

# Fightback



MND Association Norfolk, Norwich & Waveney Branch Newsletter  
Issue 83 October 2020

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

The Branch held its first online open meeting using Microsoft Teams – it was also the first 'virtual support' meeting in East Anglia! Our thanks to Liz Cooper (Area Support Coordinator) for setting up the meeting, to Malcolm for chairing the meeting and to everyone who took part.

It was quite a small meeting, which gave time for everyone to introduce themselves, listen and comment on the various presentations. Mercifully there were few technical glitches. We will meet again online on November 22 and hope that our positive experience will encourage more people to join us.

The presentation by Helen Pye, Specialist OT from Environmental Control Service Norfolk was very helpful and informative. Helen was able to share her screen with us so that everyone could view the power point presentation. If you were unable to join on the day Helen's presentation can be found at [https://www.mndnorwichandwaveney.org.uk/news\\_2020.htm](https://www.mndnorwichandwaveney.org.uk/news_2020.htm).

Helen Copsey gave an update on the developments of the Norfolk MND Care and Research Network. It is amazing what has been achieved since it was established in June 2017 supported by the MND Association. The Network has worked to improve the way that the various health professionals work together, and established formal regular meetings to bring people together.

The network operates from the Norfolk and Norwich University Hospital, but also has dedicated MND clinics at Cromer Hospital, Beccles Hospital, Queen Elizabeth Hospital King's Lynn and at nearby Tapping House. The aim continues to be making clinics as accessible as possible to people living with MND across Norfolk.

In November 2018, Emma Lerner joined the Network team as the Respiratory Physiotherapist. Emma has made a huge difference in supporting people with MND, with much of her work being undertaken in people's homes. Since the open meeting we were delighted to learn that Emma's post has been made permanent.

COVID-19 has meant that a number of consultations needed to be carried out online or by telephone, but face to face appointments have restarted where possible. However, the experience of using alternative methods of communication has been successful and will be retained where they are felt to be most helpful to people living with MND and clinicians.

*The situation is ever changing, Helen provided an update for Fightback. "The clinic team continue to offer regular telephone appointments but in some locations (such as Norwich and Cromer) people can be offered a face to face appointment if preferred or if it is more helpful from a clinical point of view."*

*Helen added, "The MND Network team are also pleased to welcome their new Administrator, Magdalena Mitcher, who can be contacted at [magdalena.mitcher@nnuh.nhs.uk](mailto:magdalena.mitcher@nnuh.nhs.uk) or on the team phone 01603 647221. Magdalena will be working on Tuesdays, Thursdays and Wednesday mornings and can help with any queries relating to appointments with the team."*

A key aim of the Network is to improve the opportunities for people with MND to participate in research if they wish to do so. By July, COVID-19 had resulted in much research activity being paused. The Network continues to recruit to the MND register, which will provide an invaluable national database for use in both delivering care and recruiting to future research. If you have MND and have not been able to attend a face to face appointment to discuss the register with the clinical team, you may wish to self-register to contribute at <https://mndregister.ac.uk/>. The Network expressed an interest in becoming a site for the MND-SMART study, and is now working actively with the lead research team to establish NNUH as a site for the study as soon as possible. The Network will update patients and families as research resumes.

Malcolm gave an update on the work of the Branch, which continues to follow guidance from the Association so that contacts are mostly made by phone.

Sue Heal gave a brief update on campaigning. Work is always going on behind the scenes to better support people living with motor neurone disease including the move to get people with MND on the extremely vulnerable list. Although the government didn't change its advice, the Association continues to encourage anyone living with MND to self-register and to get access to the support they need during the COVID-19 pandemic. More about our campaigns can be found later in the newsletter.

### **Coffee mornings**

The coffee mornings are informal gatherings for people with MND and their carers. We have missed seeing everyone in person, but the Association's advice is for us to continue running support group meetings virtually. Our first virtual coffee morning, using Zoom, took place on Wednesday 16 September. The technology worked. It was so good to see people!

We will be holding the next virtual coffee morning on Wednesday 21 October at 12 noon and hope to make this a regular event on the third Wednesday of every month until we are given the go-ahead to meet in person.

Please consider this a warm invitation and email [judyburnsthomson@yahoo.com](mailto:judyburnsthomson@yahoo.com) if you would like to join us. We would love to see you.

