

# Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter  
Issue 84 March 2021

## A 2020 Christmas gift to support the work of the Norfolk, Norwich and Waveney Branch of the MND Association from the Trustees of the Paul Bassham Charitable Trust

The Branch has been supported by Norfolk Community Foundation through Paul Bassham Community First Revenue Fund. We are very grateful to the Trustees of the Paul Bassham Charitable Trust who approved a generous donation of £5,000 to the Norfolk, Norwich and Waveney Branch of the Motor Neurone Disease Association. The money will be used to help fund our support for people living with motor neurone disease, their carers and family.



Malcolm Chubbock, Branch Chair said, “After a very challenging year this is a very welcome boost to our funds to enable us to continue supporting people facing this devastating illness.”

Norfolk Community Foundation is an independent, registered charity that bridges the gap between those in need and those who can help. As part of a national movement of Community Foundations, Norfolk Community Foundation is working together with local philanthropists to make a difference to lives in Norfolk [www.norfolkfoundation.com](http://www.norfolkfoundation.com).

## 15 October Recruitment and Opportunities Virtual Fair hosted by the University of East Anglia



This was a new experience for us all. Liz Cooper, our Area Support Coordinator, Sue and Jane were very grateful to Michelle Frost at National Office, who helped and supported us behind the scenes to set up our online booth. We would also like to express our thanks to the staff at the University who were organising the fair; it was a first for them too! They ran a number of training sessions ahead of the day and answered our many questions. The fair provided us with a wonderful opportunity to meet new people with a view to spreading awareness of the work of the MND Association and the range of roles available to volunteers in Norfolk.

Hosted online, students and alumni from the university were able to enter a virtual hall filled with volunteering and employment stands, and were able to chat with Liz Cooper, our Area Support Coordinator, and volunteers. Whilst there was a group chat on the booth there was also the facility to move into a private 'room' for a video chat. On the day Sue and Judy represented the Norfolk, Norwich and Waveney Branch, and Jane the King's Lynn Support Group.

In the weeks that followed Liz, Sue and Jane had the enjoyable task of meeting a number of students and graduates online to discuss the roles they were interested in. We are delighted that a number were happy to confirm their willingness to volunteer with us, and are now working with us. We are grateful to them for their enthusiasm and the expertise they will bring. We are also delighted that the University is continuing to support us by allowing us to use their free advertising site to feature other volunteering opportunities.

Raising awareness of opportunities to volunteer has led to further welcome expressions of interest. If you are interested in volunteering with us we would love to hear from you.

### **Introducing our new volunteers**

My name is Oliver Wardrop, I am a second year undergraduate at the University of East Anglia studying Biological Sciences (BSc). I have undertaken the role of Trust Fundraiser within the Norfolk, Norwich and Waveney Branch of the MND Association, applying for funding and grants from local trusts/freemason lodges.

I wanted to volunteer within the MND Association because I wanted to become a part of the amazing work that they do within the community, helping people affected with motor neurone disease. I hope that by taking on this role I can help the organisation to succeed in aiding people within the local area affected with MND.



Hello everyone, my name is Mili Sargeant and I am currently a student studying Geography and International Development at UEA. I wanted to take this opportunity to introduce myself as the newest Social Media Officer for the Norfolk, Norwich and Waveney branch. I am delighted to volunteer for such an important cause and I look forward to interacting with you all and, together, raising awareness for the MND Association.

Find our branch on Facebook (@MNDANorwichWaveney), Twitter (@MNDANorWave) and on our new Instagram page (@MNDNorfolk).

Hello, my name is Aidan Nicholson and I am a medical student currently intercalating studying for a master's in clinical education. I have recently agreed to join the writing team for the MND newsletter 'Fightback' whereby I will be writing about current research concerning MND. My reasoning for joining the team was an interest in the condition gathered through my neurology placement at the James Paget hospital learning about the theory of the condition as well as talking to people experiencing it first-hand. I hope that I can help raise awareness about the fantastic research being done as well as what research people can get involved with to help fight against this condition.



Thomas Jenkins wrote, "I am a recently graduated Film and Television student from UEA, currently working as a Freelance Video Editor in Norwich. My main interests are based around film, typically in screenwriting, yet most of my experience is in Editing.

