

# mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

www.mnda.org.nz

## Contents

NZ Celebrities and MND	3
Research	4-6
GP Diagnostic Tool	8-9
MND NZ AGM	13
How to Facebook	14

## Motor Neurone Disease

**Motor Neurone Disease (MND)** is a condition affecting the nerves that control muscle movement resulting in weakness and paralysis. MND is also known as ALS and Lou Gehrig's Disease. There are various subtypes including Primary Muscular Sclerosis (PMA) and Primary Lateral Sclerosis (PLS). Individuals present with different patterns of symptoms and rates of progression.

The MND Association of New Zealand Inc. exists to provide support, information and advocacy for those living with a diagnosis of Motor Neurone Disease.

**Disclaimer:** The content of this newsletter is provided for information sharing purposes only. Whilst all care is taken to use only reputable sources, content should not be construed as an endorsement by the MND Association NZ Inc. nor as a recommendation for any individual. We strongly advise you discuss options with those who know you best before making any changes to your routines.

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## Wet, Wet, Wet – but worth it!!

On the morning of Sunday September 25, in 14 towns and cities all over New Zealand, hundreds of people gathered for Walk 2 D'Feet MND events.



**ALTHOUGH THE WEATHER** was disappointing in almost all locations, the funds raised were not. This year's Walk 2 D'Feet MND events raised over \$165,000, although this is not the final figure as money is still coming in.

*"Despite torrential rain in some locations, over 4000 people took part," says MND NZ President Beth Watson. "Each Walk 2 D'Feet MND brought together a local community of people whose lives have been affected by motor neurone disease. MND can be very isolating for people with MND and their families, but people aren't in this alone."*

Half of the profits will be used to encourage and support MND research in

New Zealand, and half will help MND NZ continue its crucial work providing Fieldworkers to support people with MND and their families.

MND NZ would like to thank walk sponsor ResMed and Hound & Steed Creative Agency, in Christchurch. *"Without ResMed's support and Hound & Steed's pro bono work we couldn't have*

*achieved this six-figure fundraising milestone,"* says Beth Watson.

*"We would also like to thank the organisers of the events, who volunteered a great deal of time and energy to make this year's Walks such a huge success. We are enormously grateful to you all."*

*"Once again we are indebted to Claire Reilly for her leadership example – Claire you inspire us all. I would also like to specially acknowledge Merle, Eco, Liz and Tony, who all picked up time- and energy-consuming leadership roles, while also living with MND themselves. Their strength, stamina and determination are awe-inspiring."*

## A huge thank you to our 2016 Walk 2 D'Feet organisers

Toni Bradbourne (Auckland) Helen Palmer (Hamilton) Lana Hook (Whanganui)  
Tanya Gilchrist (Tauranga) Tony Treloar (Taupo) Jodi Edwards (Hawkes Bay)  
Bek Slingsby (Waipukurau) Liz Anderson (Masterton) Sarah Wood (Wellington)  
Eco Yanaga (Golden Bay) Bronwyn Simons (Christchurch) Merle Bradley (Hokitika)  
Shelly Skea (Dunedin) Nicola Leonard (Invercargill)

# Astral™ series

Life support ventilators



## Greater freedom

Day after day, Astral does what it does best: help people renew a sense of freedom and gain independence, whilst giving clinicians the confidence that they are providing quality ventilation wherever it's needed - in hospital and at home.

ResMed's Astral 150 life-support ventilator is a small, portable, and lightweight with external battery life and patient-friendly set-up and operation – offering greater freedom, confident care, and designed efficiency to enrich life for everyone.

To discover more about the Astral series or for information on how to buy or rent, visit **[ResMed.com/Astral](https://www.resmed.com/Astral)**.

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# Celebrities face MND too

**“I DIDN’T EVEN KNOW** what motor neurone disease was when my mother was diagnosed with it,” says **Annabel Langbein**, one of the well-known New Zealanders who appeared in the MND NZ awareness campaign.

**Bernadine Oliver Kerby**, whose father died of MND just a year ago, says her father had also never heard of MND prior to his diagnosis. “He said to the doctor, ‘Cut my leg off. If you cut my leg off, will that fix me?’ That’s how helpless he felt.” Grant Kerby was a farmer in the Waikato who died aged 68, just 14 months after he



was diagnosed with MND.

“It was 18 years ago that my dad was diagnosed with motor neurone disease,” says Masterchef **Brett McGregor**. Terry McGregor, a former Iron Man and Coast-to-Coaster, died of MND aged just 50. “The disease moved really fast,” says McGregor. “It was a real struggle for everybody. Dad was this person that never got sick.”

“My partner’s aunt was diagnosed with MND in 2009,” says **Tamati Coffey**. “The worst part was actually understand-

ing that with it, her mind was still all there. She was still witty and funny, but she had to type it all into an app on her iPad and then press ‘Voice.’”

“A close friend’s wife was diagnosed with motor neurone disease a few years ago,” says **Sir Richard Hadlee**. “It just came out of the blue. Eight months later she passed away.”

You can read more about the experiences of Annabel, Brett, Bernadine and Tamati on our website in the Help Us – Share Your Story section. [www.mnda.org.nz](http://www.mnda.org.nz).



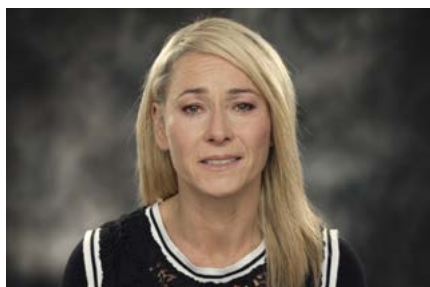
## MND Awareness Success

**YOU MAY HAVE SEEN** our MND awareness video on TV in September. It was played over 90 times on TVNZ, TV3, Prime and The Edge TV. A radio version was also created, which received thousands of plays across many major radio stations.

If you didn’t catch the ad, you can watch it on our YouTube page at [www.tinyurl.com/mndnztv](http://www.tinyurl.com/mndnztv).

Many well-known New Zealanders, including some with a deeply personal connection to MND, volunteered their time and in some cases their privacy to participate in this video for us. We are deeply grateful to Brett McGregor, Annabel Langbein, Bernadine Oliver Kerby, Tamati Coffey, Sir Richard Hadlee, Te Radar, Nigel Latta, Urzila Carlson and Simon Dallow for their contribution.

MND NZ is also grateful to Dr Claire



Reilly and Jac Kluts, who both live with MND and travelled from Christchurch to film the ad. Jac is the manager of The Radio Bureau in Christchurch, and his colleagues in the media world supported his participation by giving both our TV and radio ads a great deal of extra airplay at no cost to MND NZ.

A longer version of the ad reached an enormous Facebook audience, being watched over 67,000 times ([www.facebook.com/mndanz](http://www.facebook.com/mndanz)) and shared 1122 times, with a total of 5753 reactions and comments. We also gained over 1000 new Facebook page ‘Likes’ over this time period.

We also had some fantastic media coverage in the lead-up to the Walk 2 D’Feet MND events. *Seven Sharp* interviewed Claire Reilly about her life with MND (watch it at <http://tinyurl.com/7sharpmnd>), *Woman’s Day* interviewed Bernadine Oliver Kerby about her father’s death due to MND, *New Zealand Woman’s Weekly* featured several of the faces from our video, the *Herald on Sunday* interviewed MND researcher Dr Emma Scotter about her work, and *The Press* interviewed Jac Kluts. Claire was also a finalist in the NEXT Woman of the Year Awards. Congratulations, Claire!

