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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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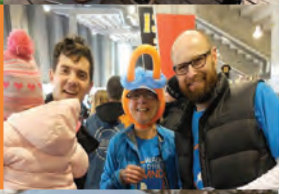
mnd
REGISTERED CHARITY CC35320
New Zealand

A first for New Zealand

We did it – thanks to the efforts of so many!

CLAIRE REILLY'S VISION was for simultaneous walks to be held around New Zealand – same day, same time – to raise awareness and funds for support and research. Thanks to the sponsors, donations and massive voluntary input from so many, on 20th September it happened across the country: Dunedin, Christchurch, Wellington, Hamilton, Tauranga and Auckland. Thousands of people braved the unpredictable spring weather – so very wet for some and unexpected sunburn for others. Such an amazing a show of support for those living with MND.

So much support from so many. Thank you all!



Spot the celebrity. Local and national figures turned out to join us around the country.

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 a registered charity number CC35320

See more photos on the Walk 2 D'Feet Facebook page:
www.facebook.com/Walk2DFeetMNDNZ

WALK
2 D'FEET
MND

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www.facebook.com/Walk2DFeetMNDNZ

… and now let's try for another first – the Lip Synch Challenge!

NATHAN, DONNA and family **from the Hawkes Bay challenge us to laugh in the face of MND.**

What a fun way to raise awareness and prompt your friends and family to make a donation – if only to avoid getting nominated yourself! If you need a laugh go the ALS LipSynch Challenge NZ Facebook page and see how it is done – then start planning your own performance. Just think who you could nominate – what song would you choose for them to Lip Synch! Nathan, a 42 year old professional photographer and his partner Donna have 8 children and he says since the diagnosis three years ago "I'm learning to live my life to the fullest and harness all the abilities I still have before I lose them".

Nathan is hoping the Lip Synch Challenge will be as big a social media phenomenon as the Ice Bucket Challenge was and he has already hooked in TV personalities. "*We still don't have a cure*," he says, "*but I now have hope*". So be part of this fun challenge and get friends and family to donate; Nathan explains how on Facebook.

See more at: www.facebook.com/groups/ALSLipSyncChallenge/

Above: Nathan and family
Right: Nathan and family joined the Auckland Walk.

Future proofing the work of MND NZ – our endowment fund

OUR VERY VALUED Treasurer and Life Member, Michelle Knox, has recently given our Association another reason to appreciate her with a VERY GENEROUS $60,000 gift to our endowment fund. For all of us who know Michelle, this generosity is not a surprise. She has not only freely shared her time and her substantial financial management skills with the Association and the Bay of Plenty Branch for many years now, but she has also made other significant financial donations. However, there is a very real poignancy to this donation as Michelle herself was diagnosed with MND in May 2013. When I asked Michelle if I could post this good news story she said she was very happy for me to do so, and added that she would love it if, by sharing her story, it encouraged others to think of contributing to the endowment fund as well. Michelle was a strong proponent of MND NZ establishing this fund in August 2012 to build the Association's sustainability. Our endowment fund is held by the Acorn Foundation which pays us an annual income of 5% of the average of funds held. As this fund builds so will our independence from the vagaries of funders, giving us more planning certainty and more control over our future. **THANK YOU MICHELLE**. *Beth Watson*

In MND NZ's 30th birthday year – we give you just a little history

IN THE EARLY TIMES, individuals had to "make it happen" themselves even more so than today. In 1978 Wym van Erpers Roijaards who had MND set up the Technical Aid Trust based at Hutt Hospital to lend computers with "talking" technology – I was told that it cost $20,000 to buy just 4 sets of software with just 2000 words in its word bank.

In 1982 Jill Braddick in Northland had to travel to Australia and America to meet others living with MND; in 1984 Vera Grant in Auckland had to contact MND Victoria to find out about Jill.

In 1984 Lois Chambers was one of several in Wellington who made her friends start a group before she died (or else I will come back and haunt you – she died one week after their first meeting in August 1986); in Christchurch in November 1988 Philippa Shepherd, who had lost her mother to MND, initiated an inaugural meeting supported by Graham East, whose wife had familial MND. 33 people attended that meeting and were addressed by Dorothy Nicholas from Auckland – Dorothy had lost her husband to MND before the "Society" formed. For around 15 years I understand that Dorothy combined the roles of vice-president, inspiration and roving fieldworker up and down New Zealand.

The Society started in Auckland – and it was not without a struggle. It cost money to incorporate, it cost much voluntary time to attend meetings, to write newsletters, to cross "'t's and dot 'i's" to "get the show on the road". But a solid core of dedicated people (and I understand their "volunteered" husbands/wives/children/neighbours/friends) ensured it happened.

Life members with Beth Watson and Dr David Oliver.

Wellington was a branch (1986), then Northland (1987 perhaps) then Christchurch (1988), then Bay of Plenty (around 1999) and Waikato 2002 I think.

Over the years the way we have "done our business" has changed. We have moved from volunteer visiting, through volunteer fieldworkers, to paid fieldworkers employed by branches to paid fieldworkers employed and managed through our National Office. The one constant seems to have been that we have always had loyal, dedicated, compassionate and caring people offering support services, whether paid or unpaid.

Although many people have brought us to our 30th year, I think it is fitting to record here the Association's roll of honour – people who have been awarded life membership or received an honour for their service.

- From Canterbury – Graham East (1999)
- From Wellington – Jack Telfer, Nedra Shand (both 1999) and Robina Davies (2006)
- From Waikato – Mary Parker (2009)
- From Bay of Plenty – Michelle Knox (2014)
- From Auckland – Dorothy Nicholas QSO (1996) John Roxburgh, Dennis Hall (both 1999)
- From Northland – Edith McCarthy (2001), Jill Braddick QSM (2004)

Just as people have growing pains, so do organisations. As I said at the start, growing up as an Association has not always been easy. And nor will it be in the future. People with MND have to dig deep when they join "the worst club in the world". As an Association we have dug deep in the past to get here. How proud I am to have been part of that achievement for almost 15 years. No doubt there will be times in the future when we have to dig deep too.