Over the last few months I have been gaining a greater understanding of how the role of an independent Video Producer works, and recently was able to demonstrate this knowledge after being brought onto the MND Association's volunteering team.

Given my lack of knowledge surrounding this particular disease, this opportunity has allowed me to learn more about something that I'm generally misinformed on, and in the future, I hope to pass on this knowledge to others like myself through the videos I produce."

My name is Elizabeth Evans, I am a 23-year-old Master's student at the University of East Anglia. I decided to join the MND Association because my grandpa sadly died from motor neurone disease and I wanted to help others experiencing the same.

Since becoming a Volunteer Fundraiser in 2020, I have raised £194 from a virtual quiz night and handmade knitted headbands.

I sold the headbands for £6 plus postage. Each headband took around 2-3 hours to make, depending on the thickness of the wool. I made red ones, blue, pink, black, cream, green, yellow, purple and white ones. I chose to do knit twist headbands because of what they represent, it signifies experiencing hard times and making it to the other side.



I hosted an online Quiz Night on Friday 5 February to encourage people to raise money by having some fun! The price to play was set at £2 per person, but many people generously donated more, by the end of the night we raised a total of £110!

I will continue to fundraise from home until I can utilize my skills and organize fundraising events back in the real world!

## Events in aid of the MND Association

### Sunday 6 December 2020 Virtual 5k Santa Run

Lisa Wilson and Jo Harmer completed the MND Virtual 5k Santa Run along Lowestoft seafront in support of the MND Association. Running in suitably festive outfits helped spread awareness of motor neurone disease!

Lisa is continuing to raise funds for the Association throughout 2021.

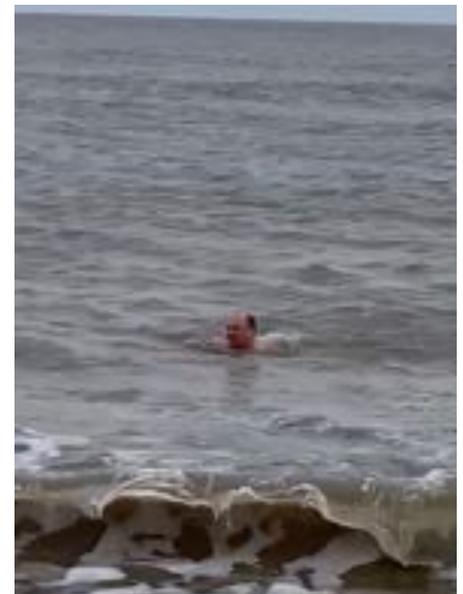
To date, through a variety of fundraising events, Lisa has raised around £4,000 since May 2019 when Steve, her late husband, was diagnosed with MND.

If you would like to read her story and/or donate visit

<https://www.justgiving.com/fundraising/greatnorthrun2020>.



### Saturday 26 December 2020 Anthony takes a dip in aid of the MND Association



I had been trying to think of something to do to raise some money for charity through most of the COVID-19 period and the first lockdown, specifically for the MND Association after hearing and watching the Rob Burrow story on TV. Then when watching Rob's mate Kev run his seven marathons in seven days I knew I had to do something a little different and something to test my mettle. I had been thinking about a Christmas / winter swim, so when someone tagged me in the Boxing Day dip for the MND Association I signed up straight away. I had done cold water swims before just never in the winter.

On the day of the swim I was actually quite calm until I got down on the beach and got undressed as it was cold as well as windy! At first I decided to walk slowly into the sea to acclimatise myself, but once I'd got up to my waist and felt the icy water on my stomach for some reason I decided to dive right in and get it over with. I tried to stay in the water and keep swimming for as long as I could, but once I felt myself going a bit numb and my teeth started to chatter I knew it was time to get out.

Luckily I had my partner, Lorna, with me to help me get dried and dressed while shivering, and our friend Katrina for moral support while social distancing.

I have raised £155 to date so far, but plan to raise more money with other ideas when we come out of lockdown – hopefully!

*Editor Sue's note – there are some friends you can always rely on to rise to a challenge; we are very grateful to Anthony for taking the plunge in aid of the Association!*

### **A Winter Walk**

The Branch decided to raise money by sponsorship and donations to boost their funds to enable them to continue supporting people affected by MND in our area. In line with COVID-19 restrictions we turned to socially distanced events. Supporters of the branch and committee members took winter walks and shared the link to our JustGiving page to allow donors to contribute.

