

Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter
Issue 87 March 2022

Sunday 7 November 2021 Open Meeting, Wortwell Community Centre

This was our first face to face meeting since the last open meeting at Wortwell in November 2019. It was wonderful to welcome thirty people, friends old and new. Despite the masks, the sanitiser and reducing the numbers on tables to four, it still felt like a happy and relaxed social gathering; there was a lovely atmosphere. The lunch was excellent thanks to Kelda and her assistant. We hope to see everyone again at our next open meeting, and that those who weren't able to attend or perhaps felt a little nervous in view of the ongoing pandemic might be encouraged to join us. Thank you to everyone who left such lovely comments and feedback for the CAF Tourle Foundation who provided a grant through the Norfolk Community Foundation to support our open meetings.



We were pleased to be joined by Professor Eneida Mioshi and Polly Trucco and to hear a presentation on their research opportunities. It was encouraging to see that a number of people took copies of Polly's questionnaire to complete. As always it was good to be joined by Helen Copsey and Emma Larner; not only do they

provide wonderful support to people living with and affected by MND but also to the Branch – we are so lucky that they are willing to give up their own time to join us for these events.

We had a selection of Association merchandise and Christmas cards for sale. Cash sales of merchandise made £49.80 and the payments through our new sumup card machine totalled £59.91 (after fees of £1.04). Thank you to everyone who gave raffle prizes, the raffle raised £116. We were also grateful for a donation in lieu of buying and sending Christmas cards.





Apologies if your photo isn't here – blame Sue!

We were sorry that Judy, who did so much to organise the event, was unwell on the day and unable to join us. Thank you Judy, we were thinking of you! Thanks to Jo for ordering the merchandise – we missed you too!



Other events in aid of the MND Association

7 October Wymondham U3A Coffee Morning

Wymondham U3A held their regular coffee weekly morning in Central Hall, Wymondham from 10am to 12 noon. Malcolm and Sue spoke to a number of people about volunteering roles within the branch as well as selling merchandise, and hope to welcome some new Association Visitors!

Chairperson Gilly, pictured on the right with Sue, has agreed to do something on a larger scale in 2022.



The Wymondham U3A also hosts an open meeting on the first Thursday of each month when they have a speaker followed by tea, coffee and chat. Sue, who is a member, was invited to say a few words about the work of the Association after the main speaker. She kept the stall running in the afternoon, and was pleased to talk with individuals about our work. The event raised £233.80, which included some very welcome donations.

Sue was invited to sell Christmas cards and merchandise at two further coffee mornings, which brought the overall total raised to £412.75 with £65.80 in donations.

Duncan Baker's London Marathon 2021 – update

The final total raised was £38,196.18; the branch received a payment of £1,219.08 via the Norfolk Community Foundation and £250 directly from the Paul Bassham Trust. Our thanks to Duncan Baker MP for raising funds to be shared between charities based, or operating in North Norfolk, and for his continued support for our campaigns both locally and nationally.

Sunday 5 December 2021 AGM Cawston Bowls Club

Malcolm Chubbock, branch chair, attended the annual general meeting of the Cawston Triple Bowls League held at Cawston Bowls Club. He had been invited to give a short talk about the work of the Norfolk, Norwich and Waveney Branch. He took the opportunity to express our thanks to the club for their very generous donation of £1,100 which we received in September. The Cawston Triple Bowls League consists of a group of ten separate bowls clubs who compete against each other during the course of a season. All their matches are played on outdoor greens, with some clubs sharing a green. The Cawston Triple Bowls League committee, consisting of members of the clubs, are elected or re-elected at each AGM, whilst the President is nominated from a different club each year.

Each September they have a President's Day with various competitions and fundraising events, the proceeds of which are donated to a charity of the President's choice. The President for the last year, Mrs Sue Ealden, nominated us as the recipient of the funds accumulated during her year in office. She chose our Branch as her friend Brenda had been supported by us prior to her death from motor neurone disease. We are extremely grateful to everyone who helped raise such a splendid sum to support our work.



Mrs Ealden has since moved away from the area and was not able to be present at the AGM. Malcolm is pictured here with Mr Colin Pardon, the current Chairman of the Cawston Triple Bowls League committee.

Sunday 19 December 2021 by Darren Millard

The Seadell Bar in Hemsby has always held a close affiliation to the MND Association. Local landlady, Jacki Aldridge's husband and father of four children passed away from motor neurone disease in December 2011 after four years of suffering with MND. Also our dear friend and work colleague Gavin Casey lost his battle with MND in April 2019.

Local entertainer Daz Lewis contacted Jacki and wanted to do a "Comeback" charity gig and asked for suggestions on a charity, there was only ever going to be one charity.

After a successful event from Daz Lewis and 2 Tons of Rock and Roll on the 19th December, the grand total raised was £844.25. This was raised from donations, raffle and a meat raffle.

Thank you to everyone who took part or helped with the event. Special thanks to Daz Lewis, 2 Tons of Rock and Roll and Allen's Butchers of Hemsby.

Saturday 12 February 2022 Charity Snowdrop Walk at Walsingham Abbey

The Walsingham Abbey estate opens its famous snowdrop walks from late January until early March. Those who have visited before will know just how magical the grounds look carpeted in snowdrops. If you haven't yet experienced that pleasure then we would invite you to look at their website and maybe visit next year. <https://www.walsinghamabbey.com/snowdrops/>



Each year they donate a day's admission at the height of the season to a Norfolk charity. We were told that this attracts anything from 300 up to 1,000 people depending on the weather on the day, and at £6 admission per adult can raise a worthwhile sum. This year the Estate Directors chose the Motor Neurone Disease Association to benefit from their charity day on 12 February 2022.

