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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). Individuals present with different patterns of symptoms and rates of progression.

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

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

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Announcing the David Oliver Beacon Award

Dr. David Oliver

MND NZ IS DELIGHTED to announce this annual award, conceived in 2015, our 30th birthday year, to honour and acknowledge individuals, groups or services providing a positive contribution to service, care, improvement, or innovation in management and support of motor neurone disease. Dr David Oliver, internationally acclaimed physician who has dedicated much of his life to enhancing the quality of life of people with MND through his practice, his writing and his teaching, generously agreed to his name to be associated with this award.

Leading for Change is the theme for the award in this inaugural year and this could be an innovation or best practice for a client, a team, a service or a zone – the interpretation is yours.

We want to celebrate good work, and share it within our MND community.

We hear about some really great service provision around the country and if you are a health professional or service provider proud of what you offer locally, please don't be shy to ask someone to nominate you or your team or your network so we get to hear about how well MND care is provided across New Zealand.

Perhaps you have MND yourself or are a family member or support person and would like to nominate a person/team/service who you feel fit the theme and deserve recognition.

We look forward to being inundated with your nominations – please send them to **admin@mnda.org.nz** or MND NZ, PO Box 24-036, Royal Oak, AUCKLAND 1345 to be received no later than 5pm on 21 June 2016.

Nomination guidelines, evaluation criteria and further information about this award are available on the MND NZ website: **www.mnda.org.nz** or from National Office: 09 6242148.

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

Orlando, Florida 2015: the premier event in the ALS/MND research calendar
– and we were there

What an amazing privilege to be part of the 2015 international ALS/MND gatherings held in Orlando Florida from 8–14 December. Six days straight of ALS/MND focus shared with people with MND, carers, international MND Association colleagues, allied health professionals, physicians, researchers and more.

I THINK ALL PARTS of the globe were represented. Certainly I met people from the Nordic countries, Europe, the Middle East, Asia, the Americas and Australasia. I went with lots of questions, I networked relentlessly, and now it is my challenge to use this learning to benefit MND NZ.

A wide range of information was shared in line with the International ALS/MND Alliance vision to share resources globally. Sharing happened across the board from the challenges Associations like MND NZ face in providing support services (the first 2 days – about 80 people) to allied health professionals sharing best practice and new ideas (3rd day about 200 people) to clinicians and scientific researchers presenting on a range of studies from clinical research to scientific testing of different disease progression mechanisms (last 3 days over 800 people). Once I mastered the art, I shared experiences on Facebook when I could.

Congratulations to Dr Gareth Miles from St Andrews University in Scotland who received the Paulo Gontijo Award for ALS/MND researcher of the year at the Symposium. He is a New Zealander so I proudly claimed him! He leads work studying the dysfunction of motor neurones affected by ALS/MND hoping to reveal targets for new treatments aiming to improve or repair the functionality of motor neurones. My post about this on our MND Facebook was seen by an amazing 5,959 people!

Ask the Experts is a session held every year at these events and is live streamed over the internet so anyone, anywhere can watch and by prior registration you can have your question asked too. The 2015 session is still available to view online at: http://asktheexpert.eventstreaming.tv/. I encourage anyone wanting an international expert to answer their tricky question to put this on their calendar for 2016 – the Irish MND Association, iMNDA, is hosting this year in Dublin so watch their website for details.

Poster presentations are an important adjunct to the Symposium and provide a great opportunity to talk one-on-one with people about their research. **Dr David Oliver presented** on the way **multi-disciplinary clinics improve respiratory care allowing** *"… wider consideration of the benefits of NIV and the discussion of disease progression and the possible consideration of later withdrawal, as recommended by the NICE Guidance. The joint clinic has allowed a clearer approach to patient care with home commencement of NIV. This has allowed a more comprehensive service to be provided, with increased support of patients and their families and increased compliance with the intervention, leading to improved quality of life."*

The Poster Sessions provided a great way to share information in "real time" and my posts can be viewed on our Facebook page: www.facebook.com/mndanz.

ALS/MND International Alliance Meetings (8, 9 December)

MND NZ is a member of the Alliance. This was a great start to my week as there were only about 80 of us and through the mix of workshops, presentations and meetings we got a chance to talk to and learn from each other. No Association is blessed with wads of money so the ideas shared were practical.

INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

I was indeed inspired and my head was reeling with opportunities for MND NZ.

- Jodi O'Donnell-Ames from "Hope Loves Company" reminded us about the needs of children whose parents have MND and shared ideas with me on comparatively simple ways to start
- The Philadelphia chapter of The ALS Association impressed with the way they offered "virtual" support
- Canadian Support workers shared some of their experiences with me – and we have been in touch since
- The Colombian presentation on caring for caregivers struck a chord for me
- Scottish colleagues invited me to visit them in Glasgow (which I did one week later and learnt so much – their population is similar to ours)
- Our Australian colleagues looked out for me and helped me so much with my networking
- Kiki Qu, a Taiwanese dynamo, said she could translate some of our material for us
- Dr Hemangi Sane, spoke of challenges to providing services in India
- Gudjon Sigurdsson (from Iceland who has MND) reminded Associations "nothing for us without us".