Anne Gillett started us off by walking almost eleven miles during the last weekend in November. Sue and Jo went next during the first weekend in December, and Sue added another 8.5 miles on 20 December. Everyone was invited to join us and chose their distance. We walked alone, but together in our endeavour.



### **Anne Gillett's 300,000 steps in 30 days**

In January, Anne responded to the MND Association's #TakeoverMND Campaign. Anne took on the Step Forward challenge and pledged to walk 300,000 steps in 30 days. Anne said, "This seemed to be just the challenge I needed entering lockdown enabling me and my partner to enjoy our daily exercise and a challenge in memory of my husband, Frank, who sadly had MND and died ten years ago in February." Anne and Ian finished their 300,000 steps on 4 February and have raised £500 so far, can you help them exceed their target of £500?

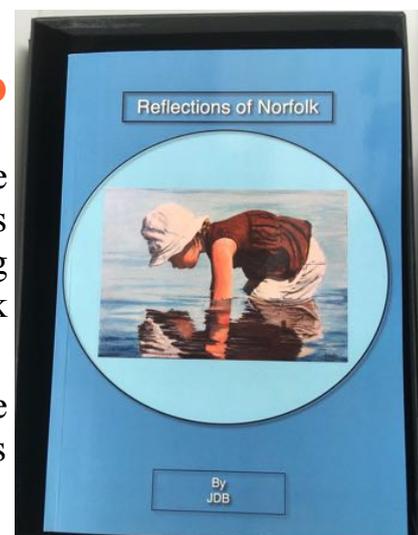
To support either event visit <https://www.justgiving.com/fundraising/MNDANORWAVE?>

## **Future events in aid of the Association**

### **David Banks' books are raising money in aid of the MND Association**

David Banks describes himself as a hobbyist author-writer. He began by writing about his 'Norfolk journey' and followed this with books about the USAAF. He has created some fascinating books and booklets about a golden era on the Norfolk and Suffolk Broads; they are beautifully presented.

David is selling his books to raise money, all profits after postage are sent to the Association. If you would like to buy any of his titles visit his website <http://evolution-norfolk-broads.co.uk>.



### **Beautiful handmade quilt for sale**

The Branch has been offered this splendid double quilt for sale to raise funds for the Branch. After some research and discussion with the donor it has been agreed to price it at £150.

If you are interested in purchasing the quilt please contact [sueheal@btinternet.com](mailto:sueheal@btinternet.com).

*Items for sale: The Association requires us to advise that we cannot accept responsibility for the condition of the items advertised; it is not endorsing or affiliated with any of the items being advertised. Arrangements for collection of free items or items for sale should be made directly between the buyer and seller.*



### **Lisa Wilson's fundraising** by Lisa

Pre-COVID-19, MND runners would be a familiar sight in our orange and blue running tops at marathons, half-marathons etc, raising money. In 2020, social isolation restrictions and nationwide lockdowns saw us running alone raising money in virtual races or by donning fancy dress in our home towns and cities for random runs.

Optimistically, for 2021, plans were made – entering Brighton Marathon in April, but now postponed until April 2022 as the original change was made for the same day as the GNR 2021, (which I have a place in and am hoping will continue to go ahead). I am still waiting for confirmation on whether Endure24 (Glastonbury for runners) will continue to go ahead in June, running in teams with other people from RUNMND and, thanks to friends but running socially distanced, I am trying to get back on the road to fitness again.

Last October, I was due to watch my friend, who had gained a good for age place for the 2020 London Marathon (VMLM) and is running in memory of Steve and for the MND Association. I did enter the ballot for VMLM 2021, but was unlucky. However, my hotel room is booked for London in October as if not I would have lost the voucher money from last year's cancellation. Instead I have entered the virtual marathon.

On October 3rd, the day after what would have been Steve's 64<sup>th</sup> birthday, I will be running my own VMLM and hopefully in the different streets of London, perhaps up around Barnet where he was born and grew up instead of Lowestoft and afterwards, me and my friend can celebrate together. The pain and struggle for this run, like so many others will be just moments in time, yet for those living with and battling MND the pain and struggles are constant. Furthermore, for once, I can have my cake and eat it but more importantly, as we say in RUNMND – there is no finish line until a cure!!

