

Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter
Issue 78 February 2019

Sunday 18 November 2018 Wortwell Christmas Open Meeting

Sixty-two people attended, including eight people living with motor neurone disease (the largest attendance we have ever had at a Branch Open Meeting), their families and carers, those bereaved by the disease, local volunteers and health care professionals. As always we were pleased to welcome new faces and to catch up with those we hadn't seen for a while. There was a lovely



atmosphere with lots of conversations taking place and new friendships made. People seemed to enjoy the opportunity to buy their Christmas cards and MND merchandise raising a record £373.75. We would like to thank everyone who kindly donated prizes for the raffle. The sale of raffle tickets raised £200 on the day when all the tickets were sold – next time we will remember to bring more than one book of tickets!

The tables looked suitably seasonal with Christmas crackers and beautiful red cyclamens. I think everyone enjoyed the Christmas lunch cooked and served by David and his team from The Butchers, Swanton Morley, as ever the portions were generous, and the committee were really thankful to them for washing up afterwards!

It was good to see both Lindsay Goward and Liz Cooper, our Regional Care Development Advisers, who offer wonderful support for people living with MND – much of it behind the scenes in meetings and organising training events. Once again we are all very grateful to Helen Copey, MND Coordinator at the Norfolk MND Care and Research Network for giving up her time to join us. Helen introduced Emma Lerner, the MND Respiratory Physiotherapist who has joined the Network very recently, and who will be working with the Network for three days a week supporting people with MND living in Norfolk. Helen expressed her appreciation for the Branch support in purchasing an expensive piece of kit – a cough assist machine that Emma will be using during home assessments.

We were delighted that Dr Ratko Radakovic, Senior Research Associate at the University of East Anglia was able to talk with us about local research opportunities, and then to lead an interesting discussion about the benefits of research in general. Kaitlin Dudley, a fellow researcher from the MND Care and Research Network also gave up her time to join us and was able to talk with individuals about the possibilities of being involved in the research. Prof. Eneida Mioshi, who leads the research team, also sent her thanks though she was unable to join us on the day. The enthusiasm shown by everyone in attendance reflected the passion shown by the research team for what they do and why they do it.

We hope you will enjoy looking at some of the photos taken on the day, which can be seen on the Branch website together with a video of Ratko's talk.

Events in aid of the MND Association

Jon and Nick's Hadrian's Wall Walk August 2018 by *Jonathan Read*

My cousin, Nick Viscito, and I decided to raise funds for the local MND Association, who were fantastic when my brother Kevin was diagnosed with the disease in November 2017, Kevin was diagnosed very late on in his illness and sadly passed away in April 2018. The local MND Association team were fantastic in helping Kevin and our family in the latter stages of his life. So, this walk was our thank you to all who helped and a chance to raise some funds.

Day 1 Friday 24 August 2018

We started our walk at Arbeia Roman Fort, which is not the actual start of Hadrian's Wall, but we wanted to walk almost coast to coast. On leaving the fort, we walked down towards a ferry to cross the River Tyne. Then we made our way into Newcastle, walking alongside the River Tyne for a few miles heading on to Heddon on the wall for day one, which ends with a steep incline into the village. Day 1 over and 23 miles in, and no real sign of the wall.

Day 2 Saturday 25 August 2018

After a good night's rest and a hearty meal in Heddon on the Wall, we set off on day 2, weather was good, not too hot but sunny. Today, we would mainly walk through beautiful countryside and at last, a few glimpses of the wall, our target was to walk another 20 miles, which we completed. We ended at Chesters Roman Fort, feet all ok and no blisters yet. Tomorrow would be the test, the most challenging part of the wall.

Day 3 Sunday 26 August 2018

We started where we were dropped off at Chesters Roman Fort, the weather was a little damp and would get worse as we started the most isolated, but most beautiful part of the wall, as the day progressed, the weather also progressed from a nice cooling shower to a full-on soaking. The wall is at its most visible on this part of the walk, and this is the most challenging part as well, but we completed the and ended the walk on day 3 at The Roman Army Museum.

Day 4 Tuesday 28 August 2018

After a rest day on the bank holiday Monday, today's trek was a straight forward walk until around 12 miles in when my legs just did not want to walk anymore. But we knew we were nearing the end of our walk. Still lots of the wall to see, and the view was just beautiful. Ended the day just outside Carlisle

Day 5 Wednesday 29 August 2018

Today was a very easy walk, still around 21 miles in distance, we walked into Carlisle, had a quick look around the castle and then headed out towards the end of our journey at Bowness on Solway. It was a strange feeling to have ended the walk across the country but a great feeling. A nice pint of Guinness was very welcome in the local pub. Total of 102 miles walked over five days of beautiful country. We have hopefully raised about £2,000 towards the local MND Association, we are still collecting too.

Now we are deciding what the challenge will be in 2019!