We were incredibly lucky with the weather, and the snowdrops obliged by coming out on time. Three volunteers from the Norfolk, Norwich and Waveney Branch were able to attend and can attest to the fact that it really was a wonderful day. We are delighted that Walsingham Estate have paid £5,965.50 into the Branch account. Thank you to everyone who visited on the day, and all those who work hard behind the scenes to make the grounds so special.

Our thanks also go to the Matthews family pictured below (with Grace & Malcolm) who organised the teas and refreshments in the parish hall in Walsingham High Street and drew in many of their family and friends to help.



There were lots and lots of delicious homemade cakes, to quote Grace (our membership secretary), "I have never seen so much cake in all my life". Apparently there were five tables laden with cakes, scones and sausage rolls. Thank you so much to everyone who baked and/or helped on the day, what a fantastic effort! There seemed to be a steady queue of people throughout the day and the hall was always busy. They raised over £1,600 from sale of refreshments, this sum was augmented by a bucket collection and friends and family donations, and a total of £2,330 was transferred to the Branch account after the event.



The estate, the Matthews family and Branch all publicised the event and our JustGiving page, and donations started to come in steadily in the days leading up to the event and afterwards. As of 3 March donations totalling £973.50 have been received; this will increase once gift aid is claimed. There were many lovely messages for Colin and the Matthews family. Thank you to everyone who has donated to our JustGiving page which remains open for donations. Our thanks also go to those who made personal donations directly to the Branch.

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

Special thanks go to Elizabeth Meath-Baker for appearing on Radio Norfolk to publicise the event and raise awareness of motor neurone disease and the support offered by the MND Association locally in Norfolk.

We are grateful to Walsingham Abbey & The Shirehall Museum and the Matthews family for all the work they put into making Saturday such a success. Our thanks also go to



those who visited on the day. The money raised in support of the work of the Norfolk, Norwich and Waveney Branch is hugely appreciated; the total raised has



gone beyond our wildest dreams and will be used in support of people living with motor neurone disease.

The Wild Rovers Shanty and Folk band held an event that evening, collecting donations of £389.73, which were transferred to the Branch.

Our thanks for permission to use the photos supplied by Elizabeth Meath-Baker.

Wednesday 23 February, Memories Never Disappear Agnes held at the Norwich Arts Centre by John Davy

The idea was quite simple. While Agnes was here, I knew she was hugely grateful for the support we got from the MND Association. She was equally keen to engage with research and ideas about how we could give something back.

It was one of those things that we did not talk about what would happen after Agnes was gone. It was not something she ever wanted to do, so I had to develop a way for Agnes to have a lasting and positive legacy for the MND Association.

What better way to do it than ask some bands we liked to come and play in our City in Agnes' name?

I reached out to my great friend James Carrington and the Blackheart Orchestra, and when they both said yes, the work began.

Two months later, the gig night was upon us, and a festival of music took place for 162 ticket holders.

Both artists had new albums, with James playing all the tracks from the new album "A quiet place in Bright Sunshine" and the Blackhearts playing hits like Sebastien. A few drinks, some laughter and some tears, along with some great music. What more could you want?

Companies sponsored artist fees, so £20 of every ticket sold goes directly to the MND Association. Half for research and half for our local branch.

And then came the JustGiving page. Supported by individuals and business colleagues, we currently stand at £11,386.00 raised with more expected soon.

At the very start, I hoped we would get to £10k, so to surpass that by such a large amount has genuinely been a blessing.

It was a party on the night with artists and fans having a great time. The endless winter is always followed by the light of summer to come. It was great to get the music to shine brightly at the end of February, to have a night that we could all enjoy, and one of which Agnes would be rightfully proud.

Liz Cooper added, "I was delighted to have been a part of the fundraising event arranged by John Davy in memory of his late wife Agnes. The bands were fantastic and the atmosphere really amazing. There was so much support in the room! John kindly invited the MND Association to have some stage time to say a few words about our work which was received with such positivity. I have been watching the JustGiving page set up in memory of Agnes, it just keeps increasing! Our heartfelt thanks to John, his family and the team for putting on this amazing event."



The Norfolk, Norwich and Waveney Branch would also like to add our thanks to John for hosting such a wonderful event. We would like to extend our thanks to James Carrington and the Blackheart Orchestra for the wonderful music on the night. It was a joy to listen to the concert that was streamed online. Thanks also go to John's team who worked so hard behind the scenes on publicity, and shared images and videos with us to add to our social media.

Saturday 26 February cheque presentation by Copperfield Lodge 9851, Gorleston

Brian Caton of Copperfield Lodge, based in Gorleston, contacted Malcolm, branch chair, to say that he would like to make a donation of £1,000 to the branch in memory of Bob Rackham who died from MND. We are very grateful for the funds which were raised over the course of a year from various small events including a raffle.



The cheque presentation took place on Saturday 26 February in Malcolm's front garden.

Pictured from left to right Malcolm Chubbock, Brian Caton, James Gray and Paul Rackham.

Sunday 13 March 2022 MND Association Charity Tattoo Day

It was just too late to add a report in this edition of Fightback. Martin and other tattoo artists based in Lowestoft planned to tattoo as many "keep moving" tattoos as possible in one day at a cost of £50 per tattoo. They aimed to raise awareness of motor neurone disease and as much money as possible. We look forward to sharing news of a fundraising day with a difference, and telling you how much was raised on the raffle and from the sale of tea, coffee and cakes throughout the day. Will Martin achieve his desired aim of completing 50 tattoos in one day?