### **Help – we need a new branch secretary! Can you help?**

We are very grateful to Patti de Clifford for stepping in temporarily to act as minutes secretary for our committee meetings, and hope we have found a replacement. However, we are still looking for a membership secretary. If you think you might be able to help please contact Judy on 07801351070 or email [judyburnsthomson@yahoo.com](mailto:judyburnsthomson@yahoo.com).

Other volunteers are always welcome. If you are interested please contact Liz Cooper, Area Support Coordinator, on 01604 800620 or email [liz.cooper@mndassociation.org](mailto:liz.cooper@mndassociation.org). Training and induction for all roles will be provided and travel/direct cost expenses are reimbursable.

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

- Anonymous donations - £170
- Sale of merchandise - £136.25
- Emergency Appeal, total to end of February - £526
- Elizabeth Evans, sale of knitted headbands - £78
- Elizabeth Evans, quiz night - £110
- Mavin Shulver, a donation - £50
- Sue Kitson, a donation - £50
- Roz Wilkinson, in memory of her Godmother - £60
- Swannington Lunch Club - £84
- Bishop Herbert Lodge - £2,750
- Faithful Lodge, Harleston - £300
- Wayford Lodge - £100
- The Sheringham Lodge - £150
- Paul Bassham Trust - £5,000
- RWE Generation UK - £500

- Sue Heal, Mission 5000 final total - £1,140

### Donations in memory of

- John Lindsay Blyth - £1,140
- David Broomfield - £30
- Pamela A. Capel - £60
- William Capps-Jenner - £30
- Robert Stephen Clifton - £107.50
- Steven Howman - £120
- Mrs Jean Lorraine Jackman - £475
- David Siggins - £170

### Internal transfers

- Interest - £6.52
- Gift Aid - £241.88

We are extremely grateful for the donations totalling £44.52, 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. A new section on the vaccination programme has been added since the last edition of Fightback.

<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.

**Look to Speak:** A new communication app launched recently. It will enable people who use eyegaze technology to communicate in more environments than ever before. The Look to Speak app is now available free on Android smartphones and can be used in places where eyegaze isn't usually available, such as while travelling or bathing.

People with MND were involved in the design process and testing, as were MND Association experts, offering valuable insight to the developers.

"Because the experts at the Association and people living with MND have been working alongside the team at Google during the design and testing phases of the app, we already know it works and are convinced it will make a real difference to many people, not just those with MND but others who are unable to use their voice." Nick Goldup, Director of Care Improvement.

**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](mailto:careadmin@mndassociation.org).

## Campaigns

**Update on the Scrap6Months campaign:** It's been over 18 months and we are still awaiting the results of the Department for Work and Pensions promised review into the benefits system for people with a terminal diagnosis. We are told that the review has been completed, but cannot be published until it is approved by the Treasury. Thank you to everyone who contacted their MP requesting that they write to the Treasury asking it to approve the changes set out in the review as a matter of urgency so that they can be passed into law as soon as possible.



Kath Blake, Sue Heal and Jane Lewis met with James Wild MP for North West Norfolk and his assistant in November. We discussed the progress of the Scrap6Months campaign, which James actively supports, the Act to Adapt report and the launch of the United2EndMND campaign. We appreciated his time and understanding of the issues faced by people living with MND. He offered to write to King's Lynn and West Norfolk Borough Council to ask about their response and any actions they might plan following receipt of the Act to Adapt report.



Jessica Morden MP spoke passionately in an End of Day Adjournment Debate on Monday 22 February starting at 10pm! You can read the full text of her speech in Hansard, where she speaks on the topic of the review into the Special Rules for Terminal Illness.

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:** Following the launch of the campaign a number of supporters contacted their local councillors to share the Act to Adapt report and raise awareness of the issues people face.



Sue Heal, Campaigns Contact, has been particularly encouraged by the response of some of the councils. She would very much appreciate hearing from you if your councillor replied, or if you have a story to share about accessing accessible housing whether it is positive or negative.

