ISSN 2357-173X AUTUMN 2014

mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

Contents

Motor Neurone Disease (MND) is a condition affecting the nerves that control muscle movement resulting in weakness and paralysis. MND is also known as ALS and Lou Gehrig's Disease. There are various forms and so each individual experiences MND differently.

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

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

Pharmac approve funding of Rilutek (Riluzole)

THE MND ASSOCIATION has lobbied strenuously for this drug to be government funded in New Zealand since that has been the case overseas for many years. **We were delighted to hear that Rilutek has now been approved by Pharmac is now available in New Zealand upon prescription by a Neurologist or Respiratory Specialist**.

Rilutek is the brand name of the drug Riluzole supplied by Sanofi Aventis in New Zealand. This medication is not indicated for all types of MND and is not suitable for everyone. Various criteria apply including having a diagnosis of the ALS (Amyotrophic Lateral Sclerosis) form of less than five years duration.

Trials in people with ALS showed an increase in survival of approximately 3 months – a small but real benefit from taking the drug.

It is important to appreciate that the disease will continue to progress despite taking this treatment but that the rate of decline has been proven to be slightly slower in some people taking Riluzole. Not everyone tolerates the treatment well and regular blood tests are recommended to check for adverse effects.

Practically, this will mean that most individuals in NZ recently diagnosed with ALS will be eligible but this needs to be discussed with your specialist. The treatment has a small part to play in management of MND. Other treatments, especially non-invasive ventilation in suitable cases, have a greater effect on survival.

For more information see our website www.mnda.org.nz
Discuss with your Neurologist or Respiratory Specialist whether this treatment may be right for you.

24th International Symposium on ALS/MND

THE 24TH INTERNATIONAL SYMPOSIUM ON ALS/MND held in Milan, Italy in December last year was described as the most successful to date with over 950 scientists, clinicians and healthcare professionals coming together.

This annual event provides an opportunity for the best international minds involved in research, care and management of people with ALS/MND to share their knowledge in the pursuit of best practice, treatments and hopefully eventually cure and prevention.

Feedback from Milan

Kate Moulson, one of our Fieldworkers, was fortunate in securing funding to attend both the Allied Health Forum and the Symposium and returned enthusiastic about our practice in New Zealand being “in step” with worldwide thinking on MND. Italy in December is not quite what we have in mind when we envisage pasta and wine under the trees but being a South Island girl, Kate was well equipped with warm clothes. Kate gives us her impressions from the interesting discussions, presentations and posters:

Kate Moulson

NIV (Non Invasive Ventilation) such as BiPap

Several presentations indicated a significant increase in the use of NIV and a trend to introducing its use earlier along with discussion around when and how to reduce and withdraw its use.

Caring for ourselves whilst caring for others

An ongoing theme important for families, carers, health professionals and service providers to be mindful of and remind each other is central to sustaining quality support to those living with a chronic condition.

Co-ordination of services

The NEMO Centre in Milan, a private facility specialising in neuromuscular illnesses including MND, presented on the Nurse Coaching concept – a role that is being used at the centre which Kate found to be a similar role to that of the Clinical Co-Ordinator recently introduced in the Canterbury/West Coast region and the Clinical Nurse Specialist in the Waikato DHB area.

Swallow assessments

Interesting informal debates were held over the use of assessments such as videofluoroscopy, cough tests etc. in the context of MND – are they necessary, what do they contribute to management?

Children with parents with MND

One of the best papers was about communicating with children who have a family member with have MND. Useful websites can be found at <u>www.als411.ca</u> and <u>www.aacy.org</u> and key messages of this talk were:

- Children will always remember **how** they were told that their parent has MND so it helps if the parents come from a place of strength.
- It will change the child forever – but that change is not always bad and good can come from it.
- Keep the lines of communication open.
- Avoid saying “everyone is going to die” to soften the blow.
- Let children know that at the moment there is no cure but there are lots of really good doctors/scientists working on finding a cure.

Cognitive and psychological changes and MND

The psychological and emotional impact of MND is well recognised and for some with this condition there are measurable changes to ability to problem solve, show empathy, and think flexibly. The Edinburgh Cognitive and Behaviour ALS Screen is being used to measure these changes and recognise the affect they have on family and carers and quality of life.