I am very confident that future Association members will value the legacy they are entrusted with and ensure the Association is here as long as it is needed. In the meantime, let us celebrate 30 years. ***Happy birthday MND NZ.***

Beth Watson, President

Left to right: Edith McCarthy, Robinia Davies, John Roxburgh, Mary Parker, Dennis Hall, Nedra Shand; Absent: Graham East

Life Membership

WHAT AN HONOUR to be part of the team conferring a life membership on Michelle Knox.

Michelle has given sterling service to our Association for many years – and we hope that she will continue to do so for some time yet.

Michelle has been with the Association for over 10 years having joined the Bay of Plenty Branch in 2005 and then joined Council in 2006. Since then she has always been a member of the national executive team serving as national vice-president in 2007 and 2008 and as treasurer from 2008 onwards. Under Michelle's watchful eye, careful management and control the Association has grown to enjoy a real degree of financial stability. Realising the increasing complexity of our finances and the minimal national office resource to manage these, Michelle, who is partner in an accounting firm, established accounting support (at very favourable rates) provided by her firm. We are indeed grateful for the professionalism and peace of mind this has brought.

Michelle Knox

Council also benefits from the considered views Michelle offers in all discussions. We also appreciate her calm and positive approach, her big warm smile and her genuine caring.

Michelle also has been a stalwart at local Branch level contributing her energy, her smiles and her understanding of the needs of people with MND.

Michelle your contribution to the Association is awesome. Congratulations indeed.

Beth Watson, President

The Sheffield Support Snood

is a lightweight neck collar developed in response to the needs of people living with motor neurone disease by a team at the Sheffield Institute for Translational Neuroscience (SITraN) in the UK. We reported on this revolutionary new neck collar in our Autumn 2015 newsletter (see **www.mnd.org.nz/newsletters**) and have now heard is expected to be available in the near future so keep a look out.

Words from the Wise

IN AUGUST, Dr David Oliver, an internationally respected Palliative Care Specialist from England with extensive experience in MND, generously fitted us into his NZ holiday. He addressed health professionals in Wellington, joined our 30th Birthday celebration and talked to our staff, Council and Life Members on MND care. During his visit he also presented alongside Dr. Emma Scotter at a public lecture in Auckland organised by the Neurological Foundation.

Dr. David Oliver

It is always good to hear from Dr. Oliver and check that we are keeping up to speed. Some key points he shared that were of particular interest were:

- **The UK National Institute for Health & Care Excellence (NICE) has completed comprehensive guidelines on Motor Neurone Disease assessment and management** including evidenced based recommendations. The draft has been published for consultation with the final document expected to be available February 2016. David has been involved in this project and encouraged us to make good use of it. See: www.nice.org.uk
- **Cough Assist Machines** are expensive items and David shared that research indicates an Ambu-bag used with a breath stacking technique has been shown to be equally effective. More information can be viewed in the NICE guidelines. Suggested reading for health professionals:
  Mustafa N, Aiello M, Lyall RA et al, Cough Augmentation in ALS, Neurology 2003; 61 (9) 1285-87.
  Rafiq MK, Bradburn M, Proctor AR et al, A preliminary RT of insufflator, ALS and FTD 2015.
  Senent C, Golmard JL et al, A comparison of assisted cough techniques, ALS 2011; 12 (1) 26-32.
- **Morphine has a range of benefits** when used in appropriate doses for managing symptoms such as general discomfort and respiratory anxiety. Its use should not just be seen as a sign of end stage care either by doctors or patients.
- **Respiratory changes cause a range of symptoms** including reduced appetite, memory problems, dreams, morning headaches.
- **Non-Invasive Ventilation such as BiPap does not suit everyone but extends life an average 10 months** for those it helps.
- **PEG feeding (a tube direct to the stomach) has not been shown to extend life but does improve quality of life**; co-ordinated planning by the health professionals involved is vital in order that the procedure is offered to the right candidates at the right time.
- **Neudextra is a drug proving effective** for controlling emotional lability in some people.

Many thanks David for your generous sharing and encouragement – come back again soon – in the summer!

Research Update

THERE IS MORE MND RESEARCH underway today than there has been at any other time. Institutions around the world are collaborating in the search for causes, treatments and cures and both the teams at the Centre for Brain Research in Auckland and at Massey University work closely with colleagues around the world.

Some highlights from recent posts:

- **Withdrawal of ventilation at the patient's request in MND:** a retrospective exploration of the ethical and legal issues that have arisen for doctors in the UK. Kay Phelps, Emma Regen, David Oliver, McDermott, and Christina Faull. Legal, ethical and practical guidance is needed for professionals who support a patient with MND who wishes to withdraw from ventilation. Open discussion of the ethical challenges is needed as well as education and support for professionals.

