

# Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter  
Issue 82 June 2020

## **Sunday 19 July 2020 – an open meeting with a difference**

The open meeting will now take place online using Teams and hosted by Liz Cooper, our Area Support Coordinator (ASC). If you would like to attend please email Malcolm at [malchubbock@hotmail.co.uk](mailto:malchubbock@hotmail.co.uk) by Friday 10 July. You will need to provide him with permission to contact you by email at least for the purposes of sending you the link to enable you to attend this meeting. It is not necessary to download the Teams App although it helps, you are able to attend using your web browser – it seems to work well with Chrome, it doesn't appear to work with Safari. Sadly you will need to provide your own refreshments!

We are delighted that Helen Pye, from the Environmental Control Service for Norfolk, is able to join us online as speaker. Her short presentation will cover environmental controls such as intercom/door release, lamps and telephone. Helen was due to speak at our AGM, we are very grateful to her for rescheduling and agreeing to join us in July.

## **Coffee mornings**

The coffee mornings are informal gatherings for people with MND and their carers. We have missed seeing everyone in person, but the current situation means that they would be unsafe. However, if people are interested in meeting online using Zoom please let us know and we will make the necessary arrangements.

## **MND Coronavirus (Covid-19) Hub**

The Association has created a dedicated webpage providing regularly updated information on Covid-19 and MND, it contains advice, frequently asked questions and links to organisations that can provide relevant support. The Ask the Experts section allows you to access videos, or transcripts of the videos, showing experts answering questions sent in by people living with MND or their carers – they contain a wealth of interesting responses. Another useful link is to the Association's online forum, an ideal resource for anyone living with or affected by MND. It is run by the Association, but most content is created by a wide range of people, offering first hand experience of MND and providing medical, emotional and practical support. Anyone can access the forum to read content, but you must register if you would like to post.

<https://www.mndassociation.org/about-mnd/coronavirus-and-mnd/>

The branch website home page contains a link to the hub, to local contacts that people living with MND and their carers might need in an emergency and other useful numbers.

## **Branch Emergency Appeal**

Normal fundraising activities have, like so many other things, been put on hold as a result of Covid-19. Jo has set up a JustGiving page to enable the Branch to raise money. This will enable us to continue supporting people affected by motor neurone disease. We hope to change the cover picture soon!



If you would like to donate visit <https://www.justgiving.com/fundraising/mnda-nor-wave>

## **A few words from Area Support Coordinator, East Anglia** by Liz Cooper

Some of you will be aware that following a structural re-organisation, the Regional Care Development Adviser (RCDA) and Volunteer Development Coordinator roles were made redundant last December. From 1 January 2020 I have taken up a new position as Area Support Coordinator in East Anglia. Sadly, my former job share, Lindsay Goward, decided to leave and I am currently working full time in the role across East Anglia.



Having been RCDA for almost 16 years (albeit part time for the past 10 years) I feel grateful in being able to reconnect with branch and care support volunteers as well as health and social care professionals in Norfolk (as Lindsay had been leading on Norfolk).

It is a pleasure to work now with both care support volunteers and branch personnel in steering the support we offer to people affected by MND in Norfolk and beyond.

The change in role means that I am now less involved in strategic influencing, planning and education with our health and social care colleagues and more involved with leading the provision of all Association volunteer services and support in East Anglia. Complex issues are referred on to our Service Development Manager, Scott Maloney. Where they relate to the provision of services (and can't be easily resolved) Scott will consider if there are systemic problems that need to be followed up, hopefully leading to the development of improved services.

Alongside the committee we are making plans to develop services in Norfolk (whilst taking into account the changes imposed upon us all in light of the Covid-19 pandemic). This includes seeking a replacement secretary for the branch, recruiting volunteers in a variety of roles and considering how best to support people remotely during lockdown.

I have been overwhelmed by the commitment of our Association Visitors, Care Service Navigators and branch committee members in adapting to new and creative ways of working. We look forward to supporting you and working with you in the future.

If anybody is interested in finding out more about volunteering with the MND Association please either drop me a line at [liz.cooper@mndassociation.org](mailto:liz.cooper@mndassociation.org) or visit:

<https://www.mndassociation.org/get-involved/volunteering/become-a-volunteer/>

### **June 21 Global MND Awareness Day**

On Sunday 21 June, like many MND/ALS communities across the world, we will be marking Global MND Awareness Day. The Association volunteer team said, "Now more than ever, with the world in the grip of a global pandemic, we want to shine the spotlight on motor neurone disease and reach out to the 5,000 people in England, Wales and Northern Ireland who are living with this brutal disease."

We are delighted that once again Norwich City Hall will be lit in blue and orange. Whilst we usually invite councillors and supporters, this year we invite people to come and take their own photos and to share them on Facebook and Twitter using #HandOf (as in extending our hand of support and love), or email [sueheal@btinternet.com](mailto:sueheal@btinternet.com) and we will share your photos.

