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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

MND Association – Brand new website

The MND Association has just launched a brand new website. Visit **www.mnda.org.nz** and see for yourself.

The blue cornflower

The blue cornflower is the international flower of hope for motor neurone disease. The Cornflower symbolizes courage. It can withstand both frost and drought and its strong blue colour never fades, no matter what it faces. Like the cornflower people with MND show tremendous courage and strength of character to cope with this most challenging of diseases.

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Research News.

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Organisations providing funding support

Kia ora and welcome to our website.

Our MND Association is a small not for profit organisation whose main purpose is to help support people with motor neurone disease and their carers. We have fieldworkers around the country who provide information, advocacy and emotional support and help people have access to the right health services at the right time. This website aims to provide useful material about the things that people affected by MND are likely to want to know, like information on MND, the latest research on MND, and where to go for help and support.

The Help Us section is where anyone can help support the work of the Association.

You are not alone.
Join the online MND community

MND Newsletter
Read our most recent newsletter

Helping people living with motor neurone disease

THE OLD WEBSITE HAD DEVELOPED QUITE A FEW PROBLEMS and it wasn't offering the type of information our visitors are looking for. So it is out with the old and in with the new.

The new website provides useful material about the things that people affected by MND are likely to want to know, such as information on MND, the latest research on MND, and where to go for help and support.

There is a lot of information on the site about MND. We know that one of the first things people do when they find out they have MND is to go online to learn more about the disease. Often the information they find is not appropriate and can be disturbing.

Well now they can turn to the new MND Association site for the majority of information they are looking for.

The site covers in some detail, subjects such as, What is MND? Risk of developing MND, Could I have MND?, How do you diagnose MND?, Types of MND, MND symptoms and progression of MND.

We understand that people with MND, their family and carers are often very interested in what's happening with research into motor neurone disease. An important part of the new website is about research, dedicated to keeping you up to date with the latest MND research from around the world.

MND Cornflowers Remembrance Field

REMEMBER YOUR LOVED ONE WHO HAS PASSED AWAY FROM MND, ON A SPECIAL MEMORIAL, ON THE NEW MND WEBSITE.

We have developed a cornflower remembrance field where you can choose a cornflower in their memory with your personal memorial message. This is a wonderful new way to remember your loved one and to support the Motor Neurone Disease Association at the same time.

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

New Zealand Research Study on MND

THE CENTRE FOR PUBLIC HEALTH RESEARCH AT MASSEY UNIVERSITY IN WELLINGTON IS WORKING ON AN IMPORTANT RESEARCH PROJECT ON MOTOR NEURONE DISEASE. The project is headed by principal investigator Dr David Mclean who was guest speaker at the last AGM.

The research project is titled *Occupational and Environmental Risk Factors for MND*.

Very little is known about the causes of Motor Neurone Disease (MND). This study aims to investigate the relationship between MND in New Zealand and a range of known or suspected occupational and environmental exposures. The study has progressed to the stage where the next step is interviewing people who have motor neurone disease.

It is in the interest of the MND Association to support local research on MND and as such we are strongly committed to facilitating the interview requirements of this study. To give the study statistical relevance it will be necessary to interview as many of our MND clients as possible.

Massey University have a research nurse who will be conducting the interviews with our MND clients. Interviews will be preferably conducted face to face or alternatively by telephone. There will be questions about education, medical history, about lifestyle factors such as smoking and alcohol use, residential history, ethnicity, hobbies and occupations. Interviews will take between 45 minutes to 1 hour to complete.

If you are interested in taking part in this important study please contact your MND fieldworker.

MND Awareness Day

THURSDAY, JUNE 21 IS MND INTERNATIONAL AWARENESS DAY AND WE ARE GOING TO MAKE IT A BIG DAY FOR MND IN NEW ZEALAND.

International Awareness Day is based on the vision of a world free from MND and MND associations all around the world do their best to raise the profile of motor neurone disease. In 2012 we want to play our part and bring MND into focus around our country.

