ISSN 2357-173X AUTUMN 2015

mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

www.mnda.org.nz

Contents

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). The various forms result in different presentations that progress at different rates in each individual.

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. The content of this newsletter is provided for information sharing purposes only. Whilst all care is taken to be sure information comes from 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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www.facebook.com/MNDBOP

30 Years Young!

2015 marks the 30th birthday of MND NZ – the Motor Neurone Disease Association of NZ Inc.

Kia ora koutou. Ngā mihi nui ki a koutou – warm greetings to you all.

WE HAVE TO THANK those people who, back in the early 1980s, saw the need for support in New Zealand for people with MND. Their task to set up an Association was not easy ... but they persisted ... and persisted ... and persisted. The first groups were in Auckland and Wellington. In Auckland the people included Vera Grant, Jill Braddick, Lea Hewitson, Ron Jacobs, Dorothy Nicholas and Tom McGeachie; in Wellington they included Lois Chambers, Joyce McCredie, Don Telfer, Kristin Arthur and Nedra Shand. How proud I am to be part of our 30 year journey – from 2001-2004 as the paid national Executive Officer and since then as a volunteer.

Our Association was set up to support people living with MND and that is still our focus. We would love to do more – especially to have more paid hours for our fieldworkers, to have better awareness, to fund research in New Zealand.

So it is fitting that in our "Big Birthday" year we are planning a major national fundraising and awareness event.

Thanks to the energy and vision of Dr Claire Reilly, who herself has MND, a "Walk 2 D'Feet MND" is being held on 20 September in the 6 main centres in New Zealand. Claire is the project manager and she has already secured involvement from several high profile New Zealanders – although we would welcome more. We would also welcome more helpers. You will be hearing more in the coming months but meantime mark your diaries, as we do hope you will help us make these events a real success. See over page for more details.

We truly appreciate all of you who help with fundraising and awareness. Whether it is organising a film night, buying our merchandise, getting sponsorship for an event you are doing, talking to your workmates, having a Care with Coins container in your home or office or, as a friend of mine does, setting aside $10 a week for MND (how we love it when her annual cheque arrives) – it all adds up. I trust that this support will continue for without your help, MND NZ cannot fill those gaps we see.

Eddie Redmayne, who played Stephen Hawking so well in the movie *The Theory of Everything*, apparently said that he gave the role "everything". He also said about Stephen Hawking: "He does not live a disease. He lives forward and has done since he was 21 years old. There's an unerring optimism to him". Our national MND Council gives the best it has and we live forward too, with unerring optimism. Optimism that we will continue to get the support we need that in turn will enable us to broaden our service delivery even wider before our next "Big Birthday" .

Do please get in touch if you would like to become involved in the next leg of our journey.

Take care folks
Kei konā kei a koutou ngā whakaaro – Our thoughts are with you

Beth

National President MND NZ

Patron: The Hon. Ruth Dyson MP Medical Patron: Professor Richard Faull Honorary Medical Advisor: Dr. Andrew Chancellor
The MND Association of New Zealand Inc. is registered charity number CC35320

Our new logo

mnd
REGISTERED CHARITY CC35320
New Zealand

TURNING 30 is a significant anniversary and we mark the start of a new era with a fresh logo reflecting the longstanding close relationship we have with MND Australia. For some time they have acknowledged us as an associate member of their organisation and their support, advice and encouragement have been much appreciated. Our new logo represents that relationship and you will increasingly see our new image appearing. Our thanks go to MND Australia for adapting their logo for our use.

Our thanks also go to Kevin Williams for the great work he did on the branding that has served us so well.

We need help to stay connected.

Spark (previously Telecom) generously sponsored our phone and internet costs over the past 12 months but unfortunately they are unable to continue this arrangement. We now need to find funding of around $1200 per month to cover these costs which are a central part of the support services we offer.

We would welcome any suggestions or offers – 60 sponsors of $20 per month is all we would need.

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, wasting. Vision, hearing and sense of touch are retained. The condition may start with reduced strength or coordination in an arm or leg, or with difficulty speaking or swallowing.

As the condition progresses the loss of movement increases and other areas, such as breathing, may be affected. The nature and rate of progression varies enormously between individuals. Life expectancy is shortened but time frames vary widely. MND can be difficult to diagnose in the early stages depending on the nature of the initial symptoms and many will have had the condition longer than they realise before presenting to a neurologist.

Motor Neurone Disease (MND) is also known as Amyotrophic Lateral Sclerosis (ALS) and Lou Gehrig's disease. This condition presents differently across individuals; some forms are given labels such as Primary Lateral Sclerosis (PLS), Bulbar Palsy, Pseudo bulbar Palsy (PBP), and Primary Muscular Atrophy (PMA). These forms of MND are 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.

In New Zealand there are approximately 300 people living with MND at any one time and it is slightly more common in men than women. It is seen across all ethnic groups.

The cause of MND is not known but considerable research is being undertaken throughout the world and significant advances are being made in 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.

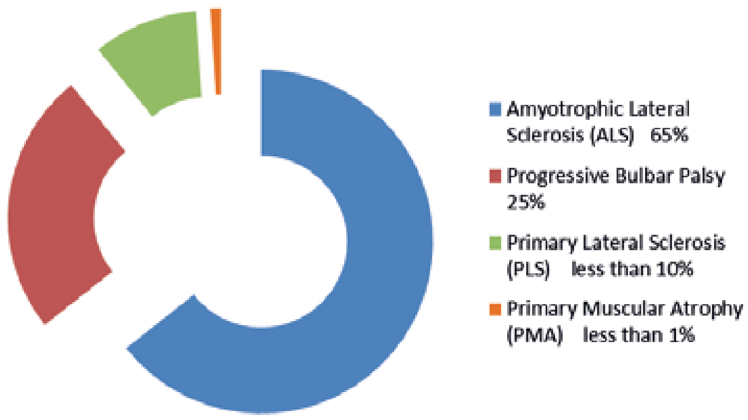
At present there is no cure for MND; one drug, riluzole, marketed as Rilutek, has been shown to extend life in some people but is not suited to everyone.

There is much that can be done to manage the condition and support quality of life.