Meeting archives, including abstracts and videos of presentations, are available on http://www.alsmndalliance.org/alsmndmeetings/past-meetings/2015-meetings

Allied Health Professional Forum (10 December) organised by the International Alliance of ALS/MND Associations. **This day burst with good presentations** and the highlights for me included (*note:*

pwALS/MND has been used to abbreviate 'people with ALS/MND'. Presenters names are in brackets):

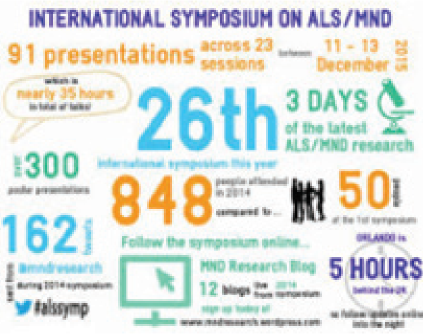
- We must constantly remind ourselves that the role of carer is vitally important and we must consider carer needs alongside pwALS/MND. **www.barwonhealth.org.au/palliative-care/toolkit** (Prof S. Aoun et al, Curtin University, WA) and developing a carer-led approach for support (Steve Bell)
- But pwALS/MND can get burnout too and ideas for addressing this in the clinical setting (Rebecca Axline)
- And health professionals also need to understand their own personal death awareness to maintain/raise their skill and compassion (Laurie B. Fieldman)
- Disclosure of familial ALS/MND to children – in this study the children wanted their parents to be more open not less, they wanted information as they felt this would help them keep control of their lives and reduce their stress. Many child participants felt a responsibility to protect their parents particularly if their parents were trying to protect them (Samantha Neumann et al)
- The needs of young carers – children and young people (under 18 years old) benefit from their own support programmes and more research is needed in this area. (Melinda Kavanaugh et al) Points that struck me particularly were
  - "once you've lived with MND, nothing in life is impossible",
  - the young carer experience can isolate young people from their peers
  - young carers are desperate to be acknowledged.

- I also refer you to the now published Olly Clabburn study we posted about in 2014 on FB – **www.researchgate.net** and above-mentioned Hope Loves Company: **www.hopelovescompany.net**
- A presentation on useful tools for initiating end-of-life discussions (Shivangee Thorne et al)
- Respiratory presentations – one about today's respiratory therapies (Jennifer Armstrong) and another about improving the respiratory referral and assessment pathway (Julie Young et al). Acknowledging that technological development is happening quickly in this area.
- Updates in the evaluation and treatment of airway protection (Emily Plowman). In the spirit of ALS/MND workers worldwide who generally want to freely share knowledge and resources, she advised that people can download EAT-IV (in 10 different languages!) and patient resources for free – she described these as "quick and meaningful aids in a busy clinic."
- Getting the right equipment to pwALS/MND at the right time. This UK project – anticipatory approaches to wheelchair provision (Karen Pearce at al) – works with providers to get chairs for pwALS/MND in a timely way – the concepts could be adapted for other equipment in other countries.
- Assistive equipment used by pwALS/MND in Australia (Karol Connors et al). People with ALS/MND benefit from having the right equipment available (one man with bulbar onset was able to continue working up to 4 days before he died – *not sure that is a good thing!*) In the study of 273 people the average was 5.3 items per participant with a range of 0-20 items and using 56 different types of equipment. 66 people had speech devices, 328 mobility devices, 649 daily living items, 172 home modifications and 11 transfer aids
- Voice banking – (Jennifer Benson) "Just Do It"
- Using mainstream technology for communication – (Ailsa Brownlee) There is no one right way for pwALS/MND to communicate and with all the technology available today health professionals need to know about the various options as well as how to establish an immediate communication system with products bought at any electronic store.

ALS/MND 26th International Symposium (11–13 December)

The Symposium is the premier event in the ALS/MND research calendar and really targets specialists not people like me. But I could follow most of the "B" stream presentations which are more clinically focussed research. I am sure the "A" and "C" streams would have been well suited to scientists and geneticists.

So much is covered in these presentations and you can view summary blogs, articles and videos at **www.mndassocation.org/symposium** but there were some standout messages for me:



Two striking key messages

- **Addressing the burden of neurodegenerative diseases – a global challenge** (R. Shakir). Neurological non-communicable diseases (MND is one) will bankrupt health budgets across the world. We need more, and better co-ordinated, research efforts. Hammer this message home at all levels in neurology and to those working with health budgets to avert a crisis.
- **Is ALS/MND a multi-step process?** (N. Pearce – another NZer by birth by the way). If it is a multistep process, and this research shows it could well be a six step process, then there are profound implications for the understanding of disease mechanisms, the interplay of risk factors and the further research needed to identify the steps. It also raises hope that the identification of the steps could lead to preventative and therapeutic measures.

A call for clarity

- **Improving the classification of ALS – can we make it logical** (A. Al-Chalabi) – as we now understand far more about the clinical profile of the disease than ever before the time has come for a formal, unified, logical classification. At present there is confusion – some types are identified on nervous system level, other on anatomical level; ALS is both an umbrella term in some countries as well as describing a clinical pattern and being used as a diagnosis. On top of this specialists tend to use their own classification systems. This is confusing for researchers and patients and makes diagnostic coding system information unreliable. Indeed, is ALS/MND the same disease in different parts of the world?

Studying the odd man out

- **How common are ALS plateaus and reversals?** (Richard Bedlack – the same man who runs the very helpful **ALSUntangled** web site and who

Dr Richard Bedlack

wears bright suits – even pink – in an attempt to brighten his patients' day) showed that ALS plateaus and small reversals are common but large sustained reversals are rare and warrant further research. Is this where the breakthrough will come? He reported that the breakthrough in AIDS treatment came through studying "the oddities" not the general pattern.

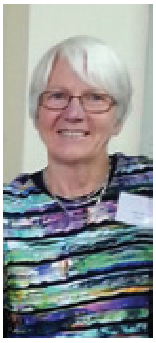
Respiratory Support

- The withdrawal of assisted ventilation is enormously challenging for professionals compounded by the fact that some professionals will only ever be faced with the situation once or twice in their career.

Discussions at prognosis

- How can the specialists possibly give the news of an MND diagnosis well? In one study 100% of patients wanted the doctor to be honest and 91% wanted the doctors to be optimistic. "Tell us honest stuff hopefully". This is seemingly an inherent contradiction which makes it really, really hard for physicians. The presenter (J. Jacobsen) suggested that the communication about prognosis be an iterative process that begins early and is tailored to the patient preferences and trajectory. And to find out what the patient wants the physician needs to "ask, ask, ask, ask … tell … ask". (i.e. the asking gets calibration so the correct question is answered) And then delivering the message with a statement of hope followed by your worry "We are all hoping that your disease will be stable for a long time, but I am worried that … (eg. you have enough information to make good decisions)".