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

The Association is continuing to host a dedicated webpage providing regularly updated information on COVID-19 and MND, and giving answers to frequently asked questions.

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

A panel of experts chaired by Nick Goldup, Director of Care Improvement, answers questions put by people affected by MND and raised anonymously. It has proved popular and is incredibly useful. The panel includes experts like Professor Ammar Al-Chalabi, Professor of Neurology and Complex Disease Genetics and Director of Kings MND Care and Research Centre. All sessions are available to watch on video, or you can read the text of the interviews – a brief description is given of the topics covered in each.

The Association's online forum provides another 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.

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

## Events in aid of the MND Association

### Thursday 18 June 2020 Ascot Ladies Day

Christine Wells organised an Ascot Ladies day for a small group of friends. They had great fun with lunch, champagne, quizzes, best hat competition and sweepstake on three races. Together they raised £131.50 for the Branch for which we are very grateful. The photo was taken very quickly before they reverted to social distancing!



### Sunday 21 June 2020 Global MND Awareness Day

Lisa Wilson began the day at Ness Point at 4:30am with her son, and an MND Association banner, to capture the sunrise on Global MND Awareness Day. Ness Point, also known as Lowestoft Ness, is the most easterly point in the British Isles.

It was much later in the day when Malcolm Chubbock, Anne Gillett and Sue Heal met in Norwich to take photos in front of Norwich City Hall shortly after 10pm. As has become customary Norwich City Hall was illuminated in blue and orange, the colours of the Motor Neurone Disease Association.

We are grateful to the Culture & Events Officer at Norwich City Council who has added the date to his diary to ensure that the light up is a recurring event.



Sue wrote to the Norfolk MPs, and some local councillors who have been involved in adopting the MND Charter. She invited them to mark the day by posting on Twitter; we are grateful to those who did or sent emails in support of our work.

### Sunday 13 September – Sunday 18 October Mission 5000

Mission 5000 is a brand new virtual fundraiser. Along with MND Association national office, branches and groups across the country the whole MND community was invited to cover 5000 miles. That represents a mile for every person living with MND in the UK.



Participants were able to choose whether to run, cycle, swim or cover their pledged miles in any way they chose, whether on one day, week or over the whole five week period – fortunately it was not a race! Just over half way through and 93,396 miles had been pledged by 765 people who had joined the challenge. £136,000 had already been donated to the Association and 20,449 miles had been covered of which 3.1 miles were cartwheeled and 40 miles walked in a hotel room in Singapore!

Sue Heal signed up with a pledge to walk 75 miles, one for every person living with MND in our branch area, plus a little extra. You can help her achieve her target of raising £1,000 to support the work of the Norfolk, Norwich and Waveney Branch by visiting <https://www.justgiving.com/fundraising/susan-heal>.

Sue's first walk, accompanied by a good friend Jenny, took her to Wymondham Halt, alongside the River Tiffey to Kimberley and back to Wymondham via the Deep Lane, a distance of 7.48 miles. What she did not take into account was the number of stiles involved, which slowed them both down! As you can see – they had good weather for a walk.

Over the next few days Sue kept walking, slowly the miles accumulated and by the end of the first week she had covered 23.92 miles. The weather turned towards the end of September and some walks were decidedly wet and muddy, fortunately her cagoule was waterproof – even if her jeans weren't.

At the time of writing she has covered a little over 97 miles, but decided to keep on walking and recording her miles using Strava until 18 October.

To date she has raised £875 and would welcome further donations to reach her target.

Our thanks to others in the area who have signed up to Mission 5000, if you would like to share your story we would love to include it in the next issue of Fightback and on our website. Send your stories and photos to [sueheal@btinternet.com](mailto:sueheal@btinternet.com).

### **Saturday 3 October 2020 Endurance Life, Coastal Trail Series, North York Moors**

Joe exceeded his target of £5,000. We thank everyone who has donated. He wrote a brief update on his Justgiving page. [www.justgiving.com/MNDMUM](http://www.justgiving.com/MNDMUM)

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

### **A little armchair fundraising?**

If you already use Amazon, then why not consider Amazon Smile? It can make payments to your chosen charity at no cost to you. Shop via <https://smile.amazon.co.uk> and select which charity you want to support, search for 'Motor Neurone Disease Association' and select us as your charity of choice. From then on a small proportion of the money is paid directly to the Association to support people living with MND. Periodically you will receive an email to let you know how much has been sent to your chosen charity.