All together, our MND awareness campaign made over 10 million impressions across TV, Facebook, radio and print. The value of this coverage was over 1500 percent more than we invested.

It is one of MND NZ’s constitutional objectives to increase awareness of MND in New Zealand. This video campaign certainly achieved that, and we hope to build on this growing awareness in future.

### Vodafone TXT2Give facility is closing

In 2014 Vodafone partnered with Fundraise Online (now named Everyday Hero) to bring TXT2Give to New Zealand enabling quick, easy text donations to New Zealand charities. Unfortunately, Vodafone have advised that since the option was only available to Vodafone customers it limited the number of donations and frustrated supporters who use a different mobile provider so the facility will be discontinued from 31 December.

# Collaboration and Communication

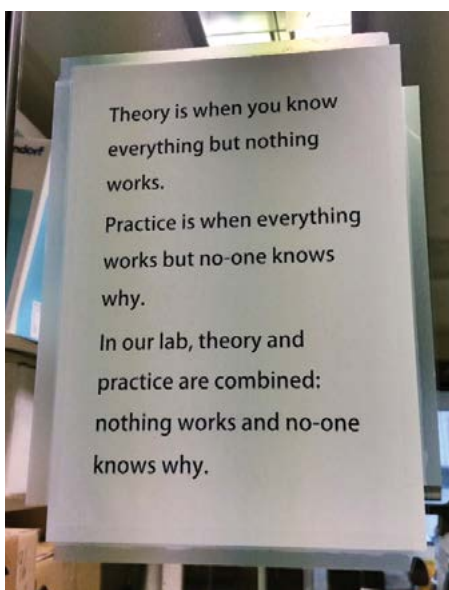
MND NZ staff had a great afternoon of sharing with the MND research team at the Centre for Brain Research.



**MND NZ Staff at the Centre for Brain Research Auckland**

**IN JULY** as part of our team professional study days MND NZ staff were treated to a visit to the Centre for Brain Research in Auckland as guests of Prof. Richard Faull, Prof. Mike Dragunow and Karen Smith who organized a wonderful afternoon for us starting with lunch. Sincere thanks to the organisers. We were all impressed by the passionate enthusiasm, dedication and knowledge of this great team of brilliant minds working daily to contribute to a breakthrough in understanding, maybe treating, maybe preventing MND ... and as we carefully moved through the laboratory, being excruciatingly careful not to touch a single thing and trying to ask intelligent questions we saw the following sign which reminded us that scientists also have a sense of humour and their feet on the ground.

*Our sincere thanks to the CBR team for making us so very welcome and for all the work they are doing.*



**MNDcare a web-based tool** developed by MND Australia to get evidence based and best practice motor neurone disease care research into practice. Health Professionals and service providers are invited to sign up for regular update emails.



**MND Aware training modules** – view online training tutorials on MND on the MNDCare website: [www.mndcare.net.au](http://www.mndcare.net.au)

MND Australia offers online training for health and community care professionals about MND.

These easy to view training modules provide health and community care professionals with a basic understanding of motor neurone disease (MND) and the impact it has on an individual's life. These online training sessions have been specifically developed for home and community care workers, case managers, health and residential care workers and consist of:

- 9 Introductory sessions (Sessions 1–9)
- 10 Symptom management sessions (Sessions 10–19)
- 7 Wellbeing and support need sessions (Sessions 20–26)

**An easy way to orientate to the needs of people with MND and to access free professional development.**



**MND UK Professional Forum** offers another online resource that enables health professionals and service providers to share their experience as they work to support people living with MND. <http://proforum.mndassociation.org/forum.php>



# Research Update



**IN OUR LAST UPDATE** we discussed the momentum building around MND research worldwide, and outlined several important new findings from international studies. Now we are seeing our MND research program building momentum here at the Centre for Brain Research at the University of Auckland. The team has been awarded Rutherford Discovery Fellowship and Marsden FastStart funding to tackle several key questions in MND biology. Our collaboration with the Centre for Public Health Research in Wellington is underway, as is our drug screening program. And using brain tissue bequeathed by New Zealand MND families we have characterised the toxic proteins that accumulate in the brain in MND. In this update we will provide more detail about our growing NZ MND research program.

## 1. Funding success

Through our new Rutherford Discovery Scheme funding we aim to work with MND NZ to develop a MND research network that links research teams, clinicians, carers, and people with MND. Beth Watson is a force of nature when it comes to networking. Together we can improve the visibility of MND research in NZ, providing a beacon for interested researchers and participants.

In addition, both the Rutherford Discovery and Marsden FastStart Schemes have provided funding for our studies of cells that control the exchange of nutrients and waste products between the blood and the brain. We have preliminary evidence that these cells are damaged in MND. We can now study these cells more closely in order to understand how they influence the survival of the motor neurons.

## 2. A blood-based “signature” for MND

Many of you will have participated in the epidemiology study being conducted by the Centre for Public Health Research (CPHR) in Wellington. The CPHR team have conducted in-depth interviews with several hundred New Zealanders living with MND to determine whether there may be risk factors for MND in their workplaces or environment. We have re-visited a select group of participants from that study to test whether their blood can yield further clues about MND. In particular we will test whether molecules from the brain can be detected in the blood, which would provide further evidence that the cells controlling exchange between the brain and blood are damaged in MND.

### 3. Drug discovery

Dr. Deidre Jansson is leading our efforts to test several thousand drugs against human brain cells grown from tissue donated by patients. These cells are grown and banked in The Centre for Brain Research Hugh Green Biobank, directed by Professor Mike Dragunow. We aim to find new drugs which can either mimic the damage to MND brain cells or, ideally, repair them. These studies will improve our understanding of the specific problems occurring in MND brain cells and how best to slow or halt the damage using therapeutics.

#### 4. Genetics and pathology of MND in New Zealand

In addition to the Biobank, the Centre for Brain Research is also home to the Neurological Foundation of New Zealand Human Brain Bank, directed by Distinguished Professor Richard Faull and co-directed by Associate Professor Maurice Curtis. Over the last 20 years, more than 20 families with MND have shared with us the incredibly precious gift of brain and spine tissue. We have now systematically examined this brain tissue and



**Mike Dragunow Emma Scotter, Deidre Jansson**

published our findings. All cases we examined showed build-up of toxic clumps of a protein called TDP-43 in the motor neurons. We identified genetic mutations in 3 cases (16%), all of whom had a family history of MND and/or frontotemporal dementia. In these cases we also found toxic protein clumps in the memory area of the brain (hippocampus). This was the first study to show that the brains of people with MND in New Zealand have similar pathology (protein clumps) to those with MND elsewhere. And indeed, that New Zealanders also show genetic traits that can cause MND. This heralds a start to New Zealand cases being included in international MND research.

## Conclusion

MND research is advancing in leaps and bounds both internationally and now here at home. We have the privilege of working with people with MND, or studying their bequeathed tissues, to answer questions about their disease. We look forward to bringing you further updates about our latest findings.

Thanks to the hugely successful Walk 2 D'Feet events, we now have funding to work alongside MND NZ to develop a MND research network that links research teams, clinicians, carers, and people with MND.