The value of planning ahead was discussed in the form of advanced care planning processes, advanced directives, and health care proxies to provide for the best management led by the wishes of the person with MND and their family.

“It was encouraging to find that despite the distance between us, around the world we are having similar thoughts and developing services along the same lines to address the needs of people living with MND. The Symposium provides a wonderful opportunity to compare notes and collect the best ideas to improve services globally.”

“Most importantly to all of those who provided financial assistance to enable me to attend this event, I can’t thank you enough. The knowledge I have gained will have such practical application in my work and that of those I work alongside.” Kate

To read more from the Milan Symposium:

<u>http://www.mndassociation.org/research/International+Symposium/Past+symposia/Reports+from+Milan+2013</u>

International Alliance of ALS/MND Associations

OUR CONGRATULATIONS GO TO CAROL BIRKS, National Executive Director of MND Australia on her appointment as Chairperson for the International Alliance. We are looking forward to meeting with Carol and David Ali, President of MND Australia when they visit New Zealand in May and will be meeting with Grant Diggle our National Manager and our Council.

The International Alliance website has a directory of member associations around the world – a very useful reference for those with family with MND overseas or planning to travel. <u>www.alsmndalliance.org</u>

Carol Birks,
MND Australia

"Don't dilly-dally – The meaning of life is life itself, live it as fully as you can." Mike Kyriazopoulos

I was diagnosed with MND in January 2013. After the initial shock I decided to start on the novel I had long been planning – which may need to be shortened to a novella in the light of MND.

Mike and wife Jo at the launch of his book

THIS WAS AN INTENSELY hectic period; the onset of my condition was so rapid that the occupational therapists could barely keep up; there were untold practicalities to sort out, like writing my will and power of attorney; and lots of great events too, like family and friends visiting from overseas and my wife and I gaining New Zealand Citizenship. Researching the story was my first task, since the setting for the book was World War 2. I made handwritten notes for as long as I could hold a pencil, thereafter, I used the voice recorder on my mobile phone. Once I was ready to start writing, I used a software programme called 'Mac Speech Dictate International' which at times is intensely frustrating, but the key is perseverance. By the time I got round to editing the text my condition had changed and I could no longer use this dictation software and was dependent on dictating the changes to my wife, Joanne.

Because I had been told by the specialist that I had only "months" to live, I was anxious that I may not get to see my book in print but determination won through and I was elated to see *Cloudy Sunday* published in October. We held a book launch party at home with friends which was a great celebration.

Sometime after the launch I began to lose my voice which was most depressing but by focusing on new projects and with the help of an eye-gaze Tobii computer device provided by Talklink, I managed to find ways to communicate and shake the blues loose.

My advice to MND'ers who have a dream to pursue is:

"Don't dilly-dally! Due to the unpredictable nature of this disease, no one can give you anything other than a guesstimate of your time left … so make sure you have a plan B in case like me you surprise everyone by achieving your goal prior to keeling over and need a new project!"

Cloudy Sunday by Michael Kyriazopoulos

Set during World War II, this beautifully written novella follows the story of Tuatahi, a young Maori man from the East Cape of New Zealand through his enlistment in the Maori Battalion and deployment to Greece to fight the invading Nazi forces on the slopes of Mt Olympus.

An excellent short read, *Cloudy Sunday* is available in paperback for $12+pp – order by email cloudy.sunday@outlook.com

Kindle version is available to buy on Amazon.

Sailing the High Seas – despite MND

RECEIVING A DIAGNOSIS OF MND certainly leaves people all at sea, perhaps even feeling like they are drowning a bit – but with support it is possible to not only come up for air but to embrace new experiences and relationships. Around 8 years ago Lawry Bassett received a diagnosis of Motor Neurone Disease and along with it the news of reduced life expectancy and increasing disability. However, Lawry has never been one to do what is expected of him and has steadfastly refused to allow MND to rob him of quality of life. His latest challenge was to join the type of 10-day cruise most of us would think twice about – he crewed on the Lord Nelson Tall Ship on a trip from Auckland to Opua.