# Events in aid of the MND Association

## Ann's Pilates Challenge

Ann, who is living with MND, took on a 2.6 challenge. She decided to do 26 exercises 26 times by 17 May for the MND Association, because as she wrote “they've supported me during the last 14 years”. In addition to the classes, which have now moved online, she chose to do her exercises with her son as adjudicator. Ann wrote, “Pilates movements are done slowly with precision and with my dodgy toe, knee, elbow, shoulder and stiff muscles this is a hard challenge for me.” When last checked Ann had raised £950, well above her £200 target – a stunning result for which we are extremely grateful. If you want to add to Ann's total visit <https://www.justgiving.com/fundraising/Ann-Franklin6>.

## Lisa's fancy dress run

Over the bank holiday weekend Lisa ran 5 miles in fancy dress and raised £140 for the MND Association. A friend, Teresa, works as a receptionist at the MND Association and over May she ran 5k every day in different fancy dress so a group of supporters joined her for the bank holiday Monday. Lisa was in '70's gear. It was hot going, as the temperature had reached 15°C even at 7.45 am.



## Future events in aid of the MND Association

### Watch the website for a date - Wymondham U3A Coffee Morning

Wymondham U3A hold regular coffee mornings every Thursday between 10am and 12 noon in Wymondham Central Hall, Back Lane, Wymondham, NR18 0QB. They kindly offered to host a coffee morning on 18 June to raise funds for our Branch, sadly the event has had to be postponed – a date will be agreed once it is safe for us to meet again.

Everyone will be invited. There will be a small entry charge to cover tea/coffee. There is plenty of paid parking in the car park behind Central Hall, a wheelchair accessible venue.

If you have raffle prizes, or ideas for activities that you think might be suitable for raising money, please contact Sue Heal on 01953 606569 or email [sueheal@btinternet.com](mailto:sueheal@btinternet.com).

### Saturday 29 August 2020 One Way Ticket with MND - Craft Fair

Lisa Wilson is organising a Craft Fair at St Andrew's Church, Roman Road, Lowestoft, Suffolk, NR32 2DQ from 10:00 – 15:00. Email Lisa at [onewayticketwithmnd@gmail.com](mailto:onewayticketwithmnd@gmail.com) for more information. Lisa says, “at the moment the craft fair is still going ahead and if social distancing is still affecting things I will have the use of 2 rooms to fit the stalls in with good social distance between each other and ensure everybody's safety is of priority. There will also be hand sanitizers available.”

Please check the website before travelling to the event in case it needs to be postponed due to the Covid-19 situation; the event will follow government and Association guidance.

### Wednesday 28 April September 2021 - Youngs Brothers Testimonial

In the last issue of Fightback we included some pre-publicity for the Youngs Brothers Testimonial at The Great Room, Grosvenor House, London W1 scheduled to take place on 29 April. Since then Covid-19 has intervened and the event has been rescheduled for next year. Tom and Ben Youngs have played for Leicester Tigers together as well as England and the British and Irish Lions. Once again you are invited to celebrate their achievements in the company of stars from the worlds of rugby, sport and entertainment. The full details of this event are available at <https://www.fireball.co.uk/event/the-youngs-brothers-testimonial/>.

The money raised during the Testimonial Year will be donated to Tom and Ben's chosen causes – the blood cancer research charity Bloodwise and the MND Association. The latter has been chosen in support of their cousin, Jake van Poortvliet, who is living in our Branch area.

### **Saturday 10 October 2020 Maverick Adidas Terrex Ultra Snowdonia**

In the last issue of Fightback Joe Gilbert wrote about his fundraising for MND Research following his mother's diagnosis. He planned to take on the ultra-marathon in May; the event has been rearranged for 10 October, and Joe is planning on taking part provided that mass events can be held. Until then Joe continues to train in the flattest area of the UK, as he said, "There is a fine line between determination and stupidity!". We wish Joe well and will continue to support him in his bid to raise £5,000 for the charity.

Joe's mother is living in our Branch area. If you would like to donate to MND Research through Joe's JustGiving page the link is [www.justgiving.com/MNDMum](http://www.justgiving.com/MNDMum).

### **October 2020 East Regional Focus Event at the Holiday Inn, Norwich North Postponed**

We were looking forward to the event being hosted in Norwich! Sadly, in line with government guidelines to limit the spread of Covid-19 the Regional Focus events planned for this year have been postponed. The Association is reviewing options for alternatives, including arranging virtual events. We will share updates on Facebook and the branch website as they become available. Updates will also appear in Thumb Print magazine, which is posted to those who have registered membership of the Association.

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

Helen, our branch secretary, has agreed to stay in post until 30 June 2020 to give us more time to find a replacement.

We are looking for secretarial support to the Branch Committee to be responsible for effective communications within the Branch. This might work well as split roles and could for example be made up of; General Branch Secretary, Membership Secretary and Open Meeting Secretary.

Please contact Malcolm on 01603 960206 or email [malchubbock@hotmail.com](mailto:malchubbock@hotmail.com) if you think you might be able to help.

### **General Branch Secretary**

As the General Branch Secretary the main activities include: Taking the lead, in consultation with the Chair and other Committee Members, in setting and issuing the Branch Committee Meeting agenda and committee papers, provide secretarial support at the meeting including taking the minutes. Writing up the minutes and action plan and circulating these by email after the meetings.