We look forward to bringing you further updates about our latest



# Massey University Research

## Occupational and Environmental Risk Factors and MND in New Zealand



MASSEY UNIVERSITY  
TE KUNENGA KI PŪREHUROA  
UNIVERSITY OF NEW ZEALAND

**THIS STUDY ON** Motor Neurone Disease, conducted by the Centre for Public Health Research at Massey University is in its final year and beginning to analyse the data collected – here the research team provide us with some initial findings.

### Preliminary Results

The results presented here are for the 265 cases (people with MND) and 532 controls (from general population) for which the interview process or data entry and cleaning had been completed at the time these analyses were conducted. (Note that we now have 298 cases and 585 controls interviewed.) Two thirds of MND patients involved in our study were male, and 70% were aged over 60. Significantly elevated risks were observed in the following groups.

Telecommunications technicians, Technical (Sales) Representatives, Petrol Station Forecourt Attendants, Agriculture and Fishery Workers, Market Farmers and Crop Growers, Fruit Growers/ Workers, Building Trades Workers, Agricultural, Earthmoving and Other Materials Handling Equipment Operators, Labourers and Builders Labourers. There was also a non-significant elevation in Electricians (OR=3.09, 95% CI 0.90-10.66). **These results suggest associations with exposure to several risk factors that have been observed in other studies including organic solvents, agricultural chemicals and electromagnetic fields.**

The analyses by industry category again showed a consistent pattern of the types of potential occupational exposures being risk factors for MND. Significantly elevated risk was again associated with work in the Agricultural sector, and in particular Horticulture and Fruit Growing but not livestock farming, the Construction sector, in Automotive Fuel

Retailing, in Computer Services, Government Administration of Justice and Technical and Further Education. Other sectors with elevated but not statistically significant risk include Dairy Product Manufacturing and Electrical Services.

We have also performed analyses of self-reported data on exposures and traumatic injuries. Although these data are self-reported and potentially susceptible to recall bias, particularly strong associations are observed for exposure to fumigants and to head injuries. **The fumigant result in particular warrants further investigation** using methods of exposure assessment that are not prone to bias.

With respect to the occupational exposures of interest we have observed a strong association with Agricultural and in particular Horticultural occupations, which is consistent with the literature on pesticides and MND, with both Automotive Fuel retailing and Agricultural/Earthmoving equipment operation which **may implicate organic solvents or vehicle exhaust emissions.** The associa-

tions observed for work as an Electrician, Telecommunications Technician, in the Electrical Services industry or Computer Services are all **suggestive of an association with electromagnetic fields of various frequencies.**

**These preliminary results are consistent with those reported in the literature, and suggest that occupational exposures may play a significant role in MND in New Zealand.**

30 blood samples (15 cases, 15 controls) have now been collected in Wellington area and all samples have been sent to Auckland Brain Research Centre for our collaborate study, the results will be updated next year.

This is the first study to investigate potential occupational and environmental risk factors for MND in New Zealand and it will allow comparisons to be made with other developed countries.

**This is the first study to investigate potential occupational and environmental risk factors for MND in New Zealand and it will allow comparisons to be made with other developed countries.**

For further information contact the project directly by calling free on 0800 793 121 or email Grace Chen:

[g.chen1@massey.ac.nz](mailto:g.chen1@massey.ac.nz)

## Keeping up to date

### Research and current practice around MND can be followed online

Our own webpage: [www.mnda.org.nz](http://www.mnda.org.nz)

UK MND Research Blog: [www.mndresearch.wordpress.com](http://www.mndresearch.wordpress.com)

Australian MND Association: [www.mndaust.asn.au](http://www.mndaust.asn.au)

MNDCare Latest News: [www.mndcare.net.au](http://www.mndcare.net.au)

Research updates: [www.als.net](http://www.als.net)

UK MND Association: [www.mndassociation.org/research](http://www.mndassociation.org/research)

American ALS Association: [www.alsa.org/research](http://www.alsa.org/research)

ALS Worldwide: [www.alsworldwide.org](http://www.alsworldwide.org)

When searching for information remember that MND (Motor Neurone Disease) is called ALS (Amyotrophic Lateral Sclerosis) in the U.S. and some other countries.

### Clinical Trials are listed at:

Australian Clinical Trials: [www.australianclinicaltrials.gov.au/home](http://www.australianclinicaltrials.gov.au/home)

U.S. Clinical Trials: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)



# MND: New Genetic Discoveries

**IN JULY**, two research papers that discovered new genes connected to the development of MND were published in the scientific journal *Nature Genetics*.

The first paper found that variations in the *NEK1* gene contribute to why people develop the rare, inherited form of MND. Variations in the *NEK1* gene were also found to be one of the many factors that tip the balance towards why people with no family history develop MND.

The second paper found that people who have a rare variation of a gene called *C21orf2* are at an increased risk of developing MND.

Variations in three other genes, called *MOBP*, *SCFD1* and *TBK1*, were also seen more often in people with MND, suggesting that these gene variations may also



increase the risk of developing MND.

These results are unusual, because the genetic variations are found in people who don't have a family history of MND. They may interact with lifestyle and environmental factors to cause MND.

It's the first time that the *C21orf2* gene has been linked to MND, opening up a new area of biology that few MND researchers have looked at previously. It could give us important clues for under-

standing MND, and ultimately developing new treatments.

The results were achieved by a worldwide collaboration, catalysed by Project MinE, in which researchers from 15 countries shared DNA samples. By sequencing the DNA of approximately 15,000 people with MND and 26,000 healthy 'controls', the researchers were able to identify these genetic changes that are more common in people with MND.

Money raised around the world from the 2014 Ice Bucket Challenge helped fund the expensive whole genome sequencing technique, which involves looking at each 'letter' that makes up our genetic code – approximately 6 billion letters per person, a huge amount of data for researchers to look through.

## Connecting with Health Professionals and Service Providers

**WE FREQUENTLY HEAR** how surprised people are at the numbers of services available offering them support, and most are provided free of charge. MND NZ welcomes opportunities to connect with these service providers to support their work and highlight the needs of people with MND.

**In March Kate Moulson provided a stand at the Nurse Maude Hospice MND Study Day in Christchurch.**

Helen Brown, MND NZ Council Member and Palliative Care Dietitian at Nurse Maude reports:

*"The day was extremely well attended with over 80 attendees from Residential Care Facilities and Hospital settings. We were very lucky to have an outstanding range of speakers from Professor Mike Dragunow from the Auckland Brain Bank on current research into MND through to Dr Rachel Wiseman a Respiratory and*

*Palliative Care Physician from Christchurch Hospital and Kate Grundy Palliative Care Physician from Christchurch Hospital."* The afternoon presentations were from the Interdisciplinary Team including the Occupational Therapist, Physiotherapist, Speech Language Therapist, Dietitian and P.E.G Nurse Specialist. *"We had 5 trade stands offering information from the MND Association, Non Invasive Ventilation, Mobility support, Advanced Care Plans and Assisted Feeding. Feedback was extremely positive and we hope to repeat this day in the future."* **Another professional development opportunity to watch out for if you work in the area of MND care.**

In June Fiona Hewerdine, Graham Jones, Tony Treloar and volunteers provided a stand at the Rotorua GP Conference attended by GPs from across the country. A great opportunity to make GPs aware of the services we can offer and the new red flags tool to aid in diagnosis of MND was distributed.