The beautiful Lord Nelson is equipped to enable people with a range of disabling conditions to test themselves to the limits. On land Lawry often needs a walking frame and wheelchair to support his mobility – at sea, despite the challenges of MND, he managed to climb the mast!

"Once under sail I was barred from using my walker on deck, as stability was of concern, so to my frustration I was confined to a wheelchair; I managed to get around OK except the companionways do not allow both sets of knuckles to pass simultaneously, so I left this ship looking like a bare-knuckle fighter!"

Lawry returned with many an interesting tale to tell from his personal "Ship's Log" and extends a special thanks to those who assisted in fundraising to make this trip possible.

Environmental factors & MND – is there a link?

THE MASSEY UNIVERSITY MND RESEARCH PROJECT is still in progress investigating the relationship between MND and a range of known or suspected occupational and environmental exposures. The research team share with us what they already know:

Environmental Factor	Anecdotal evidence	Substantiated evidence
Pesticides	"Evidence seems to be hardening" but no current indication which pesticides implicated.	? 88% increased risk
Smoking		40% increased risk
Electromagnetic field exposure	ELF (Extreme Low Frequency)	? 40% increased risk
Alcohol		Reduced risk
High BMI		Reduced risk
Head Injury		No association
Infection		No association
Inflammation		No association
NSAIDS – non steroidal pain and inflammation medications such as aspirin, ibuprofen etc.	Suggestions these medications might even protect against MND	No evidence
Sport & hard physical activity	Some indication MND occurs more in sports people	No evidence

The project continues to need candidates with MND to complete the questionnaire and contribute to the data being collected and analysed for an international study. **If you have not done so already please consider taking part**. You will find an information pack in the MND Information Kit we provide or contact Dr. Naomi Brewer and the researchers directly: Dr. Naomi Brewer, Massey University, Wellington, Ph 04 801 5799 Ext 62442 or email N.Brewer@massey.ac.nz

New Zealand Applied Neurosciences Conference 2014

NZANC
RESEARCH TO PRACTICE

THE BI-ANNUAL NEW ZEALAND APPLIED NEUROSCIENCES CONFERENCE, (NZANC) will be held this year, 18–20 September 2014, at the AUT North Shore campus in Auckland.

This unique conference brings together all aspects of expertise in Applied Neurosciences, from the neuroscientists, nurses and clinicians to those involved in the rehab, care and study of both epidemiology and individual neuroscience. We have an impressive field of international speakers including Professor Amanda Thrift, Professor Jaideep Kapur, Dr Audrey McKinlay and Dr Ralph Greenspan, all offering a variety of talks on the topics of strokes, epilepsy, brain trauma and brain mapping.

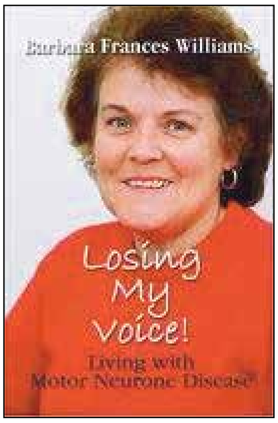
Registration and Call for Abstracts now open: http://nzanc.aut.ac.nz/

Winter is on its way

Flu and pneumonia vaccinations are worth considering as winter approaches.

Ask your GP/Specialist whether this is something you should consider.

Time to read



Losing My Voice
by Barbara Williams

Barbara was a respected Medical Researcher, Nurse and daughter of one of New Zealand's particularly well-known Prime Ministers – Sir Robert Muldoon. Diagnosed with MND in 2004, Barbara wrote her book to share how she continued to lead a very productive life whilst managing the progression the condition. For Barbara the disease affected her speech and swallowing early and she describes her experiences with tube feeding.

Her book can be purchased at: www.losingmyvoice.com or borrow a copy from your local Fieldworker or Branch.

Taking a break – what help is available?

Respite – take a break.
Definition – noun: "a short period of rest or relief from something difficult"

CARING FOR ANOTHER PERSON IS CHALLENGING. Being cared for is challenging too. Taking a break regularly is important for physical, mental and emotional well-being. Planned respite supports relationships and makes the goal of remaining in your own home achievable.

