Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter
Issue 85 June 2021

Looking for a rewarding way to make a difference?
Your branch needs you! Volunteer with us?

The Norfolk, Norwich and Waveney Branch is committed to supporting families affected by MND. The Branch committee, care volunteers and other supporters volunteer their time however, there is much to be done and not enough volunteers – can you help? Perhaps you or someone you know has a skill or interest that could support our work? We have highlighted some roles below where we have vacancies but if these don't fit your skill set but you would like to help, we would love to hear from you.

Association Visitors: Do you enjoy listening to and helping people? By giving just a few hours a week you could make a huge impact.

We are recruiting volunteer Association Visitors (AVs) across Norfolk and Waveney. In this role you would maintain contact with people living with MND, their families and carers by phone, email or face to face visits (when COVID-19 restrictions are lifted). The role is a challenging but rewarding one. By offering confidential emotional support, information and help to access the right services and equipment, you can enable people affected by MND to live life to the fullest.

All volunteers undergo training before beginning their role as an AV, and are mentored by Liz Cooper, our Area Support Coordinator.

Judy Burns-Thomson said, *"I have met some of the bravest and most courageous people. Yes, it can be emotional, but the privilege of visiting families in their home and helping them along their journey is so rewarding and worthwhile."*

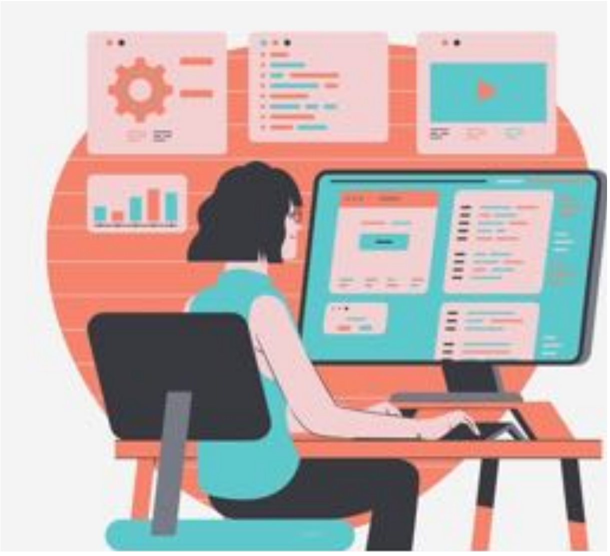
You can find our more about the AV role and apply online at https://bit.ly/3bmUUtb.

How can I help recruit AVs? We have included an A5 poster with this edition of Fightback. Please can you:

- Put it up on a local noticeboard? Perhaps in your local supermarket, library, community noticeboard, GP surgery or staff noticeboard at work.
- Request additional posters so that you can put up more or pass them on to family, friends or colleagues to put up.
- Submit our poster to a community newsletter? If so, please contact Liz for a press release.

If you would like to print more copies of the poster please email sueheal@btinternet.com or liz.cooper@mndassociation.org who can send you a pdf. Or ask Sue to post you some more.

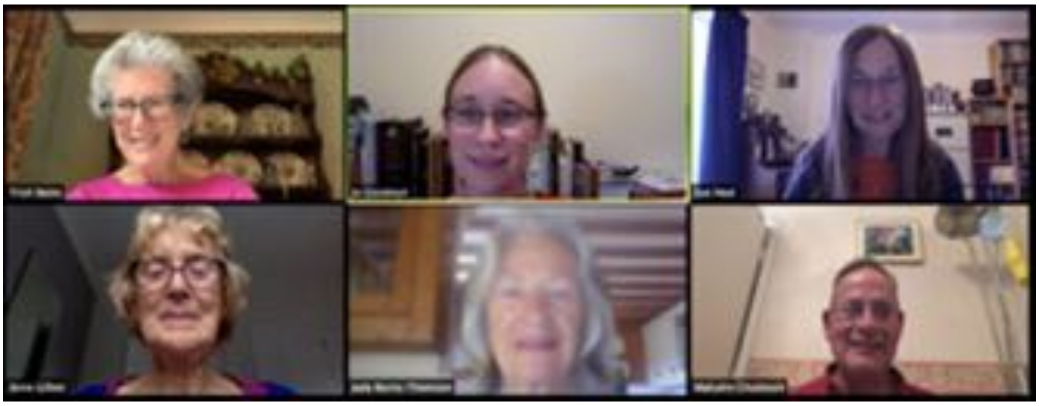
Branch Secretary: The Branch has been without a secretary since Helen Devlin stepped down in June 2020. We are very grateful to Patti de Clifford who stepped in as minutes secretary until February 2021. Sue has been printing invitations and filling envelopes and Judy has been addressing them and mailing out Fightback – but we are struggling to do everything! We are looking for a new and enthusiastic branch secretary(s) to join our team.



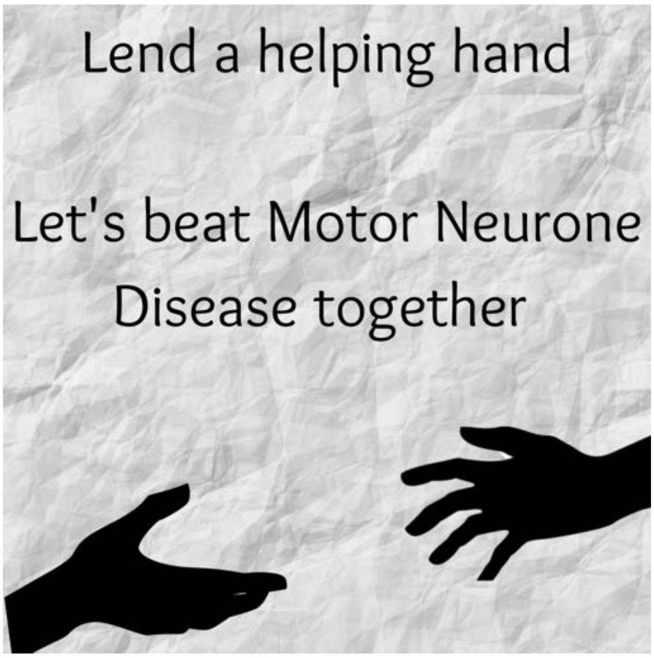
As our branch secretary you would provide secretarial and communications support to our small, but friendly committee, dedicated to supporting people with MND, their families and carers. Fearful of taking on too much? Fear not! This role is flexible and can be split into different positions – General Branch Secretary, Membership Secretary, Open Meeting Secretary – to suit the time you have available.

Interested? Contact Liz on 01604 800620 or email liz.cooper@mndassociation.org.

Committee Members: Ideally we would love to have nine or ten committee members – at the moment there are six of us. Every six weeks we meet online on a Tuesday evening starting at 6:30pm; meetings vary in length, but are usually finished in under two hours.



Interested? Talk to Malcolm on 01603 960206 or email malchubbock@hotmail.co.uk.



Do you have other skills that you would like to use in a voluntary role? Talk with Liz or Malcolm, they would love to hear from you. Training and induction for all roles will be provided and travel/direct cost expenses are reimbursable.

Please help us by collecting EDP tokens! We hope that by now some of you have spotted the newspaper tokens that can be used to win a share of the EDP Cash for Charities scheme. If you have been collecting tokens for us, please post them to Malcolm Chubbock as soon as the scheme ends on 3 July.

3 Christine Road, Spixworth, NR10 3PH

Sunday 18 April 2021 AGM

We were delighted to welcome **Chris Wade**, Director of Engagement with the MND Association, and to hear his thought provoking presentation on the forthcoming strategy to increase membership.