Future events in aid of the Association

Thursday 23 June 2022 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. There is plenty of paid parking in the car park behind Central Hall. It is a wheelchair accessible venue.

They have kindly offered to host the coffee morning on 23 June to raise funds for our Branch. Everyone is invited to swell their numbers on this occasion, there is a small entry charge of 50p to cover tea/coffee. 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.

Monday 11 July 2022 at Bawburgh Golf Club, Barnard Charity Golf Day

The Barnard Charity Day has been run by the golf club for the past 30 years in support of various local and national charities. This well recognised day is also supported by golfers from other clubs in Norfolk. This year the Bawburgh Golf Club have kindly said that the proceeds of this event will be shared between the MND Association and Bawburgh School.

Teams of 4 players will pay £200 for the round which also includes breakfast and a BBQ after the round of golf. There will also be a silent auction and raffle on the day. The silent auction is generally for donations of a meal for two, round of golf or similar. The raffle prizes are of good bottles of wine or gift sets.

This is set to be a well attended event, and your help would be appreciated – if anyone is able to offer items for the silent auction or raffle the club would be very grateful. If you would like to help on the day please contact our Care Service Navigator Trish trish.moore@mndassociation.org or by phone on 07813 094820.

If you would like to enter a team of four you can find the flyer with application form on our branch website at <https://www.mndnorwichandwaveney.org.uk/events.htm>. For more information about the day email them at golf@bawburgh.com or telephone 01603 740404.

Sunday 7 August 2022 Hoveton Village Charity Fete

The Hoveton and Wroxham Lions Club are organising a Charity Fete on Sunday 7 August between 10:00 and 16:00 at Hoveton Village Hall and playing field. They plan fun for all the family, craft stalls, trade stalls, charity stalls, games, climbing wall, amusements, classic cars, bar and refreshments. Admission £2.50 with under 16's free.

The branch are pleased to have been offered a pitch for a charity stall, which we will use to raise awareness of MND and the work of the branch locally. Of course, it would be good to raise some money too. We will have Association merchandise for sale and a guess the name of the Eagle (a soft toy). Do you have other fundraising ideas to share? If you would like to help on the day Grace has kindly offered to coordinate the rota of volunteers; contact her by email at mnda.norfolkwaveney@gmail.com or by phone (not mornings) on 07587 175141.

Sunday 2 October 2022 TCS London Marathon by Darren Millard

Hello my name is Darren, I'm 43. I started running a couple of years ago to help with my weight loss and after losing 6½ stone decided it was time to apply to run the London Marathon for the MND Association.

I lost my best mate Gavin Casey to MND in April 2019 and then a month later lost a second close friend Paul Hainsworth to the same disease. So I have plenty of motivation and support to hopefully smash this.

My just giving link is <https://www.justgiving.com/fundraising/darren-millard>.

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

- Anonymous donations - £5,365
- Swannington Lunch Club, proceeds of September raffle - £100
- Susie and David Meadows, Wedding Anniversary party donations - £1,050
- Norwich Pétanque Club, proceeds of competition and raffle - £172
- Judy Hambly, donations in lieu of Christmas presents in honour of her friend with MND - £510
- Provincial Grand Lodge of Norfolk, donations supporting Alex Baldwin's fundraising - £500
- Freemasons Suffield Lodge 1808 - £175
- Alison Ward, proceeds of tombola at Eaton Craft Fair - £192 and donations at Eaton Craft Fair - £73
- Beccles Helping Hands - £400
- Wymondham Lions International - £200
- Christine Widdows collection box - £55.57
- SB, in memory of her husband - £165
- Anne Adcock, in lieu of Christmas cards - £10
- Sue Kitson donation - £50
- Ann Franklin, in lieu of birthday presents - £80
- RH donation - £20
- PA M-B donation - £200
- Paul Bassham Community First Revenue Fund - £5,000

Donations in memory of

- Stephen Frank Appleyard - £200
- Margaret Mary Daynes - £255
- Julia Margaret Webb - £20

Internal transfers

- JustGiving - £366.98
- Gift Aid - £125

We are extremely grateful for the donations totalling £134.40, 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.

A reminder – we are still recruiting volunteers!

Have you seen the editorial in the February/March edition of Village People? We hope it will encourage more people to volunteer with us as Association Visitors. If you are able to help spread the word that would be wonderful. We are very grateful to an anonymous donor who covered the costs of our advert, and to Village People for including the editorial and art work free of charge. If you have not received a poster advertising the role and would like to put one on display then please email sueheal@btinternet.com or liz.cooper@mndassociation.org who can send you a pdf. Or ask Sue to post you one or more posters – either A4 or A5.

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

We are pleased to be joined by Beth who will be looking after our social media. Do you have any skills that you think will help us in running a successful branch?

Committee Members: We are delighted to welcome two new committee members. Grace Fleming joins as our membership and open meetings secretary, and Emma Fawkes joins as our minutes secretary. If you are interested in joining our committee please talk with Malcolm or contact liz.cooper@mndassociation.org by email or phone 01604 800620. We are a friendly bunch and look forward to welcoming you! We meet online every six weeks on a Tuesday evening starting at 6:30pm; meetings are usually finished in under two hours.

Training and induction for all roles will be provided and travel/direct cost expenses are reimbursable.