The Ministry of Health provides two types of funding to help carers have a break: Carer Support and Respite Services.

Carer Support

This is a subsidy towards the cost of paying someone to stand in whilst you take a break; it generally provides only a contribution towards the full cost – you may need to 'top-up' the payments. You can choose whether to pay a carer to come to your home or use relief care provided in a setting such as a rest home.

Q. Who is eligible?
A. Full-time (4 hours + per day) unpaid carers of people with a disability are eligible.
You don't have to live with the person you support, as long as you are their main carer and responsible for their on-going care.

Q. Who is not eligible?
A. You will not be eligible for Carer Support if the person you care for is in residential care or paying for full-time care. Carer Support is not available for short-term convalescent needs.

Q. How do I access Carer Support?
A. An assessment is needed for both the carer and the person cared for to confirm you qualify and determine how much you are eligible for. A referral needs to go to your local Needs Assessment Service Coordination organisation (NASC). Talk to your GP, Fieldworker or others involved in your care to arrange this or contact them yourself.

Q. What do I get?
A. The NASC Needs Assessor will allocate you a number of Carer Support days per year to use for a break. These need to be used within the year and cannot be carried forward. Generally the allocation is reviewed annually, however, you can ask for a review if your needs change.
The subsidy is flexible, so you can decide how you take your breaks. This does mean you have to make your own arrangements but your Needs Assessor will talk you through your options:

You might use the subsidy towards respite in a care facility
— Residential or day care

You might choose to have carers come into your home
— You can pay informal carers such as friends or family – but not the parents and partners of the person being cared for or any other family members living in the household.

You can pay formal carers, employed by homecare agencies, if these are available in your area.

Q. How does payment work?
A. You complete and return a claim form after the services are provided. You will be advised of the payment rate by the Needs Assessor and how to process a claim.

Respite Services

The other type of support is Respite Services – also known as formal out-of-home care. These are community-based services, such as rest homes, contracted by the Ministry of Health to provide this service.

Q. How do I access Respite Services?
A. As with Carer Support accessing Respite Services requires assessment by a Needs Assessor from the local NASC agency. The Assessor will check your eligibility and then work with you to identify what services best meet your needs. The amount of funded respite available to you is based on your needs and availability of local services. Respite is often planned to occur on a regular basis, but is also available in times of emergency or unforeseen event.

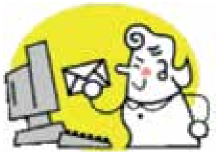
Different provision applies for people aged under 65 years and those over 65 years.

Each District Health Board contracts one or more NASC organisation and there are regional variations in processes.

For more information:

- Talk with your GP, Health Professional or Fieldworker.
- See the Ministry of Health website **www.health.govt.nz/disability** or call 0800 373 664.
- Find a local Needs Assessment Service Coordination (NASC) organisation at: **www.health.govt.nz/disability**

Article reproduced & modified with permission from Parkinson's New Zealand



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

You can:

- send your new email address to: admin@mnda.org.nz
- let your local Fieldworker know
- ring National Office on 09 624 2148

Muscle cramps

Pain is not intrinsically a part of MND, but as nerves break down and muscle tone changes secondary symptoms such as joint pain and muscle cramping occur for some. If you are experiencing pain do discuss ways of managing it with your GP, Therapists, Specialists and keep in mind the pain may be related a condition other than MND.

How do muscles work?

Skeletal muscles in the body are the muscles that are affected by cramp and dystonia. These muscles are the mechanism that allows our body to move. The movement is created when pairs of muscles work together, one muscle in the pair will contract while the other stretches causing the desired movement. To reverse the movement the muscle that had contracted stretches while the stretched muscle contracts. Many of our body's movements are created by groups of muscles, not just one pair, stretching and contracting together to perform the movement we require.

Muscle cramps

A muscle cramp is a sudden and severe pain that occurs when a muscle tightens causing it to shorten. Usually, the pain associated with muscle cramp is short lived (lasts for several minutes then eases slowly) and, if repetitive, this generally only lasts for a few days until the muscle recovers from the cause of the cramp.

What causes muscle cramp?