Chris prefaced his talk with a quick run through of the news from the organisation over the last year. In February 2020, the Association moved into its beautiful new premises in Northampton after a year of planning to ensure it was perfect for the work of the staff, but also welcoming for branches, groups and people living with MND to visit. And then COVID-19 struck ...

The challenge was to maintain key services. Money for care grants was ring fenced to protect people with MND and the research programme continued. The fundraising team, with the support of local volunteers, became creative to maximise income using virtual challenges such as the 2.6 challenge and Mission 5000 – and more recently the Ice Foot Challenge. The directors worked to manage costs. A care action plan was put in place to contact everyone with MND and keep in touch where appropriate. Advice was provided to people with MND, volunteers and staff to ensure everyone understood government guidance, which included a dedicated space on the website and links to a panel of experts. An emergency grant scheme was put in place together with more support for carers and the bereaved. Meetings moved online, volunteers were trained online and, whilst we look forward to seeing people in person, we have seen some encouraging benefits from a new way of working.

Despite the continuing pandemic there was much for the Association to celebrate at the end of 2020. The public focus on Rob Burrow provided an amazing opportunity to raise awareness of MND. Kevin Sinfield's 7 marathons in 7 days provided a boost to income. The 31st International Symposium on ALS/MND successfully moved online and was attended by over 1,000 people. Investment in research was maintained and, most importantly, support for people affected by MND continued.

Turning to membership of the Association Chris began by showing a short video: *3 Things for Calgary* http://www.3thingsforcalgary.ca/about-us. It focused on asking the citizens of Calgary to think about what they are good at, what they care about and what they have to say about it, before deciding what three things they could do to make Calgary better. It was an initiative to involve people in a collaborative effort.

Chris has been thinking about what it means to be a member of the Association, part of a community of supporters, fundraisers, donors and volunteers working towards a common cause. He recognised that not everyone knows if they are a member or not, perhaps the easiest test is 'Do you receive Thumbprint?', the magazine sent to members. He led us to consider how we might like to become more involved as a member, to become citizens of the organisation. Read on – his five key ideas were not as scary and time consuming as you might think!

1. **Telling stories** – most people who have membership of the organisation have some connection with MND. Most have a story to tell as a result of that – a current story, or a past story – a powerful story. Chris said he could go to meetings and talk about the impact of MND yet have minimal impact compared to people sharing their personal story. This could be as simple as talking to friends, or posting on Facebook – but some might consider giving a more public talk to a group at church, temple, school, university or workplace. There are plenty of ways we can tell our story and raise awareness of the disease and the Association – and possibly raise some money at the same time. We can also help by raising issues and campaigning, or recruiting volunteers.

2. **Gathering data** – people often have experience of what it is like to work with or live with MND. This can be anything from how long it takes to get diagnosed, through to how good services like speech and language therapy are in the area, or feedback on our own services and the Association. Data helps us improve our services and that of others. He compared this to the RSPB data collection facilitated by the Garden Birdwatch where members can do so much more than the staff alone.
3. **Share connections** – there are lots of ways, we all know somebody! We share connections on social media, maybe you live next door to a local councillor who could use their influence for change, perhaps you might persuade a friend to run a marathon for us, or someone with a scarce skill to volunteer with us – there are so many ways. It may be that you know somebody who knows somebody … who can help.
4. **Volunteer** – are there things people would like to do on an ad hoc basis, beyond the core roles that we are advertising within the Branch? Chris recognised the success locally in bringing in new and unusual skills. In our last edition of Fightback we welcomed five new volunteers each with a particular skill, like Tom who was at the AGM and is able to edit videos for us.
5. **Generating/contributing ideas** – Chris recognised that the staff in National Office, Regional Staff, Branch and Group volunteers have a finite number of ideas on how to do things or even what needs doing. He said, it would be wonderful if our supporters could get involved in developing new projects or designing new services.

In summary, Chris was interested not in asking volunteers to do more, but to give members more opportunities to be engaged in the work of the Association.

The MND Association has around 11,000 members, we would love to increase that number. Membership is free to people living with MND, carers, past carers, spouses and partners of people living with MND. It is important to note that we will always offer support to people living with MND, whether or not they take up membership.

Find out more about the aims of the organisation and benefits of becoming a member at https://www.mndassociation.org/get-involved/fundraising/become-a-member/.

As it was an AGM there was business to conduct, mercifully this was short and to the point as usual! **Malcolm Chubbock** presented an update on the work of the Branch. Our financial position to the year ending 31 December 2020 was positive thanks to everyone who raised funds or made donations. Malcolm highlighted the larger sums received. Of course we appreciate donations of every size, and the many fundraising events held to support our work.

Major fundraising events and donations:

- Marsh Christmas car park income from event in December 2019 which raised £20,100.
- Norfolk Community Foundation grant from the Paul Bassham Trust £5,000.
- Anonymous charity foundation grant of £4,500 to purchase riser recliner chairs.
- Donation from Bishop Herbert Lodge of £2,750.
- CAF Tourle Foundation grant of £2,149 to fund branch meetings.
- National Institute for Agricultural Merchants £2,025.
- Donation from Burton Court Lodge £2,000.

Malcolm expressed our thanks to Association Visitors Judy, Judith and Anne, and Care Service Navigators Trish and Gill.

Gill has moved on after 5 years volunteering for the Branch as an Association Visitor and Care Service Navigator. Malcolm extended our good wishes to her for the future.

Finally Malcolm expressed our thanks to Helen Devlin who was due to stand down at the branch AGM in March 2020, but continued as secretary until June 2020. Our thanks to Patti de Clifford who took over as minutes secretary until February 2021. He also thanked our Neurology nurses, and Dr Godwin Mamutse, Dr Caroline Barry, Helen Copsey and Emma Larner at the Norfolk MND Care and Research Network.

Sue Heal shared an update on campaigning, speaking briefly about three major campaigns – United2EndMND, Scrap6Months and Act to Adapt. You can read an updated update in the campaigns section of Fightback!

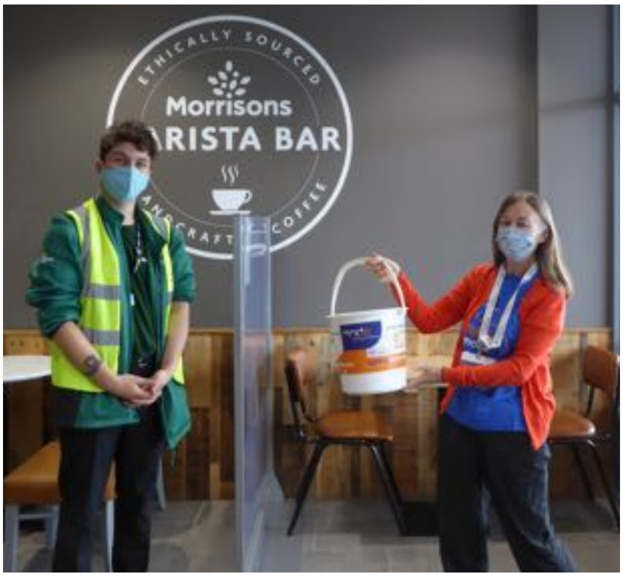
Helen Copsey gave an update on the work of the Norfolk MND Care and Research Network as follows:

