million. The result meant we could award 61 MS Go for Gold Scholarships to people living in NSW, Victoria and the ACT.

#### **Dyranda Hortle**

General Manager Strategic Marketing and Sales

#### Funds for research to find a cure

Fundraising continues to be a vital revenue stream to fund both access to services and the search for a cure.

This year significant funds were raised directly by MS and in some cases by individuals or groups participating in one of our community fundraising activities. These funds are distributed to like-minded research organisations and universities for both applied research and the search for a cure. Recipients of this funding included MS Research Australia, Monash University and the Brain and Mind Centre at the University of Sydney.

#### FUNDRAISING FOR A CURE

## MS Research Australia



Dr Matthew Miles, CEO of MS Research Australia, and Simon McKeon, AO, Patron of MS Research Australia

During 2015, MS Research Australia awarded \$1.9 million in funding to 22 new research grants across Australia. Of these, 16 were awarded to researchers in NSW or Victoria, bringing the total number of ongoing research projects in those States to 32. ASSOCIATE Professor David Booth, of Westmead Millennium Institute in Sydney, recently concluded his Senior Research Fellowship, which ran over five years. Associate Professor Booth investigated the genetics of multiple sclerosis and his results are showing great promise for use as tests for prognosis and treatment decisions for people with the disease.

Dr Stanislaw Mitew, of the University of Melbourne, is another researcher making great headway. Dr Mitew is one year into his two-year fellowship looking at myelin repair in the brain. He is exploring ways to harness the body's natural capacity for myelin repair using a type of stem cell present in the brain.

MS Research Australia also continued its role as a managing member of the International Progressive MS Alliance. The Alliance is a global initiative to fund ground-breaking research into progressive multiple sclerosis. In September 2014, the first round of 22 'Challenge Awards' were granted across nine countries, including to Dr Steven Petratos, of Monash University, for his work on neuroprotection.

#### **Recent findings**

MS Research Australia funding has also led to a number of significant recent findings. These included discoveries from Macquarie University and UNSW Australia (University of NSW) about how chemicals released by immune cells contribute to myelin damage, and important findings from the Florey Institute for Neuroscience and Mental Health about how stem cells in the brain can contribute to myelin repair.

Several pieces of work were also published on multiple sclerosis genetics from MS Research Australia collaborative platform ANZgene, which broadened our understanding of how the risk genes for multiple sclerosis change immune cell function.

The MS Research Australia Brain Bank continues to coordinate the collection and use of post-mortem tissue from people with multiple sclerosis for use in research. Since July 2014, 13 brain donations were collected and tissue has been provided for use in five research projects.

MS Research Australia and JDRF Australia were jointly awarded a grant from the Macquarie Group Foundation to conduct a collaborative project to explore the shared genetics of multiple sclerosis and type 1 diabetes. The project brings together leading experts including Professor Chris Goodnow from the Garvan Institute of Medical Research and Professor Graeme Stewart from the Westmead Millennium Institute in Sydney.

### Social and applied research

We also support social and applied research into multiple sclerosis, with the aim of improving symptom management and quality of life for people living with the disease.

For example, a longstanding team member of MS, physiotherapist Dr Phu Hoang, has developed an intervention to improve balance and reduce falls in people with multiple sclerosis. He is now conducting a large-scale clinical trial of the intervention.

MS and MS Research Australia have also partnered in providing a series of webinars featuring updates from researchers working in areas such as coping strategies, cognition and exercise.

For more information visit msra.org.au

Dr Matthew Miles Chief Executive Officer

MS Research Australia

## 2014 MS Sydney to the Gong Bike Ride

# Every rider and volunteer is a champion supporter











#### Funds raised: \$3,195,224 Participants: 9,100

On 2 November, cycling greats Brad McGee and Ben Kersten were joined by Paralympic Gold Medalist Carol Cooke at the start (pictured above, centre). SBS-BA was the top fundraising team with \$108,813 while Stephen Renkert, of Team Electrotech, was the highest individual fundraiser with \$37,825.

