

# mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

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

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**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 forms and so each individual experiences MND differently.

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:** Opinions expressed in this newsletter are those of the individuals writing and do not necessarily reflect the opinion of the Association.



## Celebrating our Supporters

You do so much to raise awareness of MND along with much needed funds – what energetic and creative people you are!

**Ice Buckets Swimming Cycling Socks Cards Sausages Walking RUNNING SILENCE Baking Haircuts...**



Carey in training

## A race against time

**IN FEBRUARY/MARCH NEXT YEAR** Carey Vivian is embarking on a 6 week, off-road charity bike ride called the Motor Neurone Cycle Challenge 2015; a 4,500km trip to promote awareness of MND aiming to fundraise at least \$50,000 for the MND NZ Association. The ride takes in all of New Zealand's cycleways, connecting trails and roads to create a route starting at Cape Reinga and finishing in Bluff; Carey will criss cross the country several times and must average over 100 km per day to complete in time. He has incorporated the Motutapu Mountain Bike race en route and is targeting many

other promotional and fundraising opportunities such as magazine articles, a bike raffle and social media. Carey has great support from family members, friends and acquaintances for the ride – but could probably do with a meal and a shower along the way! You will be able to follow Carey's progress via a GPS tracking system on his website when his ride starts in early February 2015. For more information visit [www.raceagainstime.co.nz](http://www.raceagainstime.co.nz). Donations can easily be made at [www.fundraiseonline.co.nz/MotorNeuroneCycleChallenge](http://www.fundraiseonline.co.nz/MotorNeuroneCycleChallenge) or post direct to the MND Association. Follow Carey's current training activities on his Face-



4000km Cape Reinga to Bluff February 2015.

book page: "raceagainstime" or email him direct at: [carey@raceagainstime.co.nz](mailto:carey@raceagainstime.co.nz) if you are able to provide any support along the route.

## MND News – UPSIZED

**WE HOPE YOU ENJOY READING** our larger edition – there is so much going on within the MND community and we want to share as much as we can, so we are replacing the four smaller editions with two larger publications each year in Autumn and Spring. Thanks to Sue Stewart's sponsorship in memory of her husband, Malcolm, we are able to continue printing in colour. If you would like items included in the next edition due out in March /April next year please contact us.

**REMEMBER** previous newsletters can be viewed on our website: [www.mnda.org.nz](http://www.mnda.org.nz)

## Unexpected good has come from MND for our family as we work together to Race Against Time

**ON THE FACE OF IT**, motor neurone disease has no intrinsic benefits. It's a cruel and callous affliction that takes no prisoners, offers no excuses and laughs in the face of medical science...as everyone reading this newsletter will know.

Yet, through the despair of diagnosis and the onslaught of symptoms, something unexpectedly good has come from MND for our family. And together, we are hoping we can do something positive for both the Motor Neurone Disease Association and those living with the challenges of MND around the country.

Let's start at the beginning. Our dad,



Barrie Vivian

Barrie Vivian (now 70), had barely retired in 2012 from a long career as a diesel and electrical engineer with several of his own companies, when he noticed his hands were weak and he couldn't hold handtools for long periods of time. Putting it down to 'old age', he ignored it for a while until he couldn't anymore, consulted his doctor and was referred on to a neurologist for further testing.

It was just before Christmas 2012 when the news came through that he had a form of MND. We all dealt with the news in different ways...shock, disbelief, anger. Dad's nine grandchildren, now ranging in age from nearly two to 21, tried to grasp what this diagnosis meant – if you asked them to explain it now, they'd say Grandad is easier to playfight, can't do Chinese burns anymore, sleeps on the couch a lot during the day and loves sitting in the sun listening to Roger Whittaker! It's a good summation of how this illness has affected an able, intelligent and talented person.

For us adults, the signs are more tangible. For someone who has designed and built houses, boats and even his own plane, Dad now struggles to walk for more than very short strolls and is easily exhausted. He can't write anymore, has to have his meals cut small for him, and can't even pick his little grand-daughters up off the floor.

Even worse is the deterioration of his concentration, brought on by exhaustion. We have always had a dad who could fix anything ... who could figure out how to design and build anything, who could whip up solutions to convoluted problems and fix any problems with our cars. Dad even made his own sports car, and once converted a ute to diesel fuel, one of the first in New Zealand.

So you can see why our family was knocked for six when we heard his diagnosis ... and how we all grieved in different ways. For little brother Carey, however, overcoming that shock news meant getting into gear and doing something positive when there was absolutely nothing else we could do. So he decided to combine his favourite pastime of mountain bike-riding with a 4000km charity fundraiser over 42 days to raise \$50,000 for the Motor Neurone Association of New Zealand.

When the rest of us heard his plan to bike offroad from Cape Reinga to Bluff in February next year, we secretly thought he was mad! After a while though, we realised the idea had merit and a great deal

of support. So we got behind him 100%, and the ride is now officially a family affair.

Kathryn (journalist) is providing media and communications services; Pip (graphic artist) is the designer and Paul (superyacht designer) wheels and deals donations that will be auctioned off later in the year for the charity. Several family members will bike parts of the route with Carey, or help with back-up support, and friends will offer accommodation and meals along the way.

And, of course, Dad will be watching [www.raceagainstime.co.nz](http://www.raceagainstime.co.nz) on his iPad



Off road biking has its challenges

every step of the way to see just how his youngest is doing.

MND has devastated our family but it has unexpectedly brought us closer. The four of us now communicate with each other at least weekly (we are spread from Auckland to Queenstown), we share stories and information about MND from around the world, and we fiercely compete over who can score the best donation to auction off for the fund.

Kathryn's husband Kev, who hasn't owned a bike in 20 years let alone ridden one, is going to do Cape Reinga to Auckland with Carey ... even if the latter has to tow him! And our mum Lynne, who despises Facebook, has opened an account so she can keep up with what is happening with the fundraising. Sticking together helps us to cope with what is happening, and we are determined to raise \$50,000 to help those who will be diagnosed in the future.

There's also another unexpected benefit to what we are doing. Since the website went live, we've had messages of support from people around the country coping with MND. Many have offered Carey and



his supporters meals and beds for the night ... and we are very grateful.

It's times like this that we realise that the term 'family' doesn't just mean immediate members...we feel like we belong to an exclusive nationwide 'MND family' that understands what we are going through and is reaching supportive arms around us to achieve our dream.

It's aptly named 'Race Against Time', but this charity ride is more than that. It's a chance for our family to outwardly express the love and respect we have for our dad now and forever, and a way of making a difference to people about to face MND in years to come. If we can leave a monetary legacy for research and support, then all this effort will be worth it.

And, of course, we can stand proud, look MND directly in the eye and yell, "Oi, you won't break our family's spirit... not now, not ever!" Now that's a great feeling.

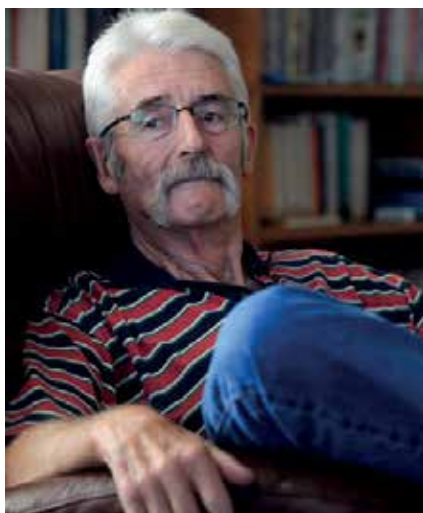
*By Kathryn Calvert, Paul Vivian, Pip Campbell and Carey Vivian*

## Silence is Golden

**So what could be harder than cycling the length of the country – perhaps spending a weekend without talking!**

**THAT IS JUST WHAT** Kerry and Kirstin did to raise funds for us and friends and family sponsored their silence to the tune of \$860!

