Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter
Issue 88 June 2022

Sunday 13 March 2022 MND Association Charity Tattoo Day

The Deerheart Collective in Lowestoft organised an event with a difference to raise money for the Norfolk, Norwich and Waveney Branch of the MND Association. Their aim was to help provide support for local people living with MND. They planned to tattoo as many “Keep moving” tattoos as they could during the day, each for the price of £50.

There was no need to make an appointment, instead there was a steady supply of tea, coffee and cake to purchase throughout the day whilst people waited their turn. In addition they held a raffle with plenty of prizes – thank you to Lisa Wilson who delivered a large number of bottles, which had been donated to help raise funds for the branch, to add to the total!

According to Emily and Jay, who went to get their tattoos, it was an incredible turnout and people enjoyed being part of the Deerheart Collective event. Emily’s ankle and Jay’s hand tattoos are pictured on the right.

Unfortunately, the weather wasn’t great and there wasn’t as much foot traffic as hoped, however the tattooists kindly added in a few individuals who went in during the following week to get their tattoos! Martin, one of the tattooists said, “it was a great day, amazing atmosphere”. He also commented on the importance of hearing first hand about the experience of families who had lost loved ones to MND during the day.

The final amount raised on the day was a fantastic £3,234.73. Of this £666 was raised from an online raffle, which was donated straight to the MND Association – the remaining £2,568.73 was donated to the Branch. A huge thank you to Martin and all of the tattooists at the Deerheart Collective for their support. It is appreciated!

Sunday 10 April 2022 Brighton Marathon *by Lisa Wilson*

On Friday 8th April, I took a train journey to Brighton to take part in the Brighton Marathon on Sunday 10th April. This time I had a staunch supporter accompany me for the weekend who waved me off into the coloured corrals at the start line on Sunday. I am so glad that he was with me as he was completing his own marathon, clapping and cheering me on at miles 2, 6, 13, 18 and at the finish line. He also managed to track down a Belgian Bun for me, which I had been talking about ever since he told me watching me complete the marathon would be the cherry on the cake for him 2 months earlier. Good to receive a medal at the end, but more important was the sweet treat which he produced at the MND Charity tent!

The marathon started well, but due to difficulties with training I was struggling by mile 18 and ended up walking/running the rest of the route. This marathon was a lot harder for me than previous marathons, and my end time was 5.34.55 one hour and 10 minutes slower than my personal best. However, whilst completing those final miles, it brought to me how our mobility can be taken for granted until it is taken away from us. Nevertheless for me, I was lucky and able to put a spurt on as I got closer to the finish line.

Although the marathon was a struggle for me, I am now back in training for the Great North Run on 11th September. This time for the half marathon which takes place in Newcastle and, yet again, I will be running in aid of the MND Association, you can donate at https://www.justgiving.com/fundraising/lisa-wilson-greatnorthrun2022. There is no finish line until a cure.

Saturday 23 April 2022 North Walsham Rugby Football Club

Malcolm Chubbock, Branch Chair was invited to attend the last home game of the season at North Walsham Rugby Football Club when the Vikings were scheduled to play against Maidenhead. He was also invited to join them at their pre-match lunch.

Prior to each home game the North Walsham RFC host a lunch for members and guests and hold a raffle, with the profits going to a charity fund. The lucky recipients are advised at the end of the season – this year it was our branch, and Ashley Hicks contacted Malcolm to pass on the good news! The club is aware of the valuable support given by the Association to two of their members who lived with motor neurone disease. The club members are also aware of high profile rugby players such as Doddie Weir, Rob Burrows and Joost van der Westhuizen. The club was kind enough to spread awareness of the petition launched by Doddie Weir asking the Government for increased funding for urgent research into devastating motor neurone disease as part of our United to End MND campaign.

This year the club raised £3,000, which was transferred to our branch bank account a few days before the match. An official presentation took place on the pitch at half-time. Also present in the photo with Malcolm is Jeff Blackett, President of the Rugby Football Union based at Twickenham, Dave Horne, North Walsham Rugby Football Club President, Ashley Hicks, Director of Finance and Keith Jarvis, Charity Fundraiser. We are hugely grateful to everyone at North Walsham RFC for their generosity in helping raise such a wonderful sum in support of people living with motor neurone disease.

It was a good day for the club too, the final score was Vikings 52, Maidenhead 22 providing a great end to a successful season. Malcolm said, it seems probable that the Vikings will be promoted to the next tier of rugby, which would mean promotion two years in a row – but the RFU won't confirm that until the Leagues are completed – we wish them well.