  Ref. BMJ Support Palliat Care doi: 10.1136/bmjspcare-2014-000826
  Published Online First 11 September 2015
- **Disappointing news for diaphragm pacing in MND.** Results from the UK clinical trial of diaphragm pacing in MND/ALS (known as DiPALS) were published online in the journal Lancet Neurology. Dr Christopher McDermott and team based at the Sheffield Institute for Translational Neuroscience (SITraN) completed a clinical trial which unfortunately showed that diaphragm pacing was not beneficial when used in addition to NIV, and was in fact harmful, with people using diaphragm pacing living on average 11 months shorter than those on NIV alone. *Posted on MND Research Blog: July 31, 2015.*
- **Diagnostic test for MND available worldwide within the year.** Associate Professor Steve Vucic at Westmead Hospital, Sydney has co-invented a diagnostic test for ALS/MND that will enable earlier and more definite diagnosis. People can wait 12–18 months before a definite diagnosis can be made but now an early feature of MND has been identified as excessive excitability of the brain and the 20 minute test detects if this is present. It is expected to be available worldwide in less than a year once it is commercialised. *Source: MND News Victoria Sept–October 2014.*
- **Gene Therapy for SOD 1 related MND.** Gene therapy is regarded as an innovative technique with huge potential for the treatment of neurological conditions including Motor Neurone Disease. For a percentage of people with an inherited form of MND this is due to a mutation (fault) in their SOD1 gene. SOD1 was the first MND-causing gene to be discovered back in 1993, and as such we are beginning to see research into SOD1-specific therapies. When the gene is defective it produces proteins that become misshapen and kill the motor neurones in which they function. Gene therapy aims to block or 'silence' the genes to prevent the production of the warped proteins. "Silencing the SOD1 gene may be as close as we can get to a cure for MND in the near future," says Prof. Mimoun Azzouz who works with Prof. Pamela Shaw at the University of Sheffield UK. "Our ultimate goal is to get the gene therapy for SOD1-related MND into the clinic as soon as possible." Research so far has been in mice but if approved a safety trial in humans – known as a Phase I clinical trial – will start later this year. *Source: mndresearch.wordpress.com*
- **Could Interleukin-2 hold the key?** Dr Brian Dickie, Director of Research Development for the UK MND Association reports that the best and brightest minds in MND research across Europe are investigating a possible new treatment for MND – a treatment that could help slow the progression of the disease. For some years now, doctors have been using a drug called Interleukin-2 to help treat people living with cancer and it has also been effective against other diseases that attack the immune system. Keep an eye on the UK MND Association website for updates.
- **TDP-43 Protein Clumps** are present in the brain or nerve cells of an estimated 97 percent of people with Amyotrophic Lateral Sclerosis (ALS). When TDP-43 clumps together cells malfunction and eventually die. Researchers are focusing on protein clumping in the hope of preventing or reversing. *Source: www.m.hopkinsmedicine.org* Dr Emma Scotter at the Centre for Brain Research in Auckland is currently working on this area of research see Dr Scotter interviewed on Facebook on the Australasian Neuroscience Society page.

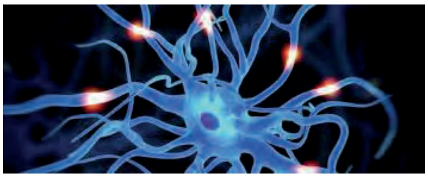
Vanessa's Story

Not all your symptoms will be due to MND

I WAS DIAGNOSED WITH MND IN JUNE 2013. There was intense turmoil before I accepted the diagnosis. After a year of rapid decline I investigated other possible conditions. I began taking vitamin B12. Since then up until today I am improving and many symptoms have disappeared. My neurologist said I may have 'an undiagnosed condition which is responding to the B12' and had no objection to my continuing with vitamins. A Haematologist has since diagnosed me with Pernicious Anaemia, a condition making me unable to absorb vitamin B12. In my case it seems there was an undiagnosed condition which has responded, hence making my overall health much better than it otherwise might have been. As a result of this improvement, two years after the original finding, my Neurologist is revisiting my diagnosis. It remains under review. **I now state absolutely that I do not regard Vitamin B12 to be a cure for MND**. At every step of this journey I have been in conversation with recognised medical personnel and have done my best to stay within accepted medical treatment levels and regimes whilst exploring ways of keeping as healthy as possible. Vanessa

MND NZ comment: There are different forms of MND and the presentation and progression varies across individuals; in some people it can take time for the final diagnosis to become clear. If you have any concerns about your diagnosis talk with your GP or Specialist.

MND Key Facts

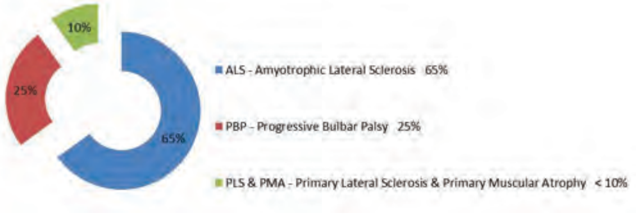


MOTOR NEURONE DISEASE is the name given to a group of neurological conditions in which the nerve supply to muscles deteriorates and the muscles affected progressively weaken. Symptoms vary between individuals but may include muscle cramps, twitching, stiffness, wasting. Vision, hearing and sense of touch 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.

Keep up to date on the latest research news through websites such as:

- Our own webpage: **www.mnda.org.nz**
- UK MND Research Blog: **www.mndresearch.wordpress.com**
- 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**
- American ALS Association: **www.alsa.org/research**
- ALS Worldwide: **www.alsworldwide.org**

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

Find out about clinical trials around the world:

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

What are the numbers in New Zealand?

- **300 people** (approx) are living with MND at any one time – the prevalence.
- **100 people** (approx) are diagnosed each year – the incidence.

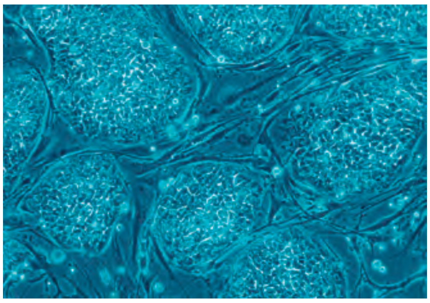
This is what we would expect for the size of our population as numbers are very similar across cultures.
MND NZ believes almost everyone diagnosed with MND chooses to register for our support so our numbers have increased steadily in recent years. An ageing population and earlier diagnosis might contribute to an apparent increase in numbers but we have no evidence that the incidence of MND is rising in New Zealand.

My stem cell journey
Terry shares his perspective

I STARTED LOOKING at clinics offering stem cell treatments just after I was diagnosed with MND/ALS. There seemed to be many cases where patients had bad experiences: losing all their money; the clinic or doctor disappearing; a clinic shut down when a patient died during a procedure. But there did seem to be a few good reviews of certain clinics in the USA and Israel. I specifically avoided clinics in China due to language barriers. I eventually choose to use the Centre for Cell Therapy & Cancer Immunotherapy (CTCI), a clinic in Tel Aviv as I was confident that hospitals and clinics are well regulated and research is happening across all fields in Israel.