Useful local information

UK Power Networks In the light of the recent storms now might be a good time to make sure you have registered for free support during a power cut. If you think you might need extra help during power cuts – perhaps because you rely on medical equipment at home or have a disability – signing up for the Priority Register could be a good idea. In the event of a power cut call 105. <https://www.ukpowernetworks.co.uk>

Anglian water also has a Priority Services Register. You can register online at <https://www.anglianwater.co.uk/help-and-advice/water-care/priority-services/>

Most **gas and electricity** suppliers have similar registers.

Local libraries offer extra support – for example the keep warm bag contains gloves, thermal top, socks, hat, scarf and blanket. The bags are on shelves in the libraries and you can just go and pick one up, no questions asked.

Norfolk Libraries are offering free Grab and Go bags, containing essential items to help people over the winter months. Keep Warm And Go bags will be available until March 2022 – so hurry. The funding for the bags comes from Household Support funding for County Councils in England.

The Norfolk Assistance Scheme is there, if you are struggling for support, and may be able to provide help. If you cannot complete an online application call 0344 800 8020. <https://www.norfolk.gov.uk/care-support-and-health/support-for-living-independently/money-and-benefits/norfolk-assistance-scheme>

The Norfolk Assistance Scheme helps people who are in financial hardship and cannot pay their living costs, for example whilst waiting for benefits or other entitlements to be sorted out. You will need to complete an application with evidence of your financial situation.

News from National Office

MND Coronavirus (COVID-19) Hub: Whilst restrictions have been removed and we adjust to living with COVID-19 the Association continues to host a dedicated webpage providing regularly updated information on COVID-19 and MND, and giving answers to frequently asked questions. <https://www.mndassociation.org/about-mnd/coronavirus-and-mnd>

Fundraising News: If you are interested in organising a fundraising event or simply raising some funds there is information at <https://www.mndassociation.org/get-involved/fundraising/>. If you would like to talk to someone about your fundraising please phone 01604 611860.

If you set up a JustGiving page, and would like the money raised to support the Norfolk, Norwich and Waveney Branch, please make it clear that we should be the recipient. Please let us know about your events so we can share the news.

This March, the Association has launched a new fundraising challenge **Give It Up! for MND**. People are encouraged to choose something that they will go without for the whole month to raise money to support families affected by motor neurone disease. For more details visit <https://giveitup.mndassociation.org/>



Sarah, who lives in our branch area, is taking part in **Give it Up!** to support a dear friend and others affected by motor neurone disease. Most people who know Sarah will be aware that she is a chocoholic. She loves the stuff! So she will be giving it up through March. In her words, "If I can do this one small thing to help fund research then it is a challenge I am happy to be part of." Visit her page to help reach her target of £200. <https://giveitup.mndassociation.org/fundraising/sarahs-fundraising-page222>

I will always be me: is written from the perspective of someone living with MND. It takes less than half an hour to read the book and it is designed to be a shared experience for family and friends. Upon finishing the story, the recording is uploaded and transformed into a digital voice by **SpeakUnique** which can then be used with communication devices when needed.

Global companies Intel, Dell Technologies and Rolls Royce came together with the Association to develop this book as part of the NextGen Think Tank which was created in 2019. The Association will provide funding for people with MND to take part, thanks to donations from Dell Technologies and Intel.

You can read more here and watch a short film featuring branch member Diana, amongst others, <https://www.mndassociation.org/i-will-always-be-me-worlds-first-e-book-that-banks-your-voice-is-launched/>

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

Care Information Finder: Have you seen the Association's care information finder yet? This new website search facility enables people to find care information resources organised by specific needs. After choosing your subject, such as 'Speech and communication', all the links to care information on that particular topic will be grouped together so that you can see everything in one place and ensure you won't miss anything that could be of help.

Please share with anyone who you think may find it useful.

<https://www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/find-information-about-symptoms-treatment-and-care/>

Online research pages updated: The research team are currently revamping the research pages on the MND Association website.

The first of these changes is the addition of a 'Latest Research News' page. Here, you can find the most up to date research news clinical trial outcomes, breakthroughs in the lab, interesting research papers and much more. <https://www.mndassociation.org/research/latest-news/>

The second change is the addition of a <https://www.mndassociation.org/research/clinical-trials/treatment-trials/>, where you can find the new and improved treatment trial pages. Here you can find information on MND clinical trials, including the latest news, recruitment status, outcomes, resources and more, all of which will be regularly updated.

Not online, you can talk about getting involved by phoning the Research Development team on 01604 611880.

Do you have experience caring for someone living with MND? If so, a new study from King's College London, funded by the Association and Marie Curie, is currently seeking volunteers to participate as peer-supporters in a 12-week programme. The study involves supporting a person who is caring for someone living with MND and is anticipated to take around 1.5 – 2 hours per week.

Peer Supporters will:

- Communicate directly with carers on a weekly basis, using an app (similar to WhatsApp but more secure) to provide support for the issues faced by carers of people affected by MND.
- Build up knowledge of the resources and support available for carers.
- Help to signpost family carers of people affected by MND to available resources and services.
- Participate in the weekly online forums providing carers with an opportunity to discuss their issues.
- Explain to carers how the MND Association can support them.

By taking part, you will get the opportunity to share knowledge and experiences whilst making a huge difference to people caring for loved ones with MND.

If you are interested in learning more about being a peer supporter in this research study, please email ella.terblanche@kcl.ac.uk, who is a research officer at King's College London.