**In September Linda and Gilly provided the MND stand at the 3 day Hospice NZ Palliative Care Confer-**



**ence in Auckland.** Linda and Gilly also attended the presentations combining personal professional development with networking and MND awareness – a great opportunity to connect with those working in MND care around the country and we hope to be able to do the same at the next conference.





## Good idea!

Managing saliva whilst sleeping can be a challenge – try using an absorbent pad such as this Dish Drying Mat available from stores such as Briscoes. Lay it on the pillow with a one-way liner above and below allowing moisture to pass through onto the mat but preventing it seeping through to the pillow.

## Dr Richard Bedlack

### ALS untangled and anecdotal Cures

The work of Richard Bedlack and his team will be followed with interest as they investigate anecdotal reports of reversal of MND (ALS) in a few individuals. He can be watched online at: <https://vimeo.com/71752685>



**OYSTER TRAVEL** is a very new website providing information related to accessible travel when there are extra needs to be considered. Maddy Widdowson set up Oyster Travel and explained *“Our intention was to make the website a one stop shop for all accessible travel needs – and we are happy to assist with finding the ideal place to stay – as I know the search can be daunting for many when faced with a catalogue of places.”*

Maddy and her team have been going around the country reviewing accommodations to get as much detailed descriptions as possible on facilities. Details such as space under the bed for a hoist, wider doorways, full access showers and bathroom facilities are identified and currently the site lists details on around 400 accommodation providers. One particularly worth mentioning is the purpose built Kakatu Retreat in Kaikoura.

If you are planning a trip over the summer and need to consider such issues as wheelchair access do take a look at [www.oysternz.co.nz](http://www.oysternz.co.nz)

## Support for GPs in making a timely diagnosis

### Might this be Motor Neurone Disease?

**A NEW DIAGNOSTIC TOOL** highlighting motor neurone disease ‘red flags’ has been circulated to GPs in New Zealand with the aim of reducing expensive referrals to the wrong specialists and speeding up time to reach an accurate diagnosis.

Many GPs will only see one or two cases of MND in their career, and often presentation is different in each case, so it is unsurprising that GPs may have difficulty recognising symptoms of MND. Approximately half of all people with MND will be referred to a non-neurology speciality in the first instance, such as ENT or orthopaedics.

A chain of referrals before an MND diagnosis isn’t unusual, says Beth Watson, MND NZ President. *“Symptoms can be similar to other conditions. People can spend months seeing various specialists and undergoing unsuccessful treatments until MND is suspected.”*

Current UK data suggests that there is an average of a 15 to 18 month delay between presentation and diagnosis. Many people report that uncertainty is even more harrowing than coping with the devastating diagnosis of MND.

To tackle some of these issues, MND NZ has introduced a ‘Red Flags’ tool to prompt GPs to consider MND as a possible diagnosis.

While MND remains an incurable disease, there is evidence that survival can be extended by several months through early good management.

*“A diagnosis of MND is traumatic, but once you know, you can make more informed decisions for you and your family,”* says Beth Watson of MND NZ. *“Early and accurate diagnosis by a neurologist is crucial in ensuring the needs of people living with MND are met from the earliest possible stage.”*

The diagnostic tool ‘Painless, Progressive weakness – Could it be MND?’ was adapted with permission from MND Australia and the MND Associations of England, Wales and Northern Ireland. The simple A4 sheet outlines MND signs and symptoms including bulbar and limb features, respiratory and cognitive features, as well as supporting factors that might point towards a diagnosis of MND.

A copy is available on our website [www.mnda.org.nz](http://www.mnda.org.nz)



# Painless, progressive weakness – Could this be Motor Neurone Disease?

## 1. Does the patient have one or more of these symptoms?

### Bulbar features

- Dysarthria
  - Slurred or quiet speech often when tired
- Dysphagia
  - Liquids and/or solids
  - Excessive saliva
  - Choking sensation especially when lying flat
- Tongue fasciculations

### Limb features

- Focal weakness
- Falls/trips – from foot drop
- Loss of dexterity
- Muscle wasting
- Muscle twitching/fasciculations
- Cramps
- No sensory features

### Respiratory features

- Shortness of breath on exertion
- Excessive daytime sleepiness
- Fatigue
- Early morning headache
- Orthopnoea

### Cognitive features (rare)

- Behavioural change
- Emotional lability (not related to dementia)
- Fronto-temporal dementia

## 2. Is there progression?

### Supporting factors

- Asymmetrical features
  - Positive family history of MND or other neurodegenerative disease
- Note that MND can present at any age.

### Factors NOT supportive of MND diagnosis

- Bladder/bowel involvement
- Prominent sensory symptoms
- Double vision/ptosis
- Improving symptoms

If the answer is YES to questions 1 and 2 – query MND and refer to Neurology.

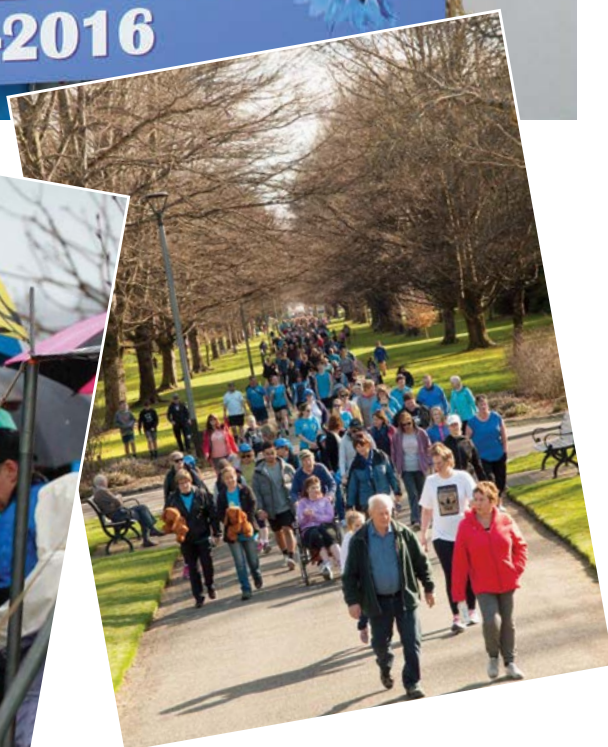
If you think it might be MND please state explicitly in the referral letter.

Common causes of delay are initial referral to ENT or Orthopaedic services.

# Walk 2 D'Feet around the Country



Toni Bradbourne (Auckland) Helen Palmer (Hamilton)  
Lana Hook (Whanganui) Tanya Gilchrist (Tauranga) Tony Treloar (Taupo)  
Jodi Edwards (Hawkes Bay) Bek Slingsby (Waipukurau)  
Liz Anderson (Masterton) Sarah Wood (Wellington)  
Eco Yanaga (Golden Bay) Bronwyn Simons (Christchurch)  
Merle Bradley (Hokitika) Shelly Skea (Dunedin)  
Nicola Leonard (Invercargill)





View more marvellous photos of Walks around the country at  
<https://nz.pinterest.com/mndnewzealand/walk-2-dfeet-mnd-2016>





# Have wheelchair – will travel

Merle Bradley



**IN DECEMBER 2014** I was diagnosed with Motor Neurone Disease. Four months later I embarked on a six-month world tour. I was quick to learn the frustrations experienced by many when using a conventional wheelchair on varied surfaces: cobbled streets, narrow footpaths (or no footpaths!).