## One Way Ticket with MND - Craft Fair

Lisa Wilson was organising a Craft Fair at St Andrew's Church, Roman Road, Lowestoft, Suffolk, NR32 2DQ to take place in August. However, it has been agreed that safety is paramount and, in the light of the COVID-19 pandemic, she has reluctantly postponed the fair. She is now working hard to ensure it is a bigger and better event that will hopefully take place next Easter. Watch for further details for 2021.

## Wednesday 28 April 2021 - Youngs Brothers Testimonial

In the last issue of Fightback we included some pre-publicity for the Youngs Brothers Testimonial to raise money for the MND Association (in support of their cousin, who is living in our Branch area) and the blood cancer research charity Bloodwise.

Details and a link to reserve a place can be found on our website at <https://www.mndnorwichandwaveney.org.uk/events.htm>.

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

We are continuing to look for secretarial support to the Branch Committee to be responsible for effective communications within the Branch. We are very grateful to Patti de Clifford for stepping in temporarily to act as minutes secretary for our committee meetings. However, we hope to find people who might take on the various roles longer term.

- General Branch Secretary
- Membership Secretary
- Open Meeting Secretary.

If you are interested in considering one or more of the roles please contact Malcolm on 01603 960206 or email [malchubbock@hotmail.com](mailto:malchubbock@hotmail.com). You can find more details about the roles at <https://www.mndnorwichandwaveney.org.uk/volunteering.htm>.

There are other opportunities to volunteer with us. 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 - £80
- Matlaske Benefice Hempstead Church virtual church service collection - £340
- Bryan and Eileen Chubbock, contents of their box - £236
- Emergency Appeal - £216
- Wymondham U3A, proceeds of a raffle held before lockdown - £166
- Graham John May - £250
- Christopher O'Flaherty - £30
- Leonard Payne - £40
- Su Summers - £161
- Paul Johnathon Wharton - £900.58
- Brian Woods - £1,034.77

### Donations in memory of

- Jane Mackintosh Armiger - £890
- William Frederick Capps-Jenner - £355
- Barbara Clarke - £340
- Pauline Layton - £810

### Internal transfers

- Interest - £30.12
- Gift Aid - £440.38
- JustGiving – £56.50

We are extremely grateful for the donations totalling £1,365.64, including a single donation of £1,300, 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

**Tuesday 13 October 2020:** All members should have received a voting pack giving details on how to take part, allowing them to vote on resolutions and pose questions to the Board and Directors on the day. Our Chair, Richard Coleman, presented the highlight and achievements of the year, and Honorary Treasurer, Tim Kidd updated members on the Association's financial performance. While this year's AGM felt different, it was an enjoyable and informative event.

If you are a Branch supporter, but have not yet joined the Association, you are always welcome to join. Membership is free for people with MND, carers, spouses and partners of people with MND, and past carers. Individuals who wish to support the Association pay an annual fee of £12, and those who are retired or otherwise not in work pay £6. Membership entitles you to receive Thumbprint (by post or online), a quarterly magazine packed with the latest MND care, research and campaigning news mixed in with inspirational stories, interesting articles and fundraising ideas, as well as voting at our Branch AGM and National AGM. <https://www.mndassociation.org/get-involved/fundraising/become-a-member/join/>. If you prefer to use a paper form, Sue Heal can send you one (contact details on the back page).

**Fundraising News:** In addition to the regular fundraising page on the Association website <https://www.mndassociation.org/get-involved/fundraising/home-fundraising/> a new section has been added called the fundraising zone at <https://www.mndassociation.org/get-involved/fundraising/zone/>, it contains a wealth of useful information to support your fundraising. A little reminder, 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 feature your events here and elsewhere.

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.

**How to apply for voice banking funding:** Visit <https://www.mndassociation.org/support-and-information/our-services/communication-aids-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 611865 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.

The Education and Information Team has successfully gained accreditation with the PIF Quality Mark (Patient Information Forum). This means the Association's care information resources are recognised as high quality and trustworthy. The scheme explores ten criteria, the most significant being that information is supported by evidence, user engagement and expert review. The PIF Tick will start to appear on Association publications.