- Dealing with correspondence by email, telephone and post as required.
- Ad hoc tasks such as a Festive (December) contacts mailing to people affected by Motor Neurone Disease (MND), and occasional branded clothing orders.
- Preparing the paperwork for circulation at the AGM. Attending the AGM and taking the minutes. Writing these up for final approval.
- Keeping and filing appropriate documentation in compliance with data protection requirements.

The role is reasonably flexible – although attendance at the Branch Committee Meetings and the AGM is required, and activity will tend to concentrate around these meetings. The role is expected to take around 16 days per year in total.

## Membership Secretary

As the Membership Secretary the main activities include:

- Updating the Branch membership records approximately fortnightly, with reference to new branch contact details received and information on the National Office database.
- In advance of Branch Committee Meetings, provide hard copies of the membership records for committee members as necessary. Updating the Chair regarding the number of people with motor neurone disease (MND).
- In advance of Association Visitor meetings (approximately six times per year) providing details of people with motor neurone disease (MND).
- In advance of the Annual General Meeting (AGM), Open Meetings and December mailing, providing the Open Meetings Secretary/General Secretary with address labels for the mailings and an updated email listing.
- Keeping and filing appropriate documentation in compliance with data protection requirements.

The role is expected to take around 5 days per year in total (more if you choose to attend the meetings).

## Open Meetings Secretary

The role primarily involves drafting the invitations for our two Open Meetings and for the Annual General Meeting (AGM), issuing these by mail and email, and logging details of attendees. Attendance at the Open Meetings and the AGM which are held at various locations in Norfolk usually on a Sunday is optional.

The role is reasonably flexible with timing to fit around your lifestyle – although activity will tend to concentrate around a month in advance of the two Open Meetings (usually held in June/July and November) and the AGM (usually held in April). The role is expected to take around 5.5 days per year in total.

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Good written and verbal communication, organisational skills and IT skills (Word, Excel and email) are required for all roles. Good writing skills would be an advantage, although we have recent examples of correspondence, meeting agendas and minutes, meeting invitations for guidance. Training and induction for all roles will be provided and travel/direct cost expenses are reimbursable. See <https://volunteering.mndassociation.org/vacancy/branch-secretary-roles-norfolk-norwich-waveney-412239.html>

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

- Anonymous donations - £4,556 of which £4,500 was specifically given to fund the provision of riser recline chairs
- Hempstead Church - £500
- CAF Tourle Foundation Fund, a donation to cover the costs associated with holding our open meetings and coffee mornings - £2,149
- Wymondham Waitrose, Community Matters - £360

### Donations in memory of

- Iain Armstrong -£425.41
- Trevor David Cox - £92.25
- Glen Taylor - £595

### Internal transfers

- Interest - £83.75

We are extremely grateful for the donations totalling £17.76 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

**The Summer Raffle** is back, with an amazing top prize of £5,000. Tickets are just £1. Every ticket sold will help improve the lives of people living with MND, and help fund vital research. If you would like to request tickets to sell to your friends, family and colleagues, you can call the raffle hotline on 0330 002 0342 or email [raffle@mndassociation.org](mailto:raffle@mndassociation.org). Alternatively you can play online at [www.raffleentry.org.uk/mnda](http://www.raffleentry.org.uk/mnda). The raffle closes on 9 July and the lucky winners will be drawn on 16 July. Good luck!

*Regulations mean entry is open to all UK residents excluding Northern Ireland, Jersey, Guernsey and the Isle of Man & tickets are not for sale to or by anyone under 16 years of age.*

**Fundraising News: Fundraising at Home #TeamMND goes virtual.** With many mass fundraising events being postponed or cancelled, many supporters across the country have taken fundraising into their own hands – from garden marathons to hair chops! To continue these amazing efforts, the Association has developed a Fundraising at Home Hub which includes lots of ideas for activities for all ages, including virtual quiz nights and climbing MountStairdon. A JustGiving page can be created too, to make others aware of your challenge and encourage them to join in. Remember that if you set up a JustGiving page and want the funds to come to the Branch you must mention the Norfolk, Norwich and Waveney Branch as the recipient – and let us know you are supporting us so we can support you! We always like to feature your events on our website, Facebook page and in Fightback!

<https://www.mndassociation.org/get-involved/fundraising/home-fundraising/>



Just one idea is the new Virtual Race that allows people to pledge to cover any distance over a chosen month, for example by running around their garden, walking up and down their stairs or going out jogging. Anyone who raises over £50 will receive a special limited edition of #TeamMND medal.

You can sign up at [www.mndassociation.org/virtual](http://www.mndassociation.org/virtual).

*When undertaking a Virtual Race, the Association encourages you to follow the most up to date government advice and to adhere to it at all times!*

Other ideas include Drysolation – could you give up alcohol until the pubs and bars open? Game Over MND – you have to look at the website! Virtual Quiz Night, Silence Speaks, exactly as you might expect and Big Steps of Hope – a virtual walk, tribute to Walk to D'feet MND.