## 2015 MS Melbourne Cycle



# Cyclists and volunteers make ride a success









Funds raised: \$536,116 Participants: 2,915

Held on 19 April, this event remains important for MS. Team Dick Whittington was the highest fundraising team with \$51,421. For the second consecutive year, Sam Beck was the highest individual fundraiser with \$30,680.

## 2015 MS Walk and Fun Run





## Three cities unite with one aim







Funds raised: \$1,590,036 Participants: 11,470

The event was held in Sydney, Melbourne and Canberra on 31 May. Udgies Crew raised the most funds for a team with an impressive \$120,175. Adriana Grasso was the highest individual fundraiser with an amazing \$118,195.

# Other ways we raise money











#### **MS Readathon**

During August 2014, children and adults picked up books to participate in the 35th MS Readathon. A total of 826 schools and 3,457 people took part, raising \$297,930. The top fundraiser was Joshua Lewsam from NSW, who raised \$4,210. He was aged 10 at the time.

#### **MS** Community Fundraising

Some people hold dinner dances, others organise sausage sizzles or ask for a donation instead of a birthday gift, while others set themselves challenges such as climbing a mountain. During 2014–15, events like these raised \$408,825.

#### **Bequests**

It is moving when a family member remembers a loved one by making an 'in memoriam' or a person elects to bestow a bequest in order to help people who live with multiple sclerosis. This year their generosity raised \$2,534,712.

#### **Direct Mail**

We organised four direct-marketing appeals in order to raise awareness of the challenges that can be brought to people's lives as a result of multiple sclerosis. We were honoured by the response, whereby approximately 12,197 donors contributed a total of more than \$1.18 million. The average donation was \$97.

#### Art Union

This year six Art Union raffles took place throughout the ACT, NSW and Victoria, generating \$847,166. They consisted of four large raffles and two Club MS member-only raffles.

#### **Trusts and Foundations**

In the past financial year we were fortunate to receive \$952,528 from 120 successful grants. These grants were given to fund assistive equipment such as wheelchairs and air conditioners; Wellness Day events in NSW and the ACT; improvements at the residential units at the Studdy MS Centre, Watsonia and Williamstown; books for the MS Library; a family camp, family days and wellness lunches in Victoria and some education sessions for all regions. There was also a significant commitment from The Profield Foundation to provide ongoing support for the MS Clinic at the Brain and Mind Centre, University of Sydney.

## 24 Hour Mega Swim, Squash and Racquetball





# Participants help fulfil dreams



#### Funds raised: \$961,823 Participants: 2,625 Events: 14

Notable swimmers include Carol Cooke, AM, MS Ambassador, founder of the MS 24 Hour Mega Swim and Gold Medal Paralympian; Ryan Ginns, winner of Big Brother 2014; Sam Bramham and Lawson Reeves, Big Brother contestants; Cameron White, Australian Racquetball Champion; and Sarah Ryan, OAM, Olympic Swimmer and Patron of MS.



Karen Ford fulfilled her dream to record a CD. Read her story on the next page.

#### **MS Financial Assistance Scheme**

The MS organisation offers a Financial Assistance Program for eligible people with multiple sclerosis to purchase or hire equipment and services to improve their quality of life and wellbeing.

Contributions come from trusts and foundations, along with the MS 24 Hour Mega Swim fundraising program, started in 2001 by Carol Cooke, AM, MS Ambassador, Paralympian Gold Medalist and world cycling champion.

In 2014–15, MS provided over \$290,270 in financial assistance to nearly 150 people, including home and vehicle modifications, aids and assistive equipment, orthotics, air conditioning, wheelchairs, scooters and health-related services.

In addition, we awarded 61 MS Go for Gold Scholarships. Most scholarships were to the value of \$3,000. (Read more on the next page.)

