

MS KEY NEWS

AUSTRALIA

SUMMER 2010

FROM THE CEO'S DESK



Welcome to the Summer issue of Key News.

Welcome to the first issue of Key News for 2010 – a new look for a new year. I hope you enjoyed the festive season and thank you for making a difference to thousands of people living with Multiple Sclerosis (MS) by choosing to support MS Australia.

Your generous support allows us to assist more people with MS every day while expanding our 50 year tradition as one of Australia's leading Not for Profit organisations.

Our cover story this issue tells us about Craig's family, who have had to face challenges like making tremendous sacrifices to pay for expensive home modifications to support Craig's wife, who lives with MS. The recently announced feasibility study into a National Disability Insurance Scheme by the Federal Government gives Craig hope for the future. We are proud of our significant role in lobbying for this change, and we will be making thorough submissions to the study to lead the call for systemic changes in the way people with disabilities are supported in this country. In the meantime, MS Australia provides funding to people like Craig to make the necessary modifications to their homes to accommodate the needs of their loved ones.

In this edition, you will also receive an insight into the valuable work of our Community Support Workers and read about the latest developments in research; the possibility of new oral medications to manage the symptoms of MS. Such research is crucial and we are always looking at ways to support the search for better treatments and, ultimately, a cure. In fact, in 2009, MS Australia – ACT/NSW/VIC contributed \$2.211 million to MS Research Australia (MSRA), making us the largest single funder of research in Australia through MSRA.

If we don't keep investing more money in research now, tomorrow's opportunity for a pain free, independent life for people with MS is limited.

Once again, thank you for taking up the challenge of helping those living with MS. Your contribution makes a real difference to helping people with MS, their partners, children and carers.

Bill Younger
CEO, MS Australia – ACT/NSW/VIC

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Disability Insurance Scheme One Step Closer

After years of campaigning by disability advocates at which MS Australia has been at the forefront, the Rudd Government recently announced it would look into an insurance scheme to provide long term care and support for people living with disabilities like MS.

The Prime Minister made the announcement late last year that the Productivity Commission would conduct a feasibility study to assess approaches for funding and delivering long term disability support, including the possibility of a no-fault social insurance scheme.

Alan Blackwood, MS Australia's Manager of Policy and Community Partnerships, said the announcement was a win for people with MS, having the potential to change the lives of millions of Australians who are either living with a disability or caring for a family member.

"For too long people living with disabilities in Australia, their family and carers have been isolated and unsupported by the system. This is a system where the cause of a disability determines what support a person gets, and a system where children are caring for disabled parents and young people are forced into aged care nursing homes because of the lack of money for carers and home modifications," Alan said.

Craig Coleman knows this all too well. He's been caring for his wife, who lives with MS, for over 15 years. Over that time, her disease has worsened so much that he has had to scale back to part time work, putting enormous pressure on the household income. Craig says an insurance scheme would give much needed security to families like his.

"The things we have had to pay for over the years because of my wife's illnesses aren't luxury items, they are basic needs. She just can't physically get in



Craig and his wife Julia with their family.

and out of the shower so we had to buy expensive bathroom modifications. It took forever to scrape the money together through funding applications and thousands of dollars of our money. If she had acquired her disability through a car accident things would be totally different. A scheme like this would be much fairer."

"If my wife keeps getting worse, we want to rest assured that there is a way of helping us deal with the increasing demands that her illness places on our family life," Craig said.

MS Australia will be making a thorough submission to the feasibility study.

MS FACTS

The average age of an MS diagnosis is just 30

An estimated 2,500,000 people around the world have MS, including around 20,000 people in Australia

MS affects three times as many women as men

87% of people who are diagnosed are of working age – but after 10 years, 80% will lose their job

MS costs Australia \$2 billion each year

Australians with MS pay \$160 million each year in health costs

48% of people with MS earn less than \$300 per week, compared with 39% of the Australian population



NSW Minister for Energy John Robertson MLC, State Member for Drummoyne Angela D'Amore with NSW/ACT Manager of Service Delivery Kate Young and person with MS Jill Hodder at the launch.

Beating the Heat

Calls from MS Australia for support for people living with the debilitating effects of heat intolerance have resulted in the recent announcement of the NSW Medical Energy Rebate by the NSW Government.

THE new rebate will provide \$130 per year to people who suffer from the condition. For people with MS, even a small increase in body temperature can lead to extreme fatigue and an increase in other MS symptoms such as blindness, incontinence and tremors.

Dr Michael Summers, MS Australia's Senior Policy Advisor says "The NSW Government's new rebate will provide much needed assistance for people with MS on low incomes who have to run their air conditioners approximately 15 times more than average NSW households.