"Not long after dad got his diagnosis he lost the ability to speak. He communicated through writing in a notepad or through a talk programme on his iPad. This was really hard for dad as anyone that knew him knew he loved to have a good chin wag at the best of times! Unfortunately the inability to speak is a reality for many others like my father & the MND organisation offer huge support. We wanted to raise funds for a fantastic charity that really helped my father and we came up with the concept that we should walk a mile in dad's shoes. So Kirstin & I stopped talking from 8pm Friday night until 10am Sunday morning. That means no answering phones, no texting, and no internet communication. The only way we can speak to people is through a notepad and pen. Now those of you who know me & Kirstin, realise that this is a very hard task to complete as we love nothing better than a good natter! But we nailed it and raised \$860." **Our sincere thanks to all involved.**



**Brian Kennedy**

## The helping 'gene' passes from one generation to the next

**KAPITI SWIMMER** Michael Roberts is paying tribute to his uncle who passed away from Motor Neurone Disease (MND) in February this year by challenging himself to a 40-hour Swimathon on September 17. "I admired the strength that he had. He was really a big role model to me."

Michael's uncle Brian Kennedy lost his wife of 34 years after she was killed in the collapse of the CTV building more than three years ago. At this time Brian Kennedy took up the role of spokesman for the victims' families. He fronted the television cameras, questioned the authorities and fought to give a voice to those who needed it.

This month Michael will undertake a 40-hour Swimathon as a way of acknowledging his uncle's strength and the struggle he went through with MND, while raising much-needed funds for MND NZ. Michael and a fellow swimmer will alternate two hour time periods in the pool



**Michael Roberts**

throughout the 40 hour period. "Even for experienced swimmers this will be a huge challenge – I believe an appropriate challenge through which we can relate to the struggles that many with MND and other serious illnesses must face every day," Michael says.

*"My memories of Uncle Brian will always be that he was a charismatic, good old kiwi bloke who loved his beer and his barbeques. He didn't always say much, but if he was around now, and I was about to do this event for any other reason, he would have been the first to support and back me 100% of the way."*

The Swimathon will be held at Coastlands Aquatic Centre in Kapiti, from 17–18 September.

Please show your support for Michael and MND at: <http://www.fundraiseonline.co.nz/MichaelRoberts/>

Watch Michael discuss the challenge here: [www.youtube.com/watch?v=7\\_jZr-2BLbs](http://www.youtube.com/watch?v=7_jZr-2BLbs)

## Keeping informed & connecting with others

- MND NZ:  
[www.mnda.org.nz](http://www.mnda.org.nz)
- MND Australia:  
[www.mndaust.asn.au](http://www.mndaust.asn.au)
- UK MND Association:  
[www.mndassociation.org](http://www.mndassociation.org)
- Facebook & Twitter
- Patients Like Me:  
[www.patientslikeme.com](http://www.patientslikeme.com)
- UK MND Assoc. Forum:  
[www.mndassociation.org](http://www.mndassociation.org)
- Healthtalkonline:  
[www.healthtalkonline.org](http://www.healthtalkonline.org)
- ALS Untangled:  
[www.alsuntangled.com](http://www.alsuntangled.com)
- Research updates:  
[www.als.net](http://www.als.net)
- Clinical Trials:  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- Cochrane Library:  
[www.thecochranelibrary.com](http://www.thecochranelibrary.com)

# The Ice Bucket Challenge for ALS/MND

MND has been in the media worldwide more than ever before. You may have seen media reports of people pouring water over their heads – water in plastic buckets, water in huge tubs on forklifts and the water is ICED. All done to raise awareness and funds for MND. Who could have predicted such a world-wide domino effect from such a simple, crazy act?

**THE ICE BUCKET CHALLENGE** is understood to have originated in the US, where they use the term ALS (Amyotrophic Lateral Sclerosis) instead of MND; the “rules” involve nominating friends and associates to complete the challenge and through social media the idea went viral. An endless list of famous names have completed the challenge and/or donated: Barack Obama, Bill Gates, Tom Cruise, Stephen Hawking, Dolly Parton, Bill Clinton, Lady Gaga – the list goes on.



Dan Carter supporting the MND cause

Closer to home we were thrilled to see our own Dan Carter accept the challenge from former Springbok Joost van der Westhuizen and Dan has posted a video of his drenching on his Facebook page – Facebook users might like to thank him for his support or send a “Like” [www.facebook.com/dancarterallblack](http://www.facebook.com/dancarterallblack). In turn Dan nominated Ali Williams, Jerome Kaino and Mils Muliaina, so keep an eye out for them and our thanks have been sent to Dan for raising our profile in New Zealand.

Meanwhile, Beth Watson, President of the Association, members of our Council,

staff and even people living with MND have also doused themselves in icy water to draw attention to MND.

In Geraldine 40-year-old doctor, Claire Reilly, who is living with MND herself said “When I was training to be a doctor this was the disease we all feared the most, because it’s like slowly watching your body die. You’re still the same



Claire & Kate in Geraldine

person you’ve always been but now you’re locked in a body that won’t listen. I’m hoping that by tipping a bucket of water over my head I can do something about this dreadful illness.” Along with our

Fieldworker, Kate, and several others, Claire completed the challenge on the village green and over \$3,000 was raised for us.

This global social media phenomenon has taken everyone by surprise, nobody planned it or expected such amazing outcomes – it has just happened as a function of current technology. The US ALS Association reports \$100 million donated in August compared to their typical \$2.7m; over a two week period the UK MND Association received £6million which would normally take them six months to raise. Here, in New Zealand, we too have been amazed by an unprecedented 600 donations in two weeks totalling \$33,000 through FundraisOnline alone and more via other donations! Normally on FundraisOnline we would see an average 20 to 30 donors giving up to \$2,000 in a whole month.

There have naturally been concerns around safety and criticism of water wastage – particularly in the midst of summer in the northern hemisphere; some have been uncomfortable with the concept, but as one person noted “The bottom line is that people weren’t talking about MND two months ago, and now they are – it is safe to say awareness has certainly been increased”. Google searches and visits to ALS/MND Association websites globally have spiked over the July to September period.

The ice bucket challenge must surely run its course soon; but it has restored our faith in people’s ability to be touched and motivated by the needs of others and the funds raised are a significant contribution.

So now we need another original, safe and simple idea with viral potential – perhaps for MND Awareness day next year!

The MND Association NZ extends our gratitude to those who have undertaken the challenge or supported those who have.

We are concerned that people participate in any such activity safely and encourage anyone with MND or other health concerns to speak with their doctor first.

## Smooth Food Ideas

Always adapt recipes according to advice from your Dietitian and Speech Language Therapist

**Quick Chocolate Pudding Melt:** 120g plain chocolate in bowl over pan of water; add 15g (3tsp) butter and 3 beaten egg yolks and stir over the heat until smooth. Remove from heat. Whisk egg whites then fold into mix. Spoon into 4 glasses & chill.

**Salmon Savoury:** Mash/puree salmon with yogurt or sour cream plus some balsamic vinegar or sieved horseradish sauce. Spread on thick pieces of soft bread with crusts removed and leave for bread to soften a little.