Cramp has a number of causes, some of the main causes are

- Lack of movement – muscles become less elastic or flexible causing cramp.
- Rest cramps – this cramp is very common especially in older adults. Rest cramps often occur during the night and can be painful and disturb sleep. The cause of rest cramps is unknown. Often this cramp is initiated by making a movement which shortens the muscle. Rest cramps in the calf muscles are common and may occur when pointing your toe while lying in bed.
- Prolonged exercise- after you have undertaken a sustained activity that your body may not be used to (for example taking up a new exercise or a big day gardening) you may suffer from cramp over the next day or two as your muscles recover from the activity.
- Dehydration or a lack of electrolytes – muscles are considered 'electric' tissues in the body. In order to move, muscles require sufficient amounts of certain ions. Many of these ions are carried in water. Where there are insufficient ions the muscles can't contract properly and this can cause cramp.

What parts of the body are affected?

Cramp is more likely to occur in the muscles of the arms and legs but can occur in almost any muscle in the body.

What treatments are there?

- Stretching and massaging the affected muscle.
- Applying heat or cold packs or a topical heating rub may help to relax the muscle.
- Medications may be suitable for some forms of MND but not all.
- Exercise: a physiotherapist can give you exercises which may help. Excessive exercise may increase the cramps.
- Ensuring you drink plenty of water and being more active may also help with muscle cramps.
  Item 6b

Soap and potato – could they be remedies for cramp?

Some say that putting a bar of soap or a potato in your bed is a remedy for cramp. Some insist it has to go in a brown paper bag, some say put it in a sock – several people have reported relief from cramps using this method. ***Please don't ask us for the research to back this one up!***

Free health advice when you need it
Healthline
0800 611 116
www.healthline.govt.nz

Healthline is a telephone health information service run by the Ministry of Health for all New Zealand families. It is a free service. The service is staffed by registered nurses who can give information and advice to help you decide on any action you might take. Phone 0800 611 116 for free 24-hour health advice – within NZ.

Interpreter support can be available via Language Line for calls made Monday to Friday from 9am to 6pm. Outside these hours, Healthline will use other interpreter services as far as possible but it may not be possible to locate an interpreter in a particular language at short notice.

Healthline does not replace the health professionals who know you well.

It worked for me … some of the solutions people have shared with us

The smartest biker in town

TREVOR IS MOST IMPRESSED with this his new toy. Given that his upper body strength and upper limb function is good but his legs and energy levels let him down at times he was looking for something that would allow him to be out and about without using a wheelchair – this nifty bike hit the spot. The TravelScoot folds down and is light to lift into the boot of the car; getting your travel scoot proficiency licence takes a bit of practice and you need reasonable strength in your hands but for Trevor it's a winner – so we now need to find him some jeans and a leather jacket!

For more information and to see the TravelScoot in action go to http://travelscootnz.co.nz/ ring: 0800 272 668 or email: daniel@travelscootnz.co.nz

Cuddle Buddies – travel pillows, body pillows

CUDDLE BUDDIES have a range of memory foam products such as travel pillows and body pillows that can be used to provide support for more comfortable positioning in bed or in a chair.

www.cuddlebuddies.co.nz

Headmaster Collar

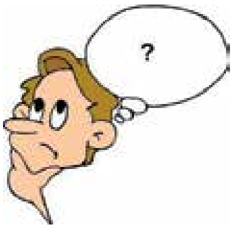
THE HEADMASTER COLLAR was designed specifically for people with MND (ALS/Lou Gehrig's Disease), MS or Arthritis to provide safe and comfortable head and neck support. Discuss this with your physiotherapist is you think you may benefit from this kind of support.

Wireless doorbells

READILY AVAILABLE in hardware stores make great personal alarms for low cost around the home indoors and out.

Boccia (Bo–tcha) – have you heard of it?

A SKILFUL, EXCITING AND STRATEGIC sport that is truly inclusive and manageable for those with any level of physical skill or impairment. Boccia can be followed through to paralympic competition level and is gaining momentum across New Zealand. Local clubs exist from Dunedin through to Northland and welcome new members and supporters. For more details see their website: **www.boccia.org.nz** or ring Luke Morris 0800 503 603.



Have you thought about?