Location	Number Awarded	Total Value
ACT	16	\$48,000
NSW	19	\$56,500
Victoria	26	\$80,000
TOTAL	61	\$184,500

# Thanks to MS Mega Swim

Money raised at MS 24 Hour Mega Swim, Squash and Racquetball events funds our MS Go for Gold Scholarship program.

Scholarships are awarded under the categories of the arts, lifestyle, education, travel, employment, sport, music and gym membership.

Last year 61 people from Victoria, NSW and the ACT were assisted in making their dreams come true. Greg Pugh and Karen Ford were among them.



### Greg's dream voyage

IN 2014, Newcastle man Greg Pugh applied for a scholarship in order to achieve his long-forgotten dream of ocean sailing.

Greg, 50, was diagnosed with multiple sclerosis in 2008; the same year in which his marriage broke up and he was retrenched. Multiple sclerosis left him with limited movement in his left arm, stiffness in his left leg and difficulties with balance.

Until then, he had raced 18-foot skiffs on Sydney Harbour and aspired to go ocean yachting. "But nobody wanted me on their boat because I couldn't do my share of the work," he says.

When he heard about Oceans of Hope, a vessel sailing the world thanks to a Danish organisation, Sailing Sclerosis, and crewed by people with multiple sclerosis, he decided to rekindle his dream.

He used the scholarship to fund equipment he needed to increase his ocean sailing skills. He sailed in the 2015 Sydney to Hobart on Wot Eva, a Sailing with DisAbilities yacht. This enabled him to be selected to sail on Oceans of Hope from Samoa to Auckland and then on to Sydney, arriving in May 2015 in time for World MS Day.

"It's been an unbelievable journey," Greg says. "We sailed in wild winds and a horrible sea on some days but I loved it. I was actually doing something that most people only read about."

### Karen records her songs

One morning in 2000, Karen Ford (pictured on the previous page) woke up to find she was paralysed from the neck down along the left side of her body.

The young mother, who lives in Grafton in northern NSW, has three children who were then aged five, nine and 14. Within a matter of weeks she was diagnosed with multiple sclerosis.

Karen regained the use of her limbs but over the years her symptoms increased.

Now aged 46, Karen has problems with balance, memory and fine motor skills. This is particularly distressing because she plays guitar, sings and writes country music.

Last year she applied for a scholarship because she wanted to record her songs before multiple sclerosis made it impossible. She was awarded \$3,000 and used it to create a nine-track CD, *Birdstown*.

Although Karen has performed with bands, she had never heard herself sing the songs she wrote. "I cried when I heard my songs. It's been a fantastic experience and I'm so grateful to have been able to realise my dream."

# MS Connect eases isolation



## MS Connect eases isolation



At 22, Scott Bushell was an up-and-coming film producer who had enjoyed success as part of the team that made the winner of 2005 Tropfest, Sydney's famous short film festival.



HE WAS about to set off on an overseas holiday and his whole life stretched before him filled with exciting possibilities. Then multiple sclerosis struck.

Scott, now 34, couldn't get out of bed, couldn't work and couldn't dress himself.

"When I was first diagnosed, I felt really alone, and incredibly frustrated that I couldn't do the things I wanted to do," he says.

He phoned MS Connect and talked to one of our MS Connect Specialists about the challenges he faced living with multiple sclerosis. "It was good to speak to someone who understands."

As a result of making contact with MS Connect, Scott attended MS education sessions that helped him to understand the disease and his various symptoms.

"At these sessions I was given brochures, which I handed on to my family members so they could learn more as well."

In addition, arrangements were made for Scott to talk to another young person who has multiple sclerosis and he also became involved with the MS group on Facebook. This closed group enables people with multiple sclerosis to chat to each other online. Together these supports eased Scott's sense of isolation.

"I spoke to other people who knew what I was going through and that made a big difference," he says. "Since then, I have made some really good friendships with people who live with multiple sclerosis."