**Remember!** Ensure, Fortisip and similar products can be used like milk in recipes. Mix into a packet of jelly or instant pudding mix. Add coffee to make a rich latte; use in baking to add nutrients and calories.

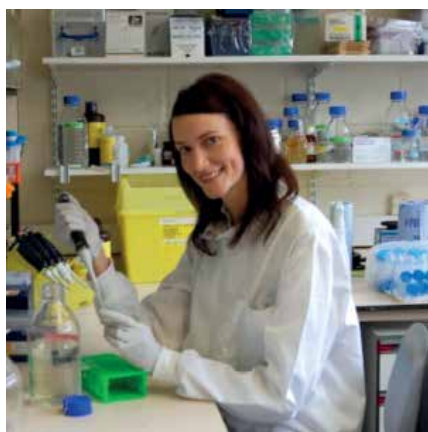




# Welcome home Dr Scotter

## FOLLOWING A DIAGNOSIS OF MND

it is common for people to ask what research is being done and to wonder if New Zealand is “up to speed” with treatments and knowledge available overseas. You can rest assured we are very much in touch. Not only do we have many people working in the field who are passionate about MND management but we also



Dr. Emma Scotter, Aotearoa Fellow, Centre for Brain Research, Auckland

have very direct links to the overseas research through individual professional connections, and the likes of the Centre for Brain Research at Auckland University and the Massey Research team.

One such connection is through Emma Scotter who returned to NZ earlier this year to continue working with the CBR team. Emma completed a PhD focussing on Huntington's Disease at the University of Auckland, graduating in 2009 and became aware of the many common features that exist across degenerative diseases of the brain. In 2010 she headed to the UK to take up a Marie Curie International Fellowship working in the laboratory with Prof. Chris Shaw at King's College London where the team are dedicated to identifying genes which cause MND and researching the function of those genes. Emma's work mainly looked at how cells dispose of the protein TDP-43, which builds up and forms abnormal clumps in the brain and spinal cord of people with MND. Emma has

published research on MND in various scientific journals and contributed to reviews and book chapters with the Shaw Team.

*“I've always been interested in degenerative diseases of the brain, but having worked on MND under Prof. Shaw, and in particular studying tissues donated by patients and hearing their stories, MND research has become my passion and focus.”*

“If you don't find me in the lab (though you probably will!), I'll be on the netball court or on an emergency chocolate run!”

Emma has already made strong connections with our Association and has provided the Research Update article for this edition. She will also be speaking at our National AGM in Christchurch in October –see page for details. We very much appreciate your support Emma and of course the work that you and your colleagues are doing in the drive to find a treatment, cure, prevention for MND.

## New Zealand research into occupational and environmental risk factors and MND

**More volunteers are urgently needed.** An opportunity to be part of research in New Zealand doesn't come along very often – if you haven't already got involved please consider volunteering.

A study on Motor Neurone Disease is currently being conducted by the Centre for Public Health Research Massey University. This will be the first New Zealand 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.

A range of known or suspected occupational, environmental and lifestyle risk factors are to be assessed, such as, exposure to severe electrical shock leading to coma and exposure to electromagnetic fields, exposure to neurotoxic agents – solvents, lead, mercury or other heavy metals, exposure to a range of chemicals,

pesticides or agricultural chemicals, military service, head trauma (risk of head injury), smoking, increasing age and family history of MND.

The study will recruit 400 cases and 800 controls. Cases will be diagnosed for MND by neurologists; Controls will be randomly selected from the New Zealand Electoral Roll, with two controls for each case, matched for age and gender.

We would like to invite all MND patients in NZ to participate in the study. We aim to get 400 patients to participate in the study and at least 300 patients by the end of 2015.

To date 161 (101 males and 60 females) patients have taken part in the study, they

come from a range of occupations with the majority of people aged 60 to 74, 266 controls have also been interviewed in this study.

The bigger the participation the better the outcome will be and the more we will learn from the disease and more we can give back to the patients and the general populations.

So If you have been diagnosed with MND, we would like to invite you to participate in our study by simply signing our study pack and post back to us, or by calling us free on **0800 793 121** or email Grace Chen on [g.chen1@massey.ac.nz](mailto:g.chen1@massey.ac.nz) and one of our lovely interview nurses will be in touch.



Leigh



Angela



Heather



Tiz



Shelley



Margaret

# Research update by Dr Emma Scotter Aotearoa Fellow, Centre for Brain Research, Auckland

There is real momentum gathering in the international brain research community as billions of dollars are being released for projects such as the BRAIN initiative and the Human Brain Project, which together aim to map, characterise and simulate the function of the human brain. The resources being dedicated to brain research are beginning to reflect the enormous financial and social burden of brain diseases. Even outside of these huge, but fledgling initiatives, major advances have already been made in the field of motor neuron disease (MND) research. Here I will outline several key findings from the last decade which have changed our understanding of the disease, and discuss how these findings might affect those living with MND.



Dr Emma Scotter

## ALS may be linked to frontotemporal dementia

ALS is the most common of the motor neuron diseases (MND), with MND used as an umbrella term to describe several different disorders of the upper and/or lower motor neurons. Motor neurons communicate movement signals from the brain to the muscles, via a pit stop in the spinal cord. In 2006, an important study[1] found that in the motor neurons of ALS patients, there were unusual clumps of a protein named TDP 43. Intriguingly, these same clumps are also seen in patients with frontotemporal dementia. This study was the first to explain the link between ALS, a movement disorder, and frontotemporal dementia, which affects mainly personality, thinking and language. Around 15% of patients with ALS show clear signs of dementia, and we now understand that patients may fall on a spectrum between ALS and frontotemporal dementia. This can have important implications for patient care.

## Major advances have been made in understanding ALS genes

In 2008, a major breakthrough was made by a team at King's College London, led by Professor Christopher Shaw, a neu-

rologist and ALS expert originally from New Zealand. His team found that errors in the TDP-43 gene were the direct cause of ALS in a small number of patients[2]. This signified to researchers that TDP-43 may be critical to the disease process; almost all patients accumulate clumps of TDP-43 protein in their neurons and this new

finding showed that incorrect forms of TDP-43 can actually cause disease, rather than occurring as a result of disease.

At present we know of around 30 faulty genes which account for approximately 15% of all ALS cases. Most of these faulty genes are seen in patients who have a family history of the disease- they inherited the faulty gene from a parent with known ALS. Some of these faulty genes have also been seen in patients with "sporadic" disease, meaning their disease seemed to occur "out of the blue". Faulty genes have been found in around 11% of sporadic cases. We have also learned that a single faulty gene can sometimes cause either ALS or frontotemporal dementia within a family, so a parent affected by frontotemporal dementia may pass on a gene which causes ALS.

The University of Sheffield is currently investigating treatment of ALS by targeting a specific faulty gene (SOD1), responsible for 1-2% of ALS. This work may pave the way for other gene-specific treatments, however the diverse genetic landscape of ALS means this won't be a one-size-fits-all approach. As we identify more and more faulty genes, these genes can be grouped into similar functions, which will enable us to piece together the jigsaw of what goes wrong in disease.

Genetic counselling is available to patients via the Genetic Health Service – see below.