COGNITIVE CHANGES AND MND. Many people experience physical symptoms that disrupt their independence but their brain function, intellect and personality remain unaffected. However, cognitive changes may be present in 30-50% of people with MND; change is often subtle e.g. altered problem solving skills, reduced empathy and apathy. 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 experience significant cognitive changes typical of a fronto-temporal dementia (FTD) and signs of this may have been evident well before the physical symptoms developed.

Riluzole is the only treatment that has shown through approved clinical trials to have the potential to slow the progression of MND. In NZ riluzole is marketed by Sanofi as Rilutek and is available on prescription from your specialist.



A Nationwide Walk 2 D'Feet MND

THE ASSOCIATION IS DELIGHTED to announce its first ever nationwide Walk 2 D'Feet on Sunday 20th September 2015. The walk will take place in 6 different cities – Auckland, Hamilton, Tauranga, Wellington, Christchurch and Dunedin – on the same day at the same time, with all funds raised going to MND NZ. Having this event nationwide on the same day is the brain child of Dr Claire Reilly, who herself has MND. At the event in Christchurch last year she got talking to our President Beth and sold the idea that MND NZ could do a nationwide event – provided it was planned in advance. Beth had been blown away by the success of the Walk in Christchurch last year and in the Bay of Plenty 2 years ago and so did not need much persuading. And MND Associations overseas also use Walk 2 D'Feet MND events successfully to raise awareness and funds, as well as spirits as people come together against the challenges of MND.


Walk to D'Feet – Bay of Plenty 2012


Walk 2 D'Feet Christchurch 2014

This is a very exciting opportunity for MND NZ. We are indeed fortunate to have the indomitable Claire working on this project for us at national level – she is seeking sponsorship, seeking commitment and support from high profile New Zealanders, hoping for TV advertising, setting up a dedicated web site for entries, arranging merchandise for sale.... the list goes on! Our President, Beth, says "Claire is a great planner, determined, not easily discouraged, courageous, positive, and very good at using social media, an amazing networker … It is testament to her spirit that she has MND herself and yet has taken on this mammoth project for the Association".

We look forward to bringing you more information in the coming months as this project comes together.

If you are able to help us with this project at a local level, including local sponsorship, sourcing auction prizes or getting local celebrities involved, or want to be kept informed of the plans please get in touch with Claire by email: clairereilly@clear.net.nz or keep an eye on our website and Facebook page https://www.facebook.com/mndanz

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ARE YOU ON FACEBOOK – did you know there is a private Facebook page specifically for those living with MND in New Zealand; a place for people living with MND across NZ to connect and share stories and ideas. Dr Claire is clearly a very resourceful individual and in addition to organising Walk 2 D'Feet she has set up a Facebook page called Kiwi**PALS**. The term PALS has long been used overseas to refer to **P**eople with **ALS** with this abbreviation relating to **A**myotrophic **L**ateral **S**clerosis an alternative name for **M**otor **N**eurone **D**isease (**MND**). Claire has incorporated this in the name KiwiPALS. To become part of the sharing you first need to have set up your own Facebook profile and then search for KiwiPALS or go to https://www.facebook.com/groups/KiwiPALS/ and request to join! Claire will accept your request I am sure!

You can also meet Claire on YouTube taking the Ice Bucket Challenge last year – just search "Dr's MND Challenge".


Dr. Claire Reilly

Cape Reinga to Bluff

CAREY VIVIAN'S AMAZING CYCLE journey, inspired by his father's own challenging journey living with MND, has raised over $40,000 thanks to a massive amount of support and encouragement. The Race Against Time raised awareness of MND across the country with Carey's progress featuring on TV, national radio, local and national newspapers, You Tube and Facebook. On arrival in Bluff Councillor Lloyd Esler presented him with a plaque acknowledging his epic 6 week, off-road, ride covering the 4,500km from Cape Reinga.

Our sincere thanks to Carey, his family and friends, those who provided accommodation and support along the route and of course those who donated so generously to provide much needed funds to keep our support services afloat.


Beth Watson cycled alongside Carey in the Motatapu Cycle Event.

Stem Cell Basics

MUCH EXCITEMENT and media attention has been generated over the possibility that stem cells could eventually be used as a therapy to repair or replace cells damaged by disease. **While stem cells may eventually evolve as part of a treatment for MND, the current message from the majority of scientists and clinicians is that numerous significant hurdles need to be overcome before stem cells can be considered a realistic option for treating the disease.**

What are stem cells?

Stem cells are cells that have not yet become specialised to perform a particular function. They can renew themselves and have the ability to develop into different cell types such as blood, muscle or nerve cells.

The main types of stem cells are: embryonic, induced pluripotent stem (iPS) cells, adult and umbilical cord stem cells.

Work is ongoing to learn more about different types of stem cells and how they might be used to treat MND – it might even be necessary to use a combination of different types of stem cell therapy to treat MND.

Stem cell therapy is the use of stem cells used in various ways such as bone marrow transplants, injections, transfusions with the aim of treating a specific condition. **At present, there is no reliable evidence to suggest that stem cells can be used as an effective treatment for MND.** However, they do provide new opportunities for researchers; scientists can now work with human motor neurones derived from the skin cells of people living with MND rather than being dependent on animal models. As the understanding of the mechanism underlying MND increases so does the potential to explore therapies.

Kiwis feedback

I have had stem cell treatment and …

> *"Following diagnosis I did some research online and in September 2014 I flew to Beijing for stem cell treatment. A day after arriving I was taken to meet the Chinese chief neurologist. During a five minute consult he asked me to walk in front of him, do a squat, and poke out my tongue – that was the extent of our meeting. Over the next two weeks I had three lumbar punctures and one intravenous injection of stem cells. The cost of this treatment was US$4,000 per lumbar injection and US$6,000 for the intravenous treatment. All up the total cost, including accommodation, was around US$22,000. It is now three months since I had treatment. Unfortunately, there has been no improvement in my condition and it has steadily worsened. Overall I would not recommend this treatment to anyone suffering from our condition. The Chinese claim an 84% efficacy rate; however there seems to be no clinical basis for this figure."*
>
> **Mark**

I have had stem cell treatment and …

> *"My treatment was in November last year in Tijuana. The treatment was expensive but since there is no mainstream medical treatment I felt stem cell treatment was worth a shot. The process involved one IV infusion in the back of my hand and another just below my belly button. I plan to return to Tijuana in July in the hope of arresting the deterioration."*
>
> **Stephen**

The challenges

- Researchers still do not understand exactly how stem cells might be beneficial for diseases such as MND.
- Studies in animals have suggested that stem cell transplants are more likely to be effective in protecting existing motor neurones than in actually replacing or repairing them; stem cells might be used to replace supporting cells, deliver nourishing substances or dampen down inflammation.
- Researchers have yet to establish the risks involved with such treatment; some stem cells have the potential to give rise to tumours.