- We are approaching the end of the first 4 year period of the Network which started in June 2017. Grateful thanks to everyone who has been so supportive – it has been a real pleasure to work with everyone. It has meant we have been able to achieve our grant objectives. We are also delighted to have been awarded a further 4 year grant to continue our work.
- Clinics – we have been able to resume our satellite clinics returning to Beccles in March and Cromer in May. We will continue to offer a blended approach to reviews, which will include face to face, phone and video appointments. The latter has been invaluable in helping us to keep in touch with patients who are unable to travel.
- Clinical teams have continued to meet to discuss patient care regularly throughout the pandemic. Our wider consultant, nursing and therapy teams have been hugely supportive of our work to support patients with MND during the pandemic.
- Emma Larner (Respiratory Physiotherapist) is now in the team permanently 4 days a week. Emma is providing invaluable support, particularly in patients' homes, with respiratory support and help with the management of symptoms. Emma also provides psychological support to those experiencing breathlessness, anxiety and difficulty in adjusting to non-invasive ventilation.
- In December 2020, the Network started a new multidisciplinary meeting for Health and Social Care Professionals (HSCPs) involved in caring for people with MND in the Norwich locality. This has been very well attended and has provided an opportunity to share ideas and learn from each other. It has included colleagues from across the community and Norfolk and Norwich University Hospital (NNUH). It has been an excellent opportunity to further develop our links with colleagues from social care and the community matron team.
- Psychological support – the Network staff are keen to continue to improve our offering in this area. Dr Caroline Barry (Consultant in Palliative Care/Network Co-director) is able to see patients in her own supportive care clinic. If there is more complex need, she has been able to refer some patients on to a Clinical Psychologist at NNUH. This has been hugely beneficial to those patients who have accessed this service.
- Education – the Network's online webinar series for HSCPs takes place 2-3 times a year, and has been very successful, with over 70 people joining the talks.
- Research – we continue to recruit to the MND Register. We hope to start recruitment to MND-SMART in the very near future. We are also continuing to work with the University of East Anglia on the work around cognitive/behavioural change in MND, notably the MiNDToolkit study.

Liz Cooper, Area Support Coordinator, welcomed our new volunteers and expressed her thanks to branch volunteers and the staff at the MND Care and Research Network.

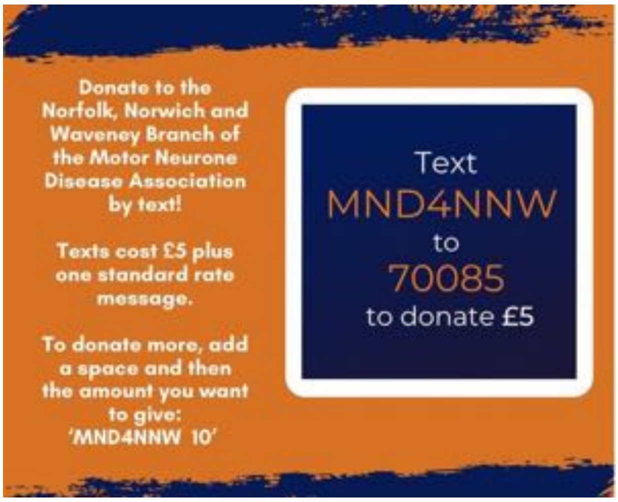
Events in aid of the MND Association

Saturday 15 May 2021 Morrisons at Bradwell store near Great Yarmouth



Sue Heal can be seen collecting a bucket of cash from Morrisons Bradwell Community Champion Cam Hodds. Thanks to Jo Goodwyn for the photo.

We would like to thank Cam for working with our branch and helping us to raise a total of £22.88. COVID-19 meant that we were not able to hold the usual style bucket collection instead buckets were left at the ends of the till points. It was an excellent opportunity to raise awareness of motor neurone disease and the work of the branch.



Donate to the Norfolk, Norwich and Waveney Branch of the Motor Neurone Disease Association by text!

Texts cost £5 plus one standard rate message.

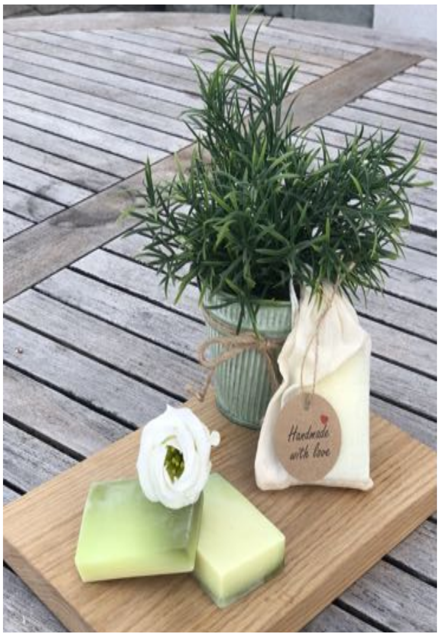
To donate more, add a space and then the amount you want to give: 'MND4NNW 10'

Text MND4NNW to 70085 to donate £5

We also trialled the use of the Text to Donate poster designed by Mili, which you may have seen on our Facebook page, and reproduced here.

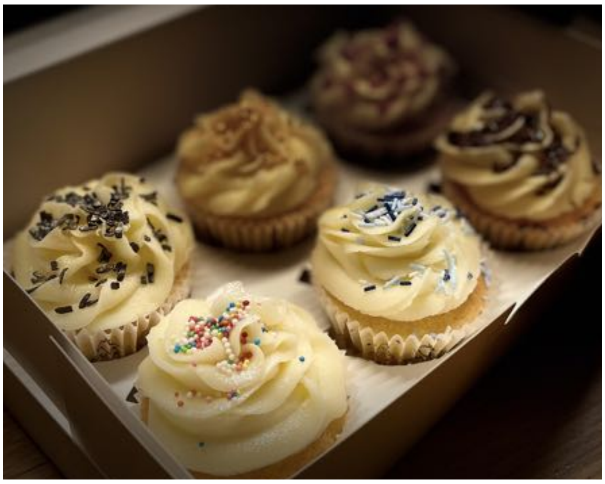
Every penny counts; we are grateful for the generosity of those who were able to donate. If you missed this bucket collection you might be able to catch us in the summer when we are hoping to hold another collection sometime in late June or July.

Fundraising abroad! *by Hannah Chippendale*



Having lost my dad to MND in June 2018, my family and I try to support the MND Association as much as we can. They were absolutely invaluable to my dad and my mum (as his carer) and we owe them so much.

Having had our plans for a 'family fun day' in Spring 2020 scuppered by COVID-19, we had to get creative in our ideas of how to raise money during a pandemic. My daughters soon realised that online would be the only way for the foreseeable future. They created a website where we could display second hand items for sale and shared the address amongst friends and family. My eldest, Lilia had also got into soap making so we started selling her soaps, along with drawings done by my younger daughter, Chloe. We also sold homemade cupcakes, which were hugely popular; obviously a good COVID-19 friendly alternative to a large cake!



We were really pleased to raise £2,000 from this initiative and we can't wait to organise another event once restrictions allow.

Ice Foot 92

Len Johnrose, a former professional footballer, was diagnosed with MND in March 2017. Now confined to a wheelchair he is challenging all 92 clubs across the top four division in England and Wales, their fans and anyone else who is cool enough to take part in his #IceFoot92 challenge. Len hopes the challenge will raise £92,000 towards the MND Association's care and research work. It was only fitting that on 26 April, Helen Copsey and Emma Larner should be the first of our branch supporters to plunge their feet in cold water!