One positive response has been from Breckland District Council. Sue had read their Housing Assistance Policy following an email from the Council Leader. The policy was designed to enable more flexible use of Disabled Facilities Grant capital, it appeared to address the needs of those in receipt of certain benefits rather than every applicant. Sue wrote to ask about the possibility of considering a fast-track for people with MND and the removal of the means test where people had received a terminal diagnosis. In responding they said, “We are very interested in taking on board the points raised in the report and in your email”.

The councillors at Broadland District Council are considering the report in greater detail and will be looking at how they can best support people living with MND. The report has also been shared with the officers responsible for housing.

East Suffolk District Council have also responded positively, having lost one of their officers to MND they are very conscious of the impact of the disease. They will share the report more widely and do what they can to provide the best support for people living with MND.

Having shared the report with South Norfolk District Council Sue had the opportunity to speak with one of the housing officers who is sharing the report with colleagues.

Norwich City Council had already agreed to treat people with MND on a case by case basis to ensure their needs were met in a timely fashion.

Jane Lewis has been in contact with North Norfolk District Council. Sue and Jane have met with Duncan Baker MP and spoken about the Act to Adapt report.

Please contact [sueheal@btinternet.com](mailto:sueheal@btinternet.com) if you have received a response from Great Yarmouth Borough Council?

Hopefully in the fullness of time these approaches will lead to changes. We would like to see local councils provide accessible housing to people with MND by:

- fast-tracking support for adaptations
- removal of the means test for low-cost and high-impact adaptations such as stairlifts
- maintaining a register of accessible housing

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

**#United2EndMND:** The campaign aims to bring together people with MND, researchers, clinicians and charities – the MND Association, My Name’s Doddie Foundation and MND Scotland - in a call to Government to fund a virtual centre for excellence for MND research leading us towards treatments and cures. Research into the causes and potential treatments has progressed, with current trials offering real promise. However, progress is largely dependent on sufficient levels of investment. The UK government’s funding for targeted MND research has plateaued around £3 million a year. We are asking for £50 million from the government over five years to set up a virtual institute for MND research. It aims to bring the MND research community even closer together without the need to operate under one roof. The institute would focus on drug discovery and development, develop a sustainable MND trials platform and implement a rigorous clinical research programme.

Find out more at <https://www.mndassociation.org/get-involved/campaigning/take-action/united-to-end-mnd/>.

**The All-Party Parliamentary Group on MND met on 25 February** to discuss research into MND. Thank you to every who invited their MP to attend. Fifty-one MPs and Peers were represented at the meeting – the highest turnout the APPG has ever had!

Dr Brian Dickie, Director of Research Development at the Association spoke about the exponential growth in global MND research, particularly over the past decade. He gave an overview of the research the Association is funding, currently 85 studies including research in France, Italy, Finland and Canada totalling £14.6 million.

Chris McDermott, Professor of Translational Neurology at the University of Sheffield at SITraN and a Consultant Neurologist at the Sheffield Teaching Hospitals Foundation NHS Trust, discussed his ground-breaking gene therapy clinical trial in those with a familial form of MND. He presented some of the encouraging findings from his research so far, including the slowing down in functional decline, and the ability to maintain breathing and limb strength.

If you would like to read more about the recent APPG meeting you can do so at <https://www.mndassociation.org/get-involved/campaigning/all-party-parliamentary-group-appg-on-mnd/>.

## **Local MND Research Update** *by Helen Copsey, MND Care and Research Network Coordinator*

**SMART-MND:** The SMART-MND trial is led by the Euan MacDonald Centre for MND Research based at the University of Edinburgh, alongside colleagues from University College London and the University of Warwick. There has been considerable media coverage of this new research study which aims to include as many people as possible affected by MND, regardless of the stage of the disease. SMART stands for **Systemic Multiple-Arm Randomisation Trial** which means that the trial SMART will test more than one drug at the same time. Trial participants taking the different treatments will be compared with a single group who receive a placebo (dummy) drug. More information can be found at <https://www.mnd-smart.org/about/about-mnd-smart>. In Norfolk we expressed an early interest to become a centre for SMART-MND, based at the Norfolk and Norwich University Hospital. The research team have been working towards being set up ready to recruit patients as soon as possible. Unfortunately the Covid-19 pandemic has meant that many research projects have had to be delayed. However, we are very keen to get started with this as soon as possible and will look forward to being able to share more information as soon as we can.