Three new MND guides are available on

- Emotional and psychological support
- Changes to thinking and behaviour
- Telling people about MND

Four information sheets have also been revised:

- Progressive Muscular Atrophy
- Riluzole
- Voice banking and message banking
- Benefits and entitlements

**New look workbook for young children:** The workbook for children aged 4-10, 'When someone close has MND', has been refreshed using characters from the storybook, 'Why are things changing?'. Following the gentle introduction in the storybook, the new workbook covers more about MND to help a child and trusted adult continue communicating about the disease. With drawing activities the workbook is only available in print. You can order a copy through Care Admin by phoning 01604 611812 or emailing [careadmin@mndassociation.org](mailto:careadmin@mndassociation.org).

**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 the Association needs your help in developing the information they provide. If you are interested email [volunteering@mndassociation.org](mailto:volunteering@mndassociation.org) or call 0345 604 4150.

**Are you helping or supporting someone who is living with MND?** *By Lindsay Goward, Community Engagement Executive with Carers Matter Norfolk*



**Carers Matter Norfolk**

COVID-19 and the lockdown has been particularly difficult for people caring or supporting someone with a diagnosis of MND. You may not have been able to have family support or support from groups and friends. Norfolk County Council has commissioned new enhanced carer services from this September which will hopefully offer more support to carers.

Carers assessments are now being carried out by Carers Matter Norfolk rather than going through Adult Social Services. If you need an assessment contact the Carers Matter Advice line on **0800 083 1148** or request one through the website. Alternatively you can ask your Association Visitor or a health or social care professional to refer you.

The assessment can offer you advice and information as well as the help and support you need in your carer role. If you need more support, you may be referred to a local Carer Connector who can look in more detail at what can assist you to continue caring, and to support your health and wellbeing. The assessment is no longer a one off thing, instead an adviser will contact you regularly to see how things are going and you can ring as often as you want if your needs change or you just need a listening ear.

An assessment can lead to you being offered practical help in the form of a short break, a grant from the health and wellbeing fund, counselling or help to access education and training. A short break can be someone staying with the person so you can go shopping, a few days for you to recharge your batteries or even help towards a joint holiday. The grants can be for anything that may enhance your health and wellbeing such as funding massage, an iPad or a spa day out. The definition of a carer for this service is wide, you do not have to be living with the person you support or caring for them full time. Contact the advice line for more information. It is hoped this new enhanced service will give you, as a carer, some practical support at a time when you need it.

Call the Carers Matter Norfolk advice line on **0800 083 1148** to have a chat with our friendly advisers. It is open 7 days a week Monday-Friday 9am-8pm and Saturday and Sunday 10am-2pm. You can also contact the service via the website [www.carersmatternorfolk.org.uk](http://www.carersmatternorfolk.org.uk).

## Campaigns

**Update on the Scrap6Months campaign:** Perhaps this should be titled, #I'mstillwaiting, or more precisely we are all waiting, for publication of the review of the Special Rules for Terminal Illness promised by the Department for Work and Pensions in July 2019. The issue continues to gain attention, both on social media, focused on Justin Tomlinson MP, Minister for Disabled People, Health and Work and in the press.



On July 22, Jessica Morden MP, presented a ten minute rule bill. During an impassioned speech Jessica said, “In particular, it addresses the need for urgent action to reform two aspects of the special rules guidelines that are a source of distress and difficulty for people living with terminal illness. They are the six-month rule which, under section 82 of the Welfare Reform Act 2012, obligates someone to provide medical proof that they have six months or less to live so that they can access benefits quickly and at a higher rate; and the three-year award – a Department Work and Pensions guideline that forces people to reapply for benefits if they live longer than three years after the benefit is awarded.” She paid tribute to campaigners and charities, mentioning the MND Association by name. Her bill is important for people living with MND for whom it is difficult to give an accurate prognosis, and where progress in treatments has been made meaning that some people may live longer post diagnosis than when the 'six-month rule' was first written into law in 1990. Her speech provided an excellent opportunity to raise awareness of motor neurone disease and the needs of people living with it.

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:** After delays, caused first by the announcement of a general election and then the COVID-19 pandemic, we are delighted to announce that the campaign launched on 24 September 2020. The first phase involves raising awareness of the issues with decision makers.

Everyone is invited to get involved by sending an email to their local councillors using the e-action inviting them to read the report produced in 2019.