Once you have emailed Ella, one of the friendly research team from King's College will give you a call to explain more about the role and discuss what is involved. If you decide to get involved, the research team will provide you training on the app and on peer support, so you are confident and empowered to be a peer supporter.

Updates from the Norfolk MND Care and Research Network

Introduction of telehealth system by *Helen Copsey*

People attending clinics at the Norfolk and Norwich, Cromer Hospital and Beccles Hospital are being invited to use a new telehealth system. This service is called Telehealth in Motor Neuron Disease (or 'TiM' for short). People living with MND and their carers can use it to tell the clinical team about their condition. The MND care team regularly review answers and can take necessary action to provide support. This might include telephoning you or speaking to other members of the MND team.

The system is easy to use and has been co-developed alongside people living with MND and their carers. Originally developed by the University of Sheffield, it is now being utilised in other MND centres nationally. Information is presented simply and questions about your condition are easy to answer, usually taking only 10-15 minutes to complete. For people with MND, questions relate to a variety of symptoms associated with the condition, including breathing, wellbeing, and appetite, and are sent once a week.

The centre will also be joining the University of Sheffield in a research study to evaluate how useful the telehealth system is in supporting people's care. Your care team may ask you whether you would be willing to help with this.

Initial funding for the delivery of the new service has been provided by the Norfolk and Norwich Hospitals Charity.

For more details or to register please contact Helen Copsey (MND Care and Research Network Coordinator) at helen.copsey@nnuh.nhs.uk or call 01603 647221 or 07788 597021.

MND-SMART by Helen Copsey

MND-SMART is a clinical drugs trial currently being undertaken in the UK. SMART stands for **Systemic Multiple-Arm Randomisation Trial** which means that the trial will test more than one drug at the same time. Trial participants taking the different treatments will be compared with a single group who receive a placebo (dummy) drug. More information can be found at <https://www.mnd-smart.org/about/about-mnd-smart>.

The Norfolk and Norwich University Hospital is now recruiting to this trial and people with MND from across the county are invited to express their interest in participating. This can be discussed with your clinical team or alternatively you can contact Helen Copsey (MND Care and Research Network Coordinator) helen.copsey@nnuh.nhs.uk or on 07788 597021.

MiNDToolkit for carers – is it for you? A novel intervention for carers dealing with behavioural changes in Motor Neurone Disease.

Eneida Mioshi and her team, which includes Helen Copsey, are conducting a research study to investigate if a novel psycho-educational tool is helpful and acceptable by carers (both family carers and paid carers) and healthcare professionals. The MiNDToolkit was specifically developed to support carers who are looking after people with MND who may present with additional non-physical symptoms such as lack of motivation, impulsivity and other symptoms that are associated with frontotemporal dementia. The MiNDToolkit combines access to bespoke online modules (you may recognise some of the local presenters) and trained healthcare professionals.

Prof Eneida Mioshi, based at the University of East Anglia, is leading this research study, which involves teams in Norfolk, Suffolk, Sussex, South Wales, Sheffield, Leicester, Calderdale and London.

If you would like more information, please email mindtoolkit.study@uea.ac.uk or read more at <https://mindtoolkit.org/>. Or perhaps express interest at your next appointment with Helen!

FACTOR-MND: A reminder that this study, based at UEA is still recruiting. It is a study aiming to understand factors affecting the wellbeing of carers of people with motor neurone disease. Based locally it would be lovely to see people lending their support by taking part.

Questionnaires will be available at our next open meeting. You can also email mnd.research@uea.ac.uk for further information or to ask for a pen and paper packet to be sent to you. Alternatively complete the online survey at <https://uea.onlinesurveys.ac.uk/factor-mnd> or phone researcher Ana Paula Trucco on 07825 863389 for further information.

Campaigns

#United2EndMND: The United to End MND campaign has successfully secured a Government investment of £50 million for targeted MND research.

The announcement came on 14 November 2021, with Prime Minister Boris Johnson congratulating the charities involved and the Sunday Express (which adopted the campaign under the banner ‘Fund the Fight to Cure MND’), on a “fantastic campaign”. Secretary of State for Health and Social Care Sajid Javid, who met a group of campaigners at Westminster in September, described the campaign as “hugely important”.

MND Association Chief Executive Sally Light called the news “game-changing” and described it as “the hope we have been longing for”.

The Government has committed to investing £375 million into research into neurodegenerative diseases. The £50 million targeted at MND research will be made available over five years – as the campaign requested.

Since the campaign began two years ago, thousands of people have joined forces to urge the Government to make this investment. This has included people with MND, leading neurologists and coalition partners the MND Association, MND Scotland and My Name’s 5 Dottie Foundation. Thank you to everyone who supported the campaign, signing letters and petitions and writing to MPs.

Following the announcement the MND Association met with Business Secretary Kwasi Kwarteng MP and Karl Turner MP to discuss the campaign.

In December, the All-Party Parliamentary Group (APPG) on MND met to discuss MND research. This provided an opportunity to build on the support of MPs from across the political parties to encourage them to take the campaign forward with us.

The campaign has not stopped with the announcement. Sue Heal has been in touch with local MPs who together with others have been pressing the Government to confirm when, and exactly how, these funds will be made available so that the current promising progress that our scientists are making towards the first-ever meaningful treatments for MND can be accelerated. Our thanks to Martin Burnell who also keeps in close contact with MP Peter Aldous, who is supporting us in pressing the Government to ensure the £50m funding is delivered to where it is needed as soon as possible.