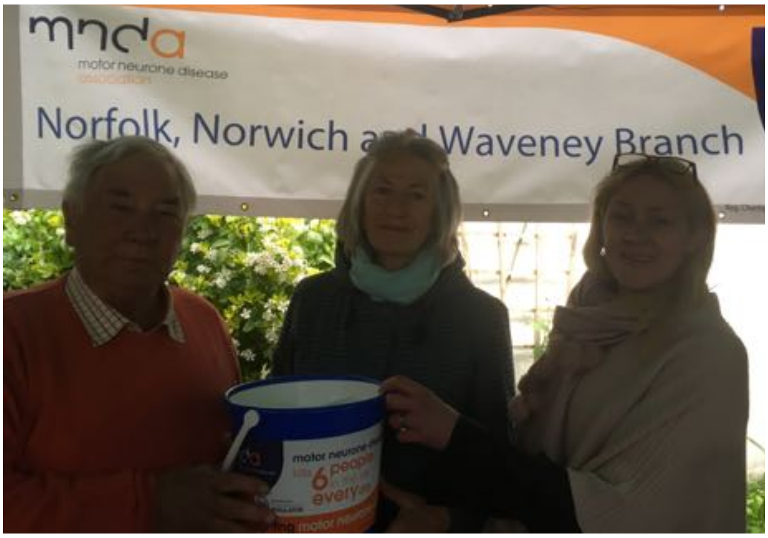
Those who step into the bucket of ice water are asked to share film footage of their challenge on social media using #IceFoot92.

Thanks to Eneida Mioshi we have a still showing Emma and Helen taken from the video, you can see the video on twitter at https://twitter.com/NorfolkMND/status/1386722365434994689, where they nominate researchers Professor Eneida Mioshi, Ratko Radakovic and a local physiotherapist.

Eneida has already responded to the challenge and exclaimed, 'That was cold!' The photo reflects the sentiment.

To take part just follow four steps:

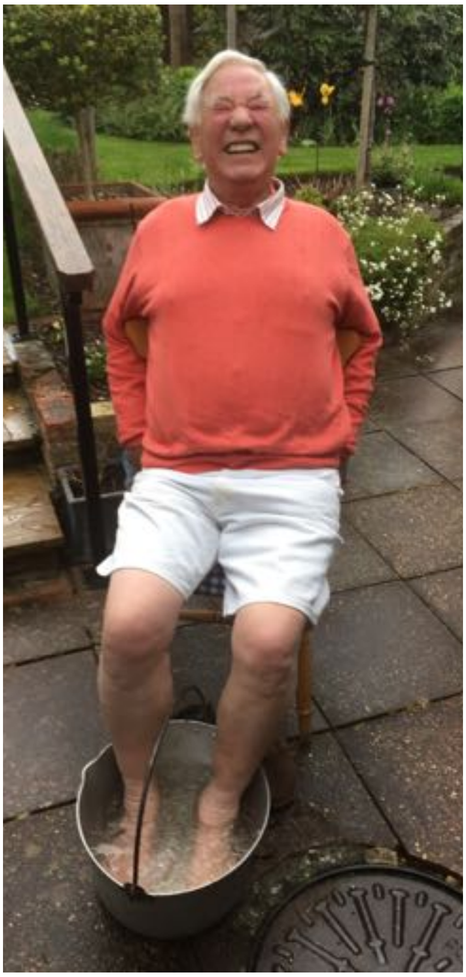
- Film yourself standing in a bucket of ice water for all or some of the 92 seconds.
- Donate £10 during filming by texting MNDLEN to 70085
- Nominate some of your mates in your film to pass the challenge on
- Share your film on your digital channels using #IceFoot92 and tagging your nominees



Not everyone is on social media. It is also possible to take a photo of your event and send it to sueheal@btinternet.com.

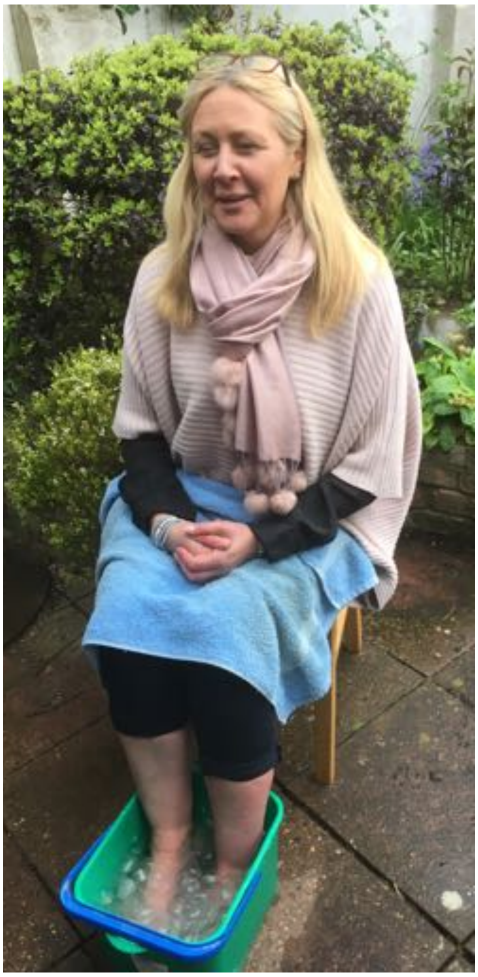
If you are not using Len's JustGiving page or texting, she can send you a form to accompany your donations when you send them to the Association.

This is exactly what Judy Burns-Thomson's friends Keith and Lucy decided to do.



Judy wrote: ‘I attended a local fundraising event in my home town of Bungay, Suffolk on Saturday 22 May. Keith Shannon and his daughter Lucy Coote both took part in the Ice Foot 92 Challenge. It was a chilly evening but the rain held off while they both immersed their feet in the buckets of ice for 92 seconds. You can see from the photo that Lucy seems to be managing the pain with a calmer disposition!

They raised over £700 for Len’s challenge. A huge vote of thanks goes to Keith and Lucy for braving the ice buckets and all their friends and family for their generous donations.’



Could you take part in Len’s #IceFoot92 challenge? If you can and do please share your stories with us, email sueheal@btinternet.com and/or tag us on social media:

Facebook @MNDANorwichWaveney
Twitter @MNDANorWave
Instagram @MNDNorfolk

Find out more about the Ice Foot 92 challenge at https://www.mndassociation.org/icefoot92/.

Introducing Professor Eneida Mioshi

In the last edition of Fightback we invited new volunteers to introduce themselves. For this edition we invited Professor Mioshi to introduce herself, her work, and her plans for raising funds for research into MND.

Eneida wrote, ‘I currently lead a research team at the University of East Anglia, investigating the impact of progressive neurological conditions on a person’s everyday life, and that of their families. I am passionate about research to improve the care and support families receive after a diagnosis of motor neurone disease, dementia, and related disorders. This also means improving how healthcare professionals conduct assessments and deliver interventions.

I am Japanese Brazilian and trained as an occupational therapist (OT) in Brazil. I did my PhD at Cambridge, investigating the impact of a rare dementia (frontotemporal dementia) on daily life and family carers. I also met my (German) husband while working in Cambridge.

After getting married, work took us to Sydney. It was in Australia that I moved my research focus into motor neurone disease. It was a fruitful time navigating research between two related conditions: frontotemporal dementia and motor neurone disease.

Our two daughters were born in Australia. With two kids, we decided to return to the UK to be 'closer to family'. That simply means long-haul flights less than 12 hours instead of a 24-hour trip, or a 'quick drive' to Germany when the pandemic allows.