Initially, I travelled to Israel to donate bone marrow for them to grow the stem cells from and then about four months later I had the first infusion – done in Switzerland as the procedure had not been approved in Israel at that point. It is a fairly straight forward procedure and painless apart from a headache for a day or two from the extra spinal fluid – one vial goes into the spinal fluid and one into the blood stream.

At CTCI the doctor, Professor Shimon Slavin, (previously head of neurology at Hadassah Hospital, Jerusalem) interviewed me for about an hour, he explained that there is NO KNOWN CURE and cannot guarantee anything apart from trying to help keep you in as best shape as possible. He explained what he would do and did both a pre-check and a post-check a day after infusion.



The benefits are hard to say – do not expect miracles, any benefit seems to be very short lived and mild to say the least, there is no dramatic change, but things did change for a few months as reflected in some of my test results.

I did do a second infusion. This time we found my brother was a tissue match and so we used his cells to grow the stem cells. The second infusion was in Israel as they have now obtained permission from the Israeli government to do the procedure in their clinic. Unfortunately, there seems to have been little difference between using my brother's cells compared to using my own cells – my progression appears to have been a steady decline.

The doctor put me on Metformin for six months after the second infusion as a study in Canada showed it seemed to help promote cell growth but I did not see any difference between the first infusion and the second with Metformin.

The cost of each procedure is about USD28000 and the clinic has a hotel in the same building which is very convenient. Travel and language are all easy, almost everyone speaks English, wheelchair assistance is good all the way on Singapore Airlines, EL AL and Air NZ, I went through Hong Kong, the clinic can organise a driver/taxi to collect from the airport to take you to the hotel and they are all very friendly and helpful. Travel and hotel etc. are extra, the hotel can organise sightseeing trips. Israel has a huge amount of history and the culture is very diverse. Food is good, either at the hotel or anywhere nearby, easily accessible by taxi; security is good and views over the Mediterranean Sea are amazing at sunset.

I guess if I had an endless amount of money I would do this again, probably because it's the only thing I found from my own research that effects some sort of change. There is a trial ongoing with Brainstorm and Hadassah Hospital in Israel which looks to be having some good outcomes, but again I understand these have only been short lived improvements. The United States Food and Drug Administration (FDA) has granted fast track designation to the following drugs and therapy being developed to treat MND: tirasemtiv (Cytokinetics, Incorporated), dexpramipexole (Biogen Idec), NurOwn stem cell therapy (BrainStorm Cell Therapeutics) and GM604 (Genervon Biopharmaceuticals). So when I win Lotto, my next choice would be to investigate GM604 (GM6). **We must live in hope and there has been so much research in recent times we must surely be making progress in the search for a cure, or at least a way of slowing the progression of this condition.**

Maintaining communication is so very important – a speech-language therapist and the Talklink Trust can help

MOST PEOPLE WITH MND will experience speech difficulties to some degree; many will manage by talking slowly and carefully but if this is not sufficient then the local speech-language therapist can advise further. Alternative communication strategies and equipment may also help and the TalkLink Trust provides free specialist assessment services to people of all ages who, due to a disability, have difficulties with speaking, writing, learning and/or with controlling their environment.

TalkLink Trust therapists can assess and advise on a range of assistance from low-tech paper-based word, number and letter charts to high-tech items such as iPads and computers to enable people to continue expressing themselves clearly. Over time options may change as needs change. Using communication technology and augmentative communication strategies is slower than natural speech, and can often be frustrating at first, but it allows the user to say exactly what they want to say and not rely on other people interpreting or guessing.

Referrals and Services

TalkLink works closely with, and receives referrals from, DHB teams and the MND Association fieldworkers. It is best to meet with TalkLink early if speech clarity is changing to allow therapists to outline options to meet ongoing needs. You can also self-refer. The first appointment is usually with a speech-language therapist (SLT) and an occupational therapist (OT). The speech-language therapist will advise about processes and difficulties with communication and the occupational therapist will assist with any physical difficulties accessing tools and equipment. Therapists will show you equipment such as call bells, voice amplifiers and special telephones as well as smartphones, speech generating devices and computers. Accessing equipment can be a challenge if upper limb function is affected and therapists can advise on alternative mouse options such as trackball, head-mouse or eye-gaze options, stylus options to make it easier to access a touch screen, alternative keyboards, and different switches to access a telephone or to assist with scanning and selecting information.

Options

By providing low-tech resources alongside high-tech equipment the aim is that communication options are always available.

Text to Speech options, such as using an iPad with a programme called Predictable, enable the user to type a message which the device then speaks out. Many people find this a great way to keep contributing in conversations.

Voice Banking For those who do not like the idea of using a synthesized voice, people can 'voice bank' whilst their voice is still natural and strong. 'Voice banking' is now quite simple, people are able to voice bank on any device for later use; **phrases can be pre-recorded so the speech generating device will speak in the person's natural voice**. You can voice bank on a mobile phone, computer, iPod, voice recorder or even in a professional recording studio if you so wish. So long as the recordings are produced in MP3 format, we can use them later within a speech generating device to enable comments using your own voice. A great way to maintain a sense of 'real' communication if your speech is changing. It is also a useful feature for those with English as a second language.

Funding of equipment

Having determined what sort of equipment may help, TalkLink therapists apply for funding to the appropriate government agency. Once the funding is approved Talklink arrange the purchase and then the TalkLink therapist will set up the equipment and teach the person and their support team how to use it effectively. TalkLink therapists then provide ongoing monitoring and support to meet any changing communication needs.