If you have read this far no doubt you are almost as tired as I was after 6 days! Hopefully you are uplifted as I was too. Uplifted that so much work is being done by so many dedicated people typically working collegially to share knowledge and pool resources to create a world free my MND.



Beth Watson President of MND NZ

Dublin, Ireland is the venue for the 27th International Symposium on ALS/MND 7–9 December 2016. These annual events are organized by the UK MND Association in partnership with the local MND Association and in 2016 this partner is the Irish Motor Neurone Disease Association – iMNDA.

The first call for papers has been made and the online submission process for abstracts for this year's symposium has opened with a deadline of 27 May 2016. Registration for the conference is now open. Visit the registration page at **www.mndassociation.org** for more information.

The International Alliance Meeting, Ask the Experts session and Allied Professionals Forum take place on the days prior to the symposium and require separate registration. A call for abstracts opens 3rd April with a deadline late May. For more information on these please visit the ALS/MND Alliance website: www.alsmndalliance.org.

A combination of formal and informal events across 4–5 days offer opportunities for learning and networking make this for an amazing opportunity for international sharing and collaboration focused solely on ALS/MND.

Research news can be followed on 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.

Clinical Trials are listed at:

Australian Clinical Trials:
www.australianclinicaltrials.gov.au/home

U.S. Clinical Trials: **www.clinicaltrials.gov**

Best Practice Guidelines for Care and Management of Motor Neurone Disease

NICE
National Institute for Health and Clinical Excellence

2016 SEES THE UK National Institute for Health & Care Excellence (NICE) publish comprehensive best practice guidelines for **MND Assessment and Management** based on the best available evidence with recommendations put together by experts, people using services, carers and the public.

The guidelines aim to improve care from the time of diagnosis and offers tools and information to health professionals as well as information for those living with MND. Whilst the recommendations are made in the context of the UK health system the principles are transferable for the purposes of:

- Avoiding unplanned hospital admissions for people with MND which come at high cost to patients, families and health services.
- Supporting people with MND to live in their own homes with appropriate access to support.
- Establishing multidisciplinary teams able to support people with MND, both in a formal clinic setting and in an outreach setting.

On his visit with us last year, Dr David Oliver gave us a taste of what to expect from these guidelines having been a part of the working party involved in their development. In our discussions with him we were encouraged to find that key features of best practice for care and management of motor neurone disease are already a part of the scene across New Zealand – we just need more of it!

We encourage health professionals working with those with MND to view this valuable tool: www.nice.org.uk

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

mnda
motor neurone disease association

Kiwibank Local Hero New Zealander of the Year Awards – Carey Vivian

Kiwibank Local Hero medal recipients of Otago. Diverse in their stories but united in their passion and determination to make a difference in their community. Carey 2nd from left.

HUGE CONGRATULATIONS go to Southland local hero, Carey Vivian. His Race Against Time MND cycle challenge raised more than $40,000 in much-needed funds for MND services and awareness of the disease around NZ. In December Carey joined other local heroes in receiving the Kiwibank Local Hero medal acknowledging the efforts of those committed to their community and making New Zealand the wonderful country that it is.

Resources for health professionals and service providers

mnd care

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

mnd Aware

MND AWARE training modules – view online training tutorials on MND care.

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

These easy to view training modules provide health and community care professionals with a basic understanding of motor neurone disease (MND) and the impact it has on an individual's life. Developed in 2011, the MND Aware online training sessions have been specifically developed for home and community care workers, case managers, health and residential care workers and consist of:

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

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

MND Support in Hawkes Bay

Graham Jones

GRAHAM IS ONE OF our team of seven Fieldworkers. Based in Tauranga, he covers the Bay of Plenty, Lakes, Hawkes Bay and Tairawhiti DHB areas. Since his position is part-time, Graham spreads himself thin to offer support across such a wide area and local visits may only be possible a couple of times a year but he does his best to connect with local health professionals and service providers as well as people with MND and their families.

Graham has been with the MND Association for over six years and his background is in palliative care and professional supervision. He is a passionate advocate for people with MND and has worked steadily over recent years to build relationships and networks with health professionals and service providers targeting best practice care. Graham says, *"Multi-disciplinary care occurs when professionals from a range of disciplines work together to deliver comprehensive care for individuals and families who travel the journey that is MND. The Allied Health professionals and Hospice team based in Hawkes Bay are a perfect example of a quality team."*

"As an MND Fieldworker much of my time is spent on the road. Outreach trips to Hawkes Bay are conducted two to three times a year. Over the period of a week each client and their family are contacted and a home visit arranged. These meetings provide an opportunity to discuss current issues in the comfort of the home. These issues are noted and communicated to the multi-disciplinary team; meetings such as this clarify the current issues faced by people living with MND and their carers and also promote timely interventions and continuity in their support."

The Hawkes Bay MND network and the Lakes area network are recent additions to the 18 multi-disciplinary teams that meet across the country; networks of service providers who commit to meeting regularly to liaise co-ordinate care and support each other in managing the challenges motor neurone disease presents. It is a great reassurance to people living with MND when they hear that the apparently fragmented services in and out of their homes communicate regularly behind the scenes

Great team work is central to best practice and MND NZ would like to acknowledge service providers making themselves available to support this valuable process.

The multi-disciplinary team in the Hawkes Bay area
L to R : Susan Heard – Speech and Language Therapist, Teresa O'Sullivan – Community Dietitian, Linda Heffernan – Community Physiotherapist, Fiona Smith – Community Occupational Therapist, Kathy Lewis – Cranford Hospice.

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.

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.

Does exercise help those with swallowing issues in Motor Neurone Disease?