**MND REGISTER:** The MND Register is funded by the MND Association and led by Professor Ammar Al-Chalabi at King's College London and Professor Kevin Talbot at Oxford University. The purpose of the study is to collect and store information about every person with MND in the UK. This will allow the research team to establish the number of people diagnosed with MND per year, how many people currently have the disease and how this is changing with time. Information such as gender and ethnicity can be used to look for characteristics of people more likely to develop MND. Collecting information about where people with MND live can also help with planning care for people with MND. It will also tell researchers more about the possible causes of MND.

Here in Norfolk we are aiming to speak to as many of our patients as possible about the MND Register and can provide more detailed information about taking part. However, if people are not currently attending face to face clinics, they can self-register at <https://mndregister.ac.uk/>.

**Factors Affecting Family Carers in Motor Neurone Disease – FACTOR-MND:** FACTOR-MND is a research project led by Professor Eneida Mioshi from the School of Health Sciences, University of East Anglia, in collaboration with the Norfolk MND Care and Research Network. This project is funded by MND Scotland. This study aims to understand factors that might affect the wellbeing of family carers of people living with MND. Learning how these factors impact on family carers' wellbeing could help us develop non-pharmacological interventions to better support them.

To take part in the research, the family carer would need to complete some questionnaires (online or paper). These questionnaires are about personal wellbeing, family, relationships, and the family member's diagnosis of MND. It is estimated that completing the questionnaires will take approximately 25 minutes; all data will be anonymised. Family carers of someone living with MND who wish to participate can join either by completing an online survey at: <https://uea.onlinesurveys.ac.uk/factor-mnd>; or will receive a pen and paper packet with a free-post envelope to send the questionnaires back to the research team at UEA.

If you would like to find out more about taking part please call the research team on 07825863389 or email [mnd.research@uea.ac.uk](mailto:mnd.research@uea.ac.uk).

**Practical Management of Behavioural Impairment in Motor Neurone Disease: MiNDToolkit Feasibility Study:** This study is being conducted by Professor Eneida Mioshi from the Faculty of Medicine and Health Sciences, University of East Anglia (UEA), with the help of Norwich Clinical Trials Unit at UEA. The study is funded by the MND Association.

This will be a small pilot study to test a new psychoeducational intervention. The intervention consists of a new collection of techniques (known as a 'Toolkit') that has been designed to help carers / family members with their management of behavioural impairment that may occur in people living with MND. This toolkit is called the 'MiNDToolkit'. The results of this pilot study will form a foundation that will lead to larger scale studies and design of further interventions and coping strategies to help people living with MND and their carers. The study will be mainly conducted online via our purpose-built website.

**We are at the final phases of building the website and will be inviting carers to join the study in the coming months.** If you would like to find out more please call the research team on 07825 863389 or email [mnd.research@uea.ac.uk](mailto:mnd.research@uea.ac.uk).

### Therapy

**Phase 3 results of NurOwn, have not shown the drug to be effective in slowing disease progression:** Updating June 2020's Fightback edition about NurOwn, a promising stem cell treatment for MND, phase three trial results unfortunately were classed as statistically insignificant. After promising Phase 2 findings, a larger patient population was set in a Phase 3 drug trial to evaluate NurOwn's safety and effectiveness in slowing MND progression in rapidly progressing patients compared to a placebo. Data showed NurOwn treated patients (34.7%) had slower disease progression compared to the placebo (27.7%). However due to unexpected high responses with the placebo, the difference did not reach statistical significance. However, in a group with less advanced disease, 34.6% of NurOwn patients had slower progression compared with the placebo's 15.6%. These results were still classified as statistically insignificant, but optimistically they are considered clinically meaningful.