Jon and Nick a long way from Norwich



Nick and Jon at the end of the walk

Wednesday 10 October 2018 Caister Ladies Group

Sue Burcham is an NHS nurse and, during her work, has cared for people living with motor neurone disease. Four members of the Caister Ladies Group, including Sue, gave presentations about their chosen charities to the rest of the group.

Following this they held a secret ballot to decide which charity should receive the donation of £500. We are delighted to report that Sue won the vote and thank everyone for their support.

As Sue's chosen charity was the MND Association, Malcolm was invited to a cheque presentation and to give a talk.

There were about forty five members present to hear Malcolm speak. He spoke about the work of the Norfolk, Norwich and Waveney Branch, about motor neurone disease and specifically the difficulties faced by people who lose their speech.

The group would like the money they have donated to be used to fund augmentative and alternative communication aids.



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Thursday 11 October 2018 Yare Probus Club

John Preus is President of the Yare Probus Club who meet for lunch at the Oaklands Hotel, Thorpe St Andrew on the second Thursday of each month. He invited Malcolm Chubbock to be the guest speaker at the President's Charity lunch. Malcolm spoke about motor neurone disease and the work of the Branch to an audience of 38 members of the club.

John lost his daughter Sarah to motor neurone disease, and is a member and supporter of the Norfolk, Norwich and Waveney Branch of the MND Association. The photo shows John presenting Malcolm with an envelope containing two cheques totalling £550 and an additional donation of £20 from a Probus member. We are very grateful to John and the Probus Club for their very generous support.



Friday 12 October 2018 'Bake it' coffee morning at Church Farm

Christine Wells (pictured on the right) organised a wonderful coffee morning and invited friends, children – and even husbands – to raise funds for the Norfolk, Norwich and Waveney Branch of the MND Association. There were huge numbers of beautiful cakes for sale. A wonderfully original cake related competition asked us to guess the number of calories in a splendid walnut cake, the answer had us all thinking we should be eating very small slices of cake! The majority of people underestimated the number of calories and no one guessed or estimated the correct number, instead we went for the closest guess.

The bring and buy stall and home made cards for all occasions were very popular. The raffle prizes tempted everyone to have a go. For those who were unable to make it to the coffee morning there was an hour of wine and cheesy nibbles in the evening. The final sum raised was £1,099.75.



Several Branch members were pleased to have been able to attend the coffee morning and to meet so many of Christine's team of helpers. We thank them all, and Christine in particular for the amount of work that she put in to make it a really enjoyable and happy event.

October/November 2018 Cycling Challenge in memory of Graham Wells by Amanda Rodwell

When a friend recently died of motor neurone disease I decided to take up a cycle challenge to raise funds for the Norfolk, Norwich and Waveney Branch of the MND Association who have been very supportive to him and his family during this



very sad and difficult time. Graham was a great sportsman and enjoyed playing golf. I am a member of Sheringham Golf Club and decided to cycle the distance between Sheringham and The Royal and Ancient Golf Club of St. Andrews, (the home of Golf) a distance of 411 miles. I planned to do this over a period of 4 weeks cycling in and around Norfolk.

I have just completed this challenge and would like to thank everyone who has generously supported me. I have raised over £1,300 all of which will be donated to the local branch of the MND Association. I celebrated the completion of the challenge with Graham's widow and friends, enjoying a pleasant cycle ride along the Marriotts Way to finish at the station in Reepham.

The Branch would like to thank Amanda and congratulate her on raising such a huge amount. We are all very grateful to her and friends who donated so generously. The event was reported on in Reepham Life <http://www.reephamlife.co.uk/?q=newsitem/3143>.

October/November 2018 – Andrew Brook's sober challenge

Andrew (on the right) raised an amazing £635 for the Branch in support of his friend Gavin Casey. Gavin received a cheque for £630 – an additional £5 in cash was donated after the large cheque was prepared. Malcolm visited Gavin and wife Louise to collect the money and to express our thanks.



Sunday 4 November 2018 – Charities Christmas Fayre at Colney Woodland Burial Park

Malcolm and Sue set up the stall with Christmas cards and Association merchandise – and a white soft toy cat! The atmosphere was friendly and warm as usual at this annual event, but sadly the footfall was low. The guess the name of the cat raised £10, but no one guessed its name. Bryan Chubbock's book sold quickly, and we wished more copies had been printed – it has been very popular. In total £105.40 was raised from the sale of merchandise.



Saturday 17 November 2018 – Harleston Christmas Fayre by *Judy Burns-Thomson*

Following last year's successful event, Pat Goose organised a Christmas Fair on Saturday 17 November in Jays Green Hall, Harleston. Judy Burns-Thomson attended on behalf of the branch and it was a busy and enjoyable morning. Stalls included a craft stall, home-made produce, Christmas gifts and novelties, face painting, a tombola and a grand raffle. The star of the show was Father Christmas who arrived to greet the children. Pat's many friends served very welcome tea, coffee and refreshments.

The fair raised £420.00 for the branch and we are extremely grateful to Pat, her friends and family for all the hard work that was involved in organising the event.