A research invitation from the Rose Centre, University of Canterbury

Prof. Maggie-Lee Huckabee PhD., Michelle Westley, Paige Thomas MSLP

HISTORICALLY, MANAGEMENT of swallowing impairment associated with Motor Neurone Disease (MND) has been limited to supportive care, behavioural strategies to protect the airway or dietary management to ensure safe oral intake for as long as possible. The role of exercise has been controversial across rehabilitation medicine with the concern that exercise may exacerbate disability through overuse and fatigue. However, there is no clear evidence to support this bias; indeed, research related to exercises for limb, speech and breathing suggests that exercises at an appropriate intensity may be beneficial in maintaining quality of life and survival.

Very recently, Dr Emily Plowman and colleagues (University of Florida, USA) completed a proof of concept study of 25 patients with swallowing impairment secondary to MND. Fifteen patients received five weeks of a floor of mouth muscle strengthening exercise programme and demonstrated improvement in measures of respiratory support and swallowing when compared to the ten patients who received no active treatment. Evaluation of long-term treatment effects has not yet been completed. Regardless, this work suggests that although the disease itself may not be cured, the associated symptoms may be amendable to at least short-term changes in function. What is unknown is if the value of this study rests with the strengthening component of the treatment or the cognitive focus on swallowing and swallowing task repetition. If the benefit arises from improved swallowing skill rather than strengthening itself, the risk of muscle fatigue associated with strengthening – whether real or only perceived – could be bypassed.

THE UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
ROSE CENTRE
FOR STROKE RECOVERY & RESEARCH
Te Puna Whakaora Rehu Ohotata
AT ST. GEORGE'S MEDICAL CENTRE
Kī te Whare Hauora o St.George

Our laboratory has developed the Biofeedback in Strength and Skill Training (BiSSkiT) protocol over the past several years. BiSSkiT uses small electrodes placed below the chin which detect movements of muscles used in swallowing and displays these as a waveform on a computer screen. The individual then learns to manipulate swallowing by manipulating the waveform on the screen. For our skill training protocol, a small target is placed randomly on the screen. The aim is to swallow so that the peak of the waveform falls within the target, which changes size with success or failure. This simple, non-invasive treatment protocol has proven very effective in patients with Parkinson's Disease, another neurodegenerative disorder.

BiSSkiT

The University of Canterbury Swallowing Rehabilitation Research Lab is conducting an exploratory study which will evaluate the BiSSkiT protocol to determine whether skill training may be of benefit to patients with MND. The research will involve four assessment sessions and 20 therapy sessions over three months. Therapy will be provided over a four-week block with one hour of therapy every day, five days per week. The initial four-week block of treatment will be followed by four weeks of no treatment; and again followed by four weeks of active treatment to evaluate effects in the context of a degenerative condition. At the conclusion of the research, if there is evidence that the therapy technique is effective, participants would be given the option of continued use of the software for treatment. This initial pilot study, if successful, will then lead into a larger study in conjunction with Dr Plowman, which compares the effectiveness of strength and skill training for improving swallowing function.

Please note: Some individuals with Motor Neurone Disease have few problems with eating and drinking but some experience significant difficulties; some notice changes as the early signs of a problem, others only notice difficulty developing over time; the extent of the difficulty varies between individuals.

This study has approval from the University of Canterbury Human Ethics committee and is currently looking for participants who have a diagnosis of MND and early indications of swallowing impairment who are able to attend sessions in Christchurch. Assessment involves eating a dry cracker so participants must be able to do this at the onset of therapy (assessment can be altered throughout the course of treatment if this is necessary).

For more information or to express

interest in being a part of this research, contact Paige Thomas – phone: (03) 364 2307, email: pat78@uclive.ac.nz

References

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MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

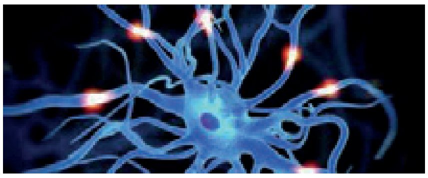
New Zealand Research into Risk Factors for MND

New Zealand Research into Occupational & Environmental Risk Factors and MND is in progress at Massey University as part of an international project. The project looking into occupational and environmental risk factors related to MND is now in its final year of data collection. **Volunteers are still wanted to complete the questionnaire in order that the project secures the numbers it needs.** An information pack is available from your Fieldworker or contact the project directly by calling free on **0800 793 121** or email Grace Chen: **g.chen1@massey.ac.nz**

For more information on this project see the *MND News Spring 2014* edition on our website under archived newsletters.

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

MND Key Facts



What is Motor Neurone Disease?

MOTOR NEURONE DISEASE is the name given to a group of neurological conditions in which the nerve supply to muscles deteriorates and the affected muscles 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 co-ordination 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.

- Motor Neurone Disease is not infectious or contagious.
- 5–10% of people affected have a family history. Research continues to identify associated genetic mutations.
- It can affect any adult, at any age, but most people diagnosed with the disease are over the age of 40, with the highest incidence occurring between the ages of 50 and 70.
- Men are affected more than women.
- It occurs across all populations around the world.
- Cause is not known but considerable research is being undertaken and significant advances are being made in understanding this condition with an expectation the causes are multiple.
- No cure has yet been identified for MND.
- Riluzole, marketed as Rilutek,is the only treatment that has shown through approved clinical trials to have the potential to slow the progression of MND in some people. It is available on prescription from a specialist but is not suited to everyone.
- There is much that can be done to manage the condition and support quality of life and a range of support services and equipment are available at no charge through government funded agencies and community groups.

What are the numbers in New Zealand?

Approximately 100 people are diagnosed each year – this is called the incidence.

Approximately 300 people are living with MND at any one time – this is called the prevalence.

This is what we would expect for the current size of our population.

MND NZ believes almost everyone diagnosed with MND chooses to register for our support. There has been some suggestions globally that the incidence of Motor Neurone Disease (MND) is increasing; this could be due to more accurate diagnostic processes and the fact that people are generally living longer and the risk increases with age.

Does MND affect your brain?