Clinical Trials

The gold standard for testing both the effectiveness and safety of any treatment is a series of carefully controlled clinical trials, which build on the conclusions reached in the laboratory. **No stem cell treatment has yet completed such rigorous testing for MND**. The first rigorous clinical trials to examine the safety of stem cell treatments in people with MND have begun in America and Israel. These early clinical trials have assessed safety only and do not include measures of effectiveness in treating the disease.

Neuralstem

Neuralstem is a stem cell treatment that involves several injections of neural stem cells into the spinal cord of patients. A phase II trial now has the American Food and Drugs Administration (FDA) approval. This trial began in September 2013 with results expected in early 2015.

Brainstorm

In June 2014 Brainstorm Cell Therapeutics launched an FDA approved Phase II trial of NurOwn in America which is expected to be completed in 2016. A further study is to begin in Israel in 2015.

There are justifiable concerns over unproven stem cell treatments. There is no reliable evidence to support the claims made by various clinics around the world currently offering stem cell treatment to people with MND; there are potential risks and high costs involved in treatments that have no scientific rationale for their claims.

For more information

www.stemcellfoundation.net.au

Acknowledged sources for this article:

Clinical Trials: www.clinicaltrials.gov

UK MND Research Blog:
www.mndresearch.wordpress.com

Research updates: www.als.net

Cochrane Library:
www.thecochranelibrary.com

Familial MND and genetic testing

GENETIC HEALTH SERVICE
NEW ZEALAND
RATONGA HAUORA IRANGA
AOTEAROA

CURRENT KNOWLEDGE indicates that only 5–10% of MND is known to be familial – meaning there is a known genetic link running through a particular family. However, for most people MND is considered to be sporadic meaning the individual has 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 MND and more genetic links are identified.

The Genetic Health Service advises:

We know of multiple genes that cause familial ALS/MND and there are likely to be more that we have yet to discover. We don't have a lot of data on every gene, because it's such a small proportion of people but there are some we know more about. Certain genes are associated with reasonable certainty that a person will get symptoms, however, it is not possible to predict when the symptoms will develop – an individual could test positive and spend their whole life concerned, but if other events or illnesses intervene they may not live long enough to develop MND.

Understanding the genetics involved in ALS/MND is constantly evolving – it's very complicated, and we don't know it all. When referred for predictive testing people can expect there will be a series of meetings to allow time to really process the information and potential implications of test results – it is important to consider what effect knowing versus not knowing might have on an individual and the extended family.

BLOOD BANKING – some people prefer the idea of storing a sample of their blood for future testing and with testing for MND being relatively new it is best to contact the Genetic Health Service directly for more information.

If you have reason to think MND might run in your family you should talk with the specialists who know you and/or your GP. You can also contact the Genetic Health Service yourself for initial advice over the phone. You can attend for counselling without going on to have the testing done. 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 also available to talk to interested local groups.

For more information

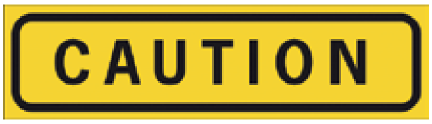
www.genetichealthservice.org.nz

Contact:
Auckland – 0800 476 123
Wellington Centre – 0508 364436
South Island Centre – 0508 364436

Read further on the Australian MND Association website:
www.mndaust.asn

or the UK MNDA:
www.mndassociation.org

Unproven treatments



AN UNDERSTANDABLE RESPONSE to receiving a diagnosis of MND is to seek answers and treatments – anything that offers some hope. Persuasive advertisements and anecdotal reports seek to separate you from your hard earned cash in return for promises of improvement or even cure. **Please be cautious – there are many unproven treatments offered with generous claims of outcomes, we encourage you to do careful research and talk with the specialists who know you best.**

SENSE about SCIENCE works with scientists and members of the public to equip people to make sense of science and evidence they have a helpful booklet free to download called "I've Got Nothing to Lose by Trying It". For more information: www.senseaboutscience.org.uk

ALS Untangled

ALSUntangled exists to scientifically review alternative treatments and help people make informed decisions. The ALSUntangled team consists of 95 respected clinicians and scientists from 10 different countries who to date have received requests to investigate more than 160 different alternative treatments claiming benefit to people with MND (ALS). Around 26 reviews have now been completed and published in the respected journal Amyotrophic Lateral Sclerosis & Fronto-temporal Degeneration. These reviews are available to view free via the website: **www.alsuntangled.com**

MND Connect

A new group meeting in Auckland

In some areas of the country groups of people living with MND meet to share their experience and support each other. There has been insufficient interest in the Auckland area for some time but we now have a cheerful, positive bunch of people who gather for coffee every few months at the Independent Living Services (ILS) Centre at Royal Oak. The venue offers a chance to view the showroom of equipment and gadgets available to make everyday activities a little easier. Contact our Auckland Fieldworkers, Lin & Linda, if you would like to know more. To find out what is available in other areas contact the local Fieldworker – see page 12.