## Research is beginning to tackle environmental causes of ALS

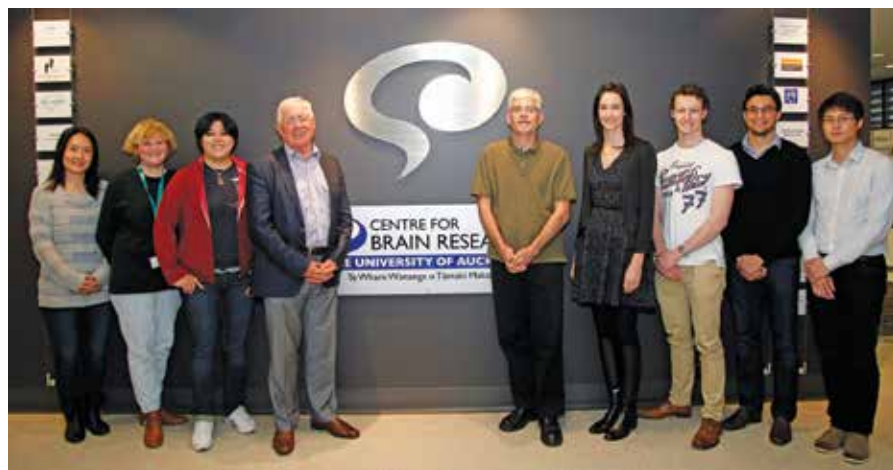
For the majority of patients who have no family history of ALS, it is more difficult to pinpoint why they developed the illness. Research increasingly points towards a combination of genetic risk factors and environmental agents. The identification of these environmental agents has important implications for treatment and prevention of ALS, but distinguishing damaging agents from the myriad a person is exposed to over a lifetime represents a major challenge. Small studies may either find spurious relationships between environmental factors and ALS, or fail to identify factors which indeed increase risk. The evidence suggesting that cigarette smoking can increase ALS risk, particularly in women, is probably the most robust. A study is currently underway at Massey University to examine environmental risk factors in NZ ALS patients and needs your input. **Ring 0800 793 121 to volunteer.**

## Drug discovery is underway worldwide

Currently Riluzole (Rilutek) is the only drug available to treat ALS. Rilutek has been PHARMAC-funded in NZ since October 2013, and your neurologist can discuss with you the benefits and considerations in taking Rilutek. While Rilutek can slow ALS, unfortunately it is not a cure.

At the Centre for Brain Research Hugh Green Biobank at the University of Auckland we are setting up a program of MND "drug discovery" through which we aim to test several thousand drugs. Many of these are novel drugs which have been generated by Professor Margaret Brimble





**The CBR Team (L to R): Sheryl Feng, Inna Semenyajenko, Sue-Ling Kim, Distinguished Professor Richard Faull, Professor Mike Dragunow, Dr. Emma Scotter, Leon Smyth, Dr. Jason Correia, Dr. Thomas Park.**

of the Chemistry Dept. of the University of Auckland. To test them, we use a “disease in a dish” approach; we grow cells from brain tissue donated by patients through the Neurological Foundation of NZ Human Brain Bank. This incredibly special donation by patients, supported by their families, offers the promise that we can identify treatments or new approaches to treatment. Prof. Mike Dragunow, director of the Biobank, will be known to those who attended last year’s MND Association Annual General Meeting, and Prof. Richard Faull, Director of the Centre for Brain Research, is a patron of the MND Association NZ.

Our expanding program of drug discovery research is just part of a major worldwide effort. While the time scale for finding useful drugs, developing them, and thoroughly testing their safety and effectiveness can be long, our growing knowledge about the disease is helping the research community to conduct drug screens with more chance of success than ever before. For example, by target-

ing TDP-43, which is abnormal in 97% of ALS patients, regardless of the cause of their disease, therapies may be found which benefit larger numbers of patients.

### Conclusion

The last decade has heralded a number of important discoveries about motor neuron disease, particularly with respect to its causes and its relationship to other diseases (such as frontotemporal dementia). These discoveries are the foundation for efforts to produce effective treatments. We at the University of Auckland are proud to be part of what can only be described as an international army of researchers trying to tackle this disease.

[1] Neumann, M., et al., Ubiquitinated TDP-43 in frontotemporal lobar degeneration and amyotrophic lateral sclerosis. *Science*, 2006. 314(5796): p. 130–3.

[2] Sreedharan, J., et al., TDP-43 mutations in familial and sporadic amyotrophic lateral sclerosis. *Science*, 2008. 319(5870): p. 1668–72.

### Genetic Health Service

**Current knowledge indicates that only 5–10% of MND is known to be familial, meaning there is a known genetic link running through a small number of families.** However, for most people MND is considered to be sporadic meaning they have developed the condition but there is no family history and no expectation they would pass it on to their offspring. The knowledge base is expanding rapidly as researchers increase their understanding of this condition.

If you have reason to think MND might run in your family you should talk with the specialists who know you but you can also contact the Genetic Health Service directly for initial advice over the phone. The service holds clinics in the main hospitals around the country and they will be able to advise you on what testing is available and the implications to consider.

**The service is available to talk to interested local groups.**

**See: [www.genetichealthservice.org.nz](http://www.genetichealthservice.org.nz)**

**Contact: Auckland 0800 476 12; Wellington Centre 0508 364 436; South Island Centre 0508 364 436**

## At the movies: “The Theory of Everything”

**THIS UPCOMING FILM** about the life and times of famed astrophysicist Stephen Hawking is going to be a real tear-jerker, the Hawking movie called “*The Theory of Everything*”, comes out in November and focuses on the relationship between Stephen Hawking and his first wife Jane, whom he met while a graduate student at Cambridge University in England.



Stephen Hawking is unique in so many ways including his journey with MND. Over 50 years ago Stephen was diagnosed with the ALS form of MND at the age of 21 and told he had a life expectancy of two years. Now, at the age of 72, Hawking uses a speech-generation computer program to communicate, and is totally dependent on others, however, he continues to conduct research and lecture as one of the most famous physicists ever, changing the way scientists understand black holes, space and time.

### Care with coins

We would be very happy to send you a label for a container to collect your spare change for us – one size fits all!



# MND key facts

**MOTOR NEURONE DISEASE** is the name given to a group of neurological conditions in which the nerve supply to muscles deteriorates and the muscles affected progressively weaken. Symptoms vary between individuals but may include muscle cramps, twitching, stiffness, and muscle wasting. Vision, hearing and sense of touch are not affected. The condition may start with reduced strength or coordination in an arm or leg, or with difficulty speaking or swallowing and as the condition progresses more muscles become affected including those involved with breathing. The nature and rate of progression varies enormously between individuals. Life expectancy is shortened but time frames vary widely. Motor Neurone Disease (MND) is also known as Amyotrophic Lateral Sclerosis (ALS) and presents differently across individuals; some forms are given labels such as Bulbar Palsy, Pseudobulbar Palsy (PBP), Primary Lateral Sclerosis (PLS), Primary Muscular Atrophy (PMA). These forms of MND are all acquired in adulthood – predominantly by those in the 50 and 60 year old age range, but also, to a lesser degree, in younger and older adults. (Neuromuscular conditions affecting motor neurones that present in children are not typically included under the term MND/ALS.)

In New Zealand there are approximately 300 people living with MND at any one time. It is slightly more common in men than women and occurs across all cultural groups. The cause is not yet known but considerable research is being undertaken throughout the world and significant advances are being made in



A motor neurone

understanding this condition. MND is not contagious. In the majority of cases it is not inherited but a small number of people affected (about 5-10%) have a family history.