For many people with MND brain function, intellect and personality remain unaffected, however, cognitive changes may be present in up to 50% of people with MND. The change is often subtle e.g. altered problem solving skills, reduced empathy and apathy and may only be evident to close family and friends but can have a significant effect on relationships, decision making and lifestyle.

A small percentage of people experience cognitive changes typical of a fronto-temporal dementia (FTD) and signs of this may have been evident well before the physical symptoms developed.

MND NZ logo on tour at high speed

Sue Stewart (Photo by Geoff Ridder www.ridder.co.nz)

SUE STEWART AND Stewart Motorsport are longstanding, faithful supporters of the Association sponsoring the printing of the newsletter – 500 copies for each of our two editions each year. In addition they raise awareness as they take our logo around the country at high speed.

Sue told us, "*The team has been together since 2010. My Husband Malcolm Stewart may be known to some readers as he rallied for over 30 years; after he died of MND in 2009 I decided to get the old team back together with new driver Ray Wilson, a longtime friend of ours, and have a bit of fun. Both the car and our service van were blank, so what better idea than to use them for mobile promotion and we had them sign written with the Motor Neurone Disease Association and the Neurological Foundation logos.*"

Sue and the team took their Classic S2 Audi Quattro rally car to an event called the Leadfoot Festival in early February this year. A fantastic event run by Rod and Shelly Millen on their property at Hahei. This was the 3rd outing for our new car and all went well, driver and car didn't miss a beat, fingers crossed the rest of the season goes as well. The festival includes all types and ages of cars and motorbikes, 115 cars and bikes in total, with the oldest car being a 1906 Darracq Grand Prix, driven by Scott Dixon.

"*We thought it would be a great event to get the car out and about and seen, to help promote both the MND Association and the Neurological foundation which is the main aim of Stewart Motorsport.*"

In March the car will be going to the South Island to do 3 or 4 events then back to the North Island later in the year.

Sue and the team continue having fun while promoting two very worthwhile causes – if the car is at a rally in your area you might like to go and have a look and introduce yourself to the team. Keep up with planned events on the Stewart Motorsport Facebook page where you will find more great photos and exposure of the MND logo.

Sincere thanks go to Sue and the team for their support for MND NZ.

Leadfoot Festival, Hahei

Clinical Trials – what to keep in mind when reading media reports

"Your doctor will be here in a minute, I'm a placebo."

THE MEDIA AND INTERNET provide plenty of dramatic headlines and can be a challenge to keep up to date with a balanced perspective. A recent press release described a "major breakthrough in ALS" – words we all get excited about. However, when the report was reviewed by the experts their response was *"I wouldn't say it's a major breakthrough – it's been known since 1993, this is just another step along the way."*

When reading about clinical trials it is important to remember that there are several stages involved before an effective treatment is being offered.

Clinical trials are research studies in human volunteers that determine whether potential treatments are safe and effective. It is extremely important to establish that the side effects of any new drug are not more threatening than the disease itself. It is also necessary to prove beyond reasonable doubt that the drug is beneficial. The only fool proof way of doing this is by monitoring the effects of the drug in a group of patients and comparing the progress of these patients with the progress of a similar group not taking the drug.

How do clinical trials proceed?

Clinical trials are divided into four phases:

- **PHASE I** examines the safety of the potential new treatment, often in just a few (5–20) people. In many cases, this phase involves healthy volunteers rather than patients. Participants are monitored for adverse reactions or side effects; if any appear that are judged to be too dangerous, the drug will not advance any further through the clinical trials process.
- **PHASE II** determines the optimal dose size, timing of doses and drug delivery route (eg by mouth, by injection) for the next phase of testing. Although Phase II testing may provide some indication of the drug's ability to treat the disease, the numbers of patients involved in this phase is too small for such findings to be relied upon.
- **PHASE III** aims to show whether or not the drug actually has a beneficial effect on patients. This stage of testing will usually involve hundreds of patients, which is enough to allow a reliable assessment of the drug's efficacy. Phase III results will determine whether or not a drug is approved for use to treat the disease.
- **PHASE IV** occurs after the drug has been approved for sale. With the drug in general use, further data can be gathered on its effects in an extremely large number of people over an extended period of time.

Who can participate in a clinical trial?

All clinical trials have strict guidelines about who can take part. Factors that allow someone to participate in a clinical trial are called '*inclusion criteria*' while factors preventing someone from participating are called 'exclusion criteria'. These criteria usually include factors such as age, type and stage of disease, previous or current treatments and other medical conditions. Inclusion / exclusion criteria are essential to ensure that the trial produces reliable results and to help maintain participant safety.

Many willing trial participants may find that they do not meet the criteria for taking part. Others may find that there is no trial centre near to where they live or that the researchers already have all the participants they need. Although this is disappointing, it is important to remember that trials are experiments, not treatments. The fact that they are happening at all is still very positive.

New Zealand has no clinical trials.

Australian Clinical Trials can be found here: www.australianclinicaltrials.gov.au

US clinical trials can be found here: https://clinicaltrials.gov/

UK clinical trials can be found here: www.clinicaltrials.gov

Trials likely to benefit the majority of people with ALS are those targeting a protein called TDP-43, unless an individual knows they have a SOD1 gene mutation, in which case trial targeting this group will be of interest.