See more at: <https://alsnewstoday.com/news-posts/2020/11/18/nurown-fails-to-slow-disease-progression-in-als-patients-top-line-data-show/>

**Edaravone reviewed: May not be as effective at increasing survival as previously suggested:** Approved MND treatment Radicava (edaravone) in a recent review was found to be well tolerated, but its disease delaying effectiveness was less evident. Radicava works by reducing motor neuron death by reducing free radicals which are unstable cells causing oxidative stress, overwhelming, and destroying motor neuron cells' antioxidant defences killing them. However, controversy has been sparked as studies surrounding Radicava have come under scrutiny. A Japanese phase three drug trial failed to show a significant difference between the treatment and a placebo with later trials unable to evaluate if it improved survival. Following this there was a review on Radicava's past studies and how it performed in six different countries: Kuwait, South Korea, Argentina, the US, Israel and Italy. Results were mixed with the US noting drug ineffectiveness in more than 50 cases out of 3,007 but in Argentina being supported as safe and well-tolerated. Regardless, investigators concluded, "more post-marketing experience with edaravone and its impact in the clinical setting need to be reported to get a better perspective of edaravone's effectiveness".

See more at: <https://alsnewstoday.com/news-posts/2020/11/17/radicava-suggests-more-real-world-data-needed-to-determine-efficacy-of-edaravone-in-als/>

**Amylyx announce the results of AMX0035's open-label study's analysis:** In a recent trial, MND patients taking AMX0035 retained physical function and survived 5 months longer than those receiving a placebo. AMX0035 protects against nerve degeneration by using a combination of two medications called PB & TUDCA. Each targets a different cell component to keep nerve cells functioning properly. The AMX0035 trial was an MND community collaboration, conducted at 25 clinics in the US. However, due to the positive effects most participants taking a placebo were given the opportunity to start taking AMX0035 after 6 months of a placebo. New data analysis from the trial suggests an even greater survival benefit than previously reported to about one year.

See more at: <https://www.neurologylive.com/view/amx0035-associated-with-survival-benefit-in-als>

### Aetiology

**An experimental test could detect MND before symptom onset:** The toxic build-up of TDP-43 occurs in about 97% of MND patients and about 45% of patients with a clinically and genetically similar condition called frontotemporal dementia (FTD). With this information by detecting TDP-43 build-up we may be able to identify and diagnose people with MND before symptoms appear allowing for more time to try therapies.

However, TDP-43 detection is difficult due to the small amount capable of being tested however a technique called RT-QulC can amplify and detect these small amounts. Researchers created a trial using 31 patients with either MND or FTD with a genetic mutation causing TDP-43 accumulation in the brain and 27 healthy people as a control. The research concluded that the likelihood of RT-QulC correctly identifying those with the disease was 94% and identifying those without the disease was 85%. These findings could potentially create a new test capable of early and accurate diagnosis of MND.

See more at: <https://alsnewstoday.com/news-posts/2020/12/14/new-test-potentially-detects-als-before-symptom-onset/>

**Dr Arpan Mehta's exciting discovery about the mitochondria's role in MND:** Research conducted at the Euan MacDonald Centre at Edinburgh University have found new information about the mitochondria and its relation to MND and its treatment. The key brain cells affected in MND are motor neurons allowing us to move, eat and breathe. 90% of the cell is made up of long, thin motor cables called axons connecting our spine to our muscles. In this research Dr. Mehta focused on the mechanisms causing these motor cable defections in MND patients. They found shorter than normal axons in people with MND and that transport of mitochondria (the cell's battery) was impaired. They believe this is due to defective energy supply from the mitochondria and by boosting this battery, the motor cables or axons can revert to normal. This is a very exciting discovery as it opens a new avenue for therapeutics focusing on this discovery. Researchers are cautiously hopeful that from this breakthrough they may find therapies that can slow the disease within the next decade.

See more at: <https://mndresearch.blog/2021/01/07/boosting-energy-in-nerve-cells-is-a-promising-target-for-mnd-treatments/>

### **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.

**The CALM Study:** 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. Access via: <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/calm-study/>

**Participants needed to assess testing tool for detecting cognitive change in people with MND:** This study's aim is to evaluate if different screening tools have similar rates of diagnosed cognitive change in people with MND. Participants take several questionnaires and tests on a computer via video call taking about two hours which can be divided into shorter sections. This study is looking for people with MND and healthy controls, both with English as their first language. Access via: <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/measuring-cognitive-and-behavioural-change-in-als/>

**The COMMEND Study:** This study's purpose is to create a new psychological therapy called 'Acceptance and Commitment Therapy (ACT)' to improve people with MND's quality of life. ACT aims to help people with MND learn techniques of how to cope with and handle distressing feelings while trying to learn how to best live their lives. To participate you would meet with a researcher to discuss the study and if you are a suitable candidate. Next you would be placed in a group with ACT therapy consisting of eight, one to one, one-hour sessions with

a therapist for over four months or in a group with usual care. Afterwards you will complete questionnaires at zero, six and nine months to see how effective ACT therapy is and the value for money it represents compared to standard treatment.