Sunday 24 April 2022 Branch AGM and Open Meeting

Malcolm Chubbock, Branch Chair began by welcoming everyone to the branch's 27th Annual General Meeting, and commenting that it was so nice to meet in person. We were joined by branch members and supporters, committee members, healthcare professionals, Association Visitors and Catherine Knights Association Trustee.

Malcolm encouraged those who were not members to join the Association and to take advantage of the benefits offered. If you are a non-member reading this you can find out more and join at https://www.mndassociation.org/get-involved/fundraising/become-a-member/. He then presented his annual report, which began with a brief account of our income and expenditure, the latter included £12,581 on patient care. Our branch members have also benefitted from generous funding towards equipment from MyName'5 Doddie Foundation, Darby Rimmer MND Foundation and Challenge MND.

Malcolm thanked everyone who raised funds, made donations or raised awareness of MND on behalf of the branch, before thanking the neurology nurse specialists who support families affected by MND, our Care Service Navigator and Association Visitors. He expressed our appreciation for the support given by the Norfolk MND Care and Research Network and the team at the Norfolk and Norwich University Hospital and University of East Anglia. We were delighted to be joined by Helen Copsey (MND Coordinator) and Emma Larner (MND Respiratory Physiotherapist), who both gave up their free time to join us.

Malcolm also thanked members of the committee for their contributions to the smooth running of the branch as we continued to adapt to new technologies to allow meetings to continue.

Sue Heal thanked Malcolm for all that he does for the Branch, and paid tribute to his mother Eileen who passed away peacefully earlier this year. Both Eileen and Bryan were staunch supporters of the branch and had been amazing fundraisers since the branch started in 1995.

Sue gave an update on the successes of our campaigns – Scrap 6 Months, United to End MND and Act to Adapt, though stressing that there were still areas needing further work! She thanked everyone who signed petitions, signed letters and wrote to their MPs. As always you can read more in the campaigns update section of Fightback.

Sue encouraged people to get involved by joining the Campaign Network https://www.mndassociation.org/get-involved/campaigning/join-us/campaign-network/. She also spoke of the cost of living crisis and asked people if they would consider signing a petition asking the Government to “Provide an energy grant to people with a disability or serious medical condition”. You can find the petition at https://petition.parliament.uk/petitions/610300 – please sign and swell the numbers!

The eight current members of the branch committee were re-elected en-bloc, though Malcolm did ask people interested in joining the committee to speak with him – there is always plenty to do and you will meet with a warm welcome!

After any other business and questions we paused for a delicious lunch prepared by Kelda’s Kitchen. Lunch was followed by tea, coffee and chocolate, and time for some socialising.

Malcolm spoke briefly after lunch to give an update on our strong start to fundraising this year with some fantastic events, which you can read about on our News page if you have not already read the last edition of Fightback. However, he did give some idea of the impact the pandemic has had on fundraising; in 2019 the amount raised was £31,000 but for 2020 and 2021 it was £19,000 and £5,000 respectively.

The guest speaker, Catherine Knights, MND Association Trustee gave an insight into what led her to get involved with MND Association and an insight into the role of a Trustee. It was clear that whilst it is a lot of work, it is also a very rewarding role and we thank her for taking it on and sharing her experiences. Catherine then took questions and comments.

Of course, no open meeting would be complete without the raffle, which raised £120. As usual there were some excellent prizes on offer. Sale of merchandise raised £63.46. Our thanks to everyone who attended, bought raffle tickets and merchandise, and helped organise, set up and clear away at the end of the meeting.

Saturday 21 and 28 May 2022 Garden Plant Sale

On Saturday 21 May, Margaret and Peter Goldsmith opened their garden in Norwich to sell plants from 9am until 4pm. They raised around £840 from the sale of plants. This was a wonderful total, but there were still plants left at the end of the day and they very kindly offered us a second opportunity to go and buy plants the following Saturday to raise even more money to support the work of our branch. The grand total from the two days was £1,045 for which we are extremely grateful.

Saturday 28 May 2022 A special afternoon cream tea in aid of the branch

This was a ticket only event with two sessions to cater for up to 80 people. In addition to the delicious tea there was a stall full of home bakes and craft items. For £1 a ticket the tombola raffle offered good value with fabulous prizes to be won. We are very grateful to everyone who made the event possible pictured from left to right – Jude Heinrich (wearing the MND t-shirt), Jan Molyneux, Jan Sears, Eileen Keeble, Barbara Booth, Jan Amiss, Corinne Riddle Croft and Maureen Morgan. And of course our thanks go to everyone who attended and helped raise the amazing sum of £801.85.

Friday 17 June Blofield Football Club cheque presentation

A charity football match was held on 7 May pitting a team of 1st team and reserve players versus the Jubilee Sunday team (with rolling substitutes). All players paid a donation to play with a qualified league referee officiating. Any player receiving a yellow card had to pay £10 towards the funds. A tombola and raffle added to the money raised.