<https://ecampaigns.mndassociation.org/page/57405/action/1?ea.tracking.id=hub>

Everyone has the right to live in a safe and suitable home. For people living with MND, this means an accessible home that enables them to maintain their independence, dignity and quality of life as the disease progresses. Yet, according to a survey by Habinteg (a housing association) in 2017 there were around 1.8 million people with an accessible housing need in the UK, with 300,000 adults with disabilities having these needs unmet.

Survey respondents identified some of the key challenges in making their homes accessible:

- Cost of adaptations (96%)
- Length of time taken (25%)
- Availability of accessible homes (21%)
- Lack of support locally (23%)
- Lack of information (22%)

The Disabled Facilities Grant (DFG) is a means tested grant towards the cost of adapting a home. In England DFGs are administered by local authorities. The maximum amount of grant that can be awarded is £30,000 in England, but local authorities have discretionary powers to introduce extra or alternative support for home adaptations. This can include raising the level of maximum grant, removing the means testing for certain items or introducing fast-tracking systems.

The Association is recommending that all authorities with responsibility for DFGs should, as a minimum, put in place a transparent, fast-track, non-means tested process for adaptations under £5,000 by 2021. We would like to see a single point of contact for people living with disabilities, and for authorities to review their compliance with target timescales to ensure that they are always met. Good practice in discretionary policies should be promoted, for example by 'passporting' people with a terminal illness and removing the means test for stairlifts. Ideally there should be no means tests for low-cost high impact adaptations or at least a 'lean' means test. The maximum grant was set in 2008 and needs to be increased. We would like to see mandatory national accessibility standards agreed for new housing developments.

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

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

mndassociation.org/acttoadapt #ActToAdapt

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

ACT TO ADAPT

To read the full report or a summary, watch videos looking at the problems and solutions, or to have your say (whether or not you have personal experience of accessing home adaptations) visit <https://www.mndassociation.org/get-involved/campaigning/take-action/act-to-adapt/>.

**Local MPs support our campaigns:** Sue Heal and Jane Lewis, Chair of the West Norfolk and King's Lynn Support Group, met with Duncan Baker MP for North Norfolk, on 28 September via Zoom. We were able to talk through the Scrap6Months campaign and were pleased when he agreed a series of actions to follow the progress of the delayed review of the into welfare support for people who are terminally ill. We had a brief discussion of the Act to Adapt report and anticipate meeting again to take this further.



Sue Heal and Malcolm Chubbock, Branch Chair, met with Jerome Mayhew MP for Broadland on 30 September to discuss our current campaigns. We are grateful to him for writing to Thérèse Coffey MP on our behalf.



Chloë Smith MP for North Norfolk has also followed up on the delayed review.

James Wild MP is supporting our Scrap6months campaign and features it on his website. On 8 October, James posed a written question “To ask the Secretary of State for Work and Pensions, when she plans to publish the conclusions of her Department's review of the special rules for terminally ill welfare claimants.” Sue and Jane look forward to meeting James in the near future.

Thank you to everyone who contacts their constituency MP as part of our e-actions.

## **Local MND Research Update** *by Dr Kaitlin Dudley*

The **CHANGE-MND study** – which looks at changes that occur in everyday life of people with MND – is still currently paused in light of COVID-19, but as soon as we are able to commence home visits again, we will be sure to inform all and begin recruiting. This is an ongoing study and has greatly benefited from peoples’ effort and time the last three years. It will likely not start again until 2021.

### **Factor-MND: A carer-focused study**

#### **Factors Affecting Family Carers in Motor Neurone Disease**

Introducing a new carer-focused study starting now by the University of East Anglia. We are interested in understanding what certain family factors may contribute to a carer’s wellbeing, such as family values and personal relationships, psychological flexibility, and potential changes in behaviour of the person with MND. This research aims to help us learn how to better support family carers of people with MND. Family carers of people with motor neurone disease are invited to participate. We are asking you to complete six questionnaires about your personal wellbeing, family, relationships, and your family member’s diagnosis of MND. There are 80 questions in total and they are mostly multiple choice, with some background questions. It is estimated this will take you 20-25 minutes. These can be completed online (via a web link below) or via paper and pen format. If you would like the pen and paper format, please reach out either via email or the telephone number listed below.