When I returned to New Zealand I was determined to find a chair that I could use on adventures. This led me to inventor and engineer Peter Thompson, who has designed the ViMo wheelchair, which is both easy to transport and push over rough and uneven surfaces. Peter is also experimenting with a user-operated electric version of the ViMo.

I started wheeling tracks around

the West Coast to trial which ones can be wheeled by someone using the ViMo all-terrain wheelchair. So far I have completed most of the West Coast Wilderness Trail, the Mananui track, the Hokitika Gorge and sections of the Punakaiki Pancake Rocks.

The Department of Conservation paired up with the Halberg Disability Sport Foundation and I undertook a wheelchair accessibility trial on the Abel Tasman Coast Track. We spent two nights in DOC huts, and a total of 30 kilometres were covered.

A lot was learnt over the three days, and DOC now has a greater understanding of the requirements of people who have limited mobility. The track is one of our less demanding Great Walks and is finished to a much higher standard than most tramping tracks, but the terrain in places was still challenging and at least two strong people were required to manoeuvre the chair.

DOC, friends, family and I, armed with some specialised equipment we've shown that it is possible to have a substantial adventure in the great outdoors. The trial was an exciting venture and the start of something great, and that I'm hoping it will be a project to help others.

With the trial completed I am continuing to head out into nature with support crews to test what other places can be navigated by the wheelchair. I am helping my friend Peter Thompson promote his wheelchairs, and working with The Hokitika



Lions and Rotary clubs who bought two chairs for the town's i-Site, to be hired out to people wanting to explore the West Coast's cycle trails and other accessible tracks and promoting the new wheelchair van. I am really keen for more people to find out about the chair that Peter Thompson has built

Being outside in beautiful natural environments is good for everyone – it's associated with lower blood pressure, faster healing, lower rates of depression, better mood and many other benefits.

My trip and the associating planning for it "brought a big zest and spark to my life" and the confidence to get out and about. I hope that the West Coast will become a destination for people who want to have a great time and enjoy the benefits of being in the outdoors.

I had been a fairly regular trumper, heading out about twice a year. I thought my tramping days were over, but the trial has given me confidence that I was able to get out on tracks. Consequently, I want as many people as possible to come to Hokitika and hire a ViMo wheelchair for \$20 per day and enjoy the many accessible tracks Hokitika has to offer.





# MND NZ Annual General Meeting

**THIS YEAR OUR AGM** was held in Hamilton with a good turnout including several local health professionals. Neurologist Chris Lynch was our guest speaker this year and his talk was very interesting; he is very caring and sensitive and handled the diverse and sometimes complex questions raised in a way we could all relate to. As with last year we were delighted to live stream the guest speaker and you can view this video on our Facebook page.

## Other matters

### Council

We farewell Henrik Dorbeck who has served on Council for 5 years bringing the family and carer perspective to our discussions. Henrik was a great practical support to National Office always available to fold newsletters, store boxes and keep us focussed on the needs of People with MND.

We welcome Anna Chalmers and Tony Treloar who now join Council bringing their own perspectives of living with the challenges MND presents.

### Walk 2 D'Feet MND 2016

Although the figures aren't quite finalised, it appears that we cleared over \$200,000. An amazing result. Around \$120,000 was raised through peer-to-peer fundraising with Everyday Hero. Our sincere thanks to ResMed for their sponsorship which enabled the Walk.

Most of our 14 Walk organisers are keen to do it all over again next year and we agreed that the 2017 Walk will be held on 12 November (let's hope for kinder weather). Planning is underway already and Annabel McAleer has done a very professional sponsorship proposal for us to use – the success this year hopefully makes it appealing for other sponsors.

### Building our MND community

Another really positive outcome of our Walk advertising has been the enormous build of our MND community. In total, the MND awareness campaign made over 10 million impressions across TV, Facebook, radio and print, at a direct cost of just one tenth of the "ratecard" value. We now have over 2600 followers on Facebook which grows and strengthens our MND community and means a much greater audience for future events, fundraising,

membership drives and awareness campaigns. It is exciting just how much value having a (part-time) communications officer is adding. Thank you Annabel. Council has confirmed the Communications role as a permanent part-time one and offered employment to Claire Reilly for another year on a fixed term contract.

### Strategic Planning Day

We held a planning day in July – thank you to everyone who contributed ideas to our Vision statement and we hope the following agreed Vision will serve us well

***Together we provide the best quality care and support to those living with MND.***

From the Strategic Planning day we identified agreed Values and developed our Business Plan and several work streams, especially policy development, which we will report progress on in the coming year. Lucy Haberfield continues to lead us in this work and we really appreciate that she is prepared to gift her time and share her skills in this area.

### *The first of our Research money is committed*

Dr Emma Scotter from the Centre for Brain Research submitted two proposals for the Research money both of which Council agreed:

- To provide a short term bridging salary for "a top scholar from the University of Oregon to support the research activities of the Scotter Lab".

- To establish a nationwide MND Research network in New Zealand in order to facilitate and disseminate research information on MND in NZ. This will include establishing an overseeing committee and setting up a research website "With a cohort of only ~300 MND patients in NZ it is critical that research groups interact with one another to make best use of data and/or samples collected. A research network would facilitate interaction among and between researchers and the public."

These two projects still allow funding for the development of an MND Register which will complement the Research Network.

### Professor Chris Shaw visiting NZ

Prof. Chris Shaw, a New Zealander who works in London, is a neurologist and researcher and one of the world's leaders in MND research. Emma Scotter did post-doctoral research under him. He is visiting the Centre for Brain Research at the end of November and he has kindly agreed to give talks to a number of audiences while in NZ, including a public lecture on the evening of Tuesday 29 November at Auckland Medical School. The time is yet to be confirmed and National Office will send out a notice.

*Mā te wā – Until next time*

*Beth Watson*

**To read more please go to our website under About Us > Our Organisation**

## Uccello PowerPour Kettle

[www.uccellodesigns.com](http://www.uccellodesigns.com)

An attractive, lightweight, balanced electric jug that it sits firmly in the base and pivots to allow easy pouring into a cup with no spilling of hot liquid.

This retails at \$98 and is available from the Independent Living Service in Auckland through their online store:

[www.ilsnz.org](http://www.ilsnz.org). Christmas is around the corner and this would make an ideal gift for anyone finding a full jug of boiling water a challenge.



# How to Facebook



**THE MND NZ Facebook page, [www.facebook.com/mndanz](http://www.facebook.com/mndanz)**, is a place where we promote understanding of MND and foster a connected MND community in New Zealand. We post about MND research and information, as well as stories about people living with MND all over the world, and general information about grief and caregiving. We would love you to join us!

If you have yet to join Facebook, here is a how-to guide. You'll need a computer with an internet connection and an email account.

The image shows the Facebook 'Sign Up' page. At the top, there's a blue header with the Facebook logo and a 'Log In' button. Below the header, there's a 'Sign Up' section with the text 'It's free and always will be.' The form includes fields for 'First name', 'Last name', 'Email or mobile number', 'Re-enter email or mobile number', and 'New password'. There's also a 'Birthday' section with 'Month', 'Day', and 'Year' dropdowns, and radio buttons for 'Female' and 'Male'. A green 'Sign Up' button is at the bottom. To the left of the form, there's an illustration of a smartphone with the Facebook logo on its screen.

Go to [www.facebook.com](http://www.facebook.com). Under 'Sign Up', you will see several boxes that require information. Fill in all your details and enter your password, then click the green Sign Up button.