Saturday 17 November 2018 – Bungay Bingo Night by *Judy Burns-Thomson*

Rosedale Funeral Home sponsored a hugely enjoyable bingo evening at Emmanuel Hall, Bungay. Lucy Coote from Rosedale was in charge of a really well organised and fun event. Tables of 6-8 including families, children and friends enjoyed the games and there were excellent prizes for the winners. Halfway through hot dogs and brownies were served and a raffle finished off the evening.

The event raised £1,800.00, which included a very generous single donation of £1,000.00. The branch is extremely grateful to Rosedale and particularly to Lucy who put such a huge effort and a lot of hard work in making the evening such a great success.

Future events in aid of the MND Association

Saturday 27 April 2019 – The Highland Fling Ultramarathon by *Joe Gilbert*

I am taking on the biggest challenge of my life to raise money for MND research after my Mum was diagnosed with MND in November 2018. I will be running 53 miles, through the Scottish Highlands over 7,500 foot elevation in April 2019, my Mum will be in my mind with every step, motivating me on to the finish line. I hope to complete it in approximately 10/11 hours. If I can raise awareness for MND along the way and help us get one step closer to finding a cure then it will make me happy.

Joe's Mum is living in our Branch area and we are delighted that he will be raising much needed funds to further research. If you would like to donate to MND Research through Joe's Just Giving page the link is <https://www.justgiving.com/fundraising/mndmum>.

August 2019 – Jemima's road trip

When John Newport's old friend Norman Palmer died from MND, he decided to do something worthwhile in his memory. Norman had a collection of old cars in his Welsh barn, one of them being Jemima, a 1937 Morris Eight pictured here. Jemima had not been driven for many years and was in quite bad shape. John arranged with Norman's widow to have Jemima brought to Norfolk for repairs, and she is now back on the road.

The plan now is for John and his wife Elly to drive Jemima from John O'Groats to Land's End this August to raise funds for the MND Association. John can give further details of the trip if you contact him on jv.newport@btinternet.com.



Jemima now has her very own Facebook page <https://www.facebook.com/Jemimas-Challenge-for-MND-Research-325038154884021/>. To donate visit <https://www.justgiving.com/fundraising/John-Newport1>.

On 21 June, Global MND Awareness Day, everyone is very welcome to come and meet Jemima outside The Forum in Norwich between 9am and 5pm. We will also be holding a bucket collection. If you would like to help please contact Sue Heal.

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

- Anonymous donations - £123.80
- Richard and Mandy Moss, donations given at a birthday event - £50
- Ron Huggins, sale of tomatoes and runner beans - £118.24
- Ron Huggins, allotment lunch raffle and donation of £50 prize from winner - £100
- Fighting Cocks at Winfarthing, collection box - £127.15
- Norwich Petanque Club, proceeds of tournament and raffle - £147
- John Preus, donation - £20
- Thelma Pointer, donation - £100
- Mary King, collection box from The Bell Hotel in Walberswick - £50
- Mrs M Mickleburgh, donation - £250
- P & R Beckwith, donation - £100
- Mrs M J Heal, donation - £25
- Jean Howes, donation - £20
- Diana Buckingham, donation in memory of Geoff - £20
- Rebecca Paterson, commission and raffle at Christmas shopping event - £175
- Fakenham Christmas Tree Festival in memory of Mr & Mrs Wright's son - £418.83
- Sale of handmade Christmas cards & fudge in memory of Maureen Peel - £159.50
- Keith and Fay Hood, further exploits of Scruffy the little Bear - £100
- 6 Group Royal Observer Corps Association, sale of books left to the Association by a member who had lived with MND - £100
- Barclays Norwich and District Pensioners Club, raffle organised by Ian Evans at Christmas lunch - £600; Barclays Bank match funding - £600
- Stewart and Sue Tubby, donation in lieu of sending Christmas cards - £50
- Sue Kitson, donation in lieu of sending Christmas cards - £50
- Ann Franklin, in lieu of birthday presents - £40
- Sale of Association merchandise - £194.50

Donations in memory of

- Paul Leggett - £253.53
- Paul Arthur Pallant - £20

Internal transfers

- Interest - £138.29
- Gift Aid through Virgin Money - £58.75
- Gift Aid through Just Giving - £85
- We are extremely grateful for the donations totalling £297.64 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

In January the Fundraising Team took over the Association's social media channels to kickstart the New Year by fundraising to #TakeOverMND. They shared fundraising ideas, tips, advice and stories about our brilliant fundraisers. In 2019 they are hoping that even more people will run, cycle, trek, swim, walk, bake or give something up to #TakeOverMND. If you want to find out more visit <https://www.mndassociation.org/get-involved/fundraising/frto> where you can watch videos including the beginner's running guide and the impact your donations make. There are lots of good ideas for fundraising in *Your events 2019 guide* which was posted out with the latest edition of Thumbprint.