- Making a Will
- Arranging Powers of Attorney
- Leaving a key and contact phone numbers with a neighbour
- Getting a personal alarm
- Getting a mobility parking permit
- Discussing a care plan to suit your needs for the future
- Registering with the Emergency Text 111 service: **www.police.govt.nz/111-txt**
- Keeping a set of contacts, directions, details of your condition on the fridge/noticeboard/by the phone for emergency use
- Total Mobility Schemes subsidise fares if you have to use taxis rather than public transport.
- Checking your Life Insurance policy – some provide for early payout in event of serious illness.
- Talking with people about what kind of care your prefer – ask about Advanced Care Planning
- Talking to WINZ about Invalid benefits and any other help you may be eligible for.
- Small pieces of equipment can make life easier – ask your Occupational Therapist, your pharmacy may have a catalogue, the local Disability Resource Centre will have a stock or look online. **www.disabilityequipment.co.nz**

Around the Country

Once upon a time … the MND Association had several local Branches around the country; groups of people passionate about raising awareness of MND and focussed on getting needs met and raising funds to support the costs of providing a local fieldwork support service. Over time branches have closed and we now have three very active groups of people to whom we are very grateful – Waikato, Bay of Plenty and Wellington. If you have any interest in establishing a group in your area or would like to be part of an existing group please do get in touch.

WAIKATO BRANCH

Te Uku Wind Farm Walk

THE MND ASSOCIATION VEHICLE currently used by our local Fieldworker, Lynne, is now 17 years old and has done 180,000km so the Branch is focussing on raising funds to go towards a replacement vehicle more suited to cover the Waikato to Taranaki territory Lynne covers. A walk to the Te Uku Wind Farm attracted over 30 walkers and 2 cyclists for the 18km return trip across the Wharauroa Plateau. It was pleasant, mild day for the first day of autumn and an enthusiastic group ranging in age from 11 to 80+ years took around 2 hours to walk up the track. After admiring the view and the turbines the group was pleased to have a break at the top for a picnic lunch and a sausage sizzle provided by Tom, Zane and Rachel Jowsey. Everyone agreed when they arrived back at the car park that it had been a most enjoyable day. At this stage we have received over $2500 in donations but know that more donations have been promised. A big thank you to all who took part and gave donations towards a new vehicle.

Off to the wind farm – Barbara and Mary put their best foot forward

Helen Palmer

Christmas lunch at Woodlands

CHRISTMAS LUNCH AT WOODLANDS seems such a long time ago now but thanks to the efforts of Branch Committee and members $1000 was raised by their Christmas Raffle and a lovely lunch was enjoyed by all including people joining the group for the first time.

Mary & Barbara counting the cash

OUR CONDOLENCES go to Alice Robertson on the death of her husband, Denny, a long term supporter of the Waikato Branch and dedicated carer to Alice. Denny's ability to keep us on our toes will be missed.

WELLINGTON BRANCH

THE WELLINGTON BRANCH arranges regular fundraising events but our committee is getting smaller so we have been unable to organize as many events as we would like. **We would be very happy for new members to join us any time**.

Our diary from last year shows that the **June/July period was a busy time of the year coinciding with MND Awareness Day which occurs on June 21st**.

- Annual film evening at the Pauatahanui Lighthouse Cinema which was sold out as usual.
- The Armstrong Run around the Bays with a number of people in wheel chairs being pushed around the course.
- A launch at Te Papa of the late Neil Ladyman's dream of providing a gift pack to newly diagnosed people with MND to help soften the challenge of receiving a diagnosis.
- Annual Memory Tree Celebration at Paraparaumu where we acknowledge those with MND both past and present. It was too wet and windy to light candles so they were lit in Annemarie's Cafe, Sopranos where she hosted a luncheon for all who attended.
- Railway Station Collection. A group of hardy souls on another very cold, wet and windy morning in Wellington gathered at the railway station with buckets and banners and encouraged people to donate and handed out packets of cornflower seeds in appreciation.
- A very successful raffle was organized by Lorraine whose husband has MND.
- The *I Am Breathing* documentary film was screened at the Cuba Lighthouse Cinema as a joint effort with the Mary Potter Hospice and the proceeds from the raffle were shared.
- We continue to sell socks and cards and give out book tokens.