How do I join the study? Either:

- Complete the online survey at: <https://uea.onlinesurveys.ac.uk/factor-mnd>
- Give us a call on **07825 863389**
- Email us at [mnd.research@uea.ac.uk](mailto:mnd.research@uea.ac.uk)

## Research

If you want to read more about ongoing research, and opportunities to get involved, there is reliable information at <https://www.mndassociation.org/research/>. If you would like to talk about getting involved contact the Research Development team on 01604 611880.

The information that follows 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 included barely scratch the surface of the work on research.

**Virtual Symposium:** Each year the MND Association, in co-operation with the International Alliance of ALS/MND Associations, hosts an International Symposium bringing together clinicians and researchers from around the world.

The COVID-19 situation resulted in the decision to cancel the International Symposium on ALS/MND planned to take place in Canada during December. Happily this has been replaced by Virtual Symposium 2020, the 31st International Symposium which will take place from 9-11 December. More details can be found on the website <https://symposium.mndassociation.org>. Over 20 keynote speakers will showcase the latest research information. In addition, over 350 e-posters have been submitted, supported by authors presenting their work via 'lightning talk' videos. It also includes a link to SympWatch, a selection of research presentations recorded at the 2019 Symposium in Perth, Australia.

**Clinical trials:** 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. In these cases the trials will be extended to make up for missed time. Some trials will now start in 2021. Others, like MIROCALS (Modifying Immune Response and Outcomes in ALS) looking at the effectiveness and safety of low dose IL2 have been able to continue with distance monitoring. Where data was already available research and analysis has continued, and a number of papers have been written and published. Researchers who use and develop computer programs to improve our understanding of disease biology have been able to continue their research remotely during the COVID-19 pandemic. Looking forward the Association has received some excellent applications for new research funding.

Recruitment has reopened for COMMEND, the Acceptance and Commitment Therapy, and Measuring Cognitive and Behavioural Change in ALS studies. Both have been adapted to consider COVID-19 restrictions and participation can be carried out remotely. The purpose of COMMEND is to develop a new form of psychological therapy that helps people learn new ways of handling difficult or distressing thoughts, to see if this leads to improved quality of life. The second study will test whether different screening tools for cognitive change lead to a similar diagnosis in the same people. You can find out more about these and other studies at <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/>

The AMRC (Association of Medical Research Charities) has made a plea to the government to act now to save charity research. Charities account for 51% of publicly funded medical research nationally. The pandemic is putting life changing charity research at risk. According to the AMRC an average of 41% of charity research spend will be cut over the next year. Paused and cut research will have a devastating impact on countless lives. 54% of charity funded clinical trials and studies were paused in June. 152 charities (including the MND Association) and 53 cross-party MPs are calling on the Government to commit to a Life Sciences-Charity Partnership Fund. Via the fund government would provide matched funding for charity research for three years.

Some MND researchers, unable to continue working on their projects, used their expertise to work in the Lighthouse COVID-19 testing labs in the UK. Sophie Nyberg, a neuroscientist, who had been working at the Sheffield Institute for Translational Neuroscience (SITraN) wrote about her experiences earlier in the year <https://mndresearch.blog/2020/07/21/lighting-the-way-from-mnd-research-to-the-covid-19-response/>.

**Biomarkers:** At the moment there is no diagnostic test for MND, instead it is diagnosed by excluding a range of other neurological and muscular conditions. Finding a simple, pain-free test that would make this process easier and faster would mean less uncertainty for patients, treatment could start earlier, and open the possibility of more people being able to participate in research into the effectiveness of existing and emerging treatments. Another reason to look for biomarkers is to keep track of the progression of the disease.

For those who are new to reading about MND research Professor Martin Turner, University of Oxford, gave a talk on the biomarker challenge at the MND Association AGM in 2018. It is still available to watch <https://www.youtube.com/watch?v=TvFwqiQzDDk&feature=youtu.be>.

More information about AMBRoSIA (A Multicentre Biomarker Resource Strategy in ALS), a five year study funded by the MND Association that is searching for unique markers of MND for faster diagnosis is available at <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/ambrosia/>.

**Diagnostic biomarkers in the blood:** In research funded by the MND Association, Dr Greig Joilin and the Hafezparast lab team at the University of Sussex, have identified a set of molecules in the blood that could potentially be used as biomarkers to help diagnose MND. In June they published the results of their work outlining their discovery, the work carried out to confirm their results and the next steps needed to refine their model.

The research blog post includes a short video animation, created by Greig, that takes you through the project and results making the complex science easy to follow and understand. It is followed by a more traditional written summary.