Now, settled in Norwich, I have finally found the courage to challenge my lack of sporting training by signing up to my first triathlon. Despite being slightly terrified about the prospect of swimming, cycling and running in one go, training is going well. Naturally, I have chosen MND research as my first fundraising target. MND Scotland is on my list too! Watch this space: https://www.justgiving.com/fundraising/Eneida-H-Mioshi.'

Future events in aid of the Association

"Take on 21 miles in June and run to Global MND Awareness Day on 21 June"

1-21 June 2021 Berenice Groves takes on the challenge!

Berenice said, "I am challenging myself to run 21 miles in 21 days." She has been a runner before with 10km being her longest distance, but she says she hasn't run for at least six months so this is definitely a challenge!

Berenice has a special reason for running to help raise some money for those affected by motor neurone disease. She said, "Sadly I lost my Dad, my hero, to MND in October 2012. So this is in his memory."

If you would like to support Berenice please visit https://www.justgiving.com/fundraising/berenice-groves.

We are delighted that others are considering taking on the challenge. We have invited them to join members of the Branch in front of Norwich City Hall at 9pm on Monday 21 June, when it will be lit in blue and orange – the Association colours.

24-25 July 2021 Lisa Wilson takes on Endure 24

Lisa signed up to take part in Endure 24 (Glastonbury for runners) in Reading in June 2021, that was postponed from last year, with other runners from the Facebook group RUNMND. Government guidance around events meant that a new venue was needed as Reading was unavailable after 21 June. It is now scheduled to take place from 12:00 Saturday 24 July until 11:59 Sunday 25 July at Temple Island Meadows, Remenham, Henley-on-Thames.

Endure 24 is a 24 hour relay race for teams of 2 – 12 runners or solo competitors. Solo runners run as many laps as they can in 24 hours. The website describes the 5 mile trail route as having eccentricities. The course is multi-terrain, uneven, the path narrow in places with lots of tree roots and trip hazards. Take care Lisa, we will be thinking of you and willing you on!

If you would like to sponsor Lisa please visit her just giving page at https://www.justgiving.com/fundraising/greatnorthrun2020 where you can read her story and about the events she hopes to complete this year.

Lisa has entered to run in Newcastle in September for the Great North Run Half Marathon, after it was cancelled last year. Additionally, due to her friend competing in this year's London Marathon in October for the Association, Lisa booked accommodation there to watch and support her. However, Lisa has decided to join in with the fun too and has entered the Virtual Marathon and will complete the 26.2 miles around London by herself on the same day.

Lisa is still hoping to hold a craft fair at St Andrew's Church, Lowestoft, later in the year to raise funds for the Association. Details will be available once a date is confirmed.

Lisa and Martin Burnell are planning an event together combining music, dancing and a raffle – we will publicise details when they are available. If you can help them with raffle prizes please get in touch with lisa.stephenwilson@gmail.com.

Hold the dates, Saturday 28 – Sunday 29 August 2021 Open Gardens at Thurning Hall

It was with much sadness that the event planned for May was unable to go ahead due to continuing COVID-19 restrictions.

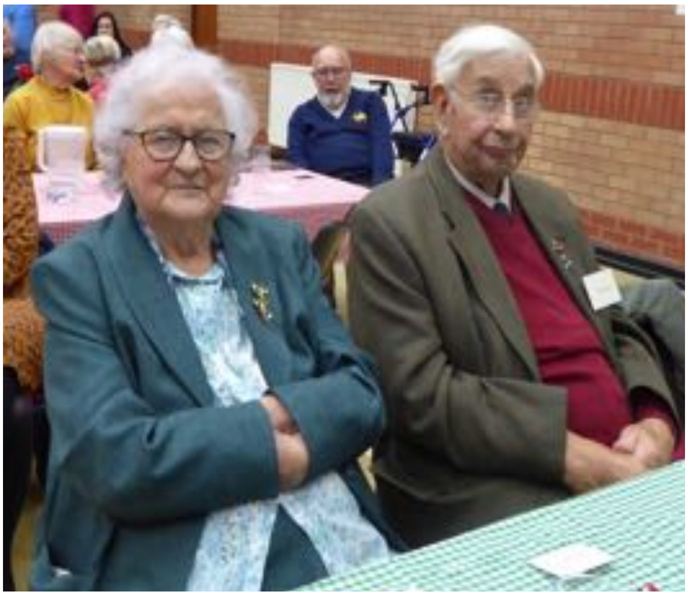
We are delighted that Lara Lacey is hoping to reschedule the event for August, however final confirmation is dependent on the insurers – we all have our fingers firmly crossed and hope to see you in the beautiful walled garden! Our thanks to Lara and her mother for their kindness in seeking to support our Branch of the MND Association by opening their gardens.

Once the event is confirmed we will post the news on our website, Facebook and Twitter – and hope that you might consider volunteering to help!

In memory of Bryan Chubbock, long time branch supporter and fundraiser

Bryan and Eileen Chubbock decided to start fundraising for the MND Association after their eldest son, John, was diagnosed with motor neurone disease in 1993. Any monies raised were to go towards research into the disease. In May 1994, they held a coffee morning in their garden, which became a successful annual event. Although John lost his fight against MND in August 1997 the fundraising continued, the aim being to get to ten coffee mornings. After the last fundraising event in May 2003 the total amount raised was nearly £39,000.

In addition to the coffee mornings Bryan and Eileen took part in the bucket collections at Waitrose at Eaton, which were held over a 3 day weekend. Bryan was a keen gardener and would sell surplus produce at his driveway with the money raised going to the Association.



Bryan and Eileen were regular attendees at branch open meetings over the course of 25 years. They attended the last in person meeting at Wortwell in November 2019 before they were suspended due to COVID-19.

Bryan decided to follow his son John, whose life story 'A Fair Bit of Truth (Plus a Little Squit) was published posthumously in November 1997, and wrote his own story. Bryan's book, entitled 'Life of Bryan (with a Y) A rural ramble ...', raised £1,600 for the branch.

It was Bryan's wish that any donations in his memory should go to the Norfolk, Norwich and Waveney Branch, the total so far is £2,863.

Our thoughts are with Eileen, Malcolm and the Chubbock family. Bryan we will miss you.

Take a Bow – *thanks to the following for donations received by the branch*

- Anonymous donations - £69
- Sale of merchandise - £15
- Anne Gillett, Winter Walk - £170
- Emergency Appeal, total to end of May - £62.50
- Oliver Wardrop, UEA Biological Society Quiz - £20
- LR donation - £100
- KH donation - £30
- EG donation - £19.52
- Morrisons, bucket collection - £22.88
- Norfolk Broads Lions Club - £200
- Eversley Lodge of Mark Master Masons (towards the cost of a riser-recline chair) - £250
- Provincial Grand Lodge of Mark Master Masons (towards the cost of a riser-recline chair) - £500

Donations in memory of

- Bryan Chubbock - £2,863.75
- David George - £175
- Lawrence Harding - £100
- Mrs Frances Diana Parker - £180
- Sandra P - £176.45
- David Siggins - £20

Internal transfers

- JustGiving - £162.50
- Interest - £7.62
- Lloyds, refund of bank charges - £13.85

We are extremely grateful for the donations totalling £19.52, which have been made to National Office for transfer to the Branch.

My apologies to those who have made donations but whose names have not appeared, these figures will appear in the next edition.