A group of people living with MND continue to maintain pressure on the Government, you can read updates on their work at <https://patientsunited2endmnd.org>.

Update on the Scrap6Months campaign: We welcome the announcement from the Department of Work and Pensions that from 4 April 2022, fast-track access to Universal Credit and Employment and Support Allowance will be extended. The life expectancy criteria has been changed from 6 months to 12 months, meaning that more people will be eligible to claim using the Special Rules for accessing benefits.

We are assured that, when Parliamentary time allows, a Bill will be brought to Parliament to enact these changes to Personal Independence Payment, Disability Living Allowance and Attendance Allowance.

We thank our local MPs who have been pressing Chloe Smith MP for North Norfolk, Minister of State for Disabled People, Health and Work, to give a more definitive time scale.

The UK Government is making a related change to the rules so that people with a terminal illness no longer need to sign-up to a Claimant Commitment to receive ESA and UC. A Claimant Commitment is typically a record of what you will do to find work or move closer to work, and what the consequences will be of not doing this.

Chloe Smith MP has suggested that these updated regulations, which came into force on 15 February 2022, will apply across Great Britain. This is another step towards making the benefits system more sensitive to the needs of people living with MND.

As many of you will know, the Special Rules for Terminal Illness (SRTI) process is the fast-track pathway for claiming benefits, meaning people do not have to go through a long and stressful assessment.

****Benefits Advice Service:** If you need help or advice claiming benefits visit <https://www.mndassociation.org/support-and-information/our-services/benefits-advice/> for more information. Alternatively call for free on 0808 801 0620 between 09:00 and 17:00 Monday to Friday, except on public holidays.**

Act to Adapt: The campaign has three main aims to:



- Introduce a fast-track process for people with MND
- Remove financial assessments for Disabled Facilities Grants for people with MND
- Maintain a register of accessible homes for people to move into

Thank you to everyone who shared the interactive ‘Act to Adapt housing map’ with their local councillors and inviting them to a councillor event in November 2021. Sue Heal attended the event, helping host one of the breakout rooms, and was pleased to see two councillors from North Norfolk and one from East Suffolk amongst the 28 councillors attending from across the country.

In December 2021, Sue received an email from Cllr Fran Whymark, Portfolio Holder for Health and Wellbeing (Broadland Council) and Norfolk County Councillor on the Health and Wellbeing Board, informing her of the introduction of a Serious Illness Grant. This grant has been designed for residents of Broadland and South Norfolk District Councils. It is intended to provide quick and straight forward financial assistance to seriously ill residents in need of adaptations, repairs or improvements to improve the ‘thermal capacity of homes’. It is a discretionary non means tested grant of up to £5,000 and can be accessed by contacting the councils’ Help Hubs. Any person diagnosed with an illness such as motor neurone disease can apply. The grant is available even if you intend to apply for a disabled facilities grant, the Help Hub should be able to signpost you to all available sources of finance for adaptations.

Subsequently Sue and Malcolm were able to meet Cllr Whymark, Mike Pursehouse Assistant Director of Individuals and Families, and Kevin Philcox, Senior Standards Manager (South Norfolk and Broadland Councils). They committed to continue working with us and are working to encourage other councils across Norfolk to adopt best practice.

Sue has also had a preliminary meeting with an officer from Great Yarmouth Borough Council to ask them to consider adopting the MND Charter and the steps they could take to best support people living with MND.

On 23 February, Sue attended the All-Party Parliamentary Group (APPG) on MND AGM as an observer. After the election of officers the meeting focused on tackling the problems faced by people in need of home adaptations as highlighted by the Act to Adapt campaign. The APPG has circulated a template letter and asked all MPs to write to their local councils to ask what measures were being taken to fast-track adaptations for people living with MND and whether they offered non-means tested support.

Social Care: Social care is a vital form of support for many people living with MND and their families, yet the social care system has been in a growing state of crisis for decades.

In the last edition of Fightback we reported on the Government's plans to increase funding for social care. The Government wants to change the way we pay for our social care, this is being done through the Health and Care Bill that is currently in the House of Lords. The Campaigns and Policy team have been following the Bill's progress and have been working with a group of charities, as part of the Care and Support Alliance, to try and make proposals fairer for people with lower income and wealth. This includes working-age adults.

You can read more about our campaigning on social care reform at <https://www.mndassociation.org/get-involved/campaigning/take-action/social-care-reform-campaigning/>.

The Association's survey for carers closed in December and the results are being analysed. If you were one of the two hundred who responded to the call to participate, please accept our thanks. The results of the survey help inform our campaign to push for reforms that deliver a sustainable system capable of meeting the needs of people living with MND effectively.

NHS Continuing Healthcare: Continuing Healthcare (CHC) is a package of care arranged and funded by the NHS. It is available to people who have been assessed as having a 'primary health need'. Whilst some people receive wonderful support through CHC we are mindful of the difficulties some people face accessing CHC and problems around sourcing appropriately trained carers. Always speak with us if you are experiencing difficulties as, whilst we don't have a 'magic wand', we may be able to help.

The Association has produced a useful guide to CHC, which you can download – alternatively phone MND Connect 0808 802 6262 to request a copy of the information sheet.

<https://www.mndassociation.org/app/uploads/2015/06/10D-NHS-Continuing-Healthcare.pdf>

The Association is looking to improve people's awareness of CHC and their experience of accessing care. We continue to work closely with the Continuing Healthcare Alliance and other charities.