21 June is a solstice – a turning point – and each year the international MND community undertake a range of activities to express their hope that this day will be a turning point in the search for cause, treatment and cure of this awful disease. We have three objectives

1. To raise awareness of motor neurone disease through the media
2. Raise money for the MND Association
3. Mobilise supporters of the MND Association to create fundraising events

MND has a low profile. The disease does not affect many people and the general public are often not aware of the disease or the existence of the MND Association and the great work we do supporting people with MND. MND Awareness Day is our chance to be seen and heard and draw attention to motor neurone disease.

We are starting to prepare a media plan with lots of facts figures and interesting things about MND. **What the media really want to hear about is people and families with experience of MND and a story to tell**. If you have a story you would like to share then we would love to hear from you. Please contact the National Manager on 09 624 2148 or email **mgr@mnda.org.nz**

We are also asking our supporters to take part in a fundraising event to raise much needed money for the MND Association. Everyone has their own ideas, but how about a fundraising morning tea where you provide a trolley of home baked goodies or perhaps a mufti day at work with a donation to the MND Association.

Biked the length of NZ for MND

WE HAVE BEEN FOLLOWING DAVID VISSER AND HIS FUNDRAISING EFFORTS FOR THE LOVE OF HIS BROTHER, FOR SOME TIME.

During Waitangi weekend David Visser completed his goal of riding his motorcycle the length of New Zealand to raise money for his brother Wilf, who has MND and for the MND Association.

David accompanied by his friend Tony Hunt rode from Wellington to Bluff to Cape Reinga and back to Wellington again, completing 4,429km in the process.

Asking David about his adventure he said 'we didn't really have rain on the trip worth mentioning. On the whole the weather was fantastic, brilliant riding conditions'. 'Our best fuel stop was at BP Mana, where about 12 or so bikers joined us along with a team from the Wellington MND Association. Thanks for the encouragement'.

David said he learned two new things on the ride. 'I learned I could have a really good sob, even while riding as I mourned the loss my dear brother is suffering and the second being that Tony and I raced on the same beach in Invercargill where the Fastest Indian movie was filmed and yes, Tony on his Indian, true to the movie, beat me hands down.'

It has been said that there is no love like the love for a brother. 'My brother Wilf is a living testament to overcoming tragedy. He inspires everyone he meets. What more can I say, he's so cool, he's my brother'.

P.E.G. an Alternative Feeding Option

NOT EVERYONE WITH MOTOR NEURONE DISEASE WILL NEED TO CONSIDER ALTERNATIVE FEEDING METHODS. Only a minority of people living with MND have tube feeding; the remainder either do not need it, choose against it or it is not appropriate for their care.

MND affects each person differently and any intervention needs to consider all of the factors involved for any one individual. When the muscles involved with chewing and swallowing are affected by MND, movement may become slow, weak and uncoordinated making eating and drinking difficult and time consuming. For some people coughing can result from food or drink going down the wrong way which can be uncomfortable and distressing and may increase the risk of chest infections.

Changing food choices to thicker drinks and softer food textures, can make swallowing more manageable and paying careful attention to the process of eating and swallowing can also help. Speech Therapists and Dietitians can play an important part in helping people to eat and drink safely whilst enjoying meals and getting adequate nutrition and hydration.

For those who progress to having severe feeding difficulties, tube feeding may be suggested via a procedure called PEG.

Who might be considering PEG?

The specialist team involved with each individual will consider a range of factors before suggesting that PEG is an option. Generally tube feeding options would be discussed before the effort of eating becomes fatiguing or distressing and before there are serious concerns about whether you are getting enough nutrition and fluid. Timing will vary to suit each person's situation and preferences but the procedure cannot be done if the breathing muscles are too weak. **For this reason discussions generally begin well before the tube is needed and PEG is not considered at the end stage of MND.**

Since PEG is performed when the breathing muscles are functioning well enough to cope with the procedure the topic may be raised earlier than you expected; you may be surprised and feel you are currently managing to eat and drink adequately. It is better that the discussion is initiated early enough to give you time to consider your response. **Not everyone offered this intervention will choose to go ahead – it is a personal choice.**

What is PEG?