News from National Office

MND Coronavirus (COVID-19) Hub: The Association is continuing to host a dedicated webpage providing regularly updated information on COVID-19 and MND, and giving answers to frequently asked questions.
https://www.mndassociation.org/about-mnd/coronavirus-and-mnd

Fundraising News: There is a range of fundraising events, as well as information to help you set up your own events at https://www.mndassociation.org/get-involved/fundraising/.

If you would prefer to talk to someone about your fundraising please phone 01604 611860.

If you would like to support the Norfolk, Norwich and Waveney Branch, and want the funds to come to us, please make it clear that we should be the recipient when you set up your JustGiving page. Tell us you are supporting us if you would like us to feature your events in Fightback, on our Branch website and our social media – Facebook, Twitter and Instagram.

Benefits Advice Service: Visit https://www.mndassociation.org/support-and-information/our-services/benefits-advice/ for more information. Alternatively call for free on 0808 801 0620 between 09:00 and 17:00 Monday to Friday, except on public holidays.

Information sheets: These are updated regularly and can be downloaded from https://www.mndassociation.org/about-mnd/information-resources/ or requested from the care admin team on 01604 611685 or careadmin@mndassociation.org.

Campaigns

#United2EndMND: Following a positive meeting of Doddie Weir with the Secretary of State for Health at the end of 2020, a meeting with Care Minister, Helen Whately MP was arranged for 29 April.

In April, Andrew Lewer MP, Chair of the All-Party Parliamentary Group on MND coordinated a letter to Care Minister, Helen Whately MP, to urge her Department to invest in MND-specific research. The letter, which was signed by 22 other MPs, including Peter Aldous MP for Waveney, Duncan Baker MP for North Norfolk, Jerome Mayhew MP for Broadland and James Wild MP for West Norfolk, set out the benefits of increased investment in MND research.

Our thanks to the MPs of Norfolk and Waveney who signed the letter, and to all those who wrote to their MPs asking for their support.

During the meeting a coalition of people living with MND, the MND Association, MND Scotland and My Name'5 Doddie Foundation received a commitment from Government officials to continue discussing the need for targeted MND research funding.

The coalition took the opportunity to present proposals for increasing targeted funding for MND research. With a need to maintain research momentum, targeted Government investment is the key to continued research into the causes of MND and the search for treatments and a cure for the disease. The coalition is seeking a £50 million commitment from the Government over five years. The investment would be used to establish a virtual MND Research Institute to help accelerate research into the disease.

Also in attendance at the meeting were experts from the Department of Health and Social Care, the Department for Business, Energy and Industrial Strategy, as well as leading research funding bodies the National Institute for Health Research and the Medical Research Council.

Speakers David Setters and Emma Moss, both living with MND, portrayed the physical and emotional impact of MND incredibly powerfully. Some of the UK's most eminent MND scientists also made a very strong case for increasing Government funding for MND research.

Watch all the presentations and speeches from Helen Whately and the United To End MND coalition here https://www.mndassociation.org/mnd-research-campaign-meets-with-minister/.

As part of our United To End MND campaign, we are continuing with our petition calling for more investment in targeted MND research. The petition – in the name of Scottish rugby legend Doddie Weir – is backed by the coalition. Can you show your support by adding your name and **spreading the word**? https://petition.parliament.uk/petitions/564582

Sue Heal, Campaigns Contact, wrote to local rugby clubs to ask for their help sharing the petition. Thank you to North Walsham Rugby Club and Norwich Rugby Club for their support.

Thank you to everyone who has signed our United to End MND petition. We have now reached over 108,000 signatures, but are hoping to raise the total over the coming weeks. The petition demonstrates significant public support for increased Government funding into targeted MND research, which will now be considered for debate in Parliament.

An article in the EDP helped raise awareness of motor neurone disease. Our thanks to the MPs who provided quotes helping to highlight the importance of our campaign.

https://www.edp24.co.uk/news/health/wymondham-woman-campaigning-for-mnd-research-funding-8029784

Thank you to everyone who invited their MP to join a virtual Parliamentary event on 18 June. Association staff, researchers, four people living with MND – some of whom are also Campaigns Contacts – and other CCs were pleased to welcome 39 MPs, including Chloë Smith MP for Norwich North, and staff representing MPs who were unable to attend. We welcome their support for increased government spending on targeted MND research.

For more information on the United To End MND campaign please visit https://www.mndassociation.org/get-involved/campaigning/take-action/united-to-end-mnd/.

Update on the Scrap6Months campaign: We remain frustrated and angry that, almost two years after the Government promised a review into access to benefits for those living with a terminal diagnosis, we are still waiting for them to publish it.

We continue to put pressure on the Government using social media. We are supported by many MPs and Peers. On 17 May, Emma Hardy MP, Peter Aldous MP and Duncan Baker MP raised our #Scrap6Months campaign in Parliament during the Department of Work and Pensions oral question time (MPs must enter a ballot to be allowed to ask a question).

The campaign continues to receive backing from senior neurologists, including Professors Chris McDermott and Ammar Al-Chalabi, whose comments were reported in a recent article:

https://www.politicshome.com/news/article/fully-paralysed-terminally-ill-patients-still-facing-inhumane-benefits-process-almost-two-years-after-promised-review.

More locally, campaigner and branch member Martin Burnell appeared in a powerful article in the Daily Express with the headline, "Act now to ease money worries of terminally ill, urge top medics". It featured a letter to Justin Tomlinson alongside Martin's personal story.

https://www.express.co.uk/news/uk/1419455/fast-access-terminally-ill-patients-elite-medical-leaders-warning

Our Scrap6Months campaign calls for everyone with a terminal illness, such as MND, to be able to access benefits using the Special Rules for Terminal Illness. You can read more here: https://www.mndassociation.org/dwp-to-review-benefit-rules-for-terminally-ill-people/.

ACT TO ADAPT
Access to home adaptations for people with motor neurone disease

Act to Adapt: Since the launch of the Act to Adapt campaign in September 2020 to advocate for accessible homes and a fairer and faster system for delivering housing adaptations for people with MND, supporters have been telling their stories and councils have been listening.

mnda motor neurone disease association

Local councils must provide accessible housing to people with MND by:

- fast-tracking support for adaptations
- removing the means test for low-cost and high-impact adaptations
- maintaining a register of accessible homes

mndassociation.org/acttoadapt #ActToAdapt

*source Motor Neurone Disease Association (2018) Act to Adapt report

ACT TO ADAPT

If you would like to share your experience of accessing home adaptations please visit https://www.mndassociation.org/get-involved/campaigning/take-action/act-to-adapt/.

The All-Party Parliamentary Group on MND is a cross-party group of MPs and Peers with an interest in MND. Established in 2002, their purpose is to increase awareness and understanding of MND amongst parliamentarians and to campaign for better access to high quality services for people affected by MND. The MND Association provides the secretariat.

Councillors discuss local services for people with MND: In March, Andrew Lewer chaired a plenary session at the Conservative Councillors' Association conference which explored the key role councils play in delivering services to people with MND in a timely, proactive and coordinated way.

Over 90 councillors joined the session. Jessica shared her experience of caring for her husband, who has MND, and their young son – explaining the emotional toll that MND can have on those living with the disease and their families, and the need for speedier access to services. Susie Rabin, the Association's Head of Policy and Campaigns, and Specialist Occupational Therapist Jane Smith focused on our Act to Adapt Campaign. Joe Mooney, Norfolk County Councillor, spoke about the process of adopting the MND Charter and the work that has gone on since. Joe retired from NCC at the local elections in May 2021. We would like to thank him for his work with us and support for the Branch during his time in office and hope that he will stay in touch.