The Spring 2020 edition of Thumbprint, the magazine of the MND Association, contained a centre page spread entitled 'Top tips for taking your fundraising inside'. We have shared some on our Branch Facebook page – but there are many more! For a fundraising pack and to tell the Association about your fundraising visit [www.mndassociation.org/fundraiseyourway](http://www.mndassociation.org/fundraiseyourway), email [fundraising@mndassociation.org](mailto:fundraising@mndassociation.org) or phone 01604 611860.

**Euphonia Project:** We need your help – read on to find out why and how!

It may sometime in the future help people with MND who have slurred speech to be better understood by voice recognition systems.

This is why the MND Association are supporting Euphonia and sharing the ways that you can get involved.

### **What is Euphonia?**

- For people who have moderate or severely slurred speech (also called dysarthria) face-to-face communication can be challenging.
- Google is researching how voice recognition systems may better recognise impaired speech.
- Improvement to voice recognition depends upon analysing impaired speech. Can you help?

### **Our request to people that currently have slurred speech (mild, moderate or severe)**

#### **Would you consider recording your voice repeating some phrases?**

- Recording is done by reading aloud phrases on a smartphone, tablet or a computer.
- The MND Association can provide all equipment and support.
- The website [g.co/euphonia](http://g.co/euphonia) also has helpful information and a video about the project.
- The Association positively encourages people living with MND to record with slurred speech, whether severe, moderate or mild.

#### **What next?**

- First, review the information on [g.co/euphonia](http://g.co/euphonia) to decide if this is for you. You can register there if you wish (if you have a gmail email address - please use that to register)
- If you decide to register, within an hour or so you are emailed a link to a web page (no software is downloaded)
- You can use Android/Apple/Windows smartphone, tablet, or laptop.
- The initial phrase set will contain 30 phrases, and takes 5-10 minutes to record. The full phrase set contains about 1500 phrases, and may take 4-7 hours. You do not need to record these in one sitting. All phrases will be saved, and you can always pick up where you left off.

Richard Cave, MND Speech and Language Therapy Project Manager at the MND Association, would love to hear from you if you can help – he would really appreciate it!

Tel: (m) 07898 721278 or email [richard.cave@mndassociation.org](mailto:richard.cave@mndassociation.org) or [richard.cave@nhs.net](mailto:richard.cave@nhs.net)

**How to apply for voice banking funding:** Visit <https://www.mndassociation.org/support-and-information/our-services/communication-aids-service/> for instructions on how to apply for funding for each voice banking service. The documents are contained within the voice banking drop down section. For more information email [communicationaids@mndassociation.org](mailto:communicationaids@mndassociation.org).

**Benefits Advice Service:** qualified advisers will help identify the benefits you may be able to claim and work out the best way of claiming them. They can also deal with complex benefits issues on your behalf and appeal against decisions.

Visit <https://www.mndassociation.org/support-and-information/our-services/benefits-advice/>. Or you can call for free on 0808 801 0620 between 09:00 and 17:00 Monday to Friday, except on public holidays.

**Updated information sheets:** Download information sheets at <https://www.mndassociation.org/about-mnd/information-resources/> or order copies from the care admin team by calling 01604 611685 or by emailing [careadmin@mndassociation.org](mailto:careadmin@mndassociation.org). People living with or affected by MND can order direct by contacting the MND Connect helpline on 0808 802 6262 or emailing [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org). A number of sheets have been re-worded and made clearer so it is always worth looking at them online to ensure you access the latest version of each sheet. Sadly, work to update some booklets and information sheets has been delayed due to the Covid-19 pandemic.

**MyBreathing:** a new website has been launched about assisted ventilation, with videos and information. Developed by SITraN at Sheffield, Optical Jukebox and Ammba, the myBreathing website includes input from the Association's Education and Information team and people living with MND. Hearing their experiences can help you make your own choice about the treatments on offer. MyBreathing is a companion to myTube, featuring tube feeding. Both sites can be found at myMND [www.mymnd.org.uk](http://www.mymnd.org.uk).

**Could you help review the Association's information?** Are you living with MND? Are you supporting someone living with MND or have you previously been a carer? Do you have a few hours to spare? Then we need your help!

You could get involved in a range of exciting projects and help develop the information provided by the Association. If you would like to take part from the comfort of your own home please email [volunteering@mndassociation.org](mailto:volunteering@mndassociation.org) or ring 0345 6044 150.

**Carers Week:** Making carers visible is the theme of Carers Week 2020, 8-14 June. See the carers week website at [www.carersweek.org](http://www.carersweek.org) for the latest information.

The Association is extremely concerned that unpaid MND carers are under immense pressure to provide more care with no breaks and very little support. As the Covid-19 lockdown eases, unpaid MND carers will continue to provide a vital but often invisible frontline role to ensure those they care for continue to remain safe while wider society slowly begins to enjoy increased freedoms again. We are calling on the UK government, Welsh Government and Northern Ireland Executive to act now to relieve some of the immediate pressures being faced by carers.