Access via: <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/acceptance-and-commitment-therapy/>

**The TUDCA-ALS Clinical Trial:** The TUDCA-ALS trial investigating TUDCA as an add on treatment for MND has reaching the halfway point in its recruitment (220 out of 440 participants). The study aims to determine if TUDCA combined with riluzole can slow progression of MND. The trial is recruiting across seven European countries including the UK. The study is recruiting people with MND who have no swallowing difficulties and are less than 18 months since symptom onset. If eligible participants will be screened to confirm, including taking blood and cerebrospinal fluid samples. After three months participants will be re-screened for eligibility and to make sure they are stable while taking riluzole. Participants will then receive their treatment capsules (either TUDCA or placebo), taking four in the morning and four in the evening for 18 months. Every three months participants will visit a clinic for routine checks of their symptoms and to give samples of blood and cerebrospinal fluid.

See more at: <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/tudca-clinical-trial/>

### Online coffee mornings

The coffee mornings are friendly informal gatherings for people with MND, their carers and friends, there is no agenda. If you are attending for the first time and haven't used Zoom before let us know if you would like a trial run before a coffee morning.

Coffee mornings will continue online on the third Wednesday of every month. Now that we have a subscription for Zoom the meetings can be a little longer – 11:30am to 1pm, 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.

### Branch Emergency Appeal

Thank you to everyone who has so generously donated to our appeal. We anticipate our fundraising remaining lower than usual throughout 2021, and will keep the appeal open. We remain conscious of the need to sustain our income to provide the same level of support and provision of equipment as in the past.

If you have asked for money be donated to support research we have ensured that this has happened through specific instructions accompanying our annual transfer to the Association. <https://www.justgiving.com/fundraising/mnda-nor-wave>



### Keeping in touch

Would you like to receive our newsletter electronically? If you would prefer to receive Fightback as a pdf sent by email please contact [judyburnsthomson@yahoo.com](mailto:judyburnsthomson@yahoo.com). Of course we will continue to send you a paper copy by mail if that is your preference, but we are trying to minimise costs where possible.

## Branch News

**Sunday 18 April 2021 2pm-4pm** Everyone is invited to join us at our next online Open Meeting. Liz Cooper will host the meeting using Microsoft Teams. Malcolm will chair the meeting. As always there will also be an opportunity to chat and ask questions. Liz will email the link shortly before the meeting to those who respond to our invitation.

The meeting will include a brief AGM, followed by a short talk. We are delighted to be welcoming Chris Wade, Director of Engagement with the Association. He will focus on our forthcoming strategy for increasing membership numbers and providing new opportunities for members to play a role in shaping our work locally and centrally. We hope to record Chris' talk and would like to take some screenshots during the meeting to use in our next newsletter and on social media. Let us know if you don't wish your image to be used.

**Advance Notice of Open Meetings:** For the foreseeable future events will be held online. Hopefully as restrictions are lifted the Association will allow us to meet in person, but for now we remain cautious and thank you for your patience.

**Virtual Coffee mornings:** For carers and people living with MND hosted by Judy and Sue. These are planned for the third Wednesday of each month starting at 11:30am and finishing around 1pm. 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](mailto: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 welcome!

**Dates for 2021 are as follows:** 17 March 21 April 19 May 16 June

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

**Website:** [www.mndnorwichandwaveney.org.uk](http://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 next deadline for receipt of articles is **21 May 2021** for the next edition.

### Useful Numbers

**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](mailto:mndconnect@mndassociation.org)

**MND Coordinator** Helen Copsey 01603 647221 [helen.copsey@nnuh.nhs.uk](mailto:helen.copsey@nnuh.nhs.uk)

**MND Administrator** Magdalena Mitcher 01603 647221 [magdalena.mitcher@nnuh.nhs.uk](mailto:magdalena.mitcher@nnuh.nhs.uk)

**Care Service Navigators** Trish Moore 07813 094820

email [trish.moore@mndassociation.org](mailto: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](mailto: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.*