## Positioned for future success

We are ready and waiting to support people affected by multiple sclerosis to access the National Disability Insurance Scheme (NDIS) following the signing of the historic bilateral agreement and the announcement of the rollout timetable for NSW and Victoria over the next three years.

> The information provided to the right relates to the financial information for Multiple Sclerosis Limited (MSL). It excludes the financial results for Australian Home Care Services Unit Trust.

The Statement of Comprehensive income and the Consolidated statement of financial position include the financial results of Australia Home Care Services Unit Trust.

Multiple Sclerosis Limited is incorporated as a company limited by guarantee pursuant to the corporation's Law. ABN 66 004 942 287. KPMG is the auditor for MSL.

. . . .

A copy of our annual report can be located on www.ms.org.au WE HAVE been active in the NDIS trial sites for two years and have great insights into the experiences of more than 300 people living with multiple sclerosis in accessing the scheme, moving back into their homes, getting back into employment, and participating and reconnecting with their families and communities.

We have had another successful year, delivering a net operating surplus as a result of bequest and investment income and operational expenditure savings of 2.7 per cent from a sustained cost management focus. We have spent \$21.6 million on services, down from \$22.2 million, due to better cost management. We believe the focus on effectiveness and efficiency is critical for sustainability of service provision ahead of the imminent change of current state-based funding to individual funding under the NDIS.

As staff leave under their own terms, we are holding vacancies and recruiting into new roles with new capability to deliver expert services in a better way. MS services are unique in that the disease traverses health and disability, and we offer specialist therapy and employment support for 'invisible' symptom management and 'tune up' health needs to maximise function. We provide more than traditional disability supports, we provide valuable wrap-around services such as peer support, education, monitoring and coordination of supports that are unmet by mainstream organisations.

To deliver on our objective to provide more expert services in a better way, we are investing in new technology, new processes and embedding new structures. Fundraising is 5.2 per cent down from the previous year, despite above budget bequest income. We are not alone in facing steep competition for philanthropy and fundraising, and we are investing in improving our fundraising effectiveness as it is key to supporting service delivery and research.

We are on a sustainable footing to provide for the ongoing demand for MS services, and the focus in the coming year is on improving the quality of specialist supports and outcomes and to promote innovation and service availability.

### A summary of our financial performance

Surplus/(Deficit)	1,351	4,435	1,488	(1,408)
Total Expenditure	33,039	32,245	33,140	34,197
Research and Advocad	y 1,005	1,100	830	854
Corporate Services	107	463	801	847
Services	21,401	21,601	22,179	23,228
Fundraising and Events	10,526	9,081	9,330	9,268
Expenditure				
Total Income	34,390	36,680	34,628	32,789
Investment Income	159	2,280	486	186
Corporate Services (Management Fees, Rental Income)	208	260	349	353
MS Services	573	624	730	688
Fundraising and Events (including Bequest Income)	16,110	15,760	16,642	15,912
Government Funding	17,340	17,756	16,421	15,650
Income	(+ )	( + )	( 7 )	(+ /
	Budget 2014–15 (\$'000)	Actual 2014–15 (\$'000)	Actual 2013–14 (\$'000)	Actual 2012–13 (\$'000)

# Financial highlights

Please note these figures are based on the MSL standalone results. They exclude Australian Home Care.

### 

MSL recorded a surplus for the current financial year of \$4,435,310.

# +

Total revenue for the financial year was \$36,680,280.

# -

Total expenditure for the year was \$32,244,970.

## 

This is an increase of \$2,947,367 on the previous year.

## $\bigcirc$

MS research and advocacy expenditure has increased to \$1,100, 000.

### <u>^</u>

Total revenue in 2014–15 increased by 5.9% on the back of increased bequests and investment income.

### •

MSL continues to rely on government funding to provide residential care and other services to people living with multiple sclerosis, and their families and carers. We received government income of \$17,755,702 and we spent \$21,600,717 on services.