A total of £1,100 was raised on the day with 50% being donated to Addenbrooke's hospital. An additional £5 was donated to MND Association making a grand total of £555 to support the work of our branch.

Malcolm Chubbock, Branch Chair, pictured on the right, attended a cheque presentation on Friday 17 June. He is joined in the photo by Patrick Murphy on the left hand side, a former player for Blofield FC, who is living with MND; Liz Sturman who organised the fundraising (and whose son was cared for by Addenbrooke's) and Paul Warman, Blofield FC player and former captain.

Future events in aid of the Association

Thursday 7 July 2022 Wymondham U3A coffee morning

You are invited to join the Wymondham U3A coffee mornings on Thursday 7 July between 10am and 12 noon in Wymondham Central Hall, Back Lane, Wymondham, NR18 0QB. There is paid parking in the car park behind Central Hall. It is a wheelchair accessible venue.

The Wymondham U3A support our branch and on this occasion members will be baking the cakes! There is a small entry charge of 50p to cover tea/coffee. The branch will have merchandise for sale, a sweepstake and quiz. In the afternoon there will be a talk "Medieval graffiti". Entry is free to members with a small cost to non-members. For more information or to donate prizes 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 is an annual fixture to raise money for local and national charities. This well recognised day is also supported by golfers from other clubs in Norfolk. Bawburgh Golf Club have already received generous donations of vouchers to play golf at prestigious golf clubs in Norfolk, which will raise money through a silent auction. Whilst the primary focus of the fundraising is the Norfolk, Norwich and Waveney Branch a proportion of the money raised will be donated to Bawburgh School to help fund replacement outdoor play equipment.

Teams of 4 players will pay £200 for the round which also includes breakfast and a BBQ after the round of golf. This is set to be a well attended event – by 5 June, sixteen teams had entered, spread the word and see if we can bring the number to the maximum of thirty.

If you would like to enter a team of four or sponsor a tee, £50 - £100 (holes 1, 9 and 18; £100 each) 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 golf@bawburgh.com or telephone 01603 740404.

If you are able provide further prizes for the silent auction or the raffle please contact our Care Service Navigator Trish trish.moore@mndassociation.org or phone 07813 094820 urgently!

Sunday 7 August 2022 Hoveton Village Charity Fete

The Hoveton and Wroxham Lions Club are organising a Charity Fete which they hope will be fun for all the family, with 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 stall should be clearly visible with our new tear-drop banners. We will have Association merchandise for sale and a guess the name of the eagle competition.

We are still looking for volunteers on the day, please contact Grace if you can help; contact her by email at mnda.norfolkwaveney@gmail.com or by phone (not mornings) on 07587 175141.

Sunday 2 October 2022 TCS London Marathon

Helen Sia and Darren Millard are running the London Marathon this year. You can read their stories and add to their sponsorship totals at:

https://www.justgiving.com/fundraising/darren-millard

https://www.justgiving.com/fundraising/helen-sia

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

- Anonymous donations - £80
- Copperfield Lodge, donation - £1,000
- Memories Never Disappear Agnes concert - £7,078.88
- TM collection box - £31.62
- TM collection box - £51.19
- PG Donation - £220
- Woodside W.I. Thorpe St Andrew collection after talk - £100
- National Service (RAF) Association Norfolk Branch - £50
- Drayton Post Office collection box - £101.60
- Phoenix Ladies Circle - £40
- Eaton open meeting raffle - £120
- Sale of merchandise - £68.46

Donations in memory of

- Eileen Chubbock - £3,040

Internal transfers

- JustGiving - £980.37
- JustGiving Branch Emergency Funds page - £983.50
- Gift Aid - £1,926.62

We are extremely grateful for the donations totalling £64.64, 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.

A reminder – we are still recruiting volunteers!

Have you seen the banner in the June/July South Norwich edition of Village People? The cost was covered by an anonymous donor, and Village People did the art work on a no cost basis. Fortunately we now have Grace Fleming as membership and open meetings secretary and Emma Fawkes has become our minutes secretary.

We are seeking to recruit volunteers in Norfolk to join a small friendly team.

Secretary – Motor Neurone Disease - the role can be split into general, membership and meetings secretary - to suit the time you are able to give.

Volunteer Association Visitors (AVs) - will need to maintain contact with people living with MND, their families and carers. Training, induction and mentoring will be provided: travel/direct cost expenses are reimbursable.

Could you give your time to support people with MND? By donating your time, energy and skills you can make a real difference to the lives of people affected by MND. You would keep in touch regularly by phone, email, on-line or with visits. Timing is flexible, to suit you and the person you support.