We want to see improved access to testing and personal protective equipment, an increase in Carers Allowance, and clear guidance that helps protect unpaid carers and those they care for as lockdown restrictions begin to be lifted. Sally Light has written an open letter which supporters have been invited to sign (we shared the link on our Branch Facebook page) and to add their experiences. It was delivered virtually during Carers Week to the Minister of State for Care Helen Whately MP, Deputy Minister for Health and Social Services in Wales Julie Morgan MS, and Northern Ireland's Minister of Health Robin Swann MLA.

The MND Association is also launching its first ever 'Commitment to Carers' following an increase in demand for support and information during the Covid-19 pandemic. The Association has committed to developing new support for people who care for a loved one with motor neurone disease, with a focus on digital and online platforms.

Further support and information is available at <https://www.mndassociation.org/support-and-information/for-carers/>.

The Association's Commitment to Carers pledges:

- To provide support to help you cope with caring for someone with MND
- To offer opportunities to relieve isolation and improve well-being and resilience
- To help you access services and support provided by others

## Campaigns

**#GetMNDOnTheList:** The Campaigns team called on the government and the Welsh Assembly to ensure people living with MND were added to the list of 'extremely vulnerable' people to shield from Covid-19. Sally Light wrote to the Secretary of State for Health and Social Care asking him to ensure that everyone living with MND received the support that this would offer. Thank you to everyone who contributed to the #GetMNDOnTheList campaign.

Since the campaign began in late March there has been considerable media coverage of the issue, over 5,200 supporters, over 120 MPs, nearly 40 clinicians and several high-profile celebrities have joined together to #GetMNDOnTheList. An article, submitted by Sue, appeared in the online EDP on 8 April followed by a full page article in the print edition the following week. Thank you to everyone who agreed to be contacted by the press and to share their story.

<https://www.edp24.co.uk/news/health/norfolk-motor-neurone-disease-coronavirus-list-campaign-1-6600085>

It is with great disappointment that we report that the government has not changed its position and will not be adding MND to the list of conditions clinically extremely vulnerable to Covid-19. The Government's position is that inclusion on the list should be limited to people with MND who have developed respiratory or bulbar symptoms. In correspondence with the Department of Health and Social Care (DHSC), Deputy Chief Medical Officer Dr Jenny Harries has said that 'patients with MND should continue to be recommended by GPs/specialists for shielding on a case by case basis, to reflect the varying degrees of severity of motor neurone disease.'

**All Party Parliamentary Group on MND meeting 5 June 2020:** The All-Party Parliamentary Group (APPG) on MND hosted its first online meeting to discuss the impact of COVID-19 on the MND community. It was chaired by Andrew Lewer MBE MP, speakers were Science Minister Amanda Solloway MP, Sally Light, Consultant Neurologist Professor Ammar Al-Chalabi, and Jessica and Shaan who are living with MND.

Panellists discussed the impact of Covid-19 on the MND Association, medical research and people affected by MND. This was followed by questions, including one from David Setters, another campaigns contact, who asked about the pace of research in MND in the light of the speed with which researchers have responded to Covid-19 when money is available.

Jessica gave a sobering and very moving account of caring for husband Shaan, who is living with MND, during the Covid-19 outbreak. She said, "I am struggling with providing all Shaan's care, as well as looking after our four-year-old. I am a strong person and we have been through a lot in recent years, but the physical and mental strain is bringing me to my knees. All the lifting, all the communication challenges and all the sleep deprivation – Shaan needs help throughout the night as well. I barely cried across the four years since Shaan's diagnosis as I've been so busy, but now I am breaking down in tears of exhaustion every few hours." Their presentation was a reminder of why we have to campaign.

<https://www.mndassociation.org/mps-meet-virtually-to-discuss-the-impact-of-covid-19-on-people-with-mnd/>

## Update on the Scrap6Months campaign:

The Department for Work and Pensions restarted its review into terminal illness. Members of the Association had an opportunity to attend an engagement event with the Department on 2 March in which people living with MND had the chance to discuss their experience of the benefits system with senior civil servants. This was a good opportunity for first-hand experience from claimants to be fed into the review process. The issue has also gained more media attention recently since Justin Tomlinson MP, the Minister for Disabled People, Health and Work, conceded in Parliament that the status quo on the Special Rules for Terminal Illness 'need to change'.



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:** Sadly the launch of the Act to Adapt Campaign scheduled for March 2020 was a casualty of the Covid-19 crisis and has been postponed.

However, we are still collecting personal experiences of accessing home adaptations. If you are living with or affected by MND and/or accessing home adaptations you can contribute to the campaign by having your say at [www.mndassociation.org/haveyoursay](http://www.mndassociation.org/haveyoursay). If you prefer a paper copy of the form and consent form please contact Sue Heal.

If you don't have personal experience of accessing home adaptations as a campaign supporter, health and social care professional or politician/decision maker, you can share a message of support for the campaign.

By sharing your experience or message, you help raise awareness and that will hopefully lead to action to make home adaptations easier for people with MND.