"We know that 90% of people living with MS find their symptoms increase dramatically when they get too hot, and with rapidly rising electricity prices the cost of keeping cool at home has become

a real problem for those on low incomes. This new rebate will make a very real difference in the lives of many people living with MS in NSW."

Jill Hodder lives with MS and has suffered from heat intolerance since her diagnosis of MS in 1997.

"Every year I dread the warmer months because when it gets hot my body just shuts down.

"Along with the emotional toll of not being able to enjoy activities outside, comes the financial strain of having to pay electricity bills just so my body can keep running. For most Australians it's a luxury to run the air conditioning during summer but for me it's a necessity," Jill said.

For more information on the Medical Energy Rebate contact MS Connect on 1800 042 138.



Help us raise \$1 million for people with MS

On Sunday, 6 June you are invited to join over 5,000 walkers and runners who will put their best foot forward in the annual MS Walk and Fun Run in Melbourne and Sydney. The stroller and wheelchair friendly walk routes will take in the two cities most scenic and iconic parklands, gardens and bridges. Take the first step in becoming part of this iconic event and register at www.mswalk.org.au.

You'll find all of the relevant information for course maps, fundraising, preparation tips and much more. Get together with a few friends, workmates or your sporting group and enter as a team.

Research update: Possible oral medications for MS



Recent reports have indicated that clinical trials of two oral medications show good results for treating the symptoms of MS.

THESE medications would be taken as capsules, as opposed to most currently available treatments which are administered by injection.

MS Australia's Dr Bill Carroll said "MS Australia welcomes research into any new therapies like these that may give people with MS more options for reducing disease activity and the possibility of less

long term disability."

The drugs are still both at clinical trial stages and yet to go through the required Therapeutic Goods Administration assessment for use in Australia.

"We are looking forward to the results of the assessment to determine when these drugs will be available to help people with MS in Australia," Dr Carroll said.

Supporting people with MS every day

Deslie, from Wangaratta, works as one of the 27 Community Support Workers across ACT, NSW and Victoria. We asked Deslie to share her experience as a Community Support Worker and some of the challenges for people living with MS in rural and regional areas.



"I work as a Community Support Worker in the Hume region of Victoria. Within this region, we have 300 registered clients with MS. CSW's play a vital role in minimising the impact of multiple sclerosis throughout regional and rural areas.

Together with my colleagues, some of the roles we undertake in the community include:

- Acting as an initial contact for those newly diagnosed
- Addressing individual needs and program planning
- Acting as an information resource for people living with MS, their family and carers and health professionals
- Providing community education
- Providing referrals to community based agencies as appropriate
- Advocacy and liaison with other community services
- Consultation and education for community health professionals on MS

Generally, there is no such thing as a typical week as a Community Support Worker. Often I can experience anywhere from 10 - 20 hours of driving each week to fulfil various aspects of the job. The majority of my time is spent working alongside clients; doing home visits, assessments and referring to appropriate community services. Other time is spent liaising with local community services and conducting presentations or education sessions to an agency or community health team.

Living in regional and rural areas for people living with MS can be a challenge that often their metropolitan counterparts don't experience. For many, the distance to travel for medical treatment and community services can be significant, as too are the long waiting lists for accessing services and supports. Often in regional and rural areas, clients can experience isolation. A friendly support network, including a Community Support Worker can help make a big difference.

I consider my role as a Community Support Worker as an essential link in the chain for helping to achieve equitable access for people with MS no matter where they live. I've had many valuable experiences working alongside people with MS. Their resourcefulness, positive attitude and willingness to share their personal journey and experiences with others, is astounding. I feel a strong sense of achievement in my role helping them every day."

Community Support Workers

There are 27 community support workers across ACT, New South Wales and Victoria. Some are located within metropolitan NSW, however the majority based in regional and rural areas. Most CSW's have an allied health background, adding value to the assistance they can provide to people with MS.

Regions covered include:

- Gippsland
- Hume
- Loddon
- Barwon South Western
- Grampians
- Canberra
- Gouldburn
- Central Coast
- Alstonville
- Tamworth
- Coffs Harbour
- Orange
- Raymond Terrace
- Wagga Wagga
- Batemans Bay
- Illawarra



Telling Real Stories

A DVD recently produced by MS Australia - ACT/NSW/VIC shows the different faces of MS.

THE DVD, entitled *Living with MS* tells the story of four real and inspiring people who have one thing in common - living with the effects of Multiple Sclerosis. Throughout the DVD, Tammy, Stephen, Patrick and Mark tell us what it's like to face the unpredictability of this disease each and every day, and introduce you to the team at MS Australia that care and support them.

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