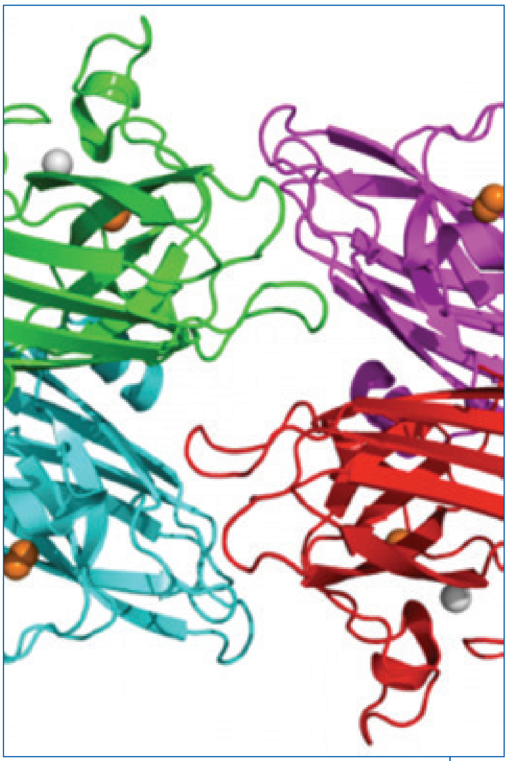
Acknowledgement for this article: UK MND Association

www.mndassociation.org/research/mnd-research-and-you/treatment-trials/

Time and distance are an ongoing challenge

WE WOULD LOVE to be able to provide as much support as you would like no matter where you live. Costs run high for our Fieldworkers to visit every corner of the country and our funding restrictions mean we can only visit outlying areas occasionally. However, technology is on our side so do watch out for future developments as we explore ways to stay in touch with you – perhaps you are interested to keep in touch by Skype or similar, if so let your Fieldworker know and perhaps we can give it a go!

Copper – ATSM
New therapy halts progression of ALS/MND in mice



RESEARCHERS AT Oregon State University published their results from pre-clinical studies in one type of mouse model that showed the progression of amyotrophic lateral sclerosis (ALS/MND) was halted for nearly two years allowing the mice to approach their normal lifespan.

The findings, scientists indicate, are some of the most compelling ever produced in the search for a therapy for ALS and were published in Neurobiology of Disease.

"We are shocked at how well this treatment can stop the progression of ALS," said Joseph Beckman, lead author on this study, a distinguished professor of biochemistry and biophysics in the College of Science at Oregon State University. In decades of work, no treatment has been discovered for ALS/MND that can do anything other than prolong human survival less than a month.

The mouse model used in this study is one that scientists believe may more closely resemble the human reaction to this treatment, which consists of a compound called copper-ATSM. Using Copper-ATSM treatment researchers were able to stop the progression of ALS in one type of transgenic mouse model, which ordinarily would die within two weeks without treatment. Some of these mice have survived for more than 650 days, 500 days longer than any previous research has been able to achieve.

Copper-ATSM is a known compound that helps deliver copper specifically to cells with damaged mitochondria, and reaches the spinal cord where it's needed to treat ALS/MND.

In some experiments, the treatment was begun, and then withheld. In this circumstance the mice began to show ALS symptoms within two months after treatment was stopped, and would die within another month. But if treatment was resumed, the mice gained weight, progression of the disease once again was stopped, and the mice lived another 6–12 months.

It's not yet known if humans will have the same response, but researchers are moving as quickly as possible toward human clinical trials, **testing first for safety** and then efficacy of the new approach.

"We have a solid understanding of why the treatment works in the mice, and we predict it should work in both familial and possibly sporadic human patients," Beckman said. "But we won't know until we try. We want people to understand that we are moving to human trials as quickly as we can."

This is not the first study of CuATSM in ALS mice and previous work has been published by investigators at the University of Melbourne in Australia. However, this paper does produce unique results which are important to the understanding and potential advancement of Cu-ATSM as a therapeutic opportunity for ALS and other neurological disorders. The treatment is unlikely to allow significant recovery from neuronal loss already caused by ALS, the scientists said, but could slow further disease progression when started after diagnosis.

Experts caution, however, that this approach is not as simple as taking a nutritional supplement of copper, which can be toxic at even moderate doses. Such supplements would be of no value to people with ALS, they said.

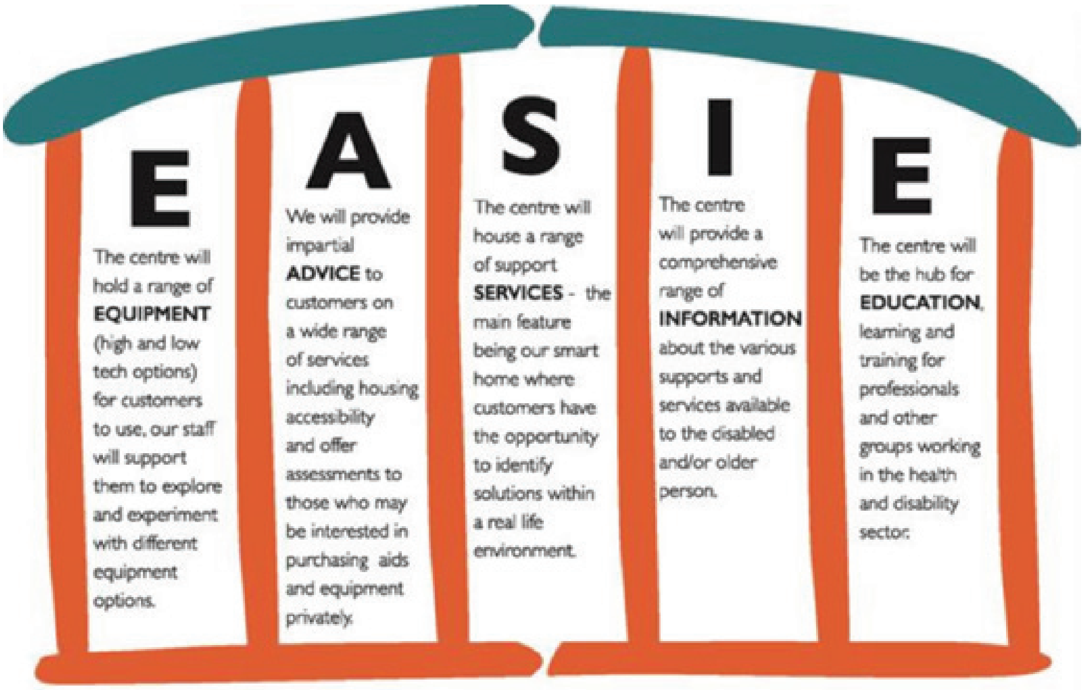
For more information:
www.oregonstate.edu
www.als.net
www.sciencedaily.com

We are so proud … we have had our first Webinar … your first what?