Local MND Research Update

The Norfolk MND Care and Research Network continues to recruit people diagnosed with motor neurone disease to the MND Register. The MND Register provides a valuable database to collect and store information about every person with MND in England, Wales and Northern Ireland. The information collected will help plan the care for people living with MND and tell researchers more about the causes of the disease.

Sadly COVID-19 has delayed the opening of new centres to recruit participants for the **MND-SMART** trials. We hope the Network will be added to the list of active centres in the near future.

Fortunately, recruitment to **FACTOR-MND**, a study that aims to understand factors that might affect the wellbeing of family carers of people living with MND, is unaffected by the pandemic. Information is collected using online questionnaires that are also available to complete on paper. If you would like to find out more about taking part please call the research team at the University of East Anglia on 07825 863389 or email mnd.research@uea.ac.uk.

Professor Eneida Mioshi gave the following update on her study looking at the practical management of behavioural impairment in Motor Neurone Disease, MiNDToolkit. "We are really pleased to re-launch this study, which had been severely affected by the pandemic. Our new online platform will enable easier access to the MiNDToolkit intervention study across the country and allow family carers to be involved in research if they wish to. We are currently investigating if this novel psychoeducational intervention is acceptable and helpful to family carers and healthcare professionals. In future, we will investigate if the MiNDToolkit can better support family carers dealing with additional behavioural changes in MND".

You can read more about opportunities to get involved in MND research locally at https://www.mndnorwichandwaveney.org.uk/local_research.htm. For more ways to get involved in MND research visit https://www.mndassociation.org/research/get-involved-in-research/ where the Association provides a list of research projects that are recruiting volunteers.

Research *by Aidan Nicholson*

Therapy

Moderate physical activity could slow muscle deterioration – Feb 2021: A new study has found that moderate physical activity can slow muscle degeneration in people with MND improving the patient's abilities to perform daily life activities and quality of life. Additionally, it showed a slowing in lung function decline however it did not prolong survival. After a literature search of 735 published studies about physical activity with MND patients this was reduced to 10 trials published within the past five years compromising 421 MND patients. The primary goal was to measure the effects of the therapeutic physical exercise via the Revised Amyotrophic Lateral Sclerosis Functional Scale (ALSFRS-R) which is a measure of MND disability. Slight increases in the ALSFRS-R scores in people receiving exercise therapy showed a gain in functional capacity in the first month of treatment. After three months the differences in the scores between patients receiving and not receiving physical therapy became significant and after six months the patients receiving treatment had a slower functional decline then the control group. Based on these findings, researchers believe that physical exercise on a medium and long term basis can slow the deterioration of muscle in patients with MND.
See more at: https://alsnewstoday.com/news-posts/2021/02/19/moderate-physical-activity-may-slow-muscle-deterioration/

Using artificial intelligence to improve care in MND – Feb 2021: A new four year study called BRAINTEASER will monitor 300 participants with either MND or multiple sclerosis (MS) via wearable sensors and apps, collecting the information and via the use of an artificial intelligence (AI) help clinicians detect, predict and manage the patient's disease progression. The five key goals are; to better describe the mechanisms behind MND and MS, classify patients according to how their disease evolves, predict disease progression, investigate the role of environmental factors in the condition and suggest intervention that delays disease progression. Participants will be monitored at four clinical centres in Italy, Spain and Portugal with the Universidad Politécnica de Madrid leading the programme with the support of six European countries.
See more at: https://alsnewstoday.com/news-posts/2021/02/04/european-consortium-brainteaser-artificial-intelligence-als-ms-care/

Imaging technique measures mitochondrial abnormalities in MND – Feb 2021: A new imaging technique called 31-phosphorus magnetic resonance spectroscopy (MRS) has recently been proven in a study in Sheffield to be able to measure mitochondrial abnormalities in MND patients. The study using 20 MND patients and 10 healthy control subjects used MRS to measure levels of mitochondria-associated molecules such as adenosine triphosphate (ATP), referred to as the cell's energy currency. By comparing the levels between subjects, researchers identified mitochondrial abnormalities in both the brain and muscle of MND patients. However, the type of mitochondria-associated molecules depleted in the two tissues were different. In MND patients in both types of tissue, cells did less work with the same amount of ATP clearly indicating a mitochondrial problem. This creates a potential investigative technique diagnosing MND by measuring the lack of these molecules and checking if therapies that try to rescue mitochondrial function work. However, researchers state they need to repeat the experiment with more people to produce statistically significant results and begin application of the theory to practice.
See more at: https://alsnewstoday.com/news-posts/2021/02/03/imaging-technique-measures-mitochondrial-abnormalities-als-study/

'Stretchable' electronic sensors may help to diagnose MND – Feb 2021: Researchers have begun to look into designs of stretchable sensory devices which can attach to skin gathering better signals from a person's body; their goal is to use this machine to more easily diagnose and monitor ALS. Researchers hope that the sensors will be able to accurately measure muscle activity affected by ALS and in the future that these sensors can be implanted in a person's body allowing for more accuracy and to allow patients to monitor their conditions from home rather than going into a clinic.
See more at: https://alsnewstoday.com/news-posts/2021/02/09/stretchable-electronics-wearable-sensors-diagnose-als/

More Tofersen news – Pre-Symptomatic Trial Scheduled to Begin 2021 – April 2021: A new trial (ATLAS) will investigate the optimal timing to begin treatment with the medication tofersen in people with the SOD1 genetic mutation but who don't have clinical MND yet. The SOD1 mutations are one of the commonest causes of familial MND accounting for one-fifth of cases. The mutations cause production of a mutant SOD1 protein which misfolds and clumps. interfering with various cellular processes, driving MND progression. Tofersen is an investigational therapy which aims to decrease levels of the mutant SOD1, slowing disease progression. In a prior Phase 1/2 clinical trial, Tofersen delivered via an injection into the spinal canal, decreased SOD1 levels in MND patients slowing functional decline. The ATLAS trial aims to see if starting Tofersen treatment before MND symptoms occur slows the manifestation of symptoms and/or slows function decline. The ATLAS trial is expected to start in the coming months at thirty worldwide sites.
See more at: https://alsnewstoday.com/news-posts/2021/04/23/aanam-atlas-clinical-trial-tofersen-presymptomatic-sod1-als-patients/

Investigating Parkinson's Treatment as Therapy for MND: A drug called ropinirole hydrochloride (Requip) approved for the treatment of motor symptoms in Parkinson's disease, has now completed trials for its use in MND. The treatment's potential was discovered via patient derived, induced pluripotent stem cell (iPSCs) motor neurons. iPSCs are mature cells, usually from the skin or blood that are reprogrammed to behave like stem cells such as spinal motor neurons, the cells that are damaged in MND. As the cells retain the genetic signature of the patient it is used to screen for potential MND therapies. Via the cells, ropinirole was identified as a potential therapy, seen to reduce the presence of harmful substances such as the toxic proteins TDP-43 and FUS. This will help to boost cellular energy production and motor neuron survival. The results of the Phase 1/2a study are expected this year.
See more at: https://alsnewstoday.com/news-posts/2021/04/22/aanam-findings-due-in-japan-study-of-repurposed-als-therapy/

Aetiology

Linking DNA damage to abnormal TDP-43 – Feb 2021: A new study has shown that abnormalities in the activity of protein TDP-43 whose gene is often mutated in MND can increase cell damage. This discovery both sheds new light on the molecular understandings of MND as well as opening new approaches to treatment. TDP-43 is in the nucleus (houses DNA of the cell) of a cell and in MND when mutated accumulates and clumps up going outside of the nucleus and invading the rest of the cell. TDP-43 dysfunction is thought to be an important factor in MND as it is known that damage to DNA causes cellular health degeneration affecting the condition's development. Researchers are poised to begin targeting the abnormal genetics as a therapeutic strategy for MND and other neurodegenerative conditions.
See more at: https://alsnewstoday.com/news-posts/2021/02/01/tdp-43-protein-accumulation-location-r-loops-dna-damage/

Take Part
There are many interesting and exciting opportunities to get involved with research which can be found at https://www.mndassociation.org/research. Alternatively to talk about getting involved phone the Research Development team on 01604 611880.