MND Research in New Zealand

Left to right: Professors Peter Thorne, Richard Faull, Alan Barber and Ian Kirk, Centre for Brain Research Directors

THE SIZE OF NEW ZEALAND's population impacts on local research, however, as the global village increasingly embraces technology we can be confident that scientists & researchers working here are closely connected and involved in international projects. The teams at the Centre for Brain Research and Massey University are currently collaborating with their colleagues around the world and ensure we are well informed. The Centre for Brain Research based at Auckland University has now combined with colleagues from universities around the country to form Brain Research New Zealand (BRNZ) which the Government has designated as one of its Centres of Research Excellence (CoRE). This step will further develop the existing relationships across the country connecting scientists and researchers with clinicians, support organisations such as our own and most importantly with people experiencing a range of brain dysfunction. Our congratulations go to our Medical Patron, Professor Richard Faull and his colleagues as they continue to expand their vision and seek answers. Read more: www.fmhs.auckland.ac.nz/en/faculty/cbr.html

Research at Auckland University

In our previous newsletter we described exciting work on MND at the Centre for Brain Research, University of Auckland by Dr Mike Dragunow and his team. This work on MND, which is underpinned by the Hugh Green Foundation-funded Centre for Brain Research Biobank (a facility for growing, studying and testing adult human brain cells), is being made possible by the generous support of the Coker Charitable Trust and more recently by the Sir Thomas & Lady Duncan Trust. In addition, Dr Emma Scotter is generously supported by a fellowship from the Aotearoa Foundation. For more information contact the Centre for Brain Research: **cbr@auckland.ac.nz**

Research at Massey University

The project looking into occupational and environmental risk factors related to MND is ongoing and volunteers are still wanted to complete the questionnaire. For more information contact Grace Chen: **g.chen1@massey.ac.nz**

International MND Research

Community Networking and Co-ordinated Care shows real benefits. A study in Paris looked into the effect of co-ordination of care for people with MND. Two groups totalling 2452 people with MND were monitored for two years and received identical care but one group had the added benefit of a community care network. The study published recently concluded: "*Network care was associated with fewer hospital admissions, reduced functional deterioration and later mortality in ALS. These results suggest that proactive coordination between carers in chronic and complex diseases could have a positive impact on hospitalization and the clinical course of the disease.*" See: **http://www.biomedcentral.com/1472-6963/15/134**

Keeping up to date

THE VOLUME OF RESEARCH and numbers of clinical trials related to MND(ALS) currently underway is possibly higher than ever. The international research community regularly announces exciting progress in their understanding of the condition.

When searching for information remember that MND (Motor Neurone Disease) is called ALS (Amyotrophic Lateral Sclerosis) in the U.S. and some other countries. Follow research updates on our webpage: www.mnda.org.nz and websites such as:

- Australian MND Association: **www.mndaust.asn.au**
- MNDCare Latest News: **www.mndcare.net.au**
- Research updates: **www.als.net**
- UK MND Association: **www.mndassociation.org/research**
- UK MND Research Blog: **www.mndresearch.wordpress.com**
- American ALS Association: **www.alsa.org/research**
- ALS Worldwide: **www.alsworldwide.org**

To find out about the various clinical trials around the world start by looking at these sites:

- Australian Clinical Trials: **www.australianclinicaltrials.gov.au/home**
- U.S. Clinical Trials: **www.clinicaltrials.gov**

Breaking the Human Genome Code

is revolutionary, ethically challenging and contributing significantly to MND research. View an interesting lecture by Prof. Winston Hide from the research team at SITraN (Sheffield Institute for Translational Neuroscience UK) who are asking questions like, "*If a neuron from a patient with ALS/MND could tell us what is happening within it, what would it say?*" See: **mndresearch.wordpress.com/2015/04/01**

Dr Samantha Price, from the SITraN team says, "We know that MND can have a variety of different causes, some genetic and some probably environmental. However, in the end all forms of the disease have some common features, such as the death of motor neurons. Once a 'final common pathway' is identified treatments can be developed to reverse it. Already this methodology is yielding new insights in the mechanism of disease in MND and will hopefully lead us to new and effective treatments in due course."

Watch Your Step – the risks of falling

A TENDENCY TO TRIP when a foot catches on a mat or a sense of being off balance as you change direction when walking is a sign your body is not quite as efficient when it moves as it previously was. Whilst these may be brief and apparently insignificant events they indicate you need to be more conscious of how you move – imagine you are doing 3 point turns rather than hand brake turns when walking!

No-one readily embraces the idea of using equipment to aid everyday activities they have done competently and automatically for so long but early use of a stick can be a good reminder to be more cautious and gives a clear message to others to give you time and space when moving – a great tool if you are in crowds or busy settings. A range of collapsible sticks are readily available in your local pharmacy and your Physiotherapist and Occupational therapist can advise on more sophisticated sticks along with walking frame options for those needing a little more support.

Plan ahead and accept the equipment offered – don't wait until you have a fall!

Our Fieldworkers hear too many tales of broken bones, or worse, from people falling; a break immediately impacts on your mobility and independence and is avoidable with care and acceptance of the need for equipment.

Plan ahead – prevention is best

- Give some thought to when and where you are at most risk.
- Ask family and friends what concerns and suggestions they have.
- Consider moving mats or furniture that may be a safety risk, such as a glass coffee table.
- Pay attention to your movements – focus on one thing at a time.
- Ask your therapists for strategies to help yourself or to help the people around you.
- Practice how you would be able to get up from the floor if you fell – it may surprise you how many sets of muscles you need to use.
- Practice using the equipment therapists provide – even if you don't feel you need to.
- Consider getting a personal medical alarm.

ACC produce a booklet "Standing Up to Falls" with suggestions that may help – call 0800 844 657 to request a copy or go to their website: www.acc.co.nz

What to do if someone falls

It may be best to help someone fall safely to the floor rather than trying to stop the fall and hurting them or yourself in the process. **If the person is unconscious or needs medical attention then dial 111 for an ambulance otherwise:**

- Once on the ground there is no hurry to get them up – stay calm and plan your next move.
- It may be best to make them comfortable on the floor with a pillow for a while to calm down.
- If you know how to help them get up safely talk the plan through together and then proceed slowly – there is no panic.
- If you feel unsafe helping on your own, consider whether there is any local help available, such as a neighbor.
- If there is no local help available then Dial 111 for an ambulance– the crew will help settle the person and check for injury. They will not take them to hospital unless necessary. It is unlikely your call will be considered an emergency so you may need to make the person comfortable on the floor initially.