AS MORE AND MORE of us become familiar with the internet doors are opening to make sharing and supporting each other readily accessible no matter where we live. A webinar is yet another tool for connecting with each other – a seminar on the web. Thanks to Ed Hall and his team at Comenius Online we were able to provide live online access to Dr. Emma Scotter's presentation at our AGM last October via a webinar. This was a new experience for us but an exciting another option for staying connected across the country – next year you might consider being part of our AGM via the internet. We are very aware of the need to keep in touch with those living some distance from our bases and thanks to Ed's skills we were excited to trial the process of being available to all, online, at the same moment in time. Ed's family have experienced MND and have continued to support our efforts for which we are most grateful as we need all the help we can get to keep up to speed!

New Zealand's first EASIE Living Centre has opened in Palmerston North

NEW ZEALAND'S FIRST EASIE Living and Demonstration Centre was officially opened in Palmerston North in February and has exciting high and low tech living options on display. For the first time in this region people looking for solutions to the challenges of everyday living activities and those working in the health and disability sector, will have a range of services encapsulated within the EASIE Living brand, under one roof – 'a one-stop-shop'.



The centre will hold a range of **EQUIPMENT** (high and low tech options) for customers to use, our staff will support them to explore and experiment with different equipment options.

We will provide impartial **ADVICE** to customers on a wide range of services including housing accessibility and offer assessments to those who may be interested in purchasing aids and equipment privately.

The centre will house a range of support **SERVICES** - the main feature being our smart home where customers have the opportunity to identify solutions within a real life environment.

The centre will provide a comprehensive range of **INFORMATION** about the various supports and services available to the disabled and/or older person.

The centre will be the hub for **EDUCATION**, learning and training for professionals and other groups working in the health and disability sector.

EASIE (**E**quipment, **A**dvice, **S**ervices, **I**nformation, **E**ducation) Living Centre is the latest innovation from Enable New Zealand. Find them on **FACEBOOK** – EASIE Living & Demonstration Centre or visit www.easieliving.co.nz for more information.

Enable New Zealand General Manager Scott Ambridge said: "*We see the centre as a 'gateway' where we will work alongside people to assist them to find the best outcomes possible, which at times is not always about spending money, for example how we can utilise natural supports. The real strength of the centre is you can find everything under one roof from information and advice about community services through to specialist advice on equipment and housing modifications. Our demonstration centre offers the opportunity for people to see/touch and try out different gadgets and equipment in a real life environment to see how these supports might work at their home.*"

The Easie Living Centre is in the former RSA building, 585 Main Street, Palmerston North and open Monday to Friday from 8.30am to 5pm, and Saturdays 10am to 3pm.

ENABLE NEW ZEALAND is based in Palmerston North and is the largest provider of support services across the health, rehabilitation and disability sector for the provision of equipment, housing and vehicle modifications; it has been providing disability support services for over 40 years, and now reaches 50,000 people a year. **ENABLE** covers the South Island, lower and middle North Island up as far as Meremere, south of Auckland.

accessable* is the equivalent organisation** for people living in the Auckland and Northland regions (north of Meremere). Auckland based, ***accessable manages the provision of equipment, housing alterations and vehicle modifications on behalf of the Ministry of Health; receives applications from specialised assessors, such as Occupational Therapists, who request adaptive equipment, housing alterations and vehicle modifications on behalf of their clients. Once eligibility is confirmed, ***accessable*** arranges for the equipment or modifications to be provided.

Ask your Occupational Therapist or Fieldworker where your nearest disability resource centre is based.

Life is Awesome …

… says the message written on Eco Yanaga's arms as she prepares to jump out of a plane.

Eco has MND. Last year she ran a half marathon and this year she challenged herself with skydiving.

"*I can't run now – but still can fall*," laughs Eco.

A challenge for us all, whether we have a diagnosis of MND, some other condition or believe ourselves to be fit and well and expecting to live forever … none of us know what tomorrow may bring, what our future holds, what might happen in the next few moments. Just how many of us live our lives with that thought in mind and make the most of now!

Kia Ora! Hello from Scotland

FORMER ENGLISH TEACHER, Liz Ogg – a self-confessed chatterbox – was devastated after she lost her voice due to MND. Free speech apps on her mobile phone along with a system of gestures have helped her continue to communicate but she is now keen to communicate internationally and her husband recently emailed us the following:

"Kia Ora! Hello from Scotland.

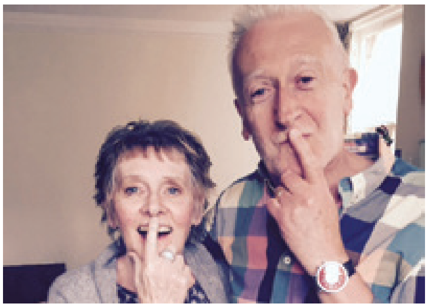
Briefly, my wife Liz, was diagnosed with bulbar MND about 30 months ago. Her condition continues to develop.

We have supported MND Scotland research through fund-raising and participation in projects. But recently, Liz wanted to reach out to others with the condition. To this end, she has launched an MND blog on the Net. It is being hosted on the MND Scotland website. Her aim is to reach out to others in the MND community and try to share experiences and solutions. Initial reaction on social media has been significant and surprisingly positive and she intends continuing the blog, covering various topics with the tone being realistic and practical along with quite a lot of humour. I am writing to ask if MND New Zealand might be interested in sharing the link to Liz's blog; MND Australia has already shared it and there is a great sense of international connection.