At present there is no cure for MND but there is much that can be done to manage the condition and maintain quality of life. Riluzole (Rilutek) is a drug that has been shown to extend life by a few months in some people but it is not suitable for everyone.

## Cognitive changes and MND

Many people with MND retain full brain function and intellect and personality remain unaffected. However, cognitive changes may be present in 30–50% of people with MND and may show in subtle ways through altered problem solving skills, reduced empathy and other changes; initially changes may only be evident to close family and friends but can have significant effects on relationships, decision making and lifestyle. A small percentage of people with MND experience significant cognitive changes and present with a less common form of dementia, called frontotemporal dementia (FTD); signs of this may have been evident well before the physical symptoms developed. A family history of dementia and/or Alzheimer's may be significant for this group of people.

## Have you thought about?

- Checking your insurance policy & Kiwisaver – does it pay out for serious illness?
- Making a Will
- Arranging Powers Of Attorney – one for financial matters and one for your care
- Leaving a key and emergency contact numbers with a neighbour
- Getting a personal alarm
- Getting a mobility parking permit, applying for the Total Mobility Scheme taxi subsidy
- Discussing a care plan to suit your needs for the future – talk with family, GP, Specialist, Hospice
- Registering with the Emergency Text 111 service – [www.police.govt.nz/111-txt](http://www.police.govt.nz/111-txt)
- Keeping a set of contacts, directions, details of your condition on the fridge/by the phone for emergency use
- Talking to WINZ about Invalid benefits and any other help you may be eligible for.
- Small pieces of equipment that can make life easier – ask your Occupational Therapist, your pharmacy may have a catalogue, the local Disability Resource Centre will have a stock or look online. [www.disabilityequipment.co.nz](http://www.disabilityequipment.co.nz)

## It worked for me

... some of the good ideas people have shared with us



Who would realise that Patrick's scarf, toned so well to match his outfit, is actually a soft hand towel cut to size which he uses to manage excess saliva.

## Flavour Swabs

**If you are unable to eat and drink you may miss flavours and smells** and a flavour swab could offer some pleasure. Try a jumbo swab moistened with flavoured liquid or oil.

For those who cough easily there **should be absolutely no excess liquid** – just dip the swab in the fluid then squeeze against the edge of the container to remove excess. Swab the tongue lightly and repeat if enjoyed. Avoid milky liquids which may leave a sour taste, some people enjoy black coffee, orange juice, tomato juice, wine! Stay sitting upright 60 minutes afterwards. Use this for enjoyment only, not nutrition, and not on days when the person is tired or unwell. Stop if you notice increased secretions or coughing, shortness of breath or discomfort.

**Remember that thorough mouth cares throughout the day and after flavour swabs will prevent a stale taste in mouth and protect against chest infections.**



# Focussing on the positives – a 'Thank You' from Sylvia

**THE DEVASTATION OF BEING DIAGNOSED** with Motor Neurone Disease is pretty hard to take on board when there is no cure and things progress to the point where you have just adjusted to one symptom and another symptom takes over.

I just hope God gives everyone with MND a sense of humour – what with all the dribbling, laughing, crying and guttural noises and now walking like a drunken sailor you need to be able to see the funny side as it progresses.

On a serious note – there are such horrible changes we have to contend with: I can no longer talk which is huge loss for someone who loved to talk – although my dear Fieldworker said I was the only person she knew without a voice, who could still hold the floor and make it hard for others to get a word in! I can no longer eat or drink and I just loved food and a glass of wine or two – it's just not the same through the P.E.G.

However, across this whole experience the overriding factor for me is the amazing love and support I have received not only from my beautiful, loving family and dear, dear friends but also from the whole medical profession and associated organizations.

Where do I start? I guess it goes back to my GP, Dr Jane Pepper, who referred me on, after several tests, to the Neurologist – where I had more tests. Eventually the diagnosis was that I had the Progressive Pseudo-bulbar Palsy version of the dreaded MND. I was then referred to



Sylvia

Dr Alison Charleston at the MND Clinic in Auckland who is such an expert in MND and I am so pleased to be under her care.

From the moment I was referred to the MND Clinic it was just amazing to find that I was contacted by so many people offering to support me with this illness. Among my first visitors was the lovely Lin, my Fieldworker from The Motor Neurone Association, Cathy the Speech Language Therapist, Erna, the Dietician, Margaret, the Occupational Therapist. Next I was involved with the Gastroenterology Department at North Shore Hospital where my P.E.G. was inserted and I was then supported by the District

Nurses from Waitemata District Health. Now I am involved with all the caring people offering support from North Shore Hospice.

Early on my Speech Language Therapist referred me to a Charitable Trust called Talklink who organized an iPad pad with an App. set up on it so that I can continue to "talk". Talklink provided great support and set up my desk top computer with a system that means I can phone people and it talks back to you once you have typed in a message.

What I do find amazing is that all the people involved with me seem to liaise with one another, which certainly makes me feel so cared for and looked after, not only in a very professional way, but as the disease is progressing, true friendship and love is developing with so many of these people. The knowledge that each one of these people are there to help me, truly carries me on, no matter what the future holds now!

I do realise how fortunate I am to have the wonderful support that I am getting here in Auckland and realise I this may not be the same for everyone around the country. Hopefully increasing technology will mean there is the potential for everyone to feel as connected and supported as I am, as this truly makes the MND journey more manageable.

As life gets more and more difficult for me I am just so very grateful to all who have taken me under their wing and are carrying me through!!!! Sylvia

## "Bringing out the best in people"

**IN RESPONSE TO A DIAGNOSIS** of MND earlier this year the Malaquin family, Clinton, Tania and their five children headed off for a month's travel around the South Island. Family and friends wanted to be supportive and Tania suggested that one of the bedrooms could do with some fresh paint, so on their return was looking forward to seeing the result. Little did they know that over 150 people from their family, friends, church and the local community had bigger ideas than just a bedroom makeover. Anita Foss was project co-ordinator and Tania's parents, Owen and Marilyn were on site each day helping in so many ways. As a result of significant donations from so many, plus support from Masterpainters Manawatu and local tradesmen, every room was repainted and refurbished; the garage was converted into a teen "pad"; a new shed built and the garden landscaped – an extreme makeover indeed! Tania has every intention of ignoring any predictions of life expectancy as there is far too much living to be done with her lovely family in their lovely home supported by such a great community. Follow Tania's blog: [www.mndjourney.blogspot.co.nz](http://www.mndjourney.blogspot.co.nz)



Tania (2nd from R), Clifton (2nd from L) and family.

# Around the Country

## WAIKATO BRANCH

**OVER THE PAST 12 MONTHS** the Waikato Branch has continued to meet bi monthly and, although few in number, a dedicated group of loyal supporters continue to support the branch and enable it to remain active. The committee continues to be committed to raising awareness and funds for the organisation. Members, families and friends assist in a variety of ways to provide a presence in local communities. Lynne Neshausen was appointed the new Fieldworker in July 2013 to cover the Waikato DHB and Taranaki area. She quickly got into the role and has provided a great service to people living with MND, and their families.



**Lynne Neshausen – Fieldworker Waikato and Taranaki**

Once again our Christmas luncheon at Woodlands was well attended and thanks to Stan we enjoyed a delicious meal. Our Christmas raffle was also a huge success and once again raised valuable funds. The Raglan group decided not to enter a float in the New Year's Eve parade this year. However, loyal supporters Tom and Betty White drove their vintage car out of the garage adorned it with some MND advertising and Rosalie Trolove elegantly seated at the back, and won \$250 for MND.