<https://mndresearch.blog/2020/06/17/identifying-potential-new-diagnostic-biomarkers-in-the-blood/>

**Emerging gene targeting therapies for SOD1:** Mutations in the SOD1 gene accounts for the second most common inherited form of MND, approximately 2% of all MND cases.

In July, The New England Journal of Medicine published two articles looking at targeting the SOD1 gene in familial ALS.

The first looked at the full results from the phase 1 and 2 trials of Biogen's Tofersen. They showed the therapy was safe and generally well tolerated over three months. It appeared to lower SOD1 protein levels in the central nervous system. The results support the continued investigation of Tofersen to confirm its safety and effectiveness in a phase 3 trial.

The phase 3 trial is currently recruiting patients with SOD1-MND in Sheffield. More details about this and other trials can be found at <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/>.

The second article described an early stage proof-of-concept study of delivering a single dose of SOD1 targeting microRNA (molecules that function to regulate the expression of genes) embedded in a vector, adeno-associated virus, via injection into the spinal canal in two patients.

<https://mndresearch.blog/2020/07/13/emerging-gene-targeting-therapies-for-sod1-als/>

**C9orf72 gene therapy trial:** The Phase 1 trial of BIIB078, the gene therapy that targets a mutation in the C9orf72 gene, has enrolled its first participant in Dublin. The C9orf72 mutation occurs when a specific sequence of DNA is repeated in the gene. The therapy prevents the production of abnormal forms of the protein encoded by the C9orf72 gene while preserving normal forms of the protein. The trial is studying the safety and tolerability of BIIB078. Involving 75 patients worldwide it will compare the effects of differing doses to a placebo. The pharmaceutical industry is looking at other gene modifiers that could be targeted which it is hoped could help others living with MND.

<https://alsnewstoday.com/news-posts/2020/09/04/first-patient-enrolled-in-als-phase-1-gene-therapy-study-in-ireland/>

**Targeting Tregs:** A type of white blood cell called regulatory T cells (Tregs) are known to help control the inflammatory response that affects motor neurone damage in the brain and spinal cord. Results from the pilot IMODALS trial show that low doses of aldesleukin, a lab-made version of interleukin 2 (IL-2), is well tolerated and can safely increase the numbers and functions of regulatory T-cells in the blood of people with ALS. Findings support further investigation of IL-2 in the ongoing MIROCALS trial over a longer period in 300 patients. This trial is no longer recruiting.

<https://mndresearch.blog/2020/07/07/targeting-tregs-imodals-study-paves-the-way-for-mirocals/>

**New insights on Riluzole's impact on survival:** Riluzole is the only drug to be licensed for the treatment of MND in the UK and approved for use by the NHS. It is not a cure for MND. The original trials showed that it had a modest impact on survival for people with MND, typically 2-3 months. However, a review conducted and published this year based on 15 population studies found significant differences between the average survival time of people who were treated with riluzole compared to those who were not. The studies indicate that riluzole extends median survival in MND patients by between 6 and 19 months.

The reviewers attempted to answer the question, 'Why the difference?'. They suggest it is possible 'the trials underestimated the long-term benefit of riluzole due to short reporting time as survival was measured from time of enrolment to tracheostomy or death. Patients who were still alive and tracheostomy-free at the end of the trial were not included in analysis.'

The authors highlight research that suggests that riluzole may work in different ways in people in the early stages of MND compared to those in more advanced stages. In the clinical trials the time between diagnosis and the start of treatment with riluzole ranged from 19-27 months. The studies did not capture data regarding the effect of riluzole on survival in the early stages of the disease. The population studies have shown that the greatest benefit of riluzole occurs early in the disease. The rationale is that early and prolonged treatment with riluzole delays motor neurone damage, hence delaying muscle degeneration, at earlier stages of the disease and will prolong those stages associated with the best quality of life. Observations also suggest survival benefits continue into later stages of the disease.

In conclusion, the research team found real-world evidence studies provide valuable information about how a drug performs in a broader patient populations, and how this is observed by clinicians, outside clinical trials. In doing so this review highlighted new data about the benefits of riluzole that were not represented in the original trial results.