The MND Association turns 40 years old this year! National Office have offered various suggestions as to how we might recognise the occasion. They include planting a memorial tree in remembrance of loved ones lost to MND, members making a memory quilt, and creating a branch timeline display that members can contribute to. Do you have ideas? Let us know.

Can you help influence the future shape of neurological services in England? A new survey is seeking to collect information about the experiences of treatment and care, social care and welfare received by people affected by neurological conditions – including MND. The survey has been organised by the Neurological Alliance of which the Association is a part. If you are living with MND or other neurological condition please complete the survey before **22 March** by visiting <http://www.myonlinesurvey.co.uk/NA18PAT/>.

Updated information sheets: Download information sheets at <https://www.mndassociation.org/about-mnd/information-resources/> or order copies from the care admin team by calling 01604 611685 or by emailing careadmin@mndassociation.org. 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.

1D – How we use your information. Following the introduction of the General Data Protection Regulation (GDPR) earlier this year, the Association has revised sheet 1D. It details why the MND Association asks for information from the people we support, and how it is used.

6B – Complementary Therapies. This sheet describes a range of complementary therapies and why they may be beneficial for some people with motor neurone disease or Kennedy's disease and their carers. It is important to take advice from your GP or consultant before trying any complementary therapies to ensure they are suitable and will not affect any current treatment. All therapy should be provided by an experienced, registered therapist.

10C – Disabled Facilities Grants. This sheet provides guidance on how and when to apply for a Disabled Facilities Grant (DFG) and other benefits regarding housing.

New bereavement booklet launched called 'Finding your way with bereavement', replaces the earlier information sheet. The content is based on feedback from volunteers and supporters and it features images and lots of quotes from people affected by motor neurone disease.

A new voice and message banking animation has been released, called 'What is voice and message banking?' It provides an audio-visual introduction to voice banking and message banking, and the differences between them. It also includes what to expect when going through the recording process. https://www.youtube.com/watch?time_continue=261&v=0WLs7iZuPNY

Changes to Quality of Life Grant: The Association offer support grants to people affected by motor neurone disease, which allow families to benefit from financial support. Until recently the limit for a Quality of Life application was £1,000. In order to continue supporting more families the limit has been reduced to £500. More information about the types of grants available and who is able to apply for them is available on the national office website at <https://www.mndassociation.org/getting-support/financial-support-information-for-people-with-mnd/>

Could you join the Information Review Group? The Association is looking for people affected by MND, to volunteer to join the Information Review Group. The group looks at drafts of MND Association information, then provides anonymous feedback to help shape publications before publication. This helps ensure information resources are fit for purpose. Members can choose the type and number of projects they take on. If you are able to help please get in contact by emailing volunteering@mndassociation.org or calling 01604 611797.

Campaigns

Scrap 6 Months campaign update: A lot has happened since the Campaigns team launched the Scrap 6 Months campaign in June 2018. The campaign aims to ensure ALL people with MND can claim benefits using the fast track process, also known as the Special Rules for Terminal Illness (SRTI). The SRTI application route is available for Employment and Support Allowance, Personal Independence Payment, Attendance Allowance and Universal Credit. It allows claimants to be awarded benefits quickly without the need to fill in a long form, attend a face-to-face assessment or have an inappropriate conversation with a work coach.



Under SRTI people's application for disability benefits can be fast-tracked if their GP, consultant or specialist nurse completes a form (DS1500) confirming there is a 'reasonable expectation of death within six months'. MND is a complex condition and it is almost impossible to give such a precise life expectancy. If strictly interpreted this would exclude many people living with motor neurone disease, hence the need to [Scrap6Months](#).

In July 2018, Madeleine Moon MP the chair of the All-Party Parliamentary Group on MND, presented her Access to Welfare (Terminal Illness Definition) Bill 2017-19. The Bill seeks to replace the current definition with a clinical judgment by an appropriate health professional.

In the run-up to the second reading of the bill Madeleine Moon MP, wrote a backbench letter to the Minister at the Department of Work and Pensions seeking Government support for her bill. You can read the letter and see the 125 MPs who signed at <https://www.mndassociation.org/wp-content/uploads/Backbench-Letter-Final-with-signatures.pdf>. Note that a number of our local MPs were not able to sign as they sit on the front benches.

A parliamentary drop-in event was arranged for 13 November to raise awareness of the bill and to gather government support ahead of the Second Reading of the Bill. Fifty-two MPs attended and, although Peter Aldous was the only MP from our region to attend, a number of local MPs expressed interest in the campaign and have asked Sue Heal, as Campaigns Contact, to keep them updated on the progress of the bill.

Thank you to everyone who emailed their MP asking them to sign the letter or sent a postcard inviting them to the drop-in event, your actions demonstrate local support for the campaign.

Sue Heal wrote to MPs to share the results of an independent poll of 1,001 GPs across the UK in October 2018. It was commissioned by the Association and shows support for a change to the definition of terminal illness for the purpose of accessing benefits.