Thank you for your time in reading this – Liz's Blog can be found at: www.lizmnd.blogspot.com

Best wishes

Alan Ogg"



What is a blog?

noun: blog; blogs

a regularly updated website or web page, typically one run by an individual or small group, that is written in an informal or conversational style.

verb: blog; blogs; blogged; blogging

add new material to or regularly update a blog eg. "it's about a week since I last blogged"

President's Piece

"Start by doing what's necessary, then do what's possible, and suddenly you are doing the impossible." St Francis of Assisi

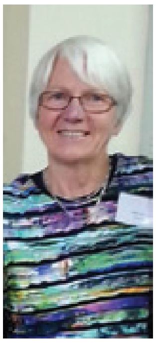
I am very aware that people living with MND achieve the impossible nearly every day – I hear this from my conversations in New Zealand and it was also a loud and strong message at the international meetings I was privileged to represent New Zealand at last December.

The MND NZ team is focussed on doing what's necessary (ensuring our fieldwork team is resourced) and extending ourselves to do what's possible. Although we are unlikely to manage the "impossible", we are proud of our "possible" achievements.

This newsletter announces the David Oliver Beacon Award (would the work you are doing for people with MND qualify you for putting yourself forward?), and the shape our nationwide Walk 2 D'Feet MND events will have this year (could you spearhead a Walk in your community?).

In July key people from throughout MND NZ are getting together to share ideas of what we want to look like in 5–10 years' time and how we might get there. Send us an email if you have an idea to offer.

I am developing recommendations for Council on the best use of the research money that was raised through our Walks last year. This has been a slower process than I had hoped but it is an important decision which we want to get "as right as we can". We will keep you posted.



It's teamwork that MND NZ achieves what it does. Thank you for the energy you give, in whatever shape or form, as without that energy we wouldn't be making the progress that we are.

Beth Watson

MND NZ welcomes new Council Executive member, Lucy Haberfield, as Treasurer

I am an experienced Corporate Support Manager with a background in Finance. I have been a Chartered Accountant since 1995 and also hold a marketing diploma. I have a particular interest in strategic and business planning and facilitated this process in my last two roles.

I am a keen trail runner and multi-sporter, having just completed the Captain Cooks Challenge on the Queen Charlotte Track. I am married with three adult children and a daughter-in-law. My husband and I live in Greytown and I commute daily to Wellington.

My history with MND is that my father passed away as a result of MND in 1999. I'm keen to be able to give something back to my community and I feel MND is a good fit.

WALK
2 D'FEET
MND

25th of September – Walk 2 D'Feet MND '16!

FOLLOWING THE overwhelming success of last year's Walk 2 D'Feet MND, we are already making plans for this year's Walk. We are keen for the Walk to be 'rolled out' to other locations, to make sure that as many of you as possible can be involved.

Despite the atrocious weather last year, over 2,500 people walked on the day and over $76,500 was raised for the MND NZ, half of which will go to research. **We are confident that we can better those numbers this year but we need your help!**

If you are interested in organising a Walk in your area – it can be as ambitious or modest as you like – doesn't need to have all the bells and whistles – we just need to give people the chance to show their support – **please contact Claire Reilly** at clairereilly@orcon.net.nz who will provide you with all the information you need. We also need volunteers in the major cities in particular Auckland and Wellington, so if you think you can help in some way please do get in touch .

Keep an eye on our website and Facebook page for the latest updates!

International MND Awareness

Awareness Month – June 2016

Awareness Week – 20–21 June

Awareness Day – Tuesday 21 June

Do you have plans to raise awareness?

Greetings from Grant

Once again, thank you for your feedback via our annual Client Satisfaction Survey which was very positive and confirmed we are on track in offering people living with MND the kind of supports they value.

30% of our clients took the time to respond to our questionnaire and told us:

- The nature of the support they need varies widely across individuals and across the course of the MND journey; people value our ability to be flexible and responsive:
  "It is so good to know our Fieldworker is there when we need them."
  "It is such a support to talk with someone who understands."
  "I know you will know where to go and what to do."
- People trust us to be a consistent and reliable source of information and support and knowing we are here is reassuring:
  100% find the newsletter, website and our Information Pack of interest.
- We are respected by health professionals and service providers:
  84% of our referrals come through health professionals indicating a high level of trust and appreciation of our services.
- People would like more of our support:
  94% indicated they would like us to initiate contact if they have not been in touch for a while; requests for a more frequent service were higher this year suggesting people are placing a high value on what we offer.
- Internet use is clearly increasing:
  79% use the internet and 100% had viewed our website and found it helpful.
  Several suggested the survey is provided via email or on our website next year.

Thank you, your feedback contributes to our service delivery planning and means we are well placed for the Ministry of Health review being carried out this year. If you missed our client survey and would like to provide feedback please feel you can contact me at any time.
E: mgr@mnda.org.nz. P: 09 624 2148

Grant Diggle

Our MND Support

Fieldwork Service is offered FREE

We employ 7 Fieldworkers around the country – **please do contact us if we can help; we will always respond as promptly as possible** but we are all part-time so there can be some delay. If you live some distance from a Fieldworker's base our support will be mainly through phone and email contact with occasional local visits.

We do not provide out-of-hours or emergency services or medical advice.

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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STAFF

Grant Diggle: National Manager, National Office Auckland
Ph: 09 624 2148 Mob: 027 2412766
Gwynyth Carr: Administrator, National Office Auckland
Ph: 09 624 2148
Lin Field: National MND Support Team Leader, Auckland
Mob: 021 2303038
Linda Oliver: Fieldworker Auckland Central, South, West & Northland
Mob: 021 0360218
Lynne Neshausen: Fieldworker Waikato, Taranaki
Mob: 029 7736662
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Moira Young: Fieldworker Wellington, Nelson/Marlborough
Mob: 021 02784494
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MND ASSOCIATION OF NEW ZEALAND INC.

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

Please contact us:

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

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
BlueWaters COMMUNITY TRUST
COGS Community Organisation Grants Scheme
NZ Lottery Grants Board TE PUNA TAHUA
Four Winds FOUNDATION LIMITED
Pub Charity
THE LION FOUNDATION Here for good!
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- Vasavour Charitable Trust
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