Spotlight on Campaigning: Would you like to know more about our campaigning work and why it matters to people living with and affected by MND? If so, join us on 23 March 18:00-19:00 as active Campaigns Volunteers, including branch campaigner Sue Heal, talk through what is involved in campaigning and why they choose to do it.

The session is perfect for those who are curious about ways of raising awareness about MND, whilst influencing policy locally and nationally. Email amy.ramsay@mndassociation.org express your interest by putting 'I'd like to attend the spotlight on campaigning event on 23/03 at 18:00' as the subject.

Research *by Aidan Nicholson*

Therapy

Gene Therapy Program for ALS due to C9orf72 Mutations Opening in UK – Oct 2021

Mutations in the C9orf72 gene are the most common genetic cause of MND, occurring in about 50% of hereditary cases and 10% of sporadic cases. In healthy cells, repeat sequences of DNA letters are passed onto the gene's messenger RNA (mRNA), which is a molecule generated from DNA and used as a template for protein production. The repeats are usually prevented from doing damage by being cut from mRNA before it leaves the cell nucleus. However, this does not occur in C9orf72 mutated cells, and toxic proteins are created which accumulate and cause damage.

Preclinical studies have demonstrated that the SRSF1 protein transports the abnormal mRNA molecules. Therefore, in studies involving fruit flies, those that had their SRSF1 protein removed exhibited a reduced transport of mutant mRNA preventing nerve cell death and resulting in fewer movement abnormalities. Research is continuing in this new and experimental branch of potential therapeutics at Sheffield University in order to assess the feasibility and efficacy of gene therapies in patients carrying C9orf72 gene mutations.

See more at: <https://alsnewstoday.com/news-posts/2021/10/04/uk-gene-therapy-program-als-motor-neurone-diseases-openin/>

Measuring Brain Activity Identifies Four MND Subtypes – Nov 2021

MND has many different presentations and existing clinical tools cannot accurately predict disease progression and survival rates. Studies suggest that this variability reflects the disruption of different neural networks in the brain – groups of connected or functionally associated neurons.

Tools that measure the electrical activity of these networks might provide insights into the functional changes associated with MND. Researchers at the University of Dublin have demonstrated that resting-state electroencephalography (EEG) can identify 4 distinct patterns of changes in electrical signals which are predictive of how the disease progresses.

This will help in identifying patients for clinical trials and in finding effective treatments for different sub-categories of MND.

See more at: https://www.tcd.ie/news_events/articles/trinity-college-researchers-make-breakthrough-in-understanding-motor-neuron-disease/

Investigational Therapy May Target Inflammation in MND – Nov 2021

TQS-168 is an investigational therapy which has demonstrated reduced inflammation in mouse and human models of MND, prolonging survival in mice. Based on these findings, the therapy is now moving into Phase 1 clinical studies. TQS-168 was designed to reduce myeloid cell activation and reprogram them to restore their normal function. Myeloid cells are a type of blood cell which are normally the first line of defence against potential harm to the body. However, in MND and other neurodegenerative diseases, these cells can become overly active and cause inflammation and damage healthy cells such as nerve cells. These pro-inflammatory cells are hallmarks of disease progression in MND. It is hoped that through future studies involving TQS-168, new disease-modifying treatments can be created which can reprogram the dysfunctional myeloid cells and benefit people with MND.

See more at: <https://alsnewstoday.com/news-posts/2021/11/12/als-therapy-tqs-168-reduces-inflammation-extends-survival-mouse-model/>

Does the Retina Hold the Key to a New MND Biomarker – Dec 2021

In a recent mouse model study, it has been shown that MND leads to neuron damage in the retina through the activation of inflammatory cells. Thus, consistent with previous retinal damage in MND evidence, retinal damage may serve as biomarkers for the diagnosis and monitoring of MND and checking of treatment efficacy. It is hoped that future research can help develop this simple, non-invasive, and less expensive method of monitoring into clinical practice.

See more at: <https://alsnewstoday.com/news-posts/2021/12/20/als-linked-neuronal-death-retina-potential-biomarker/>

Phase 2 Trial Shows Stem Cell Therapy Has Potential to Slow Progression – Dec 2021

In a small phase 2 clinical trial conducted in Israel, it was shown that repeated injections of mesenchymal stem cells (MSCs) into the spinal cord were safe and showed potential to slow the progression of MND. MSCs can mature into any other cell type and have strong immunosuppressive, anti-inflammatory, neuroprotective and regenerative properties, garnering interest as a therapeutic approach for neurodegenerative conditions.

In previous trials the positive effects of the injections of MSCs seemed to fade with time, indicating the possible need for repeat injections. In this new trial, a longer period of time with more MSC injections took place which showed no serious side effects occurring on administration, a slower rate of lung function decline and a mean reduction in rate of progression. This data has provided a hopeful indication of the future potential clinical benefits of MSC therapy with hopefully more data and trials to come.

See more at: <https://alsnewstoday.com/news-posts/2021/12/03/mesenchymal-stem-cell-therapy-safe-potential-slow-als-progression-trial/>

Aetiology

Higher ‘Good’ Cholesterol Levels Appear to Lower Risk of ALS – Oct 2021

In a recent study, certain biomarkers of lipid (fat) metabolism appeared to protect against developing MND. Specifically, people with higher levels of high-density lipoprotein (HDL – the ‘good cholesterol’, and apolipoprotein A1 (ApoA1, a component of HDL), had lower risk of MND. Additionally, a person’s risk of MND rose with higher levels of low-density lipoprotein (LDL – the ‘bad cholesterol’), and apolipoprotein B (ApoB), a component of LDL. Several studies have linked MND and lipid metabolism with patients showing changes in their lipid metabolites as much as a decade before diagnosis, making these molecules potential biomarkers for early disease detection. It is hoped that this research can develop into target population screening for MND and develop future trials of preventative therapy.