The polling found that:

- * 51% of GPs supported a change of definition of terminal illness for claiming benefits under the Special Rules for Terminal Illness, with only 12% disagreeing with the change
- * 12% of GPs were not aware that a DS1500 form (for confirming a terminal illness) could be used for conditions other than cancer
- * Only 5% of GPs said that it is always clear when to sign a DS1500 form for their patients; the figure was 7% for consultants

In addition, a group of 30 neurologists was consulted for their views on the proposed change, and 71% expressed support for a change to the current definition of terminal illness.

This information was sent to the EDP with a draft press release. We are grateful to Geraldine Scott for talking with Martin Burnell (who is living with MND) and publishing an article raising many of the key issues surrounding the campaign. We were delighted that she was able to obtain a quote from a Department of Work and Pensions spokesman. <https://www.edp24.co.uk/news/health/terminally-ill-lowestoft-man-told-he-was-fit-to-work-1-5786397>. The article appeared in the Daily Mirror giving national exposure to the campaign: <https://www.mirror.co.uk/news/uk-news/father-five-terminal-motor-neurone-13617046?>

On 23 November, the second reading of the Bill was rescheduled for 25 January. This was disappointing but not unexpected as many debates had been scheduled for the same day. Wishing to maintain the momentum of the campaign, the Association sent a letter to Amber Rudd, Secretary of State at the Department for Work and Pensions, urging the Government to look urgently at the issue of a change in the law so that everyone with a terminal illness can access welfare benefits quickly, and sensitively. A procedural error meant that the second reading didn't happen in January and we are waiting for a new date to be confirmed.

The House of Commons Work and Pensions Select Committee published a report on Universal Credit in December 2018, which recommended that the Government adopt the change proposed by Madeleine Moon's Bill. The report states: 'We recommend the Department adopt the approach taken in the Social Security Act (Scotland 2018) in determining who can use the SRTI. This would permit claimants to use SRTI if: "It is the clinical judgement of a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death".'(page 28). The MND Association's evidence was widely quoted on pages 27 to 29 of the report. The full report can be accessed at <https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/1770/1770.pdf>.

It is crucial that we continue to keep the pressure on and demonstrate to the Government that there is strong support within the MND and other terminal illnesses community for a change in the law. In December, the campaigns team launched a petition calling on the Government to change the law defining a terminal illness by removing the six-month time limit for the SRTI fast track process. Please support us by signing the petition at <http://bit.ly/S6Mpetition>. Members will have received a copy of the paper petition sheet in the January 2019 edition of Thumb Print. Please encourage everyone you know to sign the petition too.

Michael's story, a video, was launched last month showing why our Scrap6Months campaign is so important for people with MND and their families. You can find the link on our Facebook page (February 12). Together with Marie Curie the petition has been signed by nearly ten thousand supporters, many of whom want us to keep in touch with them about our campaigning activities. Thank you to everyone who has already signed the petition and shared it.



Champion the Charter: Norfolk Clinical Commissioning Groups across Norfolk adopt the MND Charter by Sue Heal

In July 2017, Malcolm Chubbock, Branch Chair, and I attended a public Q&A session organised by Healthwatch Norfolk focussing on the local Sustainability and Transformation Plan (STP). I asked, 'Can you confirm services for people with neurological disorders such as motor neurone disease are being included in the STP process? How do you intend to improve these services?' After the meeting we spoke with members of the panel, including Melanie Craig CO NHS Great Yarmouth & Waveney CCG, who sounded quite agreeable to supporting the MND Charter. She nominated Dr Mark Lim, who is the Programme Director for Clinical Commissioning at Great Yarmouth & Waveney CCG, to present the charter to the STP Clinical Care Reference Group.

Working alongside our local RCDA, Lindsay Goward, we met with Dr Lim in March 2018. By May, we had jointly authored a paper for the Planned & Unplanned Care Clinical Network Meeting outlining the background to the Charter, provision of support offered by the local Branch of the MND Association and referencing the new Norfolk MND Care and Research Network. The paper identified priorities for the CCGs if they signed the Charter. It contained anonymised case studies illustrating occasions where delays in diagnosis, provision of equipment or appropriate care packages had caused problems.

In June, we presented the paper to the Network meeting, chaired by Dr Linda Hunter (pictured on the right). We were interrogated by GPs and other health professionals in attendance. One GP suggested we should ask to bring MND into line with local Cancer provision, meaning that a referral from a GP querying a diagnosis of MND should result in a consultation with a neurologist within two weeks. Our presentation was well received; we were asked if we wished to present a second paper to CCGs and we accepted.