Acknowledgement: Adapted from an article in The Parkinsonian Newsletter Dec. 2014

Consider a personal alarm, such as the one available through St. John's, you or your companion at the time, can then raise help easily – a great reassurance for visiting family and friends. Talk with your doctor to see if funding is available towards the cost of an alarm and contact St. John's to arrange a free one month trial: 0800 50 23 23. For more information see: www.stjohn.org.nz

Fruit flies are not all bad

5–10% OF CASES OF MND occur in people known to have a family history and as a result several genetic mutations have been identified for further study. Fruit flies are used are used in the laboratory as they share 75–85% DNA with humans and fly families bred carrying MND linked mutations are being used to research toxicity. Dr Adrian Isaacs from the team at University College, London said: "*Finding out that the proteins produced by the C9orf72 mutation were toxic was a complete surprise. Our next steps are to find out exactly how these toxic proteins cause the motor neurones to die and go on to try and develop drugs that stop their production.*"

See: mndresearch.wordpress.com

26th International Symposium on ALS/MND

Orlando, USA from the 11–13 December 2015

mnda
26th International symposium on ALS/MND
Orlando 2015

EACH YEAR, the symposium attracts over 800 delegates, representing the energy and enthusiasm of the global MND research community. The symposium is the **largest** medical and scientific conference specific to MND and is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management. **Highlights from recent symposia held in Sydney, Chicago, Milan, Brussels** can be found in the 'Past Symposia' section website: **www.mndassociation.org** – a great way to see who is doing what in relation to MND care, management and research around the world."*The best aspect was the sense that so many good minds are working on MND*". These symposia are organised by the UK MND association in conjunction with the International Alliance of MND Associations. Deadline for submission of Abstracts is 29th May 2015. An extensive poster exhibition is included as well as a range of options to network with international minds focussed on ALS/MND. This event is great value for health professionals but people living with ALS/MND are also welcome and find plenty of interest. For more information email: **symposium@mndassociation.org** or see the website: **www.mndassociation.org/symposium**

Jaw support

JAW SUPPORT in some form may be a solution to mouth breathing at night resulting in a very dry mouth. Various versions can be ordered online or talk with your local pharmacy – or perhaps develop your own solution with stretch fabric or a stretch hairband. See www.mysnoring-solution.com

Pure Food Company

IF YOU FIND you manage better with a soft diet or have been advised to be cautious with the textures you eat you may be interested in the meals offered by the Pure Food Company who believe that when texture modified foods are nutritious and delicious then people's quality of life can be significantly improved. This new business began as the result of difficulty finding suitable food for a family member with MND and aims to provide an option for anyone needing to modify the texture of their food without compromising flavour. These blended foods come in pouches that keep fresh in the fridge for heating through when you are ready and provide a time saving alternative for carers or people living alone. The menu includes flavoursome meals such as Roast Lamb with Mint, Hickory Pork, Fish Pie and BBQ Chicken. See their website: www.thepurefoodco.co.nz or search their name on Facebook or ring 0800 178733. **As always, check with the specialists who know you to be sure a product is suitable for you.**

Heads up!

The Sheffield Support Snood

A REVOLUTIONARY NEW NECK COLLAR has been designed following a collaborative patient-led project with input from people living with and affected by MND.

Our necks support around 5kg of weight but none of us are aware of this until something goes wrong. Neck weakness develops in some people with MND and it can be difficult to manage. Current neck supports vary hugely from soft foam collars that can be hot and offer little support, to rigid collars designed for immobilising the neck after trauma and people find these restrictive and uncomfortable. There were no neck supports specifically designed for people living with MND so Dr. Chris McDermott, Consultant Neurologist and a Co-Director at the Sheffield (UK) Institute for Translational Neuroscience (SITraN) has been addressing this problem by working collaboratively with an extensive team, including people living with MND, to develop a solution. "*The problem is that existing collars all support the head by pushing up from under the jaw which affects basic functions such as eating and talking. People with neck weakness want to maintain these functions so the requirement is for support plus movement.*"

The Sheffield Support Snood is a lightweight neck collar developed in response to the needs of people living with motor neurone disease and as at December 2014, interest was being sought from manufacturers to get this collar into the hands of patients and clinicians as soon as possible. For more information: **www.mndassociation.org** the UK MND Association website has links to further information on this project and an information sheet on head support options.

The Carer Experience

The parents' perspective by Lloyd & Viviane Hill

A YEAR AGO, our wonderful son died after living with Motor Neurone Disease, for almost five years. I hope the following words go part way to recognising the challenges we all faced and might assist others who are living with, caring for, or grieving for someone with MND.

My first tribute to Marc is best expressed in my wife's words "he never complained". I have thought so much about those words – what a wonderful example he provided for us all. Here was a man who had been a very strong athletic fellow, full of vitality, with a passion for sport and adventure; a competent dextrous tradesman and a loving father who adored playing with his beautiful three year old daughter. Sadly he went from this to being dependent on an electric wheelchair unable to even use his hands – hands that had been so important to him.

My second tribute to Marc is another example he gave us all: 'make the most of now'. He had always 'lived life to the full' and, once over the shock of being diagnosed with MND, for most of the remainder of the time, he really did continue with his philosophy and endeavoured to make the most of every day. He set a pretty good example for us all to follow and as a great friend said, "We owe it to Marc to learn from the example he set".

In our experience there were some key factors involved in doing our best to support someone living with MND:

Keep 'life' as normal as possible – for as long as possible

Marc was fortunate to have wonderful friends "a band of brothers" who took him on many outings and helped get him 'out of himself'. Friends are a great support if they continue to do just what they have always done.

Keep life interesting

Find ways to remain involved in activities that are stimulating, distracting or uplifting – consider exploring new activities. Marc became a voracious reader and spent a lot of time on the internet looking for information on all sorts of subjects. Technology now offers such a wide range of options to pass the time with.

Understanding & awareness

Be sensitive how much information the person with MND wants regarding their condition. People generally have clear ideas on what they want and how best to manage their care but some will not be so clear and may take a step back from the problem solving leaving others to make decisions. Follow their lead – don't fight it.

Over time the person with MND will be acutely aware of their physical limitations and their dependency on others – this may show as frustration, irritation, lack of patience, high demands and anger. Family and carers may need to remind themselves these feelings are directed against MND not against those doing the caring – but it might not feel like that on a bad day!

Keep communicating and seeing each other's perspective

At times Marc struggled to recognise how difficult it was for us to put ourselves 'in his shoes' – particularly as far as his frustrations over needing help with dressing, feeding, toilet care and so forth. Marc was, naturally, an efficient and quick witted person who would surely have been quicker and more efficient than the person doing the helping and we all know how frustrating that feels. Do find ways to keep communicating even if speech becomes difficult. We all had to work on being respectful of each other's perspective and limitations, patient and honest, with a lot of understanding and involvement. It can be time consuming.