If you would like to read the full Act to Adapt report or summary, watch the videos or add your story you can use this link <https://www.mndassociation.org/get-involved/campaigning/take-action/act-to-adapt/>.

## Local MND Research Update by Dr Kaitlin Dudley

The **CHANGE-MND study** has been recruiting people living with MND and their study partners since January 2018. The **CHANGE-MND study** is currently paused because of Covid-19 and we are investigating ways to continue without face-to-face visits, e.g. post and online questionnaires.

In summary, the **CHANGE-MND study** looks to determine the changes that may occur in everyday life, wellbeing, motivation, quality of life and functioning for people living with MND, as well as their study partners (carers, relatives or close friends). This study involves researchers visiting people living with MND and their study partners at their homes to take part in interviews and brief assessments of functioning. This research works closely with the MND Care and Research Network and is funded by the Motor Neurone Disease Association. The **CHANGE-MND study** now also welcomes people with MND or family members to participate without a study partner. The study now consists of only a one-time visit from the researcher.

Below is an update on the recruitment progress of the **CHANGE-MND study** thus far:

	Recruitment Progress	
	People Living with MND	Study Partners (carers/ relatives/ close friends)
Baseline visit	33	31

The **CHANGE-MND study** is currently paused but still recruiting for when research resumes. More information can be found on the Norfolk, Norwich and Waveney Branch website under 'Local Research'.

If there is anyone interested in participating in the study please email [mnd.research@uea.ac.uk](mailto:mnd.research@uea.ac.uk). Alternatively call **01603 59 1441** (leaving a message, if necessary) and one of the research team will get back to you with further details about the study.

## Research

If you want to get involved in research or read more about ongoing research there is reliable information at <https://www.mndassociation.org/research/>. To talk about getting involved contact the Research Development team on 01604 611880. The information below is taken from links given in the MND Monthly Research Newsletters, and the MND Research blog <https://www.mndassociation.org/research/mnd-research-blog/>. The summaries that follow barely scratch the surface of the work on research supported by the Association and others.

**Clinical trials on hold:** Due to the Covid-19 pandemic, many clinical trials have been temporarily suspended to adhere to the government's social distancing guidelines with the priority to limit the risk of transmission to people affected by MND.

Further recruitment for trials will wait for Covid-19 to pass. Different centres have adapted in different ways and some ongoing trials continue with remote contact.

**Clinical Trials begin for new combination therapy:** PrimeC, a new combination treatment designed to slow down or halt progression of MND, has received orphan drug status from the US Food and Drug Administration (FDA), and is being investigated in two new clinical trials. It utilises ciprofloxacin, a prescription antibiotic, and celecoxib a prescription non-steroidal anti-inflammatory drug – it is hoped they will treat inflammation of the nervous system and the improper regulation of RNA (ribonucleic acid) behaviour.

The decision to begin testing in people came after a zebrafish model of MND significantly regained the ability to swim after treatment with PrimeC. The two trials being held in the USA and Israel, are investigating the safety, tolerability and effectiveness of PrimeC in people with MND. Effectiveness will be judged by monitoring the progression of MND symptoms, respiratory function and the level of an MND biomarker in the blood.

<https://alsnewstoday.com/2020/02/12/als-combination-therapy-primec-receives-fdas-orphan-drug-designation-enters-clinical-trials/>

**SYT13: A protective gene against motor neuron degeneration:** A study published in February showed that in MND and spinal muscular atrophy (SMA), spinal and lower brainstem motor neurones degenerate, but some motor neurone subtypes are spared, including oculomotor neurones (OMNs) that control eye movement which remains largely unaffected in MND. This suggests that factors intrinsic to these neurones protect them against damage and death.

The mechanisms responsible for these differences in degeneration are largely unknown, but the researchers showed that healthy OMNs preferentially express the protein Synaptotagmin 13 (SYT13) compared to spinal motor neurones. The study found that gene therapy with SYT13 protected motor neurones from degeneration in cell and animal models of MND and SMA.

This study serves as a proof-of-concept for a strategy of identifying factors that intrinsically promote neuronal survival as a means of finding new therapeutic targets for MND.

<https://alsnewstoday.com/2020/02/20/gene-that-protects-motor-neurons-may-be-als-sma-therapy-study-suggests/>

**NurOwn – latest news from BrainStorm Cell Therapeutics:** NurOwn is a treatment that uses bone marrow-derived stem cells, taken from a person with MND that are re-programmed into neurone-supporting cells which are then transplanted back to the same person. They can then begin to secrete neurotrophic factors to protect and promote the growth of neurones.

BrainStorm Cell Therapeutics, developers of NurOwn, announced on 11 February that they had met with the US Food and Drug Administration (FDA) to discuss the potential of NurOwn as an approved treatment for MND. NurOwn is currently being evaluated in a Phase 3 clinical trial in the USA. The FDA will look at all the evidence from the trial data and are committed to working collaboratively with BrainStorm to identify a regulatory pathway forward. “Both the FDA and BrainStorm acknowledged the urgent unmet need and the shared goal of moving much needed therapies for ALS forward as quickly as possible”.