A second paper was written and submitted to the Joint Strategic Commissioning Committee (JSCC) and presented to the JSCC in October. We were grateful to Melanie Craig (pictured on the left) for sponsoring our paper, and for her continued interest in the campaign. The five CCGs voted unanimously to support the Charter. They agreed specific areas of action; to support in raising awareness of MND amongst professionals – including promotion of the Red Flag Tool to aid diagnosis;



to promote the Association's educational resources amongst Health and Social Care Professionals; to be mindful of the rapid decline associated with MND during discharge and provision of end of life services; to raise awareness of the Norfolk MND Care and Research Network and the importance of GPs working in partnership with it; to support coordination between relevant specialities. We had been advised not mention the two week window from referral to consultant, but it was raised by a Committee member before the final vote; everyone agreed that this should be their goal. We hope to see tangible benefits as a result of the Charter's adoption, and will maintain the relationships forged throughout the campaign.

Helen Copsey, Dr Mamutse, Jean Lindsay and Sue Heal have accepted an invitation to a meeting of the Planned & Unplanned Care Clinical Network to discuss the information to be circulated to GPs and referral advice.

Norfolk Care Consultation

Norfolk County Council (NCC) wrote to people who might be affected by a proposed change to their charging policy for Adult Social Care. They asked them to complete a questionnaire to indicate their views on the changes by 23 December; a member alerted Sue Heal to the consultation. The proposal was to use lower rates of Minimum Income Guarantee for people of working age (no change for people over 65) and to take the enhanced rate of the daily living component of the Personal Independence Payment into account. This would not impact on everyone but could increase the amount people were asked to pay towards their care.

Sue, Lindsay Goward and Helen Riley (Local Campaigns Coordinator East) discussed the Association's position taking into account the views of the policy team at National Office before submitting a response. We acknowledged the significant financial pressures being faced by County Councils leading to difficult financial decisions and understood that the proposals contained within NCC's consultation were in line with the Care Act, and recognised that other local councils have made similar changes. However, we presented a reasoned argument showing how the proposals, if enacted, would negatively and disproportionately impact on people living with and affected by severely disabling conditions such as MND.

The results of the consultation were presented to the Adult Social Care Committee in March. They can be viewed in summary form on page 130 or in full in Appendix 1 page 137, by following the link to the committee papers at <http://norfolkcc.cmis.uk.com/norfolkcc/Meetings/tabid/128/ctl/ViewMeetingPublic/mid/496/Meeting/1442/Committee/10/Default.aspx>. An overwhelming number of responses to the consultation were against the proposed changes. The Adult Social Care Committee voted in support of changes to the way NCC charges for adult social care, with expected savings of £4m. It was agreed to phase in the changes. The proposed changes were reported on by the EDP at <https://www.edp24.co.uk/news/politics/norfolk-council-considers-care-charge-change-1-5842752> and the meeting at <https://www.edp24.co.uk/news/politics/norfolk-county-council-social-care-charge-changes-agreed-1-5850833>.

Please continue to let us know if there are issues that we need to address collectively.

On 17 October 2018, the All-Party Parliamentary Group (APPG) on MND met to discuss MND research.

Dr Brian Dickie, MND Association Research Director, spoke to MPs about the research funded by the Association (currently £15 million covering 92 research grants), and the annual International Symposium on ALS/MND, organised by the Association. On the plus side he highlighted the Association's strong track record of supporting clinical and healthcare research. However, he called for greater government support to increase research capacity within the UK health system to sustain the increased number and complexity of emerging treatment trials.

Chris Shaw, Professor of Neurology and Neurogenetics at King's College London, spoke about genetics and MND. He suggested that gene therapy offers future hope for people affected by MND, this follows the establishment of 'proof of principle' that motor neurones can be successfully targeted in research into the childhood condition, Spinal Muscular Atrophy.

Once again, thank you to everyone who emailed their MP about the meeting. Peter Aldous MP (Waveney) was one of the twenty-one MPs who attended.

Local MND Research Update *by Dr Ratko Radakovic*

The University of East Anglia MND research team would like to wish you a Happy New Year. The **CHANGE-MND study** has been recruiting people living with MND and their study partners for just over a year now; since January 2018.

In summary, **CHANGE-MND study** looks to determine the changes that may occur in everyday life, wellbeing, motivation, quality of life and functioning for people living with MND, as well as their study partners (carers, relatives or close friends). This study involves researchers visiting people living with MND and their study partners at their homes to take part in interviews and brief assessments of functioning. Following this initial visit, the researchers would follow-up and interview the participants every 3 months for up to a year. This research works closely with the MND Care and Research Network and is funded by the Motor Neurone Disease Association.

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

	Recruitment Progress	
	People Living with MND	Study Partners (carers/ relatives/ close friends)
Baseline visit	22	21
1 st Follow-up Visit (3 Months)	11	10
2 nd Follow-up Visit (6 Months)	7	6
3 rd Follow-up Visit (9 Months)	2	2

The **CHANGE-MND study** is still actively recruiting and more information can be found on the Norfolk, Norwich and Waveney Branch website under 'Local Research'.

If there is anyone interested in participating in the study please email mnd.research@uea.ac.uk. Alternatively call **01603 59 3259** or **01603 59 1441** (leaving a message, if necessary) and one of the research team will get back to you with further details about the study.