Please get in touch with Malcolm, Branch Chair, on **01603 960206** or email **malchubbock@hotmail.co.uk** or visit **www.mndnorwichandwaveney.org.uk**

We are encouraging more people to volunteer with us as Association Visitors. You can find our more about the role and apply online at https://bit.ly/3bmUUtb. Training and induction will be provided and travel/direct cost expenses are reimbursable.

If you would like a poster to display then please contact liz.cooper@mndassociation.org or sueheal@btinternet.com who can send you a pdf. Or ask Sue to post you one or more posters – either A4 or A5.

Useful information

Priority Registers

- UK Power Networks https://www.ukpowernetworks.co.uk. In the event of a power cut call 105.
- Anglian Water https://www.anglianwater.co.uk/help-and-advice/water-care/priority-services/

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

The Norfolk Assistance Scheme helps people, regardless of their state of health, 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.

You can apply online at https://www.norfolk.gov.uk/care-support-and-health/support-for-living-independently/money-and-benefits/norfolk-assistance-scheme.

If you cannot complete an online application call 0344 800 8020.

Holiday Insurance Malcolm contacted MND Connect recently to ask if there were insurance companies who would cover people living with MND. They provided him with a copy of their travel insurance document, which includes details of companies who have been known to cover motor neurone disease. They do not make a recommendation for any of them and always suggest people try at least three before deciding who to use.

If you would like a copy of this document please contact Malcolm on 01603 960206 or email malchubbock@hotmail.co.uk or contact Connect directly on 0808 802 6262 or via email mndconnect@mndassociation.org. Do not hesitate to talk with your Association Visitor or Connect before contacting insurance companies and completing medical screening.

News from National Office

Care Information Update: Following on from holiday insurance, the Association has produced a new booklet bringing together all our content on driving, travel and holidays, in one simple resource. For more information visit: www.mndassociation.org/mobilty.

Our main guide to support carer wellbeing has been updated. You can find this resource and an interactive version at: www.mndassociation.org/carerguide.

You can find a range of information using the new search feature on the MND Association website. It is designed to help you find information by need and list resources by subject. See the Care information finder at www.mndassociation.org/careinfofinder.

Information sheets can be requested from the care admin team on 01604 611685 or by emailing careadmin@mndassociation.org. Alternatively they can be downloaded from https://www.mndassociation.org/about-mnd/information-resources/.

Fundraising News: If you would like to talk to someone about fundraising please phone 01604 611860. Alternatively there is information at https://www.mndassociation.org/get-involved/fundraising/.

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 if you are happy for us to share the news.

The Association regularly launches fundraising challenges. You can follow their social media to see what is new without signing up to a Facebook or Twitter account. https://www.facebook.com/mndassociation/ and https://twitter.com/mndassoc.

Updates from the Norfolk MND Care and Research Network

FACTOR-MND project continues recruiting. This research study, sponsored by the University of East Anglia, aims to understand better how the experience of being a family carer for someone living with MND impacts the carer’s wellbeing.

Current MND carers are invited to complete an online survey at https://uea.onlinesurveys.ac.uk/factor-mnd, or contact the researcher, Polly Trucco, for further information or to ask for a pen and paper packet to be sent (see contact details below).

To further investigate these factors, we are also inviting current carers to participate in an interview about the experiences of caring for the person they support and how they are coping with changes in the person they care for and in their daily routine. The interview will be held either face-to-face or online, for example using a platform like zoom, and will take approximately 30-90 minutes. If you wish to take part in this study, please contact Polly Trucco for further information.

We are happy to share that preliminary findings from 46 participants have been presented at The European Network for the Cure of ALS (ENCALS), in Edinburgh, between 1-3 June, 2022. The results provide a clearer understanding of the carers’ experience, which we hope will help us to better support carers of people living with MND in the future. Thank you to all the people who have already participated.

Contact details: Polly Trucco mnd.research@uea.ac.uk 07825 863 389. You can also follow @FactorMND on Twitter.

Campaigns

Carers Week 6-12 June: Carers Week is an annual campaign to raise awareness of caring, highlight the challenges unpaid carers face and recognise the contribution they make to families and communities throughout the UK. It also helps people who don't think of themselves as having caring responsibilities to identify as carers and access much-needed support. This year the theme was make caring Visible, Valued and Supported.

Ahead of Carers Week, Carers UK together with the MND Association, Age UK, Carers Trust, Oxfam GB, Rethink Mental Illness and Lewy Body Society called on friends and family to write to their MP to ask that they support carers. We are calling on the Government to back a Recovery and Respite Plan for Unpaid Carers. This will outline additional support for carers across a range of areas, including: breaks, respite and care services, infection control, identification of carers, financial help, and support to help people juggle work alongside their caring responsibilities.