### MS Services Expenditure (\$'000)

25,000 - 20,000 - 2

Government fundingFundraising top-up

# Financial highlights



#### Research and Advocacy Expenditure (\$'000)

AdvocacyResearch



2010–11 included bequests and donations of \$644,476 specifically allocated to research.

2011–12 included donations of \$196,281 specifically allocated to research.

The 2014–15 figures include a \$250,000 loan paid to a related party.

# **Multiple Sclerosis Limited and its controlled entities**

**Consolidated statement of comprehensive income** 

These statements include the income of Australian Home Care Services, an operating subsidiary of Multiple Sclerosis Limited.

#### For year ended 30 June 2015

		onsolidated
In AUD	2015	2014
REVENUE		
Fundraising	0 005 705	0 400 74 4
Donation campaigns	2,385,735	2,433,714
Bequests	2,203,570	1,528,767
Art Union	847,166	854,141
Events	7,731,538	9,235,124
Community Fundraising	408,825	547,256
Readathon	297,930	267,364
Retail – sale of goods	1,851,849	1,721,601
Other fundraising income	33,004	53,812
Rendering of services – Multiple Sclerosis Limited		
Residential and respite care		
Government funding	7,209,596	6,632,329
Fees from residents	204,359	187,406
Other income	88,258	55,031
Community teams		
Government funding	4,915,583	4,837,519
Other income	220,236	161,886
Immunotherapy	-	237,253
Disability Day programs	698,025	788,906
Employment services	3,510,351	2,984,653
Other MS services income	1,458,002	1,264,350
Corporate services		
Management fees	70,116	69,936
Rental income	65,907	56,623
Other corporate services income	19,194	8,552
Other income MSL	106,933	128,580
MSL revenue subtotal	34,326,177	34,054,803
Rendering of services – AHCS		
Homecare income	47,490,099	49,890,455
Cleaning and laundry income	44,091,024	45,742,335
Other income AHCS	175,267	408,160
AHCS revenue subtotal	91,756,390	96,040,950
Total group revenue and other income from operating activities	126,082,567	130,095,753

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# **Multiple Sclerosis Limited and its controlled entities**