TalkLink has offices throughout New Zealand and can be contacted at 0800 TALKLINK (825 554). Further information including referral forms is also available on their website **www.talklink.org.nz**

TalkLink Regional Offices

The TalkLink **Lower North Island** office is based in Wellington and covers Hawkes Bay, Wairarapa, Hutt, Capital & Coast, Mid-Central, Wanganui, Taranaki, and Tairawhiti District Health Boards.

TalkLink, Lower North Island, Clinical Team: Jessica Hunter-Wilson SLT; Hannah Jones-Hughes SLT; Elizabeth Messina Manager / SLT Janet Low SLT; Pauline Green OT. Absent: Claire Oram Teacher

TalkLink, Lower North Island, Admin Team: Claire Thornton Administrator; Al Jackson Admin Manager; Ruth Hughson Graphic Design

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Email: wellington@talklink.org.nz

The TalkLink **Upper North Island** office is based in Auckland and covers Northland, Waitemata, Auckland, Counties-Manukau, Waikato, Lakes, and Bay of Plenty District Health Boards.

Back: Chris O'Hara (OT), Danica Mihaljevich (Admin), Polly Khushal (SLT), Jocelyn Roxburgh (SLT), Magnus Hammarsal (SLT), Mark Dewar (OT), Kate Mentis (SLT), Paula Shennan (SLT), Jessamy Amm (SLT), Ankica Middeldorp (Finance Manager), Cheryl D'Silva (Admin), Glen Dixon (UNI Manager/OT). Front: Mandy Slade (Resource Support), Justin Tate (Tech support). Absent: Adrian McPherson (OT), Alex Middeldorp (Tech support), Ann Smaill (General Manager), Emilie Logan (SLT), Fern Jones (SLT), Tara Mills (OT)

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Email: auckland@talklink.org.nz

The TalkLink **South Island office** is based in Christchurch and covers Nelson and Marlborough, West Coast, Canterbury, South Canterbury and Southern District Health Boards.

Back: Barrie Woods (Manager & Rehabilitation Engineer), Jackie Hancock (SLT), Sarah Pitcher (SLT), Anita McDrury (SLT), Paula Daniels (SLT), Marg Cuttance (Admin &Technology Trainer).
Front: Pauline Loong (SLT), Siobhan Grimshaw (OT), Wendy Dick (Office Administrator).

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PO Box 10204, Christchurch 8145.
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Email: south@talklink.org.nz

Do you realise just how smart your smartphone is

Today's phones can announce the number of the caller, read messages, dial numbers and type texts in response to spoken directions. They can even read your emails aloud if you download the Speaking Email app.
See: **www.speaking.email**

audible.com
An Amazon company

Talking Books on cassette tapes and CDs are yet another thing of the past as the app. from audible.com provides access to a range of works read aloud.

So take a look in the iTunes or Google Play Store (or find someone who can) to see what is available to make life easier.

Spam, spam, spam & spam

Please check your Spam folder to be sure our emails are getting through. Our database system, called Infoodle, enables us to do mass emailing and get the word out to hundreds of people, but a few people have found their systems think our message is Spam. You should only need to correct your Inbox settings once for all future emails to arrive in you Inbox as usual.

Can I interest you in some research?

Oliver Clabburn invites you to participate in a UK study investigating a digital therapeutic intervention for children and young people involved in the care of a family member with MND.

TECHNOLOGY IS MAKING the research community smaller and bigger at the same time; worldwide communication and collaboration is now so easy and data can be collected and shared globally. Oliver Clabburn was in New Zealand last year and is now back in the UK doing a PhD at Edge Hill University in the North West of England and would love to have input from New Zealand for his study. “I am planning to interview people up until April 2017 and interviews can be carried out via Skype as an informal conversation lasting around 20–30 minutes.”

“I have a specific research interest in young people who help care for family members who have MND, and also those young people who are bereaved due to the disease. I have been through the journey myself and I am extremely passionate about supporting children and young people who are currently having similar experiences to those I had with Dad and my Nan.”

Olly’s research is investigating the use of a digital legacy with people who are affected by MND/ALS. A digital legacy involves creating a video recording of messages, memories and accomplishments specifically for children in an individual’s family and is growing in popularity whether prompted by illness or otherwise. Olly explains “*There are many digital legacy programs which allow users to record video-messages to share with family and friends – you do not have to participate in my research to create a digital legacy.*” **RecordMeNow** is a digital legacy App. specifically designed for children and is free to download from www.recordmenow.org or the Apple App store for anyone wishing to leave a digital legacy for their family. It is free and intended for anyone to use. The system provides a selection of prompts, users then video record their responses and edit, re-record or delete as they wish. The final recording can then be exported to a DVD or any other digital source to create a digital legacy for sharing with children in the person’s family. RecordMeNow is a not-for-profit organisation and completely independent from Olly.


Oliver Clabburn

Read more about Olly’s study at the UK MND Association Research Blog: www.mndassociation.org or the Facebook page for his study www.facebook.com/mndlegacy

Olly would like to hear from you if:

- You have MND/ALS and are interested in recording/or have recorded a digital legacy for a child or young person in your family.
- You are a young person (aged 11–24) currently involved in caring for a family member with MND/ALS and interested to use a pre-recorded digital legacy as a means of support.
- You are a young person (aged 11–24) who has lost a family member who had MND interested in using a pre-recorded digital legacy to support you as you grieve.

If MND has affected your family and you feel that you might like to participate in this study, would like more information, or have a child that might like to be interviewed about using a digital legacy, please get in touch directly though Olly’s Facebook page, www.facebook.com/mndlegacy or by email: clabburo@edgehill.ac.uk

What do we tell the children?