We continue to urge people to write to their MP to back a Recovery and Respite Plan by using the template at https://carersuk.e-activist.com/page/105999/action/1. Thank you to everyone who has already written.

Leaders of the charities supporting Carers Week 2022 wrote to the Secretaries of State for Health and Social Care, Work and Pensions, Business, Energy and Industrial Strategy, Care and Mental Health, Disabled People, Health and Work and Small Business, Consumers and Labour Markets. The letter asked the Government to develop and publish a Recovery and Respite Plan for Unpaid Carers outlining immediate additional support for carers across a range of areas. They argued that doing so would recognise the vital role carers play in our society and economy, complement the Government’s other existing health and care strategies, and ensure carers get the support they need to continue caring safely and well.

There were two virtual events. Sue Heal attended the first, chaired by Helen Walker, Chief Executive of Carers UK, with Care Minister, Gillian Keegan MP. The second event with the Shadow Care Minister, Karin Smyth MP was attended by Subah who currently cares for her husband. We described, to the two MPs, issues including inadequate financial support offered to carers, a lack of respite and feelings of invisibility.

Lastly carers and representatives of the Association attended an in-person Parliamentary drop-in event where they spoke with 13 MPs and Peers including Duncan Baker MP for North Norfolk. George Freeman MP used his Facebook page to thank carers in his Mid-Norfolk constituency.

Social Care Isn’t Fixed: The social care system still remains in a state of crisis, with access, quality, and workforce issues stemming from chronic underfunding having led many individuals living with MND and other disabilities not receiving the support and services that they need in a timely manner.

The Care and Support Alliance (CSA) have launched a new campaign calling on the UK Government to address these fundamental problems. The CSA’s new campaign #SocialCareIsn’tFixed challenges the Government’s claim that the issues with the social care system are resolved, and now three years since PM Johnson’s speech where he promised to ‘fix social care – once and for all’, this action is more important than ever.

Do you think social care is fixed? Let us know by completing this mini survey at https://careandsupportalliance.e-activist.com/page/107342/survey/1.

#United2EndMND and Global MND Awareness Day: Over 11,000 emails were sent to Government Ministers Sajid Javid and Kwasi Kwarteng by supporters of the United to End MND campaign. The emails called on the Government to commit to a timeline to release the promised £50 million funding towards targeted MND research in the most efficient way possible, via a single application. Sue Heal wrote to George Freeman, her constituency MP. She asked him to use his experience as a former Life Sciences Minister with experience in the sector before entering Parliament, and his current position as a Parliamentary Under-Secretary of State for Science, Research and Innovation to support our position.

Peter Aldous MP for Waveney asked a written parliamentary question on our behalf. The question asked the "Secretary of State for Business, Energy and Industrial Strategy, what steps his Department is taking to reduce potential bureaucratic barriers for scientists wishing to access the £50 million funding for motor neurone disease research announced in November 2021?" George Freeman MP, answered "Funding for Motor Neurone Disease (MND) research is available now through applications to the National Institute for Health and Care Research (NIHR) and UK Research and Innovation (UKRI). The NIHR and UKRI are undertaking new activities to support the MND research community in effectively accessing funding. This includes a new £4.25 million MND partnership, which the government is delivering alongside charity partners, to pool expertise and resources across the research community to coordinate access to the committed funding."

Then on June 21, Global MND Awareness Day, we were pleased to read Life Arc's announcement of the start of the UK wide partnership to find a cure for MND!

They announced the award of a £4.25 million research grant that seeks to discover meaningful MND treatments within years, not decades. The grant has been awarded by charities Life Arc, MND Association, My Name'5 Doddie Foundation and MND Scotland, together with government research organisations Medical Research Council (MRC) and National Institute for Health and Care Research (NIHR).

You can read more of their announcement at https://www.lifearc.org/news/2022/new-4-25m-grant-collaborative-research-effort-to-end-mnd/.

The funding has been awarded to researchers from King's College London, University of Liverpool, University College London, University of Oxford and University of Edinburgh to establish a new UK-wide motor neurone disease partnership. The Research Blog explains how the £4.25 million will be used to accelerate the development of treatments for MND. https://mndresearch.blog/2022/06/21/global-mnd-awareness-day-celebrating-collaboration/.

PatientsUnited2EndMND described it as, "A significant step forward for the United to End MND campaign. Today's announcement of a £4.25m investment into MND research marks an important partnership between the UK's leading neuroscientists, charities and the Government's research funding councils in the fight to find effective treatments."