BAY OF PLENTY BRANCH

THIS BUSY GROUP continues to meet and would welcome new members to become involved. "We only meet six times a year and really need some extra help. You can put in as much or as little time as you can afford so we would encourage anyone with an interest in MND to contact Paula at ticktocks@slingshot.co.nz".

Fundraising

Ed and Sam Hall in NY

ED AND SAM HALL ran the New York Marathon wearing our logo! Our thanks to Ed and Sam for raising over $10,000 finishing the New York Marathon in 4hrs 11min 57 seconds and taking our logo overseas. ***A great effort and amazing outcome – thank you.***

MOTHER AND SON, Annette and Brendan Wright took part in the Lake Taupo Cycle Challenge raising over $8500 in memory of dad/husband Kevin who had ridden this course 12 times himself, prior to developing MND, and loved it. Annette was competing for the 7th time and Brendon reports his mum finished the one lap race of 160km "in a very sharp time" of 7hrs 20mins. Meanwhile, Brendan completed the two lap race, riding 320km through the night in 10hrs 52 min to finish 17th. Our thanks to the whole family involved in supporting this effort.

THANKS ALSO to Brett Smith who raised nearly $1000 for us in the same event. Brett's dad has MND and lives in Invercargill. ***Well done Brett and thank you.***

BEATLES NIGHT FUNDRAISER – Takapuna Association Football Club in Auckland has a long standing association with Motor Neurone Disease with members and relatives having experienced the challenges of MND. Brian Giblin, Mark Green and the team organise an annual Beatles Night event to raise funds for local charities and we were fortunate to be a beneficiary this year. The event is anticipated each year and very well supported with some great outfits and dance moves coming out of the closet. Our thanks go to Takapuna AFC and we are working on our outfits for next time!

Mark – the 5th Beatle

Hospitality Textiles

MANY THANKS for your loyal support in memory of Sue.

Left: Annette and Brendan Wright; right: Brendan cycled 320km

Hello from our new National Manager

THIS IS MY FIRST OPPORTUNITY to write in the Newsletter since taking over the role of National Manager from Ian Mathieson just after the last Newsletter was published. Since then I have met with a number of clients and their carers and families at the AGM held in Tauranga in October and also at the Waikato Branch Christmas party.

I filled in for Ian for 5 months in 2012 when he took extended leave to travel around Europe, so I was not unfamiliar with the role and I have been ably assisted in my first few months by Beth Watson and Ray Hall and also Lin Field and Gwynyth Carr who have shown me the ropes.

A little about my background: I am a Chartered Accountant and Chartered Secretary and whilst I worked in public practice for a time, I have spent most of my career in sales marketing and senior management in the motor industry and then as Chief Executive for the professional body of Chartered Secretaries. Several years ago I decided to work in the not-for-profit sector to give back some of the business experiences I had gained and was the Board Secretary for The Royal New Zealand Foundation of the Blind and then Manager of the Parkinson's Society before coming to this role.

Increasingly even small not-for-profit organisations like ours are being required to demonstrate high standards of governance and management and given the amounts of money that pass through these organisations, many believe this is not unreasonable.

I am looking forward to working with our Fieldworkers who do such an important job, as emphasised in our 2013 Client Satisfaction Survey where 95% said the Fieldwork Service was either extremely or very important to them.

Grant Diggle

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

Lin Field: Auckland North and Northland.
Mob: 021 2303038

Linda Oliver: Auckland Central and South.
Mob: 021 0360218

Lynne Neshausen: Waikato, Taranaki.
Mob: 029 7736662

Graham Jones: Bay of Plenty, Rotorua, Gisborne, Hawkes Bay.
Mob: 029 7775588

Reima Casey: Manawatu, Wanganui.
Mob: 029 7773331

Moira Young: Wellington, Nelson/Marlborough.
Mob: 021 02784494

Kate Moulson: West Coast, Canterbury, Otago, Southland.
Mob: 029 7779944

Reima Casey

Gwynyth Carr

Linda Oliver

Lin Field

Graham Jones

Lynne Neshausen

Moira Young

Kate Moulson

Letter from the President

TODAY I READ ABOUT LABYRINTHS and their contribution to holistic health care. I read that there is no right or wrong way to walk the labyrinth: some approach it head on and some benefit from watching how others navigate the paths. Then the writer became a little philosophical and said that on the road of life it is often challenging to determine what our next step might be.