WHAT YOU SAY, how and when will very much depend on the age of the child as well as their personality and circumstances. While honesty and openness is generally the best approach, a younger child may only need to hear “Grandma’s hand isn’t as strong as it was.” Your child’s teacher could be a good place to start in working out how to address the subject. You may want to get some advice from local agencies with experience in talking with children about difficult topics. Keeping it simple and answering questions as they arise may be all you need to do. The older child with access to the internet is likely to do their own research so you may want them to hear the facts from you first. There is no hurry to share the news until you feel the time is right. Resources that may help can be found online or ask your fieldworker:

- MND Australia – **www.mndaust.asn**.au have booklets to download or ask your fieldworker for copies.
- MND UK – **www.mndassociation.org** have advice sheets and booklets to download; search their website for
  ‘*Information for Children & Young People*’
  ‘*Communicating about MND to children and young people*’
  ‘*So What is MND Anyway*’ – for teens and young people


ALS Alberta, Canada guidelines

- ALS Alberta, Canada has guidelines for parents and health professionals as well as child friendly resources. See: **www.alsab.ca**

The social and educational effects of caring for a parent with MND

A research project completed by Oliver Clabburn in UK

CHILDREN AND young people are significant carers and very much a part of the team when there is MND in the family. *"When I was seven years old my Dad was diagnosed with Motor Neurone Disease and I found it hard to understand why he gradually stopped doing the normal 'Daddy things' like going to work; he began speaking in a strange way, and then stopped driving the car. Over a period of three years my family became full-time carers for him and this involved me too – helping when he fell over, getting him drinks, food, toileting and so much more. I was growing up doing a variety of things for my Dad which I believed to be 'normal' – yet my friends at primary school seemed to be having a very different home life to me. My experience led to my research project:* ***The social and educational effects of caring for a parent with MND*** *supported by the UK MND Association."*

Olly recognises that *"A diagnosis of MND is inevitably traumatic and creates many negative outcomes for all involved. Young carers will spend much of their time caring for their terminally ill parent and later suffer bereavement. Nevertheless, the research highlighted that there may be some positive benefits that individuals can gain."*

Six clear themes were raised by the participants in the study which were considered to be the main effects of caring for a parent with MND:

- **POSITIVE ASPECTS:** Overall the participants in the research outlined a variety of positive aspects that they have drawn from the experience. Most notably, a feeling of maturity compared to peers, the ability to accurately empathise with others, closer relationship with family members and increased motivation leading to educational success.
- **DIAGNOSIS:** Many of the young carers felt somewhat confused about what their parent being diagnosed actually meant and it often came as a surprise when a parent's care needs increased. The terminal nature of MND was often hidden from the young-people in an attempt to shelter them but this sometimes caused further confusion.
- **YOUNG CARER DUTIES:** Younger children reported an increased responsibility for household chores enabling their healthy parent to spend more time with the parent with MND. It was also noted that the young people tended to adopt a more 'social care' role, meaning they would often sit with their parent and keep them company rather doing the more intimate caring tasks.
- **RESPONSIBILITIES:** Older siblings tended to adopt a more parental role for younger siblings by helping out with school runs, help with homework or carrying out more caring tasks for the ill parent to shelter their younger sibling. It was also noted that all participants had a greater appreciation for their healthy parent and a closer relationship as a result of MND.
- **EDUCATION:** All participants emphasised the importance of school/college/university providing a period of escapism. This meant that for the time they could temporarily be 'normal'. Interestingly, some educational benefits were reported such as having a parent being permanently at home to help with homework. It was also commonly acknowledged that the disease/bereavement fueled motivation for the young person to achieve educational success.
- **SOCIAL:** It was noted that peers and friends provided an extremely important method of escapism. Participants found that they could gain advice or simply ease the burden by discussing life at home. It was additionally noted that peers may introduce the young carer to new hobbies and interests through which to escape or channel emotions. However, it was also outlined that guilt was also a common feeling when not at home with their parent.

Olly Clabburn email:
clabburo@edgehill.ac.uk

Jonathan Sweeney: Marathon Runner! … *Yeah right!*

Jonathan Sweeney

ON SEPTEMBER 20 I took part in my 5th Marathon, in Sydney – 42kms that requires me to deal with considerable physical pain and mental anguish – a major undertaking for me. To put this in perspective, if Tui had a photo of me in my running gear (on one of their boards) the caption would certainly be: ***Marathon Runner! … Yeah Right!***

The challenge had personal significance as I was proud to be taking part to honour the life of Bob Ridley a well-respected family member who was taken from us this year due to Motor Neurone Disease.

I first challenged myself to do a half marathon in 2007 which resulted in three things:

- I glimpsed the ever elusive 'Runners High', during training … hadn't seen it for 24 years and not seen it since.
- I proved I could complete 21k's in a reasonable time (2.15) at the age of 40.
- I looked at full marathon runners as though they were marginally insane.

After I read Kerre Woodham's book '*Fat chick to Marathon runner*' I decided to challenge myself once again and entered the Vancouver Marathon in May 2009 – a real struggle completing the event as a walker due to a calf injury.

So now here I am, aged 48, about 112kg on good day, doctor hassling me about BP and cholesterol and I am still digging deep. Everyone has their own story for taking on such challenges – for me, at its heart, is a need to prove others wrong! When running 'in the dark' over the final 20kms self-doubt and personal issues can prey upon you – I have certainly had some wars with myself and some years I recover quicker physically than I do mentally! "*When it gets tough, and it does, I think about all those that backed me, the messages left and why I am doing this – it spurs me on!*"

I always run for a cause and that makes it worthwhile – makes it make sense. So why do I share my story … why the honesty? – **it's about getting others to donate to this cause in whatever way they can**. The encouraging messages I receive and the monies committed are my 'wings', the light in the darkness, the cooling breeze in the heat while I am running. It is great to smash my fund raising targets but whatever people give is amazing.

Thank you to those who supported me for Sydney with encouraging words and donations – these gifts mean so much long after the running and walking finish – and there is always a good time to donate in recognition of those living a marathon challenge longer than 42km!

KIA KAHA!!!

Check out various fundraising efforts at Fundraiseonline:
www.fundraiseonline.co.nz

Turn your wheelchair into a motorbike!