Gordonton Country Market BBQ. Thank you to everyone who donated sausages, bread, onions and sauce and helped with the BBQ. We raised a very worthwhile \$420.00 plus another \$80 for socks sold. Thank you to Lesley, Barbara, Aly, Doug and his friends who did a marvellous job.

**IN MARCH ABOUT 30 PEOPLE** walked or rode bikes up the Pipiwhauroa Trail to the Te Uku Windfarm to raise funds to go towards purchasing a replacement vehicle for our Fieldworker. Thanks to FundraiseOnline and many generous

donations we raised over \$3000 so along with a grant of \$4500 from WEL Energy and support from National Office Lynne now has a new car. The previous vehicle Lynne was using was a 1997 Nissan Primera with nearly 200,000kms on the clock; Lynne is based in Hamilton and covers the Waikato and Taranaki areas so she covers quite a few miles to visiting people with MND and the various health professionals and Hospice teams involved in their care. The 2010 Honda City is making Lynne's working conditions so much more comfortable and she is delighted to now have a radio and CD player for those long drives. Our April meeting was held in Paeroa at the L&P café. A good turnout enjoyed a pleasant lunch and catchup with old friends from the Thames Valley area.

**21ST JUNE IS MND GLOBAL AWARENESS DAY** and is based on the vision of a world free from Motor Neurone Disease and MND/ALS Associations all around the world do their best to raise the profile of motor neurone disease. A small group of Waikato Branch members did their bit locally by having a display table at The Base in Hamilton – we waved our buckets in front of shoppers and once again we were humbled by people's generosity. We continue to be supported by generous people who donate items and sell raffle tickets. Thank you to all those who continue to sell socks and cards which raises both money and awareness. Thank you to our sponsors, and to all who give us donations. We are most grateful for your generosity. A generous grant of \$10,000 from the Lion Foundation towards Fieldworker salary and expenses was most appreciated.

**THANK YOU TO OUR DEDICATED COMMITTEE.** Judy, our minute taker, Barbara, who manages our finances and to all the committee members, Alice, Doug, Aly, Colleen and Lesley – your contribution is valued and appreciated.

We always welcome new members and it would be great to have new committee members to share the load and bring new ideas and fresh enthusiasm to the Branch.

## WELLINGTON BRANCH

**AT OUR AGM IN EARLY AUGUST** we farewelled two long serving committee members – both had been with us since around 2004. They will indeed be missed. Mary Gibbs as chair has kept us on track and together while Sheila Reid has kept our records faithfully, written many letters for us and reminded us what we said we would do. **THANK YOU BOTH.** It was sad to say au revoir but fortunately for us both have said they are happy to help with activities from time to time so we are very lucky. David Visser is continuing on our committee and we welcomed three new members: Margaret McKay and sisters Susan Hannagan and Helen Barnes.

It was a very interesting AGM. We had Anna Chalmers talking to us about social media and Grace Chen talking about her research on environmental factors and MND.

Around Awareness Day both our Fieldworkers were involved in events. Reima Casey in the Manawatu organised a lunch and by all accounts it was a very happy occasion. Moira Young organised an MND team – Team Cornflower – to participate once again in the Armstrong Jones 10km race. A time of fun and camaraderie (mixed with a little competition eh team!).



**Team Cornflower: Grace Chen, Kevin Fisher, Moira Young, Toni O'Hagan, Paul O'Hagan, Tony O'Hagan**

## Annual Wellington Railway Station Collection

**EACH YEAR I AM STAGGERED** at what we raise with our railway station collection and this year sure has taken the cake! A well wrapped group of 15 – branch members and willing friends and family – collected from 7am–9am. We solicited unashamedly – Moira faithfully



reports that her Tony was a real “chick draw card”; I know Moira’s smile is always a winner; young Benny sure wowed them; Susan’s gorgeous daughter took all my hopes of winning away as people flocked to her fill her bucket and Moira-Anne, Anna, Joc, Doug and Grace must have had winning smiles at the draughty corners where they stood while the rest of us made a real presence and obviously influenced people to dig into their pockets ... have I blithered on enough for you to be saying just tell us what we made yet?



**Back row L-R: Moira Young, Moira-Anne Shelley, Mary Gibbs, Helen Barnes, Beth Watson, Susan Hannagan with daughter Stella and sister Liz, Tony Young, Grace Chen. Front row L-R: the Talklink support team – Pauline Green, Liz Messina and son Benny. Others absent from photo.**

Well – the winner’s bucket was ... Tony who secured a \$50 note and solicited (yes there is that word again!) \$347.30.

**All together we collected an absolutely massive \$2362.80 with a whopping \$790 in notes this year. WELL DONE TEAM and THANK YOU WELLINGTON.**

## NEW! CANTERBURY BRANCH

**THE CANTERBURY-WEST COAST BRANCH HAS OPENED AGAIN.** A big welcome to the new Canterbury-West Coast Branch committee – Heather Brunton, Hilary Weller, Jill Gimblett, Bronwyn Simons, Fiona Chandler and Anita Osborne – who have taken up the challenge of re-establishing the Canterbury Branch. The Branch boundaries correspond with the South Canterbury DHB and the Canterbury and West Coast DHB areas – effectively from the Waitaki River in the south to Kaikoura in the north. A sincere thanks to Heather Brunton for all her ground work to make this happen – Heather I hope the support and ‘community’ the Branch brings to Canterbury-West Coast is some compensation for the work you have put in to make this happen.



**Back (L-R): Fiona Chandler, Heather Brunton, Bronwyn Simons. Front (L-R): Anita Osborne, Jill Gimblett, Hilary Weller**

And not only has the Branch re-formed but

- the group were out waving the MND flag (and collection buckets) at awareness time and collected a tidy \$557. So they were banking money even before they had set up! WELL DONE CANTERBURY-WEST COAST.
- AND branch member Hilary Weller is THE Hilary, who, with her team from Pure Trails, will ride the 150km Central Otago rail trail in ONE day – <http://www.puretrailsnewzealand.co.nz/our-mate-jim.htm> GO HILARY and PURE TRAILS
- AND the branch is organising a Walk to D’Feet MND in Christchurch on Sunday 12 October. GO CANTERBURY-WEST COAST
- AND the Timaru South Rotary Club has donated funds for a cough assist machine to be managed by a respiratory physiotherapy team in collaboration with Fieldworker Kate Moulson. That gift is indeed appreciated. GO TIMARU SOUTH ROTARY CLUB

So the Canterbury-West Coast Branch is off to a flying start. We wish you well and are here to help.

*(This piece has been written by President Beth Watson. She does apologise if she has got something not quite right.)*

**PRIOR TO VOLUNTEERING FOR THE NEW COMMITTEE**, Anita Osborne was already bringing in funds to support us. She enjoys an annual cycling trip in Australia joining Cycle Queensland and this time last year she cycled from Mission Beach to Port Douglas in the Cairns area – 7 ride days and about 520 km. “The longest day we did was 112km! The hardest day was 69km and about 1.5km of steep uphill climbs in the Palmerston Range – in the heart of the Wooroonooran National Park. With temperatures in the mid-30’s

*and a gradient that nearly made me cry, the beauty of the Atherton Tablelands was lost on me until I stumbled off the bike later in the day. We had a fantastic time and thanks to all the people who put up with my constant harassment I fundraised \$555 for MND.”*

Anita is off cycling again this year in the Noosa area and also hopes to join the Hilary and the “Our Mate Jim” MND fundraiser on the Otago rail trail.