Sort of like living with MND really. There is no right or wrong way. Some of you face the challenges head on yourselves; others of you appreciate learning from each other, the health care workers in your team and our MND Fieldworkers.

Neil Ladyman was a gentleman who faced MND head on. I'm certain he would love to think that others learnt from "watching" him. It was important for Neil to reach out to others. And he certainly did that in so many ways. He made video clips – see YouTube http://www.mnda.org.nz/awarenessday.asp?media; he shared his stories in our last newsletter and he "talked" with many of you through email. Neil felt great compassion for folk with MND in remote and rural areas. He knew that living in a well serviced city with MND was challenging enough, let alone living in the country far from services and supports. One of his last outreach activities was to remote, rural people – he fundraised for seventy surprise seasonal packages for those people. One way or other we heard from many of you how much you appreciated this so we know Neil was right on target with this idea.

On 16 December Neil passed away. Rest peacefully Neil.

Although Neil's life has ended, his legacy to MND will live on. He coached me in ways the Association too can reach out more and I want to make that outreach his legacy to our Association.

We had our first National Council meeting for 2014 in February. Perhaps of most interest to you all is that we agreed to develop a Facebook page – thanks Anna Chalmers for guiding (and cajoling) us on this. Soon we will be able to easily share what's on and what's coming up – Facebook pages seem to work well for groups like us so this is an exciting initiative.

Waiho i te toipoto, kaua i te toiroa
Let us keep close together, not wide apart

Beth

MND Awareness Day/Week/Month

June 21st is international MND Awareness Day.

EVENTS WILL HAPPEN around the country and around the world raising awareness. Do let us know what is being planned in your area.

mnd
motor neurone disease
association of new zealand inc

Cornflower Remembrance Field

SOME LIKE THE IDEA of leaving a personal memorial message on our Remembrance Field to mark their donation – there is no minimum amount.

To take a look go to our website www.mnda.org.nz. Scroll to the bottom of the page and follow the link to see the cornflowers already growing.

A sincere thanks …

TO THOSE WHO SUPPORT OUR WORK IN SO MANY WAYS:

- **Thanks to** those who do baking, photocopying, sorting, folding of newsletters, shaking of money boxes, climbing, cycling, swimming and sending us encouraging messages.
- **Thanks to** the volunteers who keep the Branches running and the volunteers who are our Council.
- **Thanks to the organisations** who approve our funding applications.
- **Thanks to the individuals & families** who donate and remember us in bequests.
- **Thanks to the staff** who "keep the show on the road".
- **Thanks for support from minimum graphics and Sue Stewart** without whom you might not be reading this newsletter!

… and of course thanks to those we may have forgotten to list!

mnd
motor neurone disease
association of new zealand inc
REGISTERED CHARITY CC35320

NATIONAL COUNCIL

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

FIELDWORKERS

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

NATIONAL OFFICE

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

MND ASSOCIATION OF NEW ZEALAND INC.

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

Please contact us:

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

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

MND Association Funders

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

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

BlueWaters Community Trust

NZ Lottery Grants Board
Te Puna Tahua
Distributor of NZ Lottery Profits

First Sovereign Trust

the Southern trust
Funding Your Community

Pub Charity

The Trusts Charitable Foundation Inc

Ministry of Health
Manatū Hauora

The Trusts Community Foundation

Eastern & Central Community Trust
Helping fund a better community

Community Trust of Southland
Te Pou Arataki Pounamu o Murihiku

Rotary Club of Newmarket
District 9920 · New Zealand

COGS
Community Organisation Grants Scheme

Four Winds Foundation Limited
Gaming Grants for Your Community

Mainland Foundation
Proud to Support Our Community

The Lion Foundation
Here for good

Thomas George Macarthy Trust
Managed by Public Trust
Established 1912

Infinity Foundation Limited

telecom

Mt Wellington Foundation Limited