On behalf of all researchers, we would like to thank all the participants and their study partners for taking part in this study and for their continued interest in this research.

Research

If you want to get involved in research or read more about ongoing research there is always a wealth of reliable information at <https://www.mndassociation.org/research/>. If you wish to talk about getting involved you can contact the Research Development team on 01604 611880.

The information below is taken from the MND Monthly Research Newsletters and the MND Research blog <https://www.mndassociation.org/research/mnd-research-blog/>.

Results of Phase 2 trial of EPI-589 announced. Planning is underway for a placebo-controlled trial investigating BioElectron's new compound EPI-589 for its effectiveness in treating MND. EPI-589 targets specific enzymes involved in regulating inflammation. Results from the latest Phase 2A trial showed that the drug is safe and well-tolerated.

<https://www.prnewswire.com/news-releases/bioelectron-announces-positive-results-from-phase-2a-als-trial-300717511.html>

New protein found to be involved in MND/FTD. Researchers from King's College London found a new protein, karyopherin-A (KPNA), that is involved in the toxic process of protein accumulation and displacement in motor neurones in people with sporadic frontotemporal dementia (FTD) and C9orf72 related MND/FTD. This makes KPNA a new therapeutic target.

<https://academic.oup.com/brain/article/141/10/2908/5104292>

Repurposed cancer drug possible treatment for MND. A recent study suggests that PARP inhibitors, a type of drug used to treat ovarian and breast cancer, might be adapted to treat people with MND. Veliparib, a PARP inhibitor is being investigated. It reduced TDP-43 aggregates, seen in 97% of MND cases, in lab-grown cells and prevented motor neurone death in rats. These findings suggest that Veliparib, and perhaps other PARP inhibitors already on the market, could be studied as possible treatments for MND.

<https://alsnewstoday.com/2018/09/28/parp-inhibitor-treating-cancer-might-be-repurposed-for-als-study-suggests/>

A phase 1 trial of AT-1501, a new antibody is being conducted by the ALS Therapy Development Institute, based in the USA. The Institute has successfully administered a dose to the first participant. Research suggests that about 70% of people with MND have an immune response, and targeting this is important in developing treatments.

AT-1501 has been developed to 'damp down' the immune system in people with MND. The trial is designed to assess the safety of the drug and how well it is tolerated by looking at how it acts in the bodies of eight people living with MND and healthy volunteers.

<https://www.als.net/news/first-drug-candidate-from-als-therapy-development-institute-starts-clinical-trial/>

Biogen, a global biotechnology company, has acquired the rights to develop and market BIIB067 (also known as IONIS-SOD1RX) as a potential treatment for people with familial MND who carry SOD1 mutations. BIIB067 is an antisense therapy, that is a synthetic DNA molecule designed to bind to the SOD1 gene. It is believed to prevent the production of abnormal SOD1 protein, potentially slowing progression of the disease.

In pre-clinical studies, mice treated with BIIB067 maintained their weight significantly better and survived longer than those treated with a placebo. It also reversed neuromuscular damage caused by the toxic SOD1 protein, protected nerve-muscle connections and prevented nerve cell loss.

The current Phase 1 trial involves 70 people with confirmed SOD1 mutations. Preliminary data collected from twenty-two participants showed that three months treatment reduced SOD1 protein levels in the cerebrospinal fluid and slowed the progression of the disease compared to people who received a placebo. Biogen is now planning a larger clinical study.

<https://alsnewstoday.com/2018/12/07/biogen-acquires-full-rights-develop-market-als-therapy-biib067/>

Psychological stress not a risk factor for MND. A recent study suggests that psychological stress does not appear to be a risk factor in the development of MND. A research team in Australia conducted an online survey with 400 people living with MND and 450 people without the disease to see if those with the disease had been exposed to more potential stressors – no differences were found between the two groups.

<https://alsnewstoday.com/2018/10/04/psychological-stress-not-risk-factor-als-study/>

Microglial activity in MND. Researchers in Massachusetts propose that targeting immune checkpoints in microglia (immune system cells found in the brain), could reduce inflammation in MND. Microglia have three essential functions

- they sense change in their environment
- they promote neuronal well-being
- they provide protection to nerve cells.

Imbalance of these functions might cause or exacerbate neurodegeneration, while correcting this imbalance may be a potential mode for therapy.

<https://www.nature.com/articles/s41593-018-0242-x>

Organ-on-a-chip technology, in which diseases are analysed in tiny amounts of fluid, has revealed a new drug combination that may treat MND. Tatsuya Osaki and colleagues loaded a microfluidic chip (the device that allows for the analysis to be performed) with healthy muscle and motor neurones from a person with MND. When activated by light, the motor neurones affected by MND showed symptoms common to the disease – the healthy muscle did not. Rapamycin and bosutinib (drugs currently in clinical trials) were applied and helped recover muscle contraction and improve neuronal survival in this chip-based model of the disease.