BATEC MOBILITY is an award winning innovative company based in Barcelona, Spain who produce equipment designed by and for people with disability. Paul Bach, a quadriplegic himself, founded the company to develop creative mobility solutions. Batec Handbikes attach easily to your wheelchair and revolutionize your mobility.
For more information see:
www.batec-mobility.com

Thank you for your donations we really appreciate them

The Association has an account with the Westpac Bank (Account Number: 03 0539 0195083 00) and deposits can be processed easily at your local branch or by online banking. When making a deposit through a bank please include the word DONATION in the reference to identify the funds in our account. We would like to provide you with a receipt for tax purposes, so please remember to email or ring National Office and provide your contact details and confirm the amount deposited so we can acknowledge your donation.

mnd Australia

MND Australia Regional Adviser Meeting, Sydney 7–8 September 2015

MND NZ IS RECOGNISED as an associate member of MND Australia and our logo has recently been changed to reflect the connection we have. MND Australia has been very supportive of us over the years and we have an open invitation to join them at their events but it has been some time since we has been in a strong enough financial position to do so. We were delighted this year to be able to send two fieldworkers from our MND support team (Graham Jones and Kate Moulson) to the annual MND Australia Regional Adviser Meeting in Sydney where they joined their Australian counterparts for the two day session.

Kate and Graham appreciated the chance to hear from each of the Australian states about services to support people with MND in their area. Each state has its own MND Association linked to MND Australia and there were representations from each: Victoria, NSW, Queensland, Western Australia, South Australia and Tasmania. Kate then presented on the framework of our Association here and the services provided by MND NZ.

The meeting provided a great opportunity to meet with others to share ideas, resources and information with the common goal of support towards a better quality of life for individuals diagnosed with Motor Neurone Disease, their families, friends and workmates.

Kate Moulson said "*I would like to offer my sincere thanks to both the MND NZ Management and Council for seeing the value of us attending this event and supporting us to get there and to the Australian Association for inviting us and making us feel so welcome. We both found this networking opportunity with our Australian counterparts invaluable and hope our attendance continues as an annual event.*" Kate Moulson, Fieldworker Canterbury, West Coast, Southland.

As part of the professional development day there were presentations on changes to disability support funding in Australia as a new Disability Service Insurance Scheme is introduced which may have similarities to the Individualised Funding scheme developing here. Workshops focussed on strategies and frameworks for coping with change and discussions about the "circle of influence" which encourages us all to identify:

- the things you can change
- the things you can influence for change
- the things you cannot change

and reminds us all to focus our energies on the areas where we can be most effective.

"*I wish to thank the Association for funding our trip across the Tasman. I believe the relationships we are growing with MND Australia are a great support for our services here in New Zealand. One thing that became obvious to me while sharing with the Australian MND support community was how much we achieve a lot with a little here in NZ.*" Graham Jones, Fieldworker Central North Island East.

Archives

Are you a new reader of MND News – read our previous Newsletters on our website: **www.mnda.org.nz/newsletters**

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 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**

Helpful Hints from some of our readers

- Pill cutters and crushers are available at your pharmacy.
- Small hot plates heated in the microwave can keep a meal warm for slow eaters.
- Saliva substitutes and breath sprays can help keep a dry mouth moist.
- Local kindergartens might appreciate your empty Fortisip bottles and tissue boxes for craft activities.
- Swimming or just being weightless in the water can be wonderful.
- Baby flannels are small to clean around a PEG tube and quick to wash and dry.
- Lint free makeup pads, cut with a slit to the centre fit well around the PEG site to keep area dry and comfortable.
- A toothbrush with ridges on the back can be used to clean your tongue – good oral hygiene reduces the risk of chest infections.
- It is never too early to get on the Hospice books.
- Get a Mobility Parking Permit and find out if there is a Total Mobility Scheme in your area for subsidised taxi fares.
- Individualised Funding is an option if you need help with personal cares – ask a Needs Assessor to explain the details.

President's Report

SEPTEMBER 20TH 2105: OUR FIRST EVER NATIONWIDE WALK 2 D'FEET MND.

Even before the event we knew it was an outstanding success as it brought our MNDers together in a show of strength and support.

The support from the community was truly heart-warming for our team of six volunteers, very ably led by Dr Claire Reilly, as we "got the show on the road". Three of our team have MND, one of our team is a full-time student, and four of us juggle paid employment. There was not an event manager amongst us – so the learning curve was "interesting" as the spin doctors would say. Not to mention a little stressful! We thank all of you who have been tried by our amateurism for your patience and forbearance as we have worked through various teething troubles with you. We'll be much better at it next time!

Over the last year many of you have asked me whether I am paid for my MND work. You have been surprised to learn that "no", I too am a volunteer. Your MND NZ Council team (all volunteers), along with Grant, our National Manger (who is paid for 24 hours per week – although he often "donates" extra time – thank you Grant) realise that we don't do a good job informing our membership of our structure – or our needs.

We are a very "lean" organisation (spin doctor jargon again) – that just means that we are under resourced. We would dearly love to have more money to pay for more fieldworker hours, as that support is the point of difference that MND NZ offers. And those of you who have engaged with our fieldworkers are almost unanimous in singing their praises – they do a fine job of accompanying and supporting families on the bumpy MND journey.

Our National Office staff do a fine job too – because like it or not a good field service always needs strong administrative backing. The National Manager role is a very big and multi-faceted one (from HR manager, fundraiser, work planner, finance manager to hands-on office helper at times), and so our volunteer role as Councillors is to support Grant and his team and try to make the load more manageable. Governance and management can get blurred but good communication makes it work.

The volunteers working in our Branches play an important role in lightening the load of paid staff too with their awareness and fundraising activities. (Do you have any time you could gift to help at local level?)

Right now as President I am gifting a lot of time as I would dearly love MND NZ to have enough reliable income to pay for some more resource to lighten this load. If gifting my time helps this end I will be well repaid.