Facebook will now open your profile and ask you a series of questions. 'Step 1' helps you link up with friends who are already using Facebook. If you have a webmail address (e.g. Hotmail, Gmail), type that email address in the box and click Find friends. Facebook will match your email contacts with Facebook users and make them your 'friends'. If you'd prefer to find your friends manually, click Skip this step.

The image shows the 'Step 1: Find your friends' screen on Facebook. It has a progress bar at the top with 'Step 1' highlighted. The main heading is 'Are your friends already on Facebook?'. Below this, there's a section for 'Email' with a text box containing 'johndoe123@gmail.com' and a 'Find Friends' button. There are also links for 'Outlook.com (Hotmail)' and 'Other email accounts'. At the bottom, there's a note: 'Facebook stores your contact list for you so that we can help you reach more people and connect friends. Learn more.'

'Step 2' helps people find you by school, university or employer. If you're hoping to renew old acquaintances, this information could help people find you. Complete the boxes and click Save & Continue – or click Skip if you'd rather not supply this information.

'Step 3' asks you to add a profile picture. Click Upload a photo to use an existing photograph saved on your computer. It's fine to use a picture of something other than yourself – many people use a cartoon character or a photo of their pet. Click Save & Continue when you've finished.

Enter your password again on the next page. Your brand new Facebook profile page will open with a bar at the top. Click the Go to your email button. This will open your email inbox where you'll find an email from Facebook containing a hyperlink. Click on this to verify your new profile.

The image shows the Facebook 'Welcome' screen. At the top, there's a yellow banner that says 'go to johndoe123@gmail.com to complete the sign-up process.' with a 'Go to your email' button. Below this, there's a blue header with the Facebook logo and a search bar. The main content area says 'Welcome to Facebook, John.' and 'Search your email for friends already on Facebook'. There's a text box for 'Your Email: johndoe123@gmail.com' and a 'Find Friends' button. On the left, there's a sidebar with 'FAVORITES' including 'Welcome', 'News Feed', 'Messages', and 'Events'.

You'll then be logged into Facebook. Welcome! Go to [www.facebook.com/mndanz](http://www.facebook.com/mndanz), and click on the thumbs-up 'Like' button directly beneath the cornflower illustration. Our posts will now show up on your 'Timeline', accessed by clicking the Home button next to your name on the main Facebook toolbar at the top of the screen.

## Privacy on Facebook

You can change the privacy settings of your Facebook updates by clicking on the sharing button to the left of the Post button. You can also change the settings of previous posts by clicking on the people icon at the top of the post, to the right of the date stamp. Available audiences include friends, groups and specific individuals.

The image shows a Facebook post creation interface. At the top, it says 'What's on your mind?'. Below this, there are icons for adding friends, location, photo, and video. To the right, there are buttons for 'Friends' and 'Post'. A dropdown menu is open, showing 'Who should see this?' with options: 'Public' (Anyone on or off Facebook), 'Friends' (Your friends on Facebook), and 'More Options'.



To access your overall privacy settings, click the subtle lock icon in the upper-right corner of the main Facebook toolbar. View and change all your privacy settings by clicking the blue See More Settings link at the bottom.

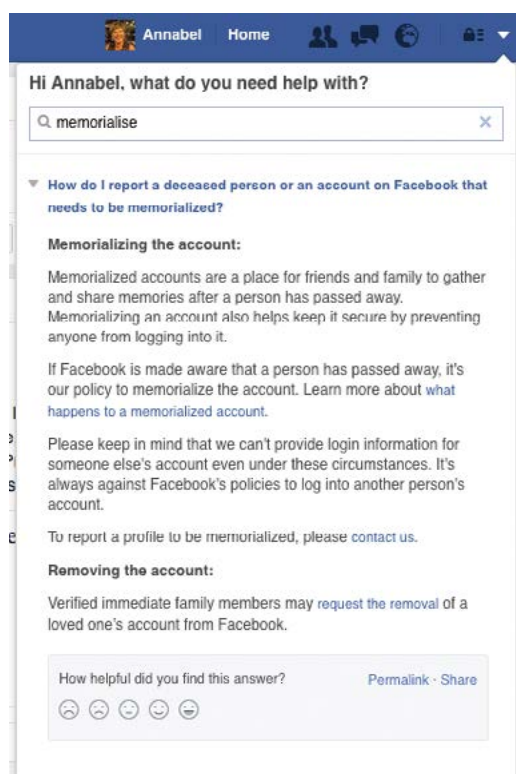
Privacy Settings and Tools			
Who can see my stuff?	Who can see my future posts?	Public	Edit
	Review all your posts and things you're tagged in		Use Activity Log
	Limit the audience for posts you've shared with friends or friends of friends?		Limit Past Posts
Who can contact me?	Who can send you friend requests?	Everyone	Edit
	Whose messages do I want filtered into my inbox?	Basic filtering	Edit
Who can look me up?	Who can look you up using the email address you provided?	Everyone	Edit
	Who can look you up using the phone number you provided?	Everyone	Edit
	Do you want other search engines to link to your timeline?	Yes	Edit

For a complete guide to all the Facebook privacy settings, see [www.techlicious.com/tip/complete-guide-to-facebook-privacy-settings](http://www.techlicious.com/tip/complete-guide-to-facebook-privacy-settings).

### 'Memorialise' a Facebook Page

Around 8000 Facebook users (of 1.65 billion total users) die every day. Facebook offers the option of having your account either deleted or 'memorialised' in the event of your death. If you go with the memorial option, you can name a 'legacy contact' who will share a final message on your behalf and respond to friend requests, but can't remove or change past posts or read private messages.

To memorialise someone else's account after they die, choose Help from the drop-down menu next to the lock icon, go to the Facebook Help Centre and type 'memorialise'. Click 'contact us' from the drop-down result, and be ready to provide Facebook with a hyperlink to an obituary or other documentation, or upload a scan or photo of their death certificate.



## The science of caregiving

**SCIENTIFIC AMERICAN MIND** takes an in-depth look at the science of caregiving in its November/December 2016 issue. We recommend hunting out this magazine at a newsagent or local library.



'The Givers' looks at why some people seem to feel little burden as caregivers, while others feel overwhelmed. It describes the research of social scientists into this area, and identifies four specific strategies proven to help caregivers manage the burdens and maximise the rewards of their role (see below). Steven Zarit, a gerontologist and professor at Pennsylvania State University, says in the article that the perception of burden depends more on an individual's beliefs, relationships and culture than on the weight of day-to-day duties. Some people think of their caregiving role as a trial, while others consider it a blessing. In practice, he says, it is a combination of both.

*"Family caregiving is a profound and deeply personal experience,"* writes the author Francine Russo. *"It touches on our mortality and vulnerability, who we are as humans, as sons and daughters, husbands, wives, fathers and mothers. It asks us to find meaning in loss and satisfaction in what many would see as drudgery or endless self-sacrifice. Fundamentally, how we think about the role of caregiving plays a powerful part in whether we buckle under the strain of that position or derive a sense of purpose and fulfilment."*

### Top tips for caregivers

Experts emphasise four key elements for managing the stress and maximising the rewards of caregiving.

**Mastery:** Learn as much as possible about the disorder you are dealing with. The more you know about typical symptoms and behaviours, the better you can anticipate problems and not take them personally – all of which helps to build a sense of competence and control.