MND Research to Receive £5.7 Million of Funding – March 2021: Leeds Rhinos Kevin Sinfield's 7 in 7 Challenge last December raised £2.2 million with a quarter of the funds targeted towards research and as a result of the heightened awareness from the fundraising activity the Association has announced it will commit an extra £2 million to MND research. That is in addition to the £3 million already committed this year.

Money from Kevin's fundraising pot will be channelled into six areas of the Associations' work spanning three years and 40% will be spent on new projects.
See more at: https://www.mndassociation.org/mnd-research-to-receive-funding/

Coping and Living Well with MND (CALM) Study – March 2021: A reminder, this Southampton University study is aimed at developing more interventions to support the psychological needs of people with MND. The research team have created a website to help cope with MND's emotional impact. The study asks people affected by MND to access the early stage of the website and provide feedback for improvement. You will need a computer or tablet to access the website and feedback will be conducted via phone or video call interviews. Study participants will receive a £10 Amazon voucher for taking part.
See more at: https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/calm-study/

Update on Tofersen Clinical Programme – April 2021: Tofersen, as referred to in the therapy section, is an investigational molecule for mutations in the SOD1 gene believed to be the genetic driver of the disease in 2% of all MND patients. Tofersen's safety and efficacy are being investigated currently in a Phase 3 placebo-control trial study. Beginning in mid-July 2021, access to compassionate use of Tofersen will be allowed for a subset of the SOD1-MND population with the most rapidly progressive disease. If results from the current phase 3 trial indicate Tofersen is safe and effective an early access program for the broad SOD1-MND population will commence.

The MND Association is in touch with Biogen and is working with them to understand what this could mean for people living with MND in the UK.
See more at: https://www.biogen.com/en_us/als-community-update.html

King's College Flyer page 18: The research team try to match healthy control participants with participants who have MND in terms of age and sex. They are particularly short of male participants between the ages of 60 and 75 – can you help?

Online coffee mornings
The coffee mornings are friendly informal gatherings for people with MND, their carers and friends, there is no agenda. Coffee mornings are continuing online for the foreseeable future. Now that we have a subscription for Zoom the meetings can be a little longer – 11:30 to 13:00. You can drop in at any time and leave when you need. The chat function enables you to communicate even if your speech is not all that it once was. If you prefer to leave the camera off that is also fine, please do whatever makes you feel comfortable.

We are hoping to introduce face to face coffee mornings when government guidelines and those of the Association allow. Watch the website for updates.

Participants wanted for research study

We are conducting a study into changes in thinking and language in Motor Neurone Disease (MND) and require **people with MND** and **healthy controls.**
(LREC 18/LO/1257)

What does the study involve?

We will give you a series of computerised questionnaires and puzzle-like tests. <u>The tasks will take about 2 hours in total</u> and can be divided into shorter sessions. You will be given generous breaks between tasks.

All study participation will take place through video call apps so you can take part **<u>from home.</u>**

You will receive a thank you **£30** gift card for taking part

Who can apply as a participant with MND?

If you:

- Have Motor Neurone Disease
- Are between the ages of 18 and 75
- Have English as your native language;

Then you may be suitable for this study

Who can apply as a healthy control?

If you:

- Are between the ages of 18 and 75
- Have English as your native language
- Are not receiving treatment for any life-limiting illness (e.g. cancer) or neurodegenerative disease (e.g. Alzheimer's disease, Parkinson's Disease) or neurological disorder (e.g. stroke);

Then you may be suitable for this study

Please contact Lyndsay Didcote if you would like to take part or to request more information:

Email: lyndsay.didcote@kcl.ac.uk
Phone: **07543 342211**

Or sign up here:
https://forms.gle/5BmEK8eZBKnMQcmz7

IRAS number 240593 Measuring Cognitive and Behavioural Change in Amyotrophic Lateral Sclerosis. Patients and Healthy Controls Recruitment Poster Version 2.0 02.08.2020

Branch News

Save the date: Sunday 8 August, 2021 12 noon - 3pm at Upton Village Hall, Cargate Lane, NR13 6AU. Everyone is invited to join us for an open air picnic. In view of the uncertain times in which we are living, we invite you to bring your own picnic. If we were to arrange a caterer, and were forced to cancel at short notice, there is the potential to waste branch funds. We hope to be able to provide cold drinks, tea and coffee. At the moment we are only allowed to have 15 people inside and 30 outside, so please let us know of your intention to attend. The idea is to have a relaxed social gathering, with the opportunity to meet friends new and old. We will have access to the disabled toilet facilities.

Advance Notice of Open Meetings: Usually we would be able to give a date and venue, but in the current climate feel that it is safer to announce this nearer the time. Watch the website!

Virtual Coffee mornings: for carers and people living with MND hosted by Judy and Sue. These are usually planned for the third Wednesday of each month starting at 11:30am and finishing around 1pm – note the change in July. Feel free to drop in and leave as you please, do not feel you must stay for an hour and a half.

Email judyburnsthomson@yahoo.com if you have not been sent the link by your Association Visitor or Care Service Navigator – or if you fancy joining us just to see what they are like – they are very friendly and relaxed events. Newcomers are always welcome!

Dates for 2021 are as follows: 14July 18 August 15 September

An update with further dates will appear on the Branch website and in the next issue of Fightback.

Website: www.mndnorwichandwaveney.org.uk We are always happy to add information about events you are planning in support of the Norfolk, Norwich and Waveney Branch.

Facebook: @MNDANorwichWaveney **Twitter:** @MNDANorWave **Instagram:** @MNDNorfolk

Newsletter Editor: Thank you to all who have sent photos and stories for inclusion in our newsletter. The deadline for receipt of articles for the next edition is **23 September 2021**.

MND Connect – 0808 802 6262. If you, or someone you know, has MND and you need help, information or support, call the MND Connect Helpline (Monday to Friday, 09:00 to 17:00 and 19:00 to 22:30) or email mndconnect@mndassociation.org
MND Coordinator Helen Copsey 01603 647221 helen.copsey@nnuh.nhs.uk
MND Administrator Magdalena Mitcher 01603 647221 magdalena.mitcher@nnuh.nhs.uk
Care Service Navigators Trish Moore 07813 094820 trish.moore@mndassociation.org

Please pass this newsletter on to people who may be interested and together we will fight for our vision of a world free of MND.

Disclaimer. *The views expressed in this newsletter are not necessarily those of the MND Association. The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise. We would like to keep in contact with you about the important work we do. If you do not wish to receive further information, please contact judyburnsthomson@yahoo.com, or write to Norfolk, Norwich and Waveney Branch, c/o MND Association, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ.*