The MND Association Research team are following this trial with interest and will report when new information is released. You can read the full press release at

<http://ir.brainstorm-cell.com/news-releases/news-release-details/brainstorm-cell-therapeutics-and-fda-agree-potential-nurownr>

**Potential stem cell therapy moves into Phase 3 trial:** NSI-566 is an investigational therapy that uses human spinal cord stem cells (HSSCs). Stem cells can differentiate into many types of specialised cells during development. When injected into the spinal cord, NSI-566 differentiates into types of neurones that surround and support motor neurones damaged by MND, by integrating into the neural network and forming connections with the patient's own neurones. The decision to move into a phase 3 trial followed a meeting with the US Food and Drug Administration (FDA) and is supported by promising data collected from a Phase 1 and Phase 2 trial (these were primarily designed to test the safety of NSI-566 in people with MND).

<https://alsnewstoday.com/2020/04/13/potential-stem-cell-therapy-nsi-566-moving-into-phase-3-trial-seneca-says/>

**Testing mitochondrial health may lead to new MND therapies:** A new tool to search for medicines that might treat neurodegenerative diseases linked to problems with mitochondria, including MND, has been developed by the Scripps Research Institute. It can screen thousands of potential medicines by directly measuring the health of the mitochondria in neurones. A test screening of 2,400 compounds found several able to improve mitochondrial health and protect them from disease-associated damage. Future studies will include identifying molecular targets for particular therapies and testing their effectiveness in cell and animal models of disease.

*“Mitochondria are tiny, specialized structures that supply cells with most of their energy by converting oxygen and nutrients into chemical energy in the form of adenosine triphosphate.”*

<https://alsnewstoday.com/2020/02/06/tool-testing-mitochondria-health-in-neurons-may-lead-to-als-therapies-study-reports/>

**Antibodies target proteins made by C9orf72 mutation:** A new study has shown that antibodies that target proteins wrongly expressed in the brain, and caused by mutations in the C9orf72 gene, eased symptoms and prolonged survival in a mouse model of MND.

Mutations in the C9orf72 gene account for about 7% of sporadic MND cases and up to 40% of familial cases, making them the most common known genetic cause of ALS. The gene is also implicated in frontotemporal dementia (FTD). How mutations in the gene cause MND or FTD is not fully understood, but it is known that they lead to the accumulation of certain defective proteins in the brain called repeat associated non-ATG (RAN) proteins. The antibodies, taken from healthy elderly donors to create human antibodies against the RAN proteins, reduced the accumulation in cell and animal models. You can read more at:

<https://alsnewstoday.com/2020/02/17/potential-protein-target-for-antibody-therapy-in-als-identified-early-study/>

**Biomarkers:** Wikipedia defines a biomarker as “a measurable indicator of the severity or presence of some disease state.” They are useful in measuring the progress of a disease. For the person living with a disease those that can be collected easily, perhaps by taking a blood or urine sample, rather than a sample of cerebrospinal fluid are preferable!

**Potential biomarker for MND found in specialised white blood cells:** A study to be reported in Neurobiology of Disease, June 2020 will report that levels of specific proteins found in specialised immune cells, such as white blood cells like lymphocytes and monocytes, can serve as biomarkers for MND. Using blood samples from people with MND, and samples from healthy people and people with other neurodegenerative diseases as controls, researchers in Italy could distinguish people with MND from both control groups and predict likely rate of disease progression and disease course.

<https://alsnewstoday.com/2020/03/24/proteins-in-white-blood-cells-may-be-biomarkers-als-diagnosis-prognosis/>

**Potential biomarker - plasma creatinine:** Creatinine is a waste product of healthy muscle and a drop in its level may indicate increased muscle wasting in patients with MND. Findings in an American study at Columbia University indicated that plasma creatinine is strongly associated with MND clinical progression and can also help predict their survival. A combination of plasma creatinine, ALS Functional Rating Scale Revised (ALSFRS-R) and Forced Vital Capacity (FVC) all measured at baseline, could explain about 56% of the variation in survival times. How each of these measures evolved over time could also predict survival.

However, this biomarker (plasma creatinine) is influenced by kidney function, making it non-specific to MND as an increased level can also suggest poor kidney function. The research team suggest it could be used as a temporary, inexpensive biomarker in patients without kidney problems, until novel biomarkers are clearly validated in MND.

<https://alsnewstoday.com/2020/04/16/plasma-creatinine-potential-biomarker-of-functional-decline-survival-in-als-patients-study-indicates/>

**New MND and FTD gene identified:** Researchers in Australia, in collaboration with researchers and patient collections around the world (including the UK MND Collections previously known as the DNA bank), identified the CYLD gene. Although mutations in the CYLD gene are likely to be very rare, the gene was found to interact with at least three known FTD/MND proteins. Mutations in these three known genes results in a loss of an important process called autophagy, the cells' waste disposal system.

The researchers found that the genetic change in CYLD can also slow down the autophagy function, allowing waste to accumulate inside motor neurones leading to a build-up of clumps of protein that are toxic to cells.