<http://advances.sciencemag.org/content/4/10/eaat5847>

29th International Symposium on ALS/MND Glasgow 2018, catch up with all the latest-news and videos at <https://www.mndassociation.org/symposium/symposium-live/>.

Over the course of three days 1,200 delegates attended over 100 oral, and more than 450 poster presentations. I find it impossible to summarise all the information available, but have shared links to the blog posts that present highlights under a variety of headings on the Branch Facebook page. This includes the blog post **What's the story with CuATSM?** which considered a flood of news stories on the outcomes of the Australian Phase 1 clinical trial investigating Copper ATSM (CuATSM) which is a small man-made compound that can selectively deliver copper to cells. The reported Phase 1 trial was only designed to test the safety and dosage of the compound CuATSM, it is not yet at a stage where clinicians can prescribe it as a treatment. Although the headlines made this look like a very exciting breakthrough it is important to be a little cautious about reading too much into the data. The test was performed on a small number of people over a relatively short period of time with an open label study (one where participants knew they were taking the active substance). The next important stage is to perform the trial on a larger number of people and really see if it can alter the disease progression. A Phase 2 clinical trial is planned for later this year in Sydney and Melbourne.

Note CuATSM is a specialised compound and is not the same as taking copper supplements, which can be poisonous in high doses.

Item for sale

Wheelchair ramp 6 ft x 2ft 6. £100

L-shaped ramps as pictured are **free**, but dismantling and transport will need to be arranged. If you are interested please phone Christine on 01603 872831, or send an email to sueheal@btinternet.com who, with your permission, will pass on your details so that Christine can contact you directly.



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. Arrangements for collection of 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.

Suffolk drop-in support meetings 2019: People living with MND, families and professionals - all are welcome. Feeling isolated or unsure about support and services available? MND Association representatives and Nurse Specialists are usually on hand to advise over a cuppa. They also hope to have guest speakers throughout the year.

The **West Suffolk** support meetings are held in Hawstead Village Hall, The Green, Hawstead, IP29 5NP. They meet on Wednesdays as follows:

6 March 2-4pm for an Irish tea; 1 May 2-4pm for a Welsh tea; 3 July 2-4pm for an English cream tea; 4 September 2-4pm Harvest; 6 November 12-2pm for a Pumpkin lunch.

To note your intention to attend please email Wendy Pott on werpott@yahoo.com or contact West Suffolk Neurological Nurses, Nicky McGreavy or Sarah Ward on 01284 748848.

The **Ipswich** support meetings are held in The Atrium, St Elizabeth Hospice, Ipswich, IP3 8LX on Monday evenings between 5pm and 7pm on the following dates:

15 April 17 June 19 August 21 October 16 December

To note your intention to attend please contact Kate Barber on 01473 707962.

Suffolk MND Association contacts: Janet Oliver 01359 241084 and Liz Cooper 0345 375 1827. Suffolk Direct (for access to social care services) 0808 800 4005.

Branch News

Annual General Meeting: Sunday 7 April 2019 1:00pm – 5:00pm – the Annual General Meeting will be held at St Andrew's Eaton Church Hall, Church Lane, Norwich, NR4 6NW. We will be providing a hot lunch. Our guest speaker is Richard Cave who will be talking about voice banking.

Advance Notice of Open Meetings: Sunday 23 June 2019 Upton Village Hall, Cargate Lane, Norwich NR13 6AU and Sunday 17 November 2019 Wortwell Community Centre, Tunbeck Close, Wortwell, IP20 0HS.

Coffee mornings are informal gatherings for carers and people living with MND hosted by Association Visitors and Committee Members. Note there are no coffee mornings in December.

At Notcutts coffee shop: The next coffee morning will be held on Wednesday 20 March from 11:00am to 1:00pm. Refreshments can be purchased in the coffee shop.

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

2019 April 17	May 15	June 19	July 17
August 21	September 18	October 16	November 20

At the Cherry Lane Garden Centre: The next coffee morning will be held on Wednesday 27 March between 11:00am and 1:00pm. Refreshments can be purchased in the coffee shop.

Advance notice of future dates for Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU

2019 April 24	May 29	June 26	July 31
August 28	September 25	October 30	November 27

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)

Louisa's Facebook page: [@fundraising4MND](https://www.facebook.com/fundraising4MND)

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 **05 May 2019** for the next edition.

Useful Numbers

Regional	Care	Development	Advisers	share	an	email	address
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eastangliarcda@mndassociation.org
Norfolk – Lindsay Goward 03453 751829. Lindsay works Tuesday, Wednesday morning, Thursday, and Friday morning.

Suffolk – Liz Cooper 03453 751827. Liz works Monday and Wednesday

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

Care Service Navigators Trish Moore 07813 094 820 email trish.moore@mndassociation.org

Gill Newton 07810 750122 email 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 secretarymndanorfolkwaveney@gmail.com, or write to her at the address given on the back page or write to Norfolk, Norwich and Waveney Branch, c/o MND Association, PO Box 246, Northampton, NN1 2PR.*