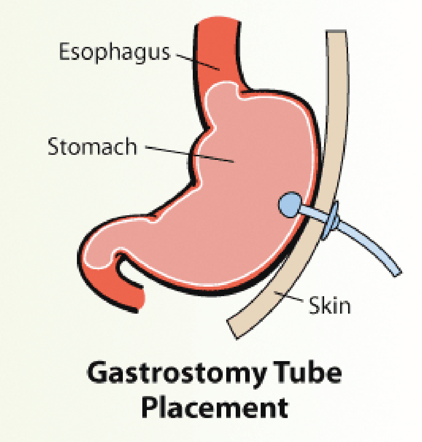
P.E.G. stands for Percutaneous Endoscopic Gastrostomy a procedure which inserts a small tube through the abdomen into the stomach. Specially formulated liquid foods (Ensure, Fortisip) and water go in through the tube to top up or maintain nutrition and hydration. Medications can also go through the tube but not most normal foods and drinks.

Alternative feeding methods will not slow the progression of the disease but for some is an option that contributes to quality of life.

How does PEG help?

- It provides an alternative feeding method to supplement or replace oral feeding.
- PEG feeding contributes to weight maintenance, reduction of fatigue and general well- being.
- It provides a better social outcome for those who prefer not to eat/drink in general company.
- It takes away the risk of food and drink going into the lungs (aspiration) during oral feeding.

What does the PEG procedure involve?



Gastrostomy Tube Placement

PEG is considered a low risk procedure and involves:

- A respiratory assessment to check on breathing prior to the procedure. It is necessary to lie flat on the back for about 30minutes.
- Mild sedation and local anaesthetic are required – the procedure does not require a general anaesthetic.
- An endoscope (camera) is inserted via the mouth into the stomach in order to see where to insert the feeding tube through the abdominal wall.

Barbara Williams with PEG. (Photo by permission from *Losing My Voice*.)

- A night or two in hospital is to be expected along with some discomfort.
- An initial period of adjustment is expected as your stomach gets used to fluid going directly in to it.
- Training will be given on how to manage the PEG tube and Community Nurses and Dietitians will support you living at home.

What does living with PEG involve?

- A flexible tube about the diameter of a pencil comes out from the abdomen above the waistline
- It can be tucked into clothing so that it is not visible and there is no smell.
- The tube needs to have water flushed through daily even if you are not using it for feeding.
- Cleaning and rotating the tube keeps the opening clear – similar to pierced ears.
- Oral hygiene still remains important in order to keep a fresh mouth.
- Showering, shallow bathing and swimming in the sea (not pools and spa pools) are still possible.
- After a few weeks most who have this procedure find they cope well with the routine of caring for their PEG and begin to see the advantages.

▶

Does PEG take away my control?

PEG feeding provides you with a choice between relying entirely on tube feeding or using a combination of both tube and oral feeding. Nutrition and hydration can be increased or decreased as required through the use of the PEG tube. Oral feeding can continue – in a manner your health professional advises to be safe. Some people do not use their PEG regularly for some time after it has been inserted but appreciate having it in place "for peace of mind".

How do I find out more?

If PEG feeding is something you want to know more about please talk with the health professionals involved with your care:

Speech Language Therapists – can assess and advise on safe swallowing strategies.

Dietitians – can advise on maintaining nutrition and hydration levels.

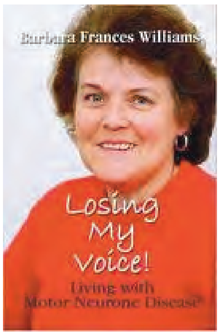
Occupational Therapists – can advise on options when hand function is affected.

GP/Medical Specialists – can advise on whether this is an option for you.

Information is also available by searching for "PEG" on the following websites. Keep in mind details may differ in New Zealand:

- www.mndassociation.org
- www.mndaust.asn.au

Losing My Voice
by Barbara Williams
ISBN: 978 0 473 12488 5



Barbara Williams, daughter of one of New Zealand's most famous Prime Ministers, Sir Robert Muldoon, wrote about her own journey with MND. She describes the range of emotions and challenges and her experience of PEG feeding.