Keep involved and share decision making

I have a vivid recollection of an occasion where Marc felt excluded from a decision – he burst out with "just because I'm in a wheelchair doesn't mean that I don't have an opinion". These words resonated with me and brought to mind what others in a wheelchair must feel from time to time.

Prepare yourselves and the children

Anyone who knew our son, knows he was a very determined man who did everything he could to extend his life and to have more time with his lovely daughter. Marc and his wife prepared her very well, almost to the point that when he died our grand-daughter accepted that this was what was always going to happen. Talking with the children takes a lot of courage and a lot of honesty but I feel sure that it has helped our wonderful granddaughter to 'move on' with her own life.

In memory of Marc Hill

Can any positives be taken from our experience?

The unavoidable truth is that MND is a progressive, life limiting disease and coming to terms with this fact is challenging. Based on our personal experience initial constructive responses to receiving a diagnosis might be:

- Organize your financial affairs and your Will.
- Appoint Enduring Powers of Attorney – for both health and property.
- Learn what care, equipment and assistance is provided through District Health Boards and other agencies.
- Talk with family members, friends, work colleagues and identify support each can offer.
- Prepare children, in an age appropriate manner, for the fact that their parent's condition will change and they will not be with them as they grow older.
- Seek help and advice on how to do all of the above.

It must be said that the past few years have been very difficult for us all, however, we have also had a significant learning experience and Marc's determination in the face of living with MND has provided some lessons we can all benefit from.

This works for me – Kiwi ingenuity

Where there's a will, there may be a way – people living with MND share their solutions to everyday challenges

Adapting to reducing strength in arms and hands

IT IS AMAZING how adaptable we humans are – some people with MND experience significant reduction in upper limb function compared to their lower limbs – they remain mobile but have reduced arm and hand movement.

Mark is in this category and shares his creative problem solving:

- Get an electric toothbrush if you can hold it with both hands – brush your teeth whilst showering so you can rinse arms and hands off after.
- Consider an electric bidet – perfect after toileting but also after a shower – heat the seat and put the blower on hot and it dries your nether regions!
- Trackpants and shorts lined with a silky fabric are easier to get on and off – consider going without underwear to make life easier!
- Find a "friendly" window latch or door handle! I've found just the right one in my bedroom – it is at waist height and I back against it and hook the waistband of my pants over it and this helps me slide up undies, track pants, shorts etc. It takes some practice though and don't pick one with a sharp edge! If you haven't got one at the right height perhaps buy one and screw to a wall or door.
- Get a step-up stool, just a one-step platform (Mitre10) so your hands are at the right height as your arms hang above the kitchen bench or your desk and stand to do things rather than sitting.
- Ask your Occupational Therapist about a Neater Eater

The Neater Eater
An eating aid system designed to enable people to feed themselves when upper limb movement is limited.

www.neatereater.co.uk

Neater Solutions – offer a range equipment. Talk with your Occupational Therapist

Equipment …

… can make a lot of difference to your energy levels, safety and quality of life. It can be a challenge to accept the idea of needing special equipment but planning ahead for your potential needs makes sense. Your Occupational Therapist can advise on equipment available through government funding such as wheelchairs, shower equipment, hoists and ramps. A range of smaller equipment exists for you to purchase either online or by visiting a disability equipment centre – find your nearest centre and some of the equipment available on the WEKA website: **www.weka.net.nz/equipment**

Key Turner

THIS NIFTY GADGET attaches to your car or door keys providing an extension handle for those finding it hard to turn keys.

Handy Bar

YET ANOTHER CLEVER TOOL that fixes into the door latch to provide a temporary handle when getting in and out of the car.

Lifting & transfer belt

A REINFORCED BELT WITH HANDLES can be helpful to steady a person during transfers – saves some uncomfortable tugging on trouser belts. Talk with your therapist to see if this would be suitable for you.

ANDREW SUGGESTS the boaties among you will be familiar with the range of products that exist to secure items on board. He told us "*The Starport system (*www.railblaza.com*) has provided me with a range of options for maintaining my independence from my wheelchair. I use an adjustable platform to fix my small tray to and a cup clamp holder and an iPad/tablet holder.*"

"***The RAM mount system** is also worth considering see www.ja-gps.com.au. There are a few different sizes but I have used the smallest which is the B size ball and I used a U-bolt base to fix to my wheelchair. I used a RAM round base fixed to my small tray as well as fixing a Starport base so that I could still use all my Starport attachments.*"

Elastic supports can reduce toes catching as you walk – talk to your therapists.

Turntable discs can be used to make transfers easier and safer and may help with getting in and out of the car.

Modified cutlery is available in various styles that make mealtimes and kitchen preparation easier.

IF COMMUNICATION is becoming difficult for you talk with your therapists or contact Talklink (www.talklink.org) directly to arrange an assessment for technology suited to your needs; the assessment is free and they can advise what funding is available.

Magnets can work magic

"Drill a hole in the handle of your walking stick and place a magnet in the end – it can then attach to anything else metal such as the fridge, table leg in a café etc. – no more nose dives as you bend to scoop up the walking stick."

My iPad – My Lifeline

DON ENCOURAGES embracing technology: "*Thanks to my iPad and Wi-Fi I can continue to be involved in everyday activities: Internet banking, Emails, Google Maps, iTunes, iBooks, Shopping online, taking, storing and displaying photos, enjoying my music. Now with the wonders of my new 3G iPad I am free to do this anywhere coverage is available much like a mobile phone.*"

Don said "*I found I had to ask the people I was communicating with to help me in certain ways*" and he offers some suggestions for anyone starting to use a communication device:

- Be patient while I type in what I want to say – wait as you would if I were talking and Proloquo speaks for me.
- Ask only one question at a time – try not to give me multiple choice answers.
- In a group conversation, please wait for me to contribute before moving on. If people continue chatting to each other while I am still typing my input may get lost as the topic has changed. Also, I find it hard to concentrate on the typing when another conversation is going on around me.
- If my answer is going to be lengthy I am happy for the person to leave me to complete it and when they come back I can push the 'speak' button.
- I find it handy to prepare things I want to say in advance and save them or leave them on the screen or then play when needed.
- The pre-set items in the software programme, Proloquo, are useful to ask for what I need or tell how I feel and they can be customised, but I can still use the keyboard so I haven't had to use them much.