**Anita Osborne**

**COUGH ASSIST MACHINES** are expensive items and not yet available in most areas of the country. However, The Rotary Club of Timaru South and the Mainland Foundation have each donated \$10,000 to purchase two machines that will be managed by the Christchurch Respiratory Physiotherapists for people with MND across the Canterbury and South Canterbury areas. These machines are not necessary or suitable for everyone with MND but they are very much appreciated by those who find them helpful.



## BAY OF PLENTY BRANCH

**BAY OF PLENTY BRANCH** is keen to organise another Walk to D'Feet MND following the success of their event last year. The walk raises both awareness and much needed funds and is seen as a "walk of honour" to acknowledge those living and working with MND. If you are available to help us organise the next walk or would like to be involved in some way please get in touch.

## NATIONAL OFFICE

**Welcome to our electronic world**  
Connecting, communicating,  
creating a community

**WE NOW HAVE AN ENHANCED OFFICE DATABASE SYSTEM** – Infoodle – which, among many other benefits, means that our National Office can now send emails, virtually at 'the touch of a button', to people on our database. This saves significantly on postage and it allows us to share news and information much faster.



And to complement that we have joined the social media world with Facebook and Twitter. While our website is the official 'front door' of the Association it is static and not easily updated. Facebook is more like a noticeboard with events, MND information, interesting articles and research. And if Facebook is the noticeboard, then Twitter is you with the microphone having your say. Our Twitter handle is #MND\_NZ. Our thanks go to Anna Chalmers for all her help with this new way of connecting.



Did you realise that you don't have to have a Facebook or Twitter account yourself to see our posts? Why not take a look and check us out? In August we had Na-

tional President, Beth Watson, throwing a bucket of ice over herself as part of the global MND Ice Bucket Challenge. (Apparently in the US they raised \$160,000 in 10 days through this challenge ... *The ALS Association's National President, Barbara Newhouse said "It's just been wonderful visibility for the ALS community. It is absolutely awesome. It's crazy, but it's awesome, and it's working."*)

Let's keep our community communicating and connected – you can help in various ways:

- 'Like' us on Facebook [www.facebook.com/mndanz](http://www.facebook.com/mndanz) and comment on our posts. Message us or email suggestions for posts such as your own events or stories or items of interest on MND.
- 'Follow' us on Twitter [www.twitter.com/mndanz](http://www.twitter.com/mndanz)
- View us on YouTube and 'share' our videos [www.youtube.com/mndassocnz](http://www.youtube.com/mndassocnz). Keep an eye out for MND related videos and let us know if you see one we should post.

Of course not everyone is "wired" so we continue to post our newsletter in hard copy for those who prefer it; our Fieldworkers are real people who maintain contact through visits and phone calls, and Branch meetings and Support Groups offer the chance to meet face to face in some areas of the country.

Our social media co-ordinators would be pleased to hear from you. Contact Anna Chalmers [afchalmers@gmail.com](mailto:afchalmers@gmail.com) and Barb Gilchrist [gilchrist8@xtra.co.nz](mailto:gilchrist8@xtra.co.nz)



### Keeping in touch by email

Do remember to let us know if your email address changes.

## Client Survey – how do you think we are doing?



Many thanks to those who took the time to complete and return the questionnaire we circulated recently. It is a requirement of the Ministry of Health that

we seek annual feedback on the services we provide and your comments helps us keep on track. We have had over 30% returned to date and more arriving. The final collation will be reported to the Ministry and we will use your comments to shape our services. The vast majority of respondents expressed satisfaction with the help we provide and it was clear some people prefer more contact than others with many saying "It is just good to know you are there if I need you". A balanced perspective was shared by one client who wrote: "Support is as helpful as you want it to be but not everything can be done for you – much has to be done by you and a positive attitude is vital from the start."

**Please help us support you to maintain that positive attitude – our Fieldworkers are employed part time and may be based several hours away from your location but if you have not heard from us for a while and would like to, then do give us a call or send us an email.**

Thanks to Infoodle's information management system we are pleased to be steadily improving our efficiency and ability to collate our data and extend our communication networks to raise



awareness and support the needs of the MND community.



# A word from the National Manager

## What's on Grant's mind?

A new broom sweeps clean and National Office has at last completed a long overdue tidy up.

As our financial year has just ended I thought this would be an opportunity to give you an update on where we are as regards our finances and how we fund our activities.

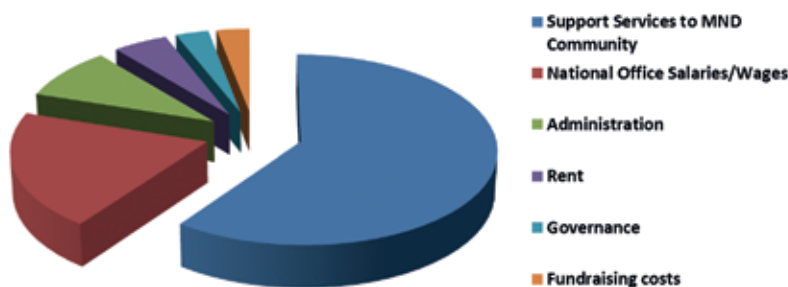
## How do we use our funds

Our principle activities are around providing support and information to people living with MND along with their family, whanau, friends and the health professionals and service providers involved with them. These services involve our team of fieldworkers, our website, our publications, our liaison with government agencies, the media and many other activities. The support we provide to people with MND and the wider MND community accounts for around 70% of our total costs so these areas are always the main focus of our fundraising efforts. Meanwhile, the infrastructure behind these services and the costs involved in running a national office make up the balance.

## Where do our funds come from?

We are constantly making grant applications to organisations such as the Community Organisation Grants Scheme (COGS), the Lottery Grants Board and a large number of philanthropic chari-

## How did we use our funds this year?



## Where did our funds come from this year?

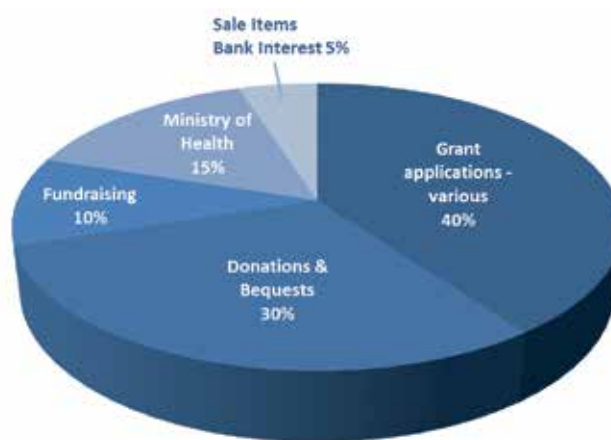


table trusts and other providers. In the past year we received 40% of our funding from these sources. Quite properly, these funders require a lot of detailed information about the Association, what we do and how we do it, so each funding application takes a significant amount of time to complete.

We also need to be careful that we don't apply for and get funding from two different sources to cover the same costs at the same time. This can be a challenge as when we make an application we have no way of knowing whether the entire amount will be approved or a portion of the amount or whether the application will be declined in total. Whilst most funding applications are completed at our National Office, our Branches also make applications particularly to local funders to support local activities. Once we have spent the funding we are, understandably, required to complete an accountability report with details of how and where we spent the funds.