**Consolidated statement of other comprehensive income (continued)** 

n AUD EXPENDITURE a) Expenditure incurred by Multiple Sclerosis Limited Fundraising expenses Residential care expenses Community care expenses Community care expenses Disability Day programs expenses Disability Day programs expenses Employment services expenses Corporate services expenses Retail expenses Corporate expenses Differ expenses MSL expenditure subtotal b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses Corporate and regional overhead expenses	<b>2015</b> 7,168,051 7,920,196 4,951,969 948,792 3,458,439 3,553,034 1,912,464 347,103 1,216,634 31,476,682 32,212,945 35,068,085 23,252,951 90,533,981	2014 7,832,185 7,718,905 5,943,272 349,960 956,590 3,060,264 3,952,402 1,498,282 811,671 818,641 32,942,172 35,026,012 36,878,051 22,730,291 94,634,354
a) Expenditure incurred by Multiple Sclerosis Limited Fundraising expenses Residential care expenses Community care expenses mmunotherapy expenses Disability Day programs expenses Employment services expenses Other client services expenses Retail expenses Corporate expenses Dise expenses MSL expenditure subtotal b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	7,920,196 4,951,969 948,792 3,458,439 3,553,034 1,912,464 347,103 1,216,634 31,476,682 32,212,945 35,068,085 23,252,951	7,718,905 5,943,272 349,960 956,590 3,060,264 3,952,402 1,498,282 811,671 818,641 32,942,172 35,026,012 36,878,051 22,730,291
Fundraising expenses Residential care expenses Community care expenses mmunotherapy expenses Disability Day programs expenses Employment services expenses Other client services expenses Retail expenses Corporate expenses Other expenses MSL expenditure subtotal b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	7,920,196 4,951,969 948,792 3,458,439 3,553,034 1,912,464 347,103 1,216,634 31,476,682 32,212,945 35,068,085 23,252,951	7,718,905 5,943,272 349,960 956,590 3,060,264 3,952,402 1,498,282 811,671 818,641 32,942,172 35,026,012 36,878,051 22,730,291
Residential care expenses Community care expenses mmunotherapy expenses Disability Day programs expenses Employment services expenses Other client services expenses Retail expenses Corporate expenses Dther expenses <i>MSL expenditure subtotal</i> b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	7,920,196 4,951,969 948,792 3,458,439 3,553,034 1,912,464 347,103 1,216,634 31,476,682 32,212,945 35,068,085 23,252,951	7,718,905 5,943,272 349,960 956,590 3,060,264 3,952,402 1,498,282 811,671 818,641 32,942,172 35,026,012 36,878,051 22,730,291
Community care expenses mmunotherapy expenses Disability Day programs expenses Employment services expenses Other client services expenses Retail expenses Corporate expenses Dther expenses <i>MSL expenditure subtotal</i> b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	4,951,969 948,792 3,458,439 3,553,034 1,912,464 347,103 1,216,634 31,476,682 32,212,945 35,068,085 23,252,951	5,943,272 349,960 956,590 3,060,264 3,952,402 1,498,282 811,671 818,641 32,942,172 35,026,012 36,878,051 22,730,291
mmunotherapy expenses Disability Day programs expenses Employment services expenses Other client services expenses Retail expenses Corporate expenses Other expenses <i>MSL expenditure subtotal</i> b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	948,792 3,458,439 3,553,034 1,912,464 347,103 1,216,634 31,476,682 32,212,945 35,068,085 23,252,951	349,960 956,590 3,060,264 3,952,402 1,498,282 811,671 818,641 32,942,172 35,026,012 36,878,051 22,730,291
Disability Day programs expenses Employment services expenses Other client services expenses Retail expenses Corporate expenses Other expenses <i>MSL expenditure subtotal</i> b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	3,458,439 3,553,034 1,912,464 347,103 1,216,634 <i>31,476,682</i> 32,212,945 35,068,085 23,252,951	956,590 3,060,264 3,952,402 1,498,282 811,671 818,641 <i>32,942,172</i> 35,026,012 36,878,051 22,730,291
Employment services expenses Other client services expenses Retail expenses Corporate expenses Other expenses <i>MSL expenditure subtotal</i> b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	3,458,439 3,553,034 1,912,464 347,103 1,216,634 <i>31,476,682</i> 32,212,945 35,068,085 23,252,951	3,060,264 3,952,402 1,498,282 811,671 818,641 <i>32,942,172</i> 35,026,012 36,878,051 22,730,291
Other client services expenses Retail expenses Corporate expenses Other expenses <i>MSL expenditure subtotal</i> b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	3,553,034 1,912,464 347,103 1,216,634 <i>31,476,682</i> 32,212,945 35,068,085 23,252,951	3,952,402 1,498,282 811,671 818,641 <i>32,942,172</i> 35,026,012 36,878,051 22,730,291
Retail expenses Corporate expenses Other expenses <i>MSL expenditure subtotal</i> b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	1,912,464 347,103 1,216,634 <i>31,476,682</i> 32,212,945 35,068,085 23,252,951	1,498,282 811,671 818,641 <i>32,942,172</i> 35,026,012 36,878,051 22,730,291
Corporate expenses Other expenses <i>MSL expenditure subtotal</i> b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	347,103 1,216,634 <i>31,476,682</i> 32,212,945 35,068,085 23,252,951	811,671 818,641 <i>32,942,172</i> 35,026,012 36,878,051 22,730,291
Other expenses MSL expenditure subtotal b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	1,216,634 <i>31,476,682</i> 32,212,945 35,068,085 23,252,951	818,641 <i>32,942,172</i> 35,026,012 36,878,051 22,730,291
MSL expenditure subtotal b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	31,476,682 32,212,945 35,068,085 23,252,951	32,942,172 35,026,012 36,878,051 22,730,291
b) Expenditure incurred by AHCS Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	32,212,945 35,068,085 23,252,951	35,026,012 36,878,051 22,730,291
Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	35,068,085 23,252,951	35,026,012 36,878,051 22,730,291
Homecare direct expenses Cleaning and laundry direct expenses Corporate and regional overhead expenses	35,068,085 23,252,951	36,878,051 22,730,291
Cleaning and laundry direct expenses Corporate and regional overhead expenses	35,068,085 23,252,951	36,878,051 22,730,291
Corporate and regional overhead expenses	23,252,951	22,730,291
AHCS expenditure subtotal		
Total Expenditure	122,010,663	127,576,525
Share of losses of equity accounted investee	-	
Group surplus/(deficit) from operations	4,071,904	2,519,228
Finance income	412,004	445,271
Finance expenses	(48,597)	(37,589)
Group net finance income	363,407	407,682
Tax expense	-	
Total surplus/(deficit) for the year	4,435,311	2,926,910
Group other comprehensive income		
tems that may be reclassified subsequently to surplus or deficit:		
Available-for-sale financial assets – net change in fair value	149,686	376,580
Available-for-sale financial assets – reclassified to surplus or deficit	(1,608)	(210,510
	148,078	166,070
Total comprehensive (loss)/income for the year	4,583,389	3,092,980
Contribution to total comprehensive income	201	5
Multiple Sclerosis Limited		
Australian Home Care Services	3,325,109 1,258,280	
Total	4,583,38	