You can read more about the discovery, including a summary from the lead researcher, Dr Carol Dobson-Stone at <https://mndresearch.wordpress.com/2020/04/07/cyld-new-ftd-and-mnd-gene/>.

### **Support meetings Covid-19 update**

Following the change to government guidelines announced on 28 May, the rules regarding meeting up with others were relaxed to allow up to six people to meet outside from 1 June. Whilst we would love to spend time with people, our primary consideration is to ensure that we minimise the risk of spreading Covid-19, especially to those who might be particularly vulnerable. The Association has advised us **not** to resume face to face meetings, events or other activities on behalf of the MND Association with individuals outside of your household.

Teams, including the panel of clinical experts, are reviewing all the advice, options, opportunities and risks. Based on that review we will be advised of appropriate revisions to our ways of working. Thank you for your patience and support at this time.

Dates and details of events that were planned are given but for the time being remain suspended. Please **check the website or phone the organiser** before you travel to any event.

**Suffolk support meetings 2020:** The meetings are currently on hold due to the Covid-19 situation. This was the planned schedule, but please check for updates on our website.

People living with MND, families and professionals – all are welcome. Feeling isolated or unsure about support and services available? MND Association representatives and Nurse Specialists are usually on hand to share ideas and support over a cuppa. They also hope to have guest speakers throughout the year.

The **West Suffolk** support meetings are usually held on Wednesdays in Hawstead Village Hall, The Green, Hawstead, IP29 5NP. but are currently on hold due to the Covid-19 situation. This is the schedule, but please check for updates on our website.

1 July 14:00 – 16:00                      2 September 14:00 – 16:00                      4 November 12:00 – 14:00

Contact Wendy Pott on [werpott@yahoo.com](mailto:werpott@yahoo.com) or West Suffolk Neurological Nurses, Nicky McGreavy, Sarah Ward or Wendy Webb on 01284 748848.

**Ipswich** support meetings are held in The Atrium, St Elizabeth Hospice, Ipswich, 565 Foxhall Road, IP3 8LX on Monday evenings 17:00 – 19:00. Contact Gill Solway on 07799 417604.

Suffolk MND Association contact is Janet Oliver 01359 241084 or Suffolk Direct (for access to social care services) 0808 800 4005.

**Coffee Mornings:** There is an informal get-together for coffee on the first Wednesday of every month between 10:30 and 12:30 at Dobbies Garden Centre, Woodbridge, IP13 6HX.

Anyone living with MND, their family, carers or friends are very welcome. You can just drop in or let Gill Solway, Association Visitor, know by phone 07799 417604 or email [gillsolway22@gmail.com](mailto:gillsolway22@gmail.com).

**MND Carers Friendship Group West Norfolk:** This informal group is for carers and former carers of people with MND. Meetings are on-hold until further notice.

**The CAF Tourle Foundation Fund:** As mentioned earlier, we are grateful to The CAF Tourle Foundation Fund which has approved a grant of £2,149.35 to the Branch. This is specifically to cover the costs associated with our Open Meetings and Coffee Mornings. Fortunately they have kindly agreed to give us an extension as the original grant was made on the understanding that it would be spent within twelve months from the date of the award.

Once events resume we must fulfil the conditions of the grant, to maintain records as evidence of holding the meetings which include attendee lists, photographs etc. As usual when taking photographs we will display a sign which asks you to notify us if you would prefer not to have your photo taken and to wear a small orange sticker on your name badge to remind us!

## Branch News

**Advance Notice of Open Meetings:** Sunday 22 November 2020 at Wortwell Community Centre, Tunbeck Close, Wortwell, IP20 0HS. We are hoping that it will be possible to hold our AGM and Open Meeting at Wortwell. At the moment it is impossible to say whether this will be possible. This is usually a very happy occasion with a splendid Christmas lunch, it is also the opportunity for our supporters to buy their Christmas cards and other seasonal merchandise. Keep the date, but accept that it may need to change for reasons beyond our control. Check the website nearer the time or contact Malcolm for an update if you are not able to go online.

**Coffee mornings** are informal gatherings for carers and people living with MND hosted by Association Visitors and Committee Members. You do not need to let us know you are coming, just turn up – you will be made welcome. There are no coffee mornings in December.

**At Notcutts coffee shop:** Wednesday from 11:00 to 13:00. *On hold due to Covid-19.*

**Advance notice of future dates for Notcutts, Daniels Road, Norwich, NR4 6QP**

**2020** 15 July 19 August 16 September 21 October 18 November

**At the Cherry Lane Garden Centre:** Wednesday from 11:00 to 13:00.

**Advance notice of future dates for Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU** *On hold due to Covid-19.*

**2020** 29 July 26 August 30 September 28 October 25 November

**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

**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 **30 September 2020** 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)

**Care Service Navigators** Trish Moore 07813 094820 email [trish.moore@mndassociation.org](mailto:trish.moore@mndassociation.org)

Gill Newton 07810 750122 email [gill.newton@mndassociation.org](mailto:gill.newton@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 [judyburnsthompson@yahoo.com](mailto:judyburnsthompson@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.