This book is available online from: www.losingmyvoice.com

MND gets behind Brain Days

BRAIN AWARENESS WEEK IS A GLOBAL CAMPAIGN TO INCREASE PUBLIC AWARENESS ABOUT THE PROGRESS AND BENEFITS OF BRAIN RESEARCH. The theme this year was 'brain fitness' and Brain Days around the country gave the New Zealand public a unique opportunity to hear from some of our top neuroscientists and clinicians about their work.

Our fieldworkers provided MND exhibits in Whangarei, Auckland and Wellington, as we see Brain Days as an excellent opportunity to build interest and awareness in MND. Over 280 leaflets on MND were distributed across these three events and we were impressed with the level of interest in Motor Neurone Disease.

Moira Young, our fieldworker in Wellington very much appreciated the support provided by members of the local branch and reported her first experience of Brain Day as most enjoyable. Linda Oliver and Lin Field, Auckland fieldworkers, once again worked the stand in the beautiful Owen Glenn building at Auckland University and Lin also covered the Whangarei day at Forum North establishing some valuable local links.

Every year it is a surprise how many people choose to use their Saturday to learn more about the brain and the events are a valuable way of connecting with the public.

It was also great to talk with people who have had connections to the Association in the past and who were pleased to see MND represented in such a forum alongside the bigger Groups.

Friends of the MND Association

HELP US HELP PEOPLE LIVING WITH MOTOR NEURONE DISEASE.

A Friend of the MND Association is usually someone who has an emotional connection to motor neurone disease through an individual they care about or someone who supports the work of the association and wants to help.

As a Friend we will make contact with you from time to time, by email, giving you the opportunity to make a donation towards a particular project we require funding assistance for. There is absolutely no pressure. You can choose to support the project, or not and the size of your donation is up to you.

Becoming a Friend is easy. All you have to do is visit our website **www.mnda.org.nz** and join up. An email pops back to National office and we will send you back a reply, acknowledging you have just become a friend of the MND Association.

RECOGNISING SUE STEWART AS A FRIEND. Sue Stewart, a Friend of the MND Association, donated $3000 towards the printing costs of this newsletter. Thanks so much Sue.

Featured Fundraisers

Congratulations to three fantastic female fundraisers taking part in challenging events to raise money for the MND Association.

Diane Robinson (right)

Diane is taking part in the TriWoman MINI Triathalon

Diane is taking part to celebrate her good friend Nicola Kissel who sadly passed from MND and to raise some money for the MND Association. Physical exercise and organised sport is not Diane's thing so she is putting herself well outside her comfort zone to take part in the event.

Lauren Godfrey

Lauren is taking part in an extreme fundraising adventure

She is competing in three events, the Kapiti Women's Triathlon, The Wellington Round the Bays and the Kathmandu Adventure Series in the Marlborough Sounds. Lauren (Lozza) has had friends who have been sadly affected by MND and she recognises the wonderful work done by the MND Association and wants to raise some money to help our organisation.

Toni Bean (left)

Toni is the marathon lady

She plans on competing the North Shore half marathon, the full Auckland marathon and the Kerikeri half marathon.

Toni is taking part in this marathon event on behalf of her father who passed away from MND and to raise as much money as possible to support those that are also affected by MND and their families.

The MND Cornflower

THE BLUE CORNFLOWER is the international flower of hope for motor neurone disease. The Cornflower symbolizes courage. It can withstand both frost and drought and its strong blue colour never fades, no matter what it faces. Like the cornflower, people with MND show tremendous courage and strength of character to cope with this most challenging of diseases.

MND team take on Sydney

THE MND ASSOCIATION SENT A SMALL AND ENTHUSIASTIC TEAM TO THE INTERNATIONAL MND SYMPOSIUM IN SYDNEY AND WHAT AN AWESOME EXPERIENCE WE HAD.

The event was held at the Sydney Hilton with over 650 delegates from 38 different countries attending meaning it was too big an opportunity to miss.

The MND Association was able to send a team of five, the National Manager and four fieldworkers for the five days of the symposium. What a worthwhile experience we all had, from networking during the several social events and between the different sessions, to absorbing the huge amount of material presented on MND, to savouring the experience of staying in a high rise in down town Sydney.

The Symposium was made up of three separate meetings. The Ask the Experts session was first up consisting of four 20 minute presentations from well known experts on MND followed by a Q&A session from people with MND and their carers. The Forum was broadcast live on the internet allowing questions from people who were not in attendance.