See more at: <https://alsnewstoday.com/news-posts/2021/10/28/higher-good-cholesterol-blood-levels-linked-lower-als-risk/>

Too Little, Too Much Physical Activity May Shorten Survival – Oct 2021

Recent studies from Germany have shown that heavy physical activity whilst working is associated with nearly two times greater risk of MND. Additionally, MND patients reporting pre-diagnosis and current moderate physical activity have had better prognosis than patients who were inactive or conducted regular, intensive physical activity. The question of whether vigorous activity is an environmental risk factor of MND has long been a topic of debate. This debate gained increased traction with the trend that professional athletes are known to develop MND at a higher rate and at a younger age than the general public.

However, the studies' results from Germany have not proved that physical activity causes MND, but rather that there is an association, which is sure to inspire further research to clarify this important topic.

See more at: <https://alsnewstoday.com/news-posts/2021/10/27/too-little-too-much-physical-activity-shortens-survival-in-als-patients/>

Take part in research

The best advice is to talk with your care team to find out which research studies are recruiting locally and are appropriate to your situation. You can also look on the Association website at <https://www.mndassociation.org/research/clinical-trials/treatment-trials/> where you will see trials which are in the spotlight. Some opportunities were covered in the update earlier in this edition of Fightback.

Online coffee mornings – now we can offer greater choice of groups

- **The branch continues to offer monthly coffee mornings** on Zoom from 11:30-13:00 on the third Wednesday of each month. These are friendly informal gatherings hosted by Sue, and other volunteers, for people with MND, their carers and friends, there is no agenda. You can drop in at any time and leave when you need.

Dates for 2022 are as follows: 20 April 18 May 15 June

Email sueheal@btinternet.com if you would like to receive the link. Newcomers are always welcome!

Sue and Judy are still hoping to introduce face to face coffee mornings soon. Subject to the current guidelines we hope to re-start our coffee mornings at Notcutts in May, watch our website for details <https://www.mndnorwichandwaveney.org.uk/events.htm>.

- **Evening online support group for carers of people with MND.** The meetings take place on the last Wednesday of the month at 6:30pm. Dates for 2022 are 30 March, 27 April, 25 May, 29 June, 27 July, 31 August, 28 September, 26 October and 30 November. If you would like to be emailed the zoom link please get in touch with alli.anthony@mndassociation.org or carmen.brown@mndassociation.org.
- **Daytime online support group for carers of people with MND.** Join us for a virtual cuppa and friendly chat with other carers of people with MND in London and the South East. Meetings take place on the first Tuesday of each month at 11am. Dates for 2022 are 5 April, 3 May, 7 June, 5 July, 2 August, 6 September, 4 October and 6 December. For more information and zoom link email ahmed.abdeldayem@mndassociation.org.

****Richard Cave, Project Manager Speech and Language Therapist at MND Association will be attending the April SE online support meeting for people affected by MND to talk about his role and the e-book *I will always be me* used to assist in voice banking.****

Items for people living with MND

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.

A ramp is available as pictured on the right. For further information please contact Trevor at titmarsh21@gmail.com.

The ramp is 30 cm high, there is also a ramp to go over door thresholds as pictured. The delivery note refers to these dimensions (inc1xDM5 &1AX24), Trevor will be able to confirm the external ramp length and width.

Visit <https://www.enable-access.com> site to see examples of the ramps.



Branch News

AGM and Open Meeting: Sunday 24 April 2022, 12:30- 16:00 – the Annual General Meeting, usually short, will be held at St Andrews Eaton Church Hall, Church Lane, Norwich, NR4 6NW. We will be providing a hot lunch as outlined in your letter of invitation. Our guest speaker will be Association Trustee Catherine Knights who will speak for about 15 minutes about the role of the trustees. We will hold a raffle and have Association merchandise for sale.

Advance Notice of Open Meetings: Sunday 24 July 2022 Upton Village Hall, Cargate Lane, Norwich, NR13 6AU and Sunday 13 November 2022 Wortwell Community Centre, Tunbeck Close, Wortwell, IP20 0HS.

Website: www.mndnorwichandwaveney.org.uk

We are always happy to add information about events you are planning in support of the Norfolk, Norwich and Waveney Branch.

Facebook: [@MNDANorwichWaveney](https://www.facebook.com/MNDANorwichWaveney)

Twitter: [@MNDANorWave](https://twitter.com/MNDANorWave)

Instagram: [@MNDNorfolk](https://www.instagram.com/MNDNorfolk)

Newsletter Editor: Thank you to all who have sent photos and stories for inclusion in our newsletter. The deadline for receipt of articles for the next edition is **1 June 2022**.

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

Area Support Coordinator Liz Cooper 01604 800620 liz.cooper@mndassociation.org

MND Coordinator Helen Copsey 01603 647221 helen.copsey@nnuh.nhs.uk

MND Administrator Keeley Papworth 01603 647221 keeley.papworth@nnuh.nhs.uk

Care Service Navigator Trish Moore 07813 094820 trish.moore@mndassociation.org

Please pass this newsletter on to people who may be interested.

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 Grace Fleming at mnda.norfolkwaveney@gmail.com or write to Norfolk, Norwich and Waveney Branch, c/o MND Association, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ.*