On Sunday 26 June, the Association confirmed that a solution has been agreed to enable researchers to access the £50 million funding committed by the government for MND research as reported in the Daily Express. Sally Light, MND Association CEO said, "We've been working hard to show the government that the current system – applying hundreds of times for small pots of money – will not accelerate progress in MND research, and we're pleased they have finally listened to our concerns."

Read more comment and analysis about the significance of these announcements at https://patientsunited2endmnd.org/2022/06/21/announcement/.

Update on the Scrap6Months campaign: We are pleased that from 4 April 2022, fast-track access to Universal Credit and Employment and Support Allowance has been extended. This means that more people will be eligible to claim using the Special Rules to provide a faster simpler route to access benefits.

As announced during the Queen's Speech, the UK Government is set to expand access to all three remaining benefits, Personal Independence Payment (PIP), Disability Living Allowance (DLA), and Attendance Allowance (AA), across England and Wales. The first reading took place on 11 May, the second on 24 May. On 22 June we were pleased to hear that the Social Security Bill has now passed through the House of Lords, we are now hoping that it will be passed quickly in the House of Commons.

Thank you to everyone who has supported this campaign since it launched in June 2018.

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
Access to home adaptations for people with motor neurone disease

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

We are pleased to see the Government has published new guidance for Disabled Facilities Grants (DFG) delivery, including the Act to Adapt campaign's two main asks as examples of good practice by councils under a specific section highlighting MND.

- Some local authorities include provisions within their policy, such as: a fast-track process with no means testing for works up to £5,000

- Ignoring the earnings of the person with MND in the means test where larger scale works are assessed as being necessary and appropriate.

This comes after the Association participated in stakeholder discussions last year with the Department for Levelling Up, Housing and Communities on the development of the guidance.

Cost of living crisis: Please sign the petition asking the Government to "Provide an energy grant to people with a disability or serious medical condition". Millions of UK citizens have a disability or serious medical condition that means they use more energy. https://petition.parliament.uk/petitions/610300.

NHS Continuing Healthcare: This item also appeared in the last edition of Fightback. 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. Work is already underway to review the information that we provide and the ways in which it can be more widely publicised both for people living with MND and health and social care professionals.. We are also looking at ways in which people might best be supported during the application process. We continue to work closely with the Continuing Healthcare Alliance and other charities.

Spotlight on Campaigning: April's Association Podcast, MND Matters Episode 14 took as its title, *How campaigning works*. This episode features Andrew Lewer MBE MP, chair of the All-Party Parliamentary Group on MND, who discusses how he raises the profile of MND in Parliament. He shares his views on the importance of campaigning and how it can help people living with MND. Branch Campaigns Contact, Sue Heal talks about how she got involved in MND campaigning and now raises awareness of MND locally and nationally. Nicola Waters, a member of the Patients United 2 End MND group, who is living with MND, discusses her experiences of campaigning and influencing decision makers for others living with MND.

From signing petitions, writing letters and emails, meeting your MP or councillor, to knocking on the door of 10 Downing Street there are lots of different ways to get involved. If you would like to keep up to date with our campaigns you can join the Campaign Network at https://www.mndassociation.org/get-involved/campaigning/join-us/campaign-network/.

The podcast aims to share experiences, offer informal advice and support, and raise awareness of a variety of issues. You can search MND Matters in your chosen podcast provider's list or access episodes at https://www.mndassociation.org/media/mnd-matters/.

Research *by Aidan Nicholson*

Therapy

Treg Therapy ALS001 Found to Ease Oxidative Stress in Early Trial – April 2022

In a recent small early trial in America, treatment with a new therapy called ALS001 for MND was shown to reduce markers of oxidative stress, a type of cell damage and inflammation. Due to its successes in Phase 1 trials, it is now being evaluated in a Phase 2 trial. This new treatment comes from a type of novel therapy called regulatory T-cell or 'Treg' therapy. Tregs are an immune cell that normally helps to reduce inflammation and promote tissue repair. ALS001 involves isolating Tregs from an individual, growing out more Tregs in a lab and then infusing the cells back into the person. With more trials and data it is hoped this new type of therapy will become more mainstream and be effective for use in people with MND.

See more at: https://alsnewstoday.com/news-posts/2022/05/02/coya-treg-therapy-als001-als-reduces-inflammation-early-trial/

Patient Dosing Begins in Phase 2 of Oral HIMALAYA Trial – May 2022

Phase 2 trials have begun, evaluating the safety and effectiveness of the investigational oral therapy SAR443820 (AKA DNL788) in people with MND; 260 adults are being recruited at sites in the US and Europe including Plymouth in the UK. DNL788 is a small molecule that works by suppressing an enzyme called RIPK1 whose over-activation is associated with nerve cell death and abnormal microglia activity (microglia are the immune cells of the central nervous system). Suppressing RIPK1 was previously shown to ease disease progression in preclinical models in ALS, MS, and Alzheimer's. In the previous Phase 1 trial involving 14 healthy adults, three ascending doses of the medication were shown to be well tolerated and bound effectively to the RIPK1 enzyme.