The Allied Professionals Forum followed next with a full days presentation from non medical health professionals. The Symposium itself ran over the remaining three days, with separate scientific and clinical programmes.

The depth and breadth of information provided was extraordinary and our fieldworkers gained a great deal of professional knowledge on MND both through attendance of the presentations and through discussions with their colleagues.

Our team came back tired from such a full on programme and importantly more knowledgeable and skilled on providing a professional fieldwork service for our MND clients.

MND Association's got the numbers covered

THE MND ASSOCIATION is the national body for people with MND along with their carers and families. As such it is important that we are the authority on MND with accurate and up to date statistics and numbers related to motor neurone disease.

Until recently our methods of capturing this data has not been as accurate as it could have been. The MND Association has now embraced the digital age and all our statistical reporting, provided by our hardworking team of fieldworkers, is completed online with easy-to-use software.

This will provide accuracy for our Ministry of Health reporting and a reliable measure of MND client numbers and trends nationally. Importantly, we now have confidence in our MND statistics reporting, enabling the association to generate accurate, on-going statistics on MND as the national authority on motor neurone disease.

Hints and Tips

HINTS AND TIPS FROM PEOPLE WITH FIRST HAND EXPERIENCE OF LIVING WITH MND

Eating and Drinking

Eating and drinking can become a problem for some people living with MND. Here are some practical solutions that could make a real difference.

Straws

- Using bendy straws and a straw clip attached to glasses and cups gives more flexibility with the positioning of drinks and stops the straw moving about.
- Using straws with a non-return valve (Pat Saunders Straws) reduces the amount of suction required to drink.
- Placing a drinks carton with a straw in it, in a top shirt pocket aids independence.

Utensils

- Drinking soup from a cup rather than a bowl is less effort than using a spoon. An insulated plate or mug will help keep food/drinks warm while you eat at your own pace.
- Using a long handled fork with a serrated edge or using a spoon instead of a knife and fork may help with independence at meal times or use.
- Keep food and drink close at hand with a lazy suzanne turn table.
- Place your plate and cup on a non slip mat to help to prevent unnecessary movement.

Cooking

- When cooking veg's, place vegetables within a chip basket to avoid having to drain away boiling water.
- Making frozen lollipops by freezing fortified, nutritious drinks is a pleasant alternative way of consuming calories.

Chewing gum

- Chewing gum may help to produce saliva, very helpful if your mouth tends to dry up when talking.

Pureeing foods

- Make it easier for you to continue eating your favourite foods by blending them in an electric blender.

Around the Country

BAY OF PLENTY

ON THE 29TH OF FEBRUARY MND WERE THE RECIPIENT CHARITY AT THE ANNUAL TWILIGHT CHARITY CONCERT AT BAYSWATER LIFESTYLE VILLAGE. The event was held indoors due to the uncertain weather conditions, so we all sat in comfortable chairs in the warmth of the lovely entertainment lounge and had our picnics there! The bar was open as well so we literally wined and dined. The Ratana Big Band donated their time and wonderful talents to the MND cause and entertained us royally, firstly with the Silver band selection of Christian and semi-classic tunes – then in the second half, with the Brass, a great selection after the style of the Glen Miller big bands era. It was a toe tapping, hum-along musical feast, thoroughly enjoyed by everyone; we did not want them to stop and we sincerely thank the Ratana Band members for their generosity and kindness.

Di Burt entertained us with a bracket of songs during the band's intermission and finished by singing a very special duet in memory of her partner Rhys with their 3 year old daughter Anahera, a lovely little girl who seems made of music and who not only stole her mother's microphone, but stole our hearts as well!

We know that some of the residents of Bayswater and their families have also suffered because of Motor Neurone Disease and sincerely commend them and everyone else, for their involvement in and commitment to, the lengthy preparations for the very successful and enjoyable 2012 Concert. **At the end of the evening it was announced that the Bayswater Lifestyle Village Concert, with raffles and donations had collected the incredible amount of $1280.00 for motor neurone disease.** It was overwhelming and we members of the Bay of Plenty Branch of M.N.D. cannot thank you enough for such a magnificent contribution to the Association.