**Coping strategies:** Turn to advocacy and support groups, counsellors and therapists to learn specific skills such as how to develop a more positive view of a loved one's behaviour and how to think about one's own journey as a caregiver. Learn to focus on good care for your relative rather than making the person happy, which is often an impossible job.

**Social support:** Set aside any notion that you should be able to handle the responsibilities on your own. Reach out to family, friends, religious organisations, volunteer organisations and illness-specific support groups for sympathy, for humour and for hands-on help.

**Stress reduction:** Do exercise and do use respite programs. Also, try mindfulness training. Although working with an expert in meditation is ideal, apps such as Calm and Headspace can be helpful.

By Francine Russo, extracted from 'The Givers' in Scientific American Mind, Nov/Dec 2016

# Presidents Piece



**Ngā mihi nui ki a koutou – warm greetings to you all**

It's one of the funny things in life that once something comes to your attention then you seem to keep hearing about it. I guess it is all about heightened awareness, and on that note let me say that is certainly what we are achieving with our Walks 2 D'Feet MND. Now when I tell people I am involved with MND, rather than getting a blank stare and "what's that?" as I did in the past, I find many people say "oh yes I have heard of that."

However, I digress. Back to what has come up several times for me recently – and that is the idea that death is a natural part of living and we could do better as a society by being more prepared to have conversations about this.

My first encounter was reading the book *Being Mortal* by Atul Gawanda. I found it a great read. As Katherine Boo says in the fly leaf "A deeply affecting, urgently important book –one not just about dying and the limits of medicine, but also about living to the last with autonomy, dignity and joy". It got me reflecting that perhaps that is why so many people with MND inspire me – they have shared their wishes about dying (as this book recommends) and that has freed them to live well. (*Note to self* – have those important conversations with the special people in my life.)

My next encounter was a Modern Etiquette article by Lee Suckling in our Saturday newspaper magazine talking about what happens to social media accounts when you die – it seems that most social media networks do have processes set up. You can search for it on the Stuff website – it's well worth a read. Facebook offers the option of deleting or memorialising your page. The article suggests we would be wise to create a social media Will to manage our digital footprint after our death. (*Note to self* – create a social media Will)

And then I saw posted on our MND NZ Facebook page that 8 August was *Dying to Know Day* – "bringing to life conversations and community actions around death dying and bereavement" as "Being more comfortable talking about death can help break down barriers and build compassionate communities ready and able to respond to terminal illness, death and loss when it occurs."

And then on 12 October Jessie Mulligan on RNZ had such an interesting upbeat interview with Australian Molly Carlile the self-described death talker. You can listen online just search Molly Carlile on [www.radionz.co.nz](http://www.radionz.co.nz).

Must go folk – I have those *Notes to self* to action so I can enjoy my Christmas with family and friends.

Whatever your journey, I trust you are sharing it with your special people and I trust that you have some Christmas plans lined up to look forward to as well.

**Beth Watson**

**WELCOMING OUR  
NEW LIFE MEMBER**

## Geoff Thompson

**AT THE END OF LAST YEAR** MND NZ was honoured to have Geoff accept life membership of our Association with this confirmed at our recent AGM. Before his retirement from legal practice in 2015, Geoff served as the Honorary Solicitor for MND NZ for over 15 years, taking up the role in 1999 when the National Office moved from Auckland to Wellington (and remaining in the role when the National Office moved back to Auckland in 2007). His wife Jan, a member of the National Executive in 1999, introduced Geoff to MND NZ. I wonder if she ever imagined how long lasting the relationship would be. Typically when legal advice is sought it is needed "now" and Geoff was always there for MND NZ when we needed him. He advised us on employment matters, guided us through complex bequests, reviewed constitutional changes – a wide brief indeed. But whether the matter was small or large, simple or complex, he always gave it the benefit of his sharp legal mind and his considerable legal ability. And he was always approachable and patient. Thank you Geoff. Prior to serving MND NZ, Geoff had a distinguished political career and in the 1999 New Year Honours he was appointed a Companion of the New Zealand Order of Merit for services to politics.



**Geoff Thompson with wife, Jan, Ruth Dyson and Beth Watson**

In April 2016 Beth Watson, Bruce Stokell and our Patron Hon Ruth Dyson had morning tea with Geoff and Jan and presented him with his certificate.

## WELCOMING OUR NEW LIFE MEMBER

### Reima Casey



**UPON REIMA'S RETIREMENT** she has accepted life membership in acknowledgement of over 20 years involvement with the Association. Reima has been providing support services to people with MND and their families for 21 years – initially in the Manawatu region and recently extended to the Whanganui area. She began as a volunteer Fieldworker in 1995 and provided voluntary support for many years before becoming a paid staff member. Reima is a deeply compassionate person with a gentle quiet manner. She works well with people across all walks of life. She has been a respected member of our Fieldwork team; a real team player who contributed grounded, practical ideas to discussion. Her work has been especially valued by the many families she has supported over the years as institutional supports for people with MND are not as well developed in the DHB areas in which she worked as in other parts of New Zealand. Over the years, in various parts of New Zealand, I have met people who tell me how important her support was to them and have asked me to pass their thanks on to Reima. Life membership is an honour bestowed for outstanding service – Reima richly deserves this award. *Beth*

## Farewell to Michelle

**MICHELLE GAVE** sterling service to our Association for over 10 years. That service began with the Bay of Plenty Branch in 2005 but the Association quickly realised her talents and in 2006 she became involved at national level when she was elected Vice-President. She traded that role for Treasurer in 2007. Her financial skills were really treasured. She took the reins at a very difficult time for our Association as it was facing insolvency – it nearly had to terminate the contracts of the staff. Thanks to Michelle's watchful "hawk-eye", business prudent mind, and careful financial management, the Association has come to a degree of financial stability in recent years. Michelle saw financial stability for MND NZ as critically important. She also saw that the Association needed to diversify its income streams and be less dependent on discretionary funders. She was instrumental in establishing an endowment fund for us with the Acorn Foundation – one that returns a guaranteed income as a percentage of invested funds each year. Michelle's dream was to build that fund year on year. It is our challenge to maintain the momentum of that fund.

Michelle was "blown away" with the success of our first ever nationwide Walks 2 D'Feet MND in 2015 in 6 locations: not only the financial return but also the outpouring of community support and aroha. I was delighted to learn that Michelle lived long enough to hear of the even greater success of the 2016 Walks.



But Michelle's contribution to MND NZ was not only financial. Council benefited from the considered views she offered in all discussions – always with what was best for MND NZ and the families living with MND in mind. And Michelle continued to serve on the Bay of Plenty Branch throughout her time on National Council. She ended her service in 2015 due to the progression of her Motor Neurone Disease. We all loved her – her calm and positive approach, her big warm smile, her genuine caring, her readiness to laugh and, above all, her generosity of spirit.

In 2014 Michelle was made a Life Member of MND NZ.

## Client Survey – We want to know what you think of us!

**WE HAVE RECENTLY CIRCULATED** our annual satisfaction survey and for the first time we have canvassed health professionals and service providers involved in MND care around the country.

Some surveys were sent by email as an invitation to use the Survey Monkey system and some by post.

If you have not received the Survey and would like to please let us know.