That the Walks were also a financial success will indeed help us. We want money for research because a cure MUST be found. And in the meantime we need money to grow our valuable support service and yet not exhaust our staff.

So we are delighted to welcome Kathryn Calvert to our MND team on a limited hours 12 month contract to help us with our communications and engagement. Until now we have relied on wonderful volunteers. (And they promise to continue to help.) But we hope that having Kathryn on board will improve our ability to respond, build on opportunities that present, and help us plan.

2015 has seen MND NZ proudly celebrate 30 years of dedicated service from so many. We now must ensure that we will be here to support people with MND until there is a cure.

Beth Watson

Puppies urgently needing homes!

HOPE PUPPIES. If you missed out on a puppy at the Walk 2 D'Feet or recognise a great Christmas present when you see one you can purchase these adorable pups on our website **www.mnda.org.nz** or by contacting Beth Watson email: **watsonsdb@xtra.co.nz**

Small cuddles:
$8 each or 3 for $22 plus p&p

Larger cuddles:
$20 each or 3 for $55 plus p&p

Find wheelchair-accessible toilets and parking spaces by using the Wheelmate App

IT WOULD BE GOOD to get NZ data on this useful App. which enables wheelchair users to find clean, accessible toilets and parking spaces when on the move. WheelMate is powered by wheelchair users who add and the location themselves, ensuring it works the way it should to give an instant overview of your nearest wheelchair-friendly toilets and parking spaces. Download free from the iTunes or Google Play sites.

International Symposium on ALS/MND: Destination Orlando

THE UK MND Association held the inaugural symposium in 1990 attended by 50 MND researchers based on a belief that the key to defeating MND lies in fostering strong collaboration between leading researchers around the world, and sharing new understanding of the disease as rapidly as possible. It has since grown to be a truly international event with 848 people attending last year in Brussels reflecting the large global MND research community that now exists. It is the largest medical and scientific conference specific to MND and is the premier event in the MND research calendar for discussing the latest advances in research and clinical management and nurtures worldwide collaboration. This year's symposium is the 26th event and will be held in Orlando, USA between the 11–13 December. Initial details of the main presentations are able to view online and more details will be added about the many smaller meetings, poster sessions and special interest group meetings – a busy three days for everyone.

Who can attend the symposium?

The symposium is mostly aimed at a 'specialist audience' of researchers, healthcare professionals and clinicians.

People living with MND and their carers can and do attend, but the symposium is principally aimed at specialist MND researchers. For those without specialist knowledge the symposium can be incredibly complex but the team behind the MND Research Blog do their best to translate the highlights without too much of the science jargon!

Daily updates will be posted on the MND Blog site during the symposium.

For more information:
www.mndassociation.org

Greetings from Grant

ELSEWHERE YOU WILL HAVE READ of the tremendous success of our Walk2D'Feet. I want to thank our President Beth Watson, our Project Manager Dr. Claire Reilly and her team of organisers, Tony Treloar, Steve Spencer, Helen Palmer, Bronwyn Simons, Dylan Mead and all the volunteers who gave so much of their time to ensure the event was a success. Also to our many sponsors especially ResMed, Fujitsu and Sanofi for their generous support. The funds raised will be used for research and also to support the work we do in the community assisting and supporting those living with MND, their carers, families and the health professionals who support them.

This has been a big year for the Association with our 30th anniversary and we incorporated the celebration of the event attended by our Life Members and Dr David Oliver together with a meeting of our National Council and a series of meetings of our Fieldworkers to both ensure the most efficient use of Associations funds and also to bring together as many people as possible.

Our Fieldwork Service is the centre of what we do as an Association and I want to pay tribute to our Fieldworkers ably lead by Lin Field and supported by Gwynyth Carr our Office Administrator. We continue to look at how we can improve our service delivery to ensure we are relevant to those we assist and support.

Finally I would like to acknowledge Ray Hall our Vice President who passed away suddenly in August. Ray was a tireless worker for the Association over many years and also provided me with his wise and considered counsel. I will miss his regular visits to our office and his cheerful encouragement.

Grant Diggle

MND Support Fieldwork Service

Please do contact us if we can help

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. We offer an outreach service to clients living some distance from the fieldworker's base and may not meet with them face to face but 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** – Auckland based **Mob:** 021 036 0218 **Email:** aklfieldwork@mnda.org.nz
Waitemata DHB (North)	**Lin Field** – Auckland based **Mob:** 021 230 3038 **Email:** nthfieldwork@mnda.org.nz
Waikato DHB, Taranaki DHB	**Lynne Neshausen** – Hamilton based **Mob:** 029 773 6662 **Email:** wktofieldwork@mnda.org.nz
Bay of Plenty DHB, Lakes DHB, Tairawhiti DHB, Hawkes Bay DHB	**Graham Jones** – Tauranga based **Mob:** 029 777 5588 **Email:** bopfieldwork@mnda.org.nz
Whanganui DHB, Mid Central DHB	**Reima Casey** – Feilding based **Mob:** 029 777 3331
Capital & Coast DHB, Wairarapa DHB, Hutt DHB, Nelson & Marlborough DHB	**Moira Young** – Wellington based **Mob:** 021 0278 4494 **Email:** wgtnfieldwork@mnda.org.nz
Canterbury, S. Canterbury DHB, West Coast DHB, Southern DHB	**Kate Moulson** – Geraldine based **Mob:** 029 777 9944 **Email:** southisfieldwork@mnda.org.nz

mnd 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.

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

MND Association Funders

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

The Southern trust – Funding Your Community
BlueWaters Community Trust
COGS Community Organisation Grants Scheme
NZ Lottery Grants Board – Te Puna Tahua – Distributor of NZ Lottery Profits
Four Winds Foundation Limited – Gaming Grants for Your Community
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Foundation North – Te Kaitiaki Putea o Tamaki o Tai Tokerau
Thomas George Macarthy Trust
ResMed
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