Google Chromecast

Don has also acquired Google Chromecast, a readily available media streaming device that plugs into the TV, so he can view images from my iPad up on the TV screen."*I would find life very difficult without my iPad*," says Don.

Please do contact us if we can help

THE FIELDWORK SERVICE of the Motor Neurone Disease Association exists to support and inform individuals living with MND, their family and supporters and the service providers involved in their care. Our team come from a range of relevant backgrounds: nursing, therapists, counselling and offer experience and sensitivity.

We generally have around 300 people registered for our free support service at any one time. Our funds allow us to employ seven part-time Fieldworkers totalling approximately 155 service hours per week, less than 4 full – time equivalent staff, to cover the whole country.

Our Fieldworkers assist by:

- listening and trying to understand needs and concerns.
- providing information about MND to those newly diagnosed and as the condition progresses.
- helping people understand the information and apply it to individual situations.
- helping people understand the health system and identify and access services they need.
- providing information and support around MND care to health professionals & service providers.
- promoting communication and co-operation between the individuals and agencies involved.

Linda, Kate, Lin, Gwynyth, Moira, Grant, Graham (absent: Reima, Lynne)

- offering opportunities to be in contact with others affected by MND.
- offering continuity of contact from diagnosis on.

Our seven Fieldworkers work part time and will not always be available when you call. **We do not provide out of hours or emergency services or medical advice.** Although clients living some distance from the Fieldworker's base may not meet with them face to face we do our best to develop a supportive relationship by phone, email and mail contact.

Find your nearest Fieldworker

Northland DHB Waitemata DHB (West) Auckland DHB Counties Manukau DHB	**Linda Oliver**
Waitemata DHB (North)	**Lin Field**
Waikato DHB Taranaki DHB	**Lynne Neshausen**
Bay of Plenty DHB Lakes DHB Tairawhiti DHB Hawkes Bay DHB	**Graham Jones**
Whanganui DHB Mid Central DHB	**Reima Casey**
Capital & Coast DHB Wairarapa DHB Hutt DHB Nelson & Marlborough DHB	**Moira Young**
Canterbury, S. Canterbury DHB West Coast DHB Southern DHB	**Kate Moulson**

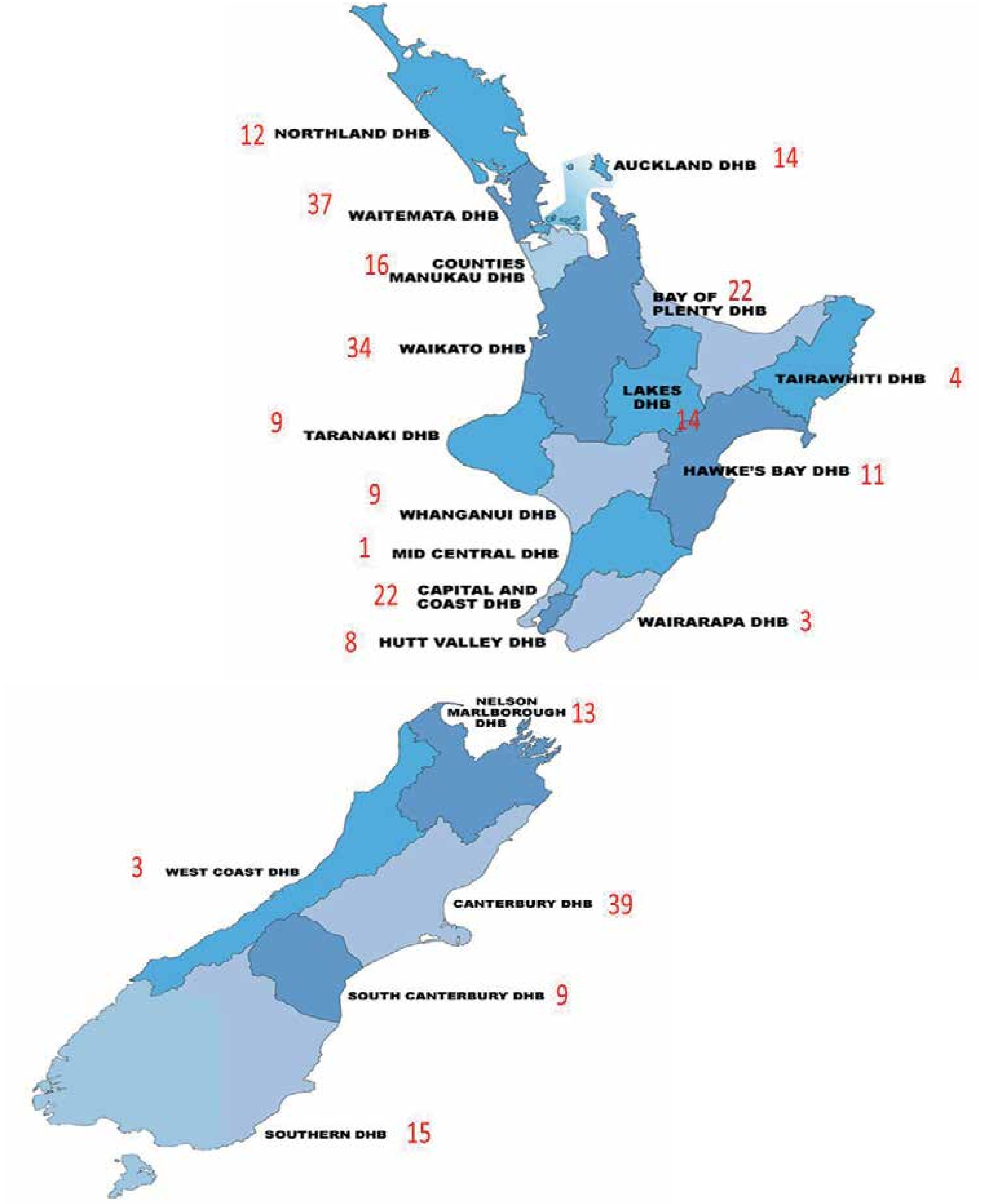
21st June 2015

21st June is marked internationally as MND Awareness Day but in reality each year the whole month of June develops an MND focus so watch out for events or start to plan your own – **awareness leads to understanding which leads to support**.