# A hopeful gift for Christmas

**WE'VE BEEN DEEPLY MOVED** by the generosity of Katherine Lancaster this Christmas. This young musician and trained opera singer very generously recorded a three-song CD as a Christmas gift for her close friend Jeremy Williams, who has MND. The project took Katherine six months to save for and record, complete with bespoke orchestral backings. We are delighted that Katherine then approached MND NZ with the idea of selling the CD more widely as a Christmas fundraiser, with the money raised to be split equally between MND NZ's core support services and the MND NZ Research Fund.

'Katherine Lancaster at Christmas' is available for \$20 on our website at [mnda.org.nz/merchandise](http://mnda.org.nz/merchandise), or can be ordered by emailing [katerinasingsopera@gmail.com](mailto:katerinasingsopera@gmail.com). Katherine has a truly stunning voice and her versions of 'O Holy Night', 'O Mio Babbino Caro' and 'Moon River' are a pleasure to listen to. We do hope that you'll consider buying a copy for yourself or as a gift this Christmas.



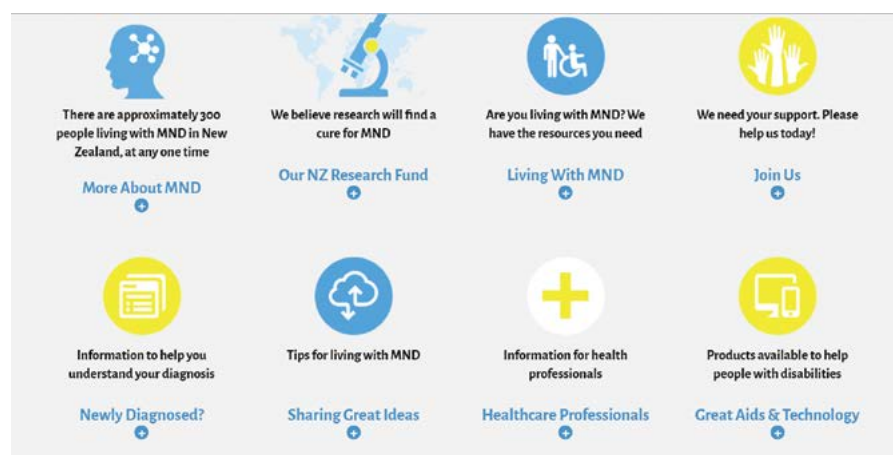
# David Oliver Beacon Award



**OUR INAUGURAL** award winner was Karen Thomas, the neurology nurse specialist based at Waikato Hospital.

The nomination said that Karen does not watch, wait and wonder what will happen but makes things happen. She is very much a team player. Her philosophy is that the needs of MND clients are of the utmost importance and are of an urgent nature and she goes the extra mile to ensure they are met. She analyses a situation then suggests a method of hastening assessments and interventions to achieve a timely outcome that enhances quality of life. Numerous examples were presented of Karen's supportive and pro-active approach. The nomination advised that clients sing her praises constantly. "... she is a gem ... she's my rock on the inside (DHB) ... I only need to phone her and a script (from the Neurologist) is faxed to the pharmacy ... Karen is always there for me ..." Coincidentally our AGM was in the Hamilton and so we had the pleasure of presenting the award as part of our AGM afternoon. Karen was delighted to be the recipient. She is a modest person and in her acceptance speech she paid tribute to the others in the multidisciplinary team and to fine work of her predecessor, Pat Simpson, who established this role in the Waikato. Karen was presented with a "treasure box" made of interwoven wood and containing a letter from David Oliver. The box symbolised that we treasure her services to people with MND and that support is an intertwined, team effort.

## Our New Website [www.mnda.org.nz](http://www.mnda.org.nz)



Thanks to the generosity of Hound & Steed and the work of Annabel McAleer, our Communications Manager, we now have a fresh new website that we hope you will find informative and easy to navigate.

**Do take a look and let us know what you think.**

# Greetings from Grant



## **Farewell Reima Casey and thank you for caring so much for so long.**

What will we do without your calm, loving presence? Reima is taking a very well earned retirement and joining her family in Queenstown; she will be sorely missed by all who know her. Reima exemplifies all the qualities that add up to why our support and assistance is so highly rated by clients, carers, families and health professionals. I know you will join us in wishing Reima a long and happy retirement on the mainland.

## **Welcome Gilly Noon**

Gilly has 25 years' experience of working with people at challenging times in their lives.

With a counselling background as well as qualifications in professional supervision, she has experience across a range of settings including Hospice, education, custodial services and not-for-profit agencies involved with health and disability challenges such as MND. She is familiar with community work and networking and most recently she was working with Strengthening Families on the Hibiscus Coast. Having lived in the Rodney and Northland areas for ten years Gilly is familiar with the area and understands the importance of being connected to community teams and resources.

## **MND Australia Conference**

In September Lin Field our Support Team Leader and I attended the MND Australia Conference in Melbourne. This well attended event was addressed by a number of leaders in the MND community and covered current clinical issues, research, and support for people living with MND, their carers and families including the work of MND Australia and a number of other topics.

For those who like to learn more here is the link to the Conference web page <https://www.mndaust.asn.au/Get-informed/For-health-professionals-and-service-providers/National-MND-Conference-2016.aspx>.

Following the Conference Lin attended the annual meeting of the MND Australia support staff whilst I attended a meeting of some of the MND Australia Board members and their State Managers.

Lin reports that both Australia and ourselves have comparable services however in Australia there is a need for their Association to be heavily involved in equipment rental and supply to clients given they don't have the same government and government agency support we enjoy in New Zealand. Australia is also establishing a National Disability Insurance Scheme (NDIS) and so much of the meeting was taken up with the complexities of the implementation of this scheme. In addition the Federal and State governance model provides complexities that thankfully we do not have to deal with.



**Grant and Lin with Carol Birks MND Australia Executive Director.**

My meeting with the Board and State Managers allowed us to compare our governance and management

in both countries. Our number of clients (300) compared to theirs (2000) of course means there are some differences around the scale of our respective operations however we still have the same objectives and goals. In addition we have the advantage of one government and its agencies to deal with rather than their tiered and State structure.

Attending the Conference and meetings allows us to maintain our close contact with MND Australia and be able to benchmark our services and the quality of delivering those services.



**Representatives of MND Associations from Australia and New Zealand connected with each other in Melbourne.**

**We value your feedback so please feel you can contact me at any time. E: [mgr@mnda.org.nz](mailto:mgr@mnda.org.nz). P: 09 624 2148**

#### NATIONAL COUNCIL

President	Beth Watson
Vice President	Richard Ryan
Secretary	Bruce Stokell
Treasurer	Lucy Haberfield
Councillors	Andrew Pardoe-Burnett, Fiona Hewerdine, Helen Brown, Helen Palmer, Tony Treloar, Anna Chalmers

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**Graham Jones:** Fieldworker Bay of Plenty, Rotorua, Gisborne, Hawkes Bay. Mob: 029 777 5588

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#### Please contact us:

- If you have any suggestions for inclusion in the next newsletter
- If your address has changed
- If you know someone who would like to receive our newsletter
- If you no longer wish to receive MND News or would prefer to receive by email.

**Our thanks go to minimum graphics for design and layout of MND News and to Stewart Motorsport for sponsoring the printing.**

## MND Association Funders

The MND Association would like to thank the following organisations for their contributions towards the support services we provide.



- Vasavour Charitable Trust
- Iris & Eric Nankivell Charitable Trust
- Onehunga One Tree Hill Rotary Club