BAY OF PLENTY RESUMES SUPPORT GROUP MEETINGS. After several enquiries from clients about a support group, we will be resuming the MND Clients and Carers Support group meetings. We realise that some Carers may have to come on their own and that some family members may also like to attend. Those of you who have lost someone to MND are especially welcome.

WAIKATO

IT WAS THE MOTOR NEURONE DISEASE SUPPORT GROUP'S SIXTH WIN IN AS MANY YEARS when the local group again won 1st prize in the Raglan New Year's Eve annual parade. In an attempt to give other organisations an opportunity to get a slice of the winnings the organisers had three categories this time. However, such was the standard of the MND float that it scooped all three categories, Community, Education/Safety and Sustainable Theme.

Creative talent and months of hard graft by a group of local women and their husbands resulted in the Big Fat Gypsy Wedding float having the "Wow" factor, mainly due to the dedication of chief seamstress, Rosalie Trolove. It was definitely the best float the group have put together yet.

With bride, bridesmaids, flower girls and page boy dressed in brilliant fuschia pink and white the float was a standout favourite with the judges and crowd alike.

The groups other winning themes over the years have been Swan Lake Recycled, Winter Wonderland, Clowning Around, Flower Power and Party Girls.

The group of loyal supporters, plus people living with MND and family members from the wider Waikato Area, have also taken part in the Round the Bridges fun run in Hamilton the past two years to raise awareness of Motor Neurone Disease.

Plans are in progress to organise an event for Global Awareness Day on 21st June, somewhere in the Waikato Region. Once again we will be relying on committee members, clients and our loyal supporters to make this a significant event.

WELLINGTON

FUNDRAISING AT THE PETONE FAIR. The Jackson Street Fair in Petone is an annual event where the whole of Jackson St is closed off for most of the day. There are hundreds of stalls with the road chock full of eager shoppers. Patsy has been organising a stall for MND for some years now and she and Marieke devote the whole day to it with helpers like Anna also joining in.

This year we were very fortunate to have some gorgeous knitting donated to us to sell and it proved very popular – lots of grannies stopped to look at the baby things as well as young mums. Nice to see the craft of knitting still highly valued! Along with the usual socks and cards, we had the walking sticks that Neil sourced – again very popular.

A lot of people stopped because they knew someone who had had MND and often simply made a donation without buying anything at all. As well as fundraising it is an excellent awareness raising event.

NATIONAL COUNCIL

President	Helen Palmer
Vice President	Ray Hall
Secretary	Bruce Stokell
Treasurer	Michelle Knox
Councillors	Beth Watson, Wendy Henderson, Andrew Pardoe-Burnett, Henrik Dorbeck
FIELDWORKERS	Auckland North & Northland: Lin Field Auckland Central & South: Linda Oliver Wellington, Nelson, Marlborough: Moira Young Bay of Plenty: Graham Jones Manawatu–Wanganui: Reima Casey Central North Island: Helen Milloy South Island: Kate Metcalf

NATIONAL OFFICE

National Manager: Ian Mathieson
Fieldwork Support Officer: Lin Field
Administrator: Gwynyth Carr

WAIKATO BRANCH

Helen Palmer, Alice Robertson, Barbara Cameron, Brendan Kawau, Dianne Landon, Val Waters, Judy Chrystall, Judith Bishop, Betty White, Doug Farrow, Aly Timmings

BAY OF PLENTY BRANCH

Jan Fraser-McKenzie, Michelle Knox, Mairi Karl, Geoff Bayly, Janet Hutchings, Lyn Hayson, Athol Newson

WELLINGTON BRANCH

Mary Gibbs, Sheila Reed, Bruce Stokell, Beth Watson, Marlene Casey

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Moira Young joins the MND team

WELCOME TO MOIRA YOUNG our new MND fieldworker for Wellington. Moira joined us in December last year, just in time to attend the MND symposium in Sydney. Moira is passionate about supporting people with MND and is doing an outstanding job with her MND clients in the Wellington region, Wairarapa and Nelson/Marlborough.

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.

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

Thanks to minimum graphics for design and layout of *MND News*.

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