Remember to ask your GP about winter vaccinations – flu, pneumonia and whooping cough vaccines are available.

Client distribution

People living with MND are spread across the country and most choose to register with the Association. Our data from September 2014 showed the following client distribution.



Greetings from Grant

Grant Diggle

THIS YEAR MARKS the 30th anniversary of the formal establishment of the Association. Our Certificate of Incorporation was issued on 21st March 1985 to the then named "The Motor Neurone **Society** of New Zealand Incorporated". Seven years later in March 1992 we changed our name to "The Motor Neurone Disease **Association** of New Zealand Incorporated". From those early beginnings with a small group of volunteers raising funds and awareness to support people living with MND we have grown and developed so we now have seven Fieldworkers working with around 300 people living with MND plus their carers and families and the health professionals that support them. We estimate that for every person living with MND we support up to seven other people. We have branches in Waikato, Bay of Plenty, Wellington and Canterbury West Coast with active committees and volunteers raising much needed funds to support the costs of their local Fieldworker and raising awareness of MND.

As we explained in our last Newsletter we now have an operating budget of nearly half a million dollars each year most of this covering the costs of our much valued Fieldwork Service. In our 2014 Client and Carer Satisfaction Survey over 95% of respondents said our Fieldwork Service was either extremely important or very important to them. This service is centre to our organisations reason for existing.

As part of our continuing professional development each year we bring all the Fieldworkers together for several days so we can review how we deliver our services to our clients and how we can improve our delivery and also to learn more about the current research into MND and how this might impact on our service delivery. In November we had a very successful meeting also attended by our President Beth Watson. It was timely that Beth attended as at the previous months Annual General Meeting and Special General Meeting our members approved a number of changes to our Constitution to bring this important document up to date and also to clarify the way we conduct the Association's business and the relationships of the various governance arms of the Association, our National Council and our Branch Committees. Beth and I were able to explain the changes to the Fieldworkers and the impact on the Associations business. We were also joined by Dr. Alison Charleston who gave an overview of some current research into MND and also shared some of her invaluable insights into her work with her MND patients. We would like to thank the Iris and Eric Wilfred Nankivell Charitable Trust for their generous support towards the costs of our Fieldworker Days.

In December Ray Hall our Vice President, Lin Field our Fieldwork Support Officer and I were guests of the Centre for Brain Research at The University of Auckland who celebrated their fifth anniversary. Distinguished Professor Richard Faull, Director of the Centre, is also our Medical Patron so it was especially pleasing to be invited to attend. The Centre is a very important part of the ongoing research into MND and the range of other neurological conditions. We are privileged to be a Partner Organisation of the Centre and to support the work being done by this world leading team.

As we commence the fourth decade of the Association I would like to thank the many, many people who have contributed their time, energy and efforts to bring us to this milestone and ensure we are in a good position to continue to provide our services to people living with MND, their carers, families and the health professionals who support them.

Grant

For sale ! For sale ! For sale ! For sale !

We have various items for sale – great gifts and a contribution to our funds.

Cornflower cards

6 different original cornflower designs painted for us by Waikato artists. A pack of 12 mixed cards with envelopes.
$8 plus package & postage.
Order from Moira–Anne email: **moiraanne@gmail.com**

Socks

Our very popular and comfortable socks are available in anklet style sizes 4–6, 7–10 and 10–13 and long top style size 6–10.
$8 a pair plus package & postage.
Order from Moira-Anne email: **moiraanne@gmail.com**

Walking sticks with light attached

Great for night time trips to the kitchen or bathroom; height adjustable
$40 plus package & postage
Order from Moira-Anne email: **moiraanne@gmail.com**

Twirling forks

Battery driven rotating forks help pick up food – great for pasta
$8 plus package & postage
Order from Moira-Anne email: **moiraanne@gmail.com**

Cornflower seeds

A hardy pretty addition to your garden or in a pot.
$2 per packet plus package & postage.
Order from Janet Hutchings email: **janetrh@xtra.co.nz**

MND logo chilly bags

$30 plus package & postage
Order from Janet Hutchings email: **janetrh@xtra.co.nz**

MND logo pens

Order from Janet Hutchings email: **janetrh@xtra.co.nz**

MND logo water bottles

Order from Janet Hutchings email: **janetrh@xtra.co.nz**

Care with Coins

Henrik Dorbeck came up with a way to help us with your "Forgotten Silver"

Ask us for a Care with Coins label

Thank you to those who make regular deposits into our bank account as a result of their coin collection – we are so very grateful – your contributions do not pass unnoticed.

"Forgotten Silver" is the title of a mockumentary made by Sir Peter Jackson in the 80s about a fictional NZ film maker. The title has stuck in my mind over the years and now the name seems appropriate for my own little campaign. Shortly after my wife passed away from MND I started thinking how I could help the Association with raising funds. I came up with my "Forgotten Silver" idea – we may be reluctant to part with the gold coins but many are irritated by the silver that builds up in our wallets and purses. I now have a jam jar on the bench in the kitchen and I put my silver in it. Over a period of time the jar fills and when I took it in recently it totalled $85. This has now become a habit for me and over the period of a year I can fill two or three jars.

When I joined the MND NZ Council I raised the idea and came up with the current "Care with Coins" adhesive labels that can be easily shared around to stick on containers and start collecting "Forgotten Silver". I now include one of the labels when wrapping gifts to family and friends for Christmas and birthdays – a subtle way of suggesting they may like to collect in memory of my wife. What I am doing is but a small contribution towards funding our Fieldworker Service supporting those living with MND but the coins add up quickly and painlessly.

Can you imagine what it could come to if all of us did it? Contact your Fieldworker or National Office for more labels.

Henrik

mnd
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New Zealand

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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.

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 the following organisations for their contributions towards the support services we provide.

ASB Community Trust
Te Kaitiaki Putea o Tamaki o Tai Tokerau
supported by ASB

BlueWaters Community Trust

NZ Lottery Grants Board
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Helping fund a better community

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