## Donations and Bequests

We very much appreciate the donations and bequests we receive which accounted for 30% of our income in this financial year. By their nature bequests are one off receipts – not a source of finance we can depend on to sustain our operations, but very welcome gifts.

## Fundraising Activities

Other fundraising activities including FundraiseOnline, the Give a Little Foundation and the numerous and generous individual events our members and supporters organise each year provide around 10% of our total income. We also have a contract with the Ministry of Health and this contributes 15% of our costs. Interest on the capital funds we have invested for the longer term and the sales of merchandise such as socks, cornflower seeds and cards make up the 5% balance of income.

Our financial result for the 2013/2014 year ended June was a small deficit of



A new broom sweeps clean and National Office has at last completed a long overdue tidy up.

\$3,000 and our aim is to achieve a “break-even” each year so we can continue providing our services well into the future. Whilst, as a result of several significant bequests, we are in a good financial position, our challenge for the future is to convince funders we are still in need of their continued support. Our aim is to maintain stable and sustainable finances to be sure we can provide our various support services safe in the knowledge

that we have the funding in place to do so. If you wish to see a copy of our Annual Report we will be posting this online at [www.mnda.org.nz](http://www.mnda.org.nz).

*As always our sincere thanks go to the many, many people who give their time, energy and imagination to support us – we would be lost without you.*

**Grant Diggle**



## National AGM

**1pm Saturday  
18th October**

**The Corporate Club,  
651 Pound Road, Yaldhurst 2014,  
Christchurch**

**Guest Speakers:** Dr. Emma Scotter, Research Fellow at Centre for Brain Research, Auckland University;  
Grace Chen, Research Assistant, Centre for Public Health Research, Massey University, Wellington

**Come along if you can get to the Christchurch area, meet the Council and some of the team and hear Dr. Emma Scotter, share about current research.**

## Hello from our staff – please do contact us if we can help

**Grant Diggle:** National Manager, National Office Auckland Mob: 027 241 2766

**Gwynyth Carr:** Administrator, National Office Auckland. 09 624 2148

**Lin Field:** Fieldworker Auckland North and Northland. Mob: 021 230 3038

**Linda Oliver:** Fieldworker Auckland Central and South. Mob: 021 036 0218

**Lynne Neshausen:** Fieldworker Waikato, Taranaki. Mob: 029 773 6662



**Grant Diggle**

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

**Reima Casey:** Fieldworker Manawatu, Wanganui. Mob: 029 777 3331

**Moir Young:** Fieldworker Wellington, Nelson/Marlborough. Mob: 021 027 84494

**Kate Moulson:** Fieldworker West Coast, Canterbury, Otago, Southland.  
Mob: 029 777 9944



**Reima Casey**



**Gwynyth Carr**



**Linda Oliver**



**Lin Field**



**Graham Jones**



**Lynne Neshausen**



**Moir Young**



**Kate Moulson**



# Letter from the President



**IN A DOCUMENTARY I SAW RECENTLY** on Huntington's disease the young woman featured in the film

said that her family could not manage living with this disease without support. She talked about the value of friends, neighbours and work colleagues. But she also said how supportive it was to be part of the Huntington's community – from the local support worker with specialist knowledge through to being part of a national and international community.

We know that families living with MND find that being part of our MND family is supportive.

Earlier this year we launched MND NZ on Facebook ([www.facebook.com/mndanz](http://www.facebook.com/mndanz)) and set up a Twitter account ([www.twitter/mndanz](http://www.twitter/mndanz)). We are finding these are great ways to share stories and news in real time. And there has been a lot to share.

There was activity all over New Zealand around June 21 – International Awareness day for MND. A very special thanks to everyone who bravely shared their story on TV or in the paper or in their workplace; or who organised or participated in an event; or who rattled a bucket or held a fundraising lunch or otherwise solicited funds. Together we brought MND to a much wider audience.

But activities aren't confined to awareness time. There is always something happening – in September Hilary and her team from Pure Trails will ride the 150km Central Otago rail trail in ONE day – see [www.puretrailsnewzealand.co.nz](http://www.puretrailsnewzealand.co.nz); on September 17–19 Michael is doing a 48 hour Swimathon in Kapiti. On Sunday 12 October there is a Walk to D'Feet MND in Christchurch, and in February Carey will mountain bike from Cape Reinga to Bluff in 42 days

to raise funds for MND, so follow us on our Facebook page "Motor Neurone Disease Association of NZ" to keep up to date.

And awareness isn't confined to activities either. Did you know that the Association has sale items? These raise awareness too. We have 'everyday' cornflower cards – 6 different original designs done by Waikato artists. 12 mixed cards and envelopes cost just \$8 plus p&p.



We also sell very popular and comfortable socks available in sizes 4–6, 7–10 and 10–13 in ankle style and a size 6–10 in long top socks. They retail at \$8 a pair plus p&p. Orders from Moira-Anne at [moiraanne@gmail.com](mailto:moiraanne@gmail.com).



And for the gardeners amongst you or perhaps as a memorial gift, the Bay of Plenty Branch sells packets of cornflower seeds at \$2 a packet.



Awareness is also advocacy. During the election build up our Association has put questions to MPs about their party's policies for the disability sector. We hope the political activists amongst you have also used this opportunity. Earlier in the year we were part of a joint submission on the Bill before Parliament that proposed doing away with requirements for new buildings to be accessible. We had strong support for our submission from MPs across the political spectrum so we are optimistic that new buildings will continue to have to meet accessibility guidelines. And did you know that the disability sector has active and skilled accessibility lobbyists who cover all parts of New Zealand? If you face accessibility challenges do get in touch and we will connect you with the nearest specialist who will lobby on your behalf.

And finally I WELCOME the re-formed Canterbury Branch. Welcome, welcome, welcome. What a joy to have you people giving your time to be local cheerleaders for people with MND.

If anyone in other parts of New Zealand would like to get a cheerleading group of MND supporters together, I would love to hear from you.

Nā tō rourou, nā taku rourou ka ora ai te iwi – With your food basket and my food basket the people will thrive.

**Beth Watson**

President of MND Association Inc. NZ



## NATIONAL COUNCIL

President	Beth Watson
Vice President	Ray Hall
Secretary	Bruce Stokell
Treasurer	Michelle Knox
Councillors	Helen Brown, Henrik Dorbeck, Barbara Gilchrist, Helen Palmer, Andrew Pardoe-Burnett, Richard Ryan

## FIELDWORKERS

**Lin Field:** Auckland North and Northland, **Linda Oliver:** Auckland Central and South, **Lynne Neshausen:** Waikato, Taranaki, **Graham Jones:** Bay of Plenty, Rotorua, Gisborne, Hawkes Bay **Reima Casey:** Manawatu, Wanganui, **Moir Young:** Wellington, Nelson/Marlborough, **Kate Moulson:** South Island

## NATIONAL OFFICE

National Manager: Grant Diggle  
Fieldwork Support Officer: Lin Field  
Administrator: Gwynneth Carr

## MND ASSOCIATION OF NEW ZEALAND INC.

Yarnton House, 14 Erson Ave, PO Box 24036,  
Royal Oak, Auckland 1345  
Tel: 09 624 2148  
www.mnda.org.nz

## 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.

**Note: Opinions expressed in the newsletter are those of the individuals writing and do not necessarily reflect the opinion of the Association. Our thanks to minimum graphics for design and layout of MND News.**

# MND Association Funders

The MND Association would like to thank and acknowledge the support received from the following organisations who contribute to the costs of providing our services to people with MND.