<https://mndresearch.blog/2020/07/28/review-of-evidence-suggests-riluzole-treatment-may-lead-to-extended-survival/>

**Food and Drug Administration gives the go-ahead for a new clinical trial:** Seelos Therapeutics have been given permission by the US FDA to launch a phase 2b/3 clinical trial investigating SLS-005 as a treatment for MND. The active ingredient in SLS-005 is a sugar molecule called trehalose, which is not found in mammalian cells. Studies have found that trehalose is able to cross the blood-brain barrier in humans and influence cellular behaviour, stabilizing proteins and activating autophagy (the cells' 'digestive system' that removes and recycles damaged cellular components, clearing toxic protein clumps). This may help to delay the progression of symptoms, preserve motor neurones and increase the size of muscle fibres.

**Neuroprotective M102 progresses into clinical trials:** Researchers at the University of Sheffield Institute for Translational Neuroscience (SITraN) discovered that M102 was a neuroprotective molecule in preclinical studies. This demonstrated the potential for a treatment to stop the progress of MND. It is now entering its first clinical study in people with motor neurone disease through a partnership between researchers at SITraN and Aclipse Therapeutics. The project is being supported in part by a \$700,000 grant from FightMND, an Australian not for profit organisation that supports research into MND.

<https://alsnewstoday.com/news-posts/2020/09/25/university-of-sheffield-aclipse-advance-als-treatment-m102-clinical-trial/>

**Support meetings COVID-19:** Government guidelines have undergone many changes. At all times the Association has worked within the guidelines with the priority of safeguarding the health of both people with MND that we support and the dedicated volunteers. We are advised not to hold face to face support meetings, events or other activities on behalf of the MND Association with individuals outside of our own households.

Teams, including the panel of clinical experts, continue to review all the advice, options, opportunities and risks regularly. 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.

Events that were planned and publicised in earlier editions of Fightback remain suspended. Please **check the website or phone the organiser** for the most recent information.

**Suffolk support meetings 2020:** Meetings are currently on hold due to the COVID-19 situation.

Support from Association Visitors continues by telephone, email and online platforms.

For information about support meetings in West Suffolk 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.

For information about support meetings in Ipswich or the informal get-togethers 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.

## Items for people living with MND

A **Power Pack** for a manual wheelchair. This was provided by the MND Association, so will be passed on free of charge.

Also available an **adult wheelchair cape**, large, navy.

If you are interested in either or both of these items please contact Frances on 07754 396363, to arrange collection from Beccles.

*Free items and items for sale to people living with MND: Note whilst we are able to offer a free advertising service 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. Where specialist equipment is concerned, you are strongly advised to seek advice from your occupational therapist as to suitability and health and safety requirements.*

## Branch Emergency Appeal - with a new picture!

Branch funds are holding up well following the very successful fundraising event held by Marsh at the end of 2019, and a number of smaller events organised by our supporters. However, due to the COVID-19 situation our fundraising has reduced during 2020, and we are mindful of the need to sustain our income to provide the same level of support and provision of equipment as in the past.

We would like to thank everyone who has made a donation, and will keep the appeal running for those who would like to support our work in this way.



<https://www.justgiving.com/fundraising/mnda-nor-wave>

## Branch News

**Sunday 22 November 2020** will not be held at Wortwell Community Centre, please do not travel to the venue. We are hosting a brief AGM followed by our Open Meeting using Microsoft Teams as indicated in the accompanying invitation. We are delighted to welcome Lindsay Goward whom many of you will remember was our Regional Care Development Adviser until earlier this year. Lindsay is now working with Carers Matter Norfolk and will talk about their work.

We are sorry to miss what is usually a very happy occasion with a splendid Christmas lunch, and the opportunity for our supporters to buy their Christmas cards and seasonal merchandise. If you would like to place an order directly go to <https://shop.mndassociation.org/christmas-2020/>.

**Advance Notice of Open Meetings:** For the foreseeable future these events will be held online.

**Virtual Coffee mornings:** for carers and people living with MND hosted by Association Visitors and Committee Members. Email Judy Burns-Thomson for the link. These are planned for the third Wednesday of each month starting at 12 noon excluding December.

**Dates until the end of the 2020 are as follows.**

21 October                      18 November

**Dates for the first part of 2021 are as follows.**

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

20 January                      17 February                      17 March                      21 April

**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](https://www.facebook.com/MNDANorwichWaveney)                      **Twitter:** [@MNDANorWave](https://twitter.com/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 **28 February 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)

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 [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.*