See more at: https://alsnewstoday.com/news-posts/2022/05/10/patient-dosing-starts-phase-2-trial-oral-sar443820-als/

FOCUS-C9 Trial for C90rf72-MND is Recruiting in the UK – May 2022

A new experimental therapy called WVE-004 for people with MND associated with C90RF72 gene mutations has shown proof of concept efficacy in cell and animal models, a new study shows. The new therapy based around nucleic acid reduces the toxic RNA molecules and small proteins associated with C90RF72 mutations. This is of particular importance as the C90RF72 mutations are the most common genetic cause of MND, found in up to half of familial cases and up to one in ten sporadic cases. The FOCUS-C9 trial is recruiting adults, aged 18-80 at locations in Ireland, UK (London, Sheffield and Oxford), Netherlands, Canada, and Australia.

See more at: https://alsnewstoday.com/news-posts/2022/05/05/wave-life-als-therapy-demonstrates-proof-of-concept-preclinical-studies/

AMX0035 – The Potential Future of MND Treatment – May 2022

AMX0035 is a medication made up of two compounds, TUDCA (tauroursodeoxycholic acid) and PB (sodium phenylbutyrate). TUDCA is thought to block key cell death pathways increasing the threshold for cell death whilst PB reduces stress on the endoplasmic reticulum in cells increasing survivability. Overall, the combination of the two is thought to improve the survivability of motor neurons, the specialised cells which are the targets of MND. Many trials have occurred testing the suitability of AMX0035 as a treatment for MND. Most recently in June of this year Canada approved AMX0035 as treatment for MND but is dependent on the ongoing Phase 3 PHOENIX trials.

See more at: https://www.mndassociation.org/research/clinical-trials/treatment-trials/amx0035/ and https://www.mndassociation.org/research/clinical-trials/treatment-trials/amx0035/

Biogen's Tofersen Trial: The Open Label Extension Data – June 2022

Tofersen is a treatment called antisense oligonucleotides (ASO) which target specific genes thought to cause MND – in this case the SOD1 genetic mutation. More specifically it acts by stopping the production of abnormal SOD1 proteins toxic to motor neurons. Many clinical trials have shown the efficacy and safety of the potential treatment.

Most recently the results of Biogen's phase 3 clinical trials have been presented at a conference in Scotland. An earlier clinical trial (called VALOR), where two groups of participants took the medication or placebo for 6 months, showed no difference in MND progression whilst taking the medication. However, it did show that Tofersen reduced the amount of SOD1 protein and that genetic markers of the condition were reduced. Following these encouraging findings an open label extension phase, where all participants regardless of original group took the medication and were monitored for 52 weeks. The new data presented in Edinburgh led to 'cautious optimism that the treatment may be effective if given for a longer time'. In summary, the results of the extension showed Tofersen reduced SOD1 protein levels and these stayed reduced over the 52 weeks. Neurofilament light chain levels in the blood (a potential MND biomarker) were reduced. Participants who took Tofersen at the very start of the trial lived longer than those who started taking Tofersen during the extension phase. These findings are extremely promising and hopefully will encourage further research into the use of Tofersen as a treatment for MND and for additional genetic therapies.

ATLAS, a Phase 3 clinical trial of Tofersen, has begun recruiting in the U.S., Japan and some of Europe. The trial is currently in preparation in the UK, the Association will provide updates.

See more at: https://mndresearch.blog/2022/06/10/valor-biogens-tofersen-trial-a-look-at-the-open-label-extension-data/

Aetiology

Environmental Exposure and MND Risk – April 2022

New studies are being done to establish the cause-and-effect relationships between environmental and occupational exposures with MND to identify risk factors and hopefully prevent the development of MND. Crucial to the new studies is the understanding of the 'MND exposome', defined as the effect of environmental exposures (e.g., pesticides, pollutants) and the corresponding biological responses across a person's lifespan. When combined with genetic mutations making a person more vulnerable to developing MND, the MND exposome may trigger neurodegeneration.

Pollutants such as organochlorine pesticides have already been shown to increase the risk of MND. They were banned in the 1980s, but can remain in the environment from decades to hundreds of years. The key focus of current research is to understand air pollution's role in the MND exposome which will help build a body of evidence proving a cause-and-effect relationship between environmental risks and MND prevalence.