# **Multiple Sclerosis Limited and its controlled entities**

**Consolidated statement of financial position** 

### As at 30 June 2015

713 dt 00 burle 2013	Con	solidated
In AUD	2015	2014
ASSETS		
Cash and cash equivalents	7,891,794	5,453,183
Other financial assets	4,673,850	1,005,724
Trade and other receivables	7,082,232	8,599,789
Non-current assets held for sale	1,102,988	-
Total current assets	20,750,864	15,058,696
Property, plant and equipment	15,582,591	16,454,824
Intangible assets	13,845,908	14,783,645
Available-for-sale financial assets	4,223,249	3,952,900
Other receivables	1,053,520	
Total non-current assets	34,705,268	35,191,369
Total assets	55,456,132	50,250,065
LIABILITIES		
Trade and other payables	5,003,854	5,147,893
Employee benefits	13,583,549	15,019,124
Deferred income and funds in advance	8,142,079	6,489,948
Hire purchase liabilities	56,480	116,416
Provisions	154,747	157,817
Total current liabilities	26,940,709	26,931,198
Employee benefits	1,459,741	1,103,544
Hire purchase liabilities	126,091	184,043
Provisions	314,922	-
Total non-current liabilities	1,900,754	1,287,587
Total liabilities	28,841,463	28,218,785
Net assets	26,614,669	22,031,280
NEL 92212	20,014,009	22,031,200
Members' funds		
Accumulated surplus	25,591,783	21,156,472
Fair value reserve	951,108	803,030
Bequest reserve	71,778	71,778
Total members' funds	26,614,669	22,031,280

# Financial highlights



MS Services Expenditure by Category 25,000 — 20,000 — 15,000 — 10,000 — 5,000 — 0 — 2010-11 2011-12 2012-13 2013–14 2014-15 Other Community Visitors/Volunteers MS Connect Employment services MS Care Residential and respite

Where the money came from	+	+
Please note these figures are based on the MSL standalone results. They exclude Australian Home Care.	Fundraising and Events: \$15,760,000	Government funding: \$17,756,000
<b></b>	+	+
MS Services: \$624,000	Corporate Services: \$260,000	Interest and dividends: \$2,280,000
<b>Total Income</b> \$36,680,000		

# Where the money was spent



Research and Advocacy: \$1,100,000 Corporate Services: \$463,000

Fundraising and Events:

\$9,081,000





Multiple Sclerosis Limited operating as MS ABN: 66 004 942 287

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