See more at: https://alsnewstoday.com/news-posts/2022/04/28/aan-2022-how-environmental-exposure-affects-als-disease-risk/

Biomarkers Measuring Changes in Speech in the TARGET ALS Trial – May 2022

A new study based in Arizona is asking people with MND and their family members or friends to participate in a biomarker study aiming to create a bank of biological samples and clinical data collected over time. This data will then be made readily available to the scientific community to further the understanding of how MND progresses and how best to treat it. The study is expecting to collect samples (blood, urine, cerebrospinal fluid, speech records and lung measures) from at least 200 MND patients and 80 healthy individuals over five years. Of significance is the correlation between early symptoms such as vocal problems and disease biomarkers. The researchers will collect voice samples which will be recorded at home on a special app, and some participants will also record at-home measurements of their vital capacity (a test that measures how much air can be breathed out in one forced breath.

See more at: https://alsnewstoday.com/news-posts/2022/05/24/als-biomarkers-study-open-patients-healthy-family-friends/

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.

Peer-to-peer support research trial: Researchers from King's College London are still looking for participants to take part in a clinical trial which aims to test a new online peer-to-peer support programme for carers of people living with MND. They are looking for current caregivers and peer supporters who have had experience caring for someone with MND. Peer supporters will receive training on how to provide one-on-one support, whilst current caregivers will either receive the virtual peer-to-peer support or be directed to educational resources.

For more information contact ella.terblanche@kcl.ac.uk.

Online research pages: Find the most up to date research news at https://www.mndassociation.org/research/latest-news/

Find information on MND clinical trials, including the latest news, recruitment status, outcomes at https://www.mndassociation.org/research/clinical-trials/treatment-trials/.

Alternatively phone the Research Development team on 01604 611880 where you can ask about opportunities to get involved.

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, **excluding September**. 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: 20 July 17 August Not September! 19 October 16 November

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

Coffee mornings at Notcutts, Daniels Road, Norwich, Norfolk, NR4 6QP, from 11:00-13:00 on the following Wednesdays. These informal gatherings are hosted by Malcolm, Sue and others, for people with MND, their carers and friends.

Dates for 2022: 13 July 24 August 21 September 12 October 23 November

Coffee mornings at Fritton Village Hall, Hill House, Beccles Rd, Fritton, Great Yarmouth NR31 9HB from 11:00-13:00 on the following Wednesdays. These informal gatherings are hosted by Judy and Colleen for people with MND, their carers and friends.

Dates for 2022: 27 July 31 August 28 September 26 October 30 November

Hopefully we will not need to cancel any meetings due to COVID-19 or other circumstances; updates will appear on https://www.mndnorwichandwaveney.org.uk/events.htm. There is no need to let us know you are coming to the coffee mornings.

Evening online support group for carers of people with MND. These meetings take place on the last Wednesday of the month at 6:30pm. If you would like to be emailed the zoom link please contact alli.anthony@mndassociation.org or carmen.brown@mndassociation.org.

Dates for 2022: 27 July 31 August 28 September 30 November

Daytime online support group for carers of people with MND. These meetings are run by one of our Area Support Coordinators, you are invited to join a virtual cuppa for a 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 11:00am. For more information and to receive the zoom link please contact ahmed.abdeldayem@mndassociation.org.

Dates for 2022: 5 July 2 August 6 September 4 October 1 November 6 December

Daytime online for all affected by MND. An informal meet up to share your story, ideas and meet others living with and affected by MND in the South East Region. Meetings take place on the third Tuesday of each month from 11:00 – 12:30. For more information and joining detail, please contact liz.cooper@mndassociation.org or dawn.pond@mndassociation.org.

Dates for 2022: 19 July 16 August 20 September 18 October 15 November 20 December

Under 50s Group. These meetings are for people with MND under 50 and their loved ones. This friendly group provides an opportunity to meet others in a similar position, exchange information and share knowledge. Meetings take place on Zoom every 4th Tuesday of the month at 6:30pm. For more information and joining details, please contact ahmed.abdeldayem@mndassociation.org or david.whalley@mndassociation.org

Dates for 2022: 26 July 23 August 27 September 25 October 22 November 13 December

Branch News

AGM and Open Meeting: Sunday 24 July 2022, 13:00 – 16:00 at Upton Village Hall, Cargate Lane, Norwich, NR13 6AU. We will be providing a light lunch. We are also looking forward to "An afternoon with Joyce Grenfell" introducing a number of Joyce's characters. As always we will hold a raffle and have Association merchandise for sale. We look forward to an afternoon of socialising and laughter – with good food!

Advance Notice of Open Meeting: 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 **Twitter:**@MNDANorWave
Instagram:@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 **26 September 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.*