

Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter
Issue 86 October 2021

Sunday 29 August 2021 Charity Garden and Petite Craft Fair, Thurning Hall

On 29 August, Jo, Sue and Malcolm arrived at 9am to begin setting up the Branch stall in the beautiful gardens at Thurning Hall – we were soon joined by Judy, Trish and Sandi. The craft stalls supporting the event provided a showcase for the work of local artisans selling their homemade wares from pottery, to wood work, quirky plant holders with plants, bead work and wax melts to mention just a few.



The gardens opened at 10:30am to welcome 250 ticket holders and guests. Lara, second from right, and her team managed the car park, entrance, track and trace, and gave out leaflets raising awareness of MND and our need for Association Visitors. Collection buckets were available so that guests could make donations – we received £159.99. Money raised from the sale of tickets after the major expenses had been met – costs levied by Eventbrite and the hire of portaloos – was a fantastic £1,035.



Refreshments were available for purchase throughout the day – teas, coffees, hot chocolate and carrot cake, and from the bar something a little stronger. At the end of the day the Sunset Cafe made a donation of £50 to the Branch.

The raffle raised £255, with the first prize being the beautiful double quilt that had been donated to the Branch. The quilt had a history, a lady living with MND started the quilt, but sadly died before it was finished – the work was taken on and completed by the local quilting group. We were delighted to be joined by a member of the group who also volunteered to help us on the day together with her husband.

We held a silent auction for a Norwich City Shirt, which raised £125. It too had a history, having been given as a birthday present to a gentleman living with MND. His widow generously donated the shirt to us with the wish that it be offered for auction to raise funds in support of the work of our Branch.

The sale of merchandise raised £205.30. Possibly the most popular item was the MND Association koala, though we also sold some early Christmas cards!

Sue created the rota for the day and wishes to thank everyone who volunteered to help either on the stall or as stewards helping people navigate the one-way system around the beautiful gardens – Judy, Christine, Anne, Malcolm, Judith, Alan, Monica, Michael and Trish M. Special thanks to Jo, Trish and Sandi who were also there all day. Trish summed it up when she said, “What a great day, it was lovely seeing you all.” It was our first in-person



event since the start of the pandemic in 2020. It was a very happy event in wonderful surroundings providing an opportunity to meet up and to make new friends. We were also lucky with the weather, the rain waited until we had packed up at the end of the day.



We are extremely grateful to Lara Lacey, pictured on the right drawing the raffle tickets, and her mother, for opening their gardens in support of the Norfolk, Norwich and Waveney Branch of the MND Association and making everything possible. We appreciate just how much extra work the pandemic created behind the scenes; thank you – it is appreciated.

There was a personal reason for organising this event and supporting the Branch, a much loved close relative was diagnosed with motor neurone disease in 2018. A moving tribute to Jake was published in the EDP earlier this year <https://www.edp24.co.uk/news/jake-van-poortvliet-holt-rugby-player-tribute-8151928>.

Other events in aid of the MND Association

Saturday 21 August Open Garden Cawston

We are very grateful to Tina and Tim Macdonald who opened their garden to visitors in support of the MND Association. Tim's Uncle John died of motor neurone disease; Tim said his Uncle was a lovely man who never complained even when the disease meant that his body would not do as he wanted it to.



Local businesses donated raffle prizes including a mega hydrangea from the Woodgate Nursery, Cawston

Road and a £25 voucher from the Marsham Arms. Tim and Tina added a £25 garden voucher.

Cake and a cuppa were available, or a beer for those who preferred, for a small donation. The event raised £250 for the branch.

Trish Bates, our treasurer, visited the gardens and took some photos. The wooden owl in the photo came from Uncle John's garden.

Sunday 12 September, Lisa's Great North Run Half Marathon

Lisa travelled to Newcastle by train on Friday 10 in readiness for the Great North Run, a half marathon, on Sunday. The photo shows Lisa at the start and then at the end of the race with the shirt and medal. She finished in 2 hours 27 minutes and 9 seconds, 27 minutes longer than her personal best, but still an amazing achievement. Lisa was pleased considering that a demanding full-time job leaves little time for training.



The organisers planned a one-off new route for 2021 in order to ensure safety for social distancing. It started and finished in Newcastle with runners crossing the Tyne Bridge twice. Runners who had previously run the race said it was tougher than previous

years, especially as the end towards the finish line on the Town Moor was not downhill to the usual finish line.



In Lisa's words, "the atmosphere was great and the constant calling out to each other as MND runners either overtook each other, or were on opposite sides, along with the crowd cheering us on, offering sweets to keep us going and the kids holding hands out to high five us was memorable." For Lisa, "the hardest point for me was the usual cross over the finish line, knowing that Steve was not there to greet me as he always did in the past". Fortunately her friend Pat, who was unable to run through injury, was on the end of the phone as Steve would have been for the last mile.

Lisa had been planning to take part in Endure24, but the team entry has been deferred until 2022. Her next venture is the Brighton Marathon next April with training beginning in a couple of weeks.

If you would like to sponsor Lisa please visit her just giving page at <https://www.justgiving.com/fundraising/greatnorthrun2020>.

Sunday 3 October 2021 The London Marathon

The 2021 London Marathon was scheduled to be the 41st running of the annual marathon. COVID-19 resulted in the race being postponed from April until October to maximise the chances of a mass participation event. This year's London Marathon saw up to 50,000 people run a course that spanned Greenwich to The Mall – including Duncan Baker MP for North Norfolk, and a further 50,000 took part in a "virtual marathon" around the world!

Duncan Baker's London Marathon 2021

On Sunday 3 October, Duncan Baker MP ran 26 miles to raise £26,000 for 26 charities chosen by the residents of North Norfolk. On Friday 9 July, during a live draw, the MND Association was chosen for mile 10. All of the charitable organisations that he is supporting are either based in North Norfolk or operate projects and programmes in the constituency. He is working with the Norfolk Community Foundation, who will receive all donations on his behalf and ensure they are distributed to the 26 charities once he has completed the marathon. To donate visit uk.virginmoneygiving.com/DuncanBakerMP. As of 30 September he had raised £25,847.91, much of it from writing to businesses in the constituency and talking to people directly about his goals.

Duncan hosted an online chat with representatives of each of the charities on his Facebook page. Mile 10 featured on his Facebook page on 15 September; you can watch Sue and Judy in conversation with Duncan shared to the Branch Facebook page the same day <https://www.facebook.com/MNDANorwichWaveney>.

We thank Duncan for his fundraising support for the Branch and support for our campaigns.

Future events in aid of the Association

Helen's London Marathon 2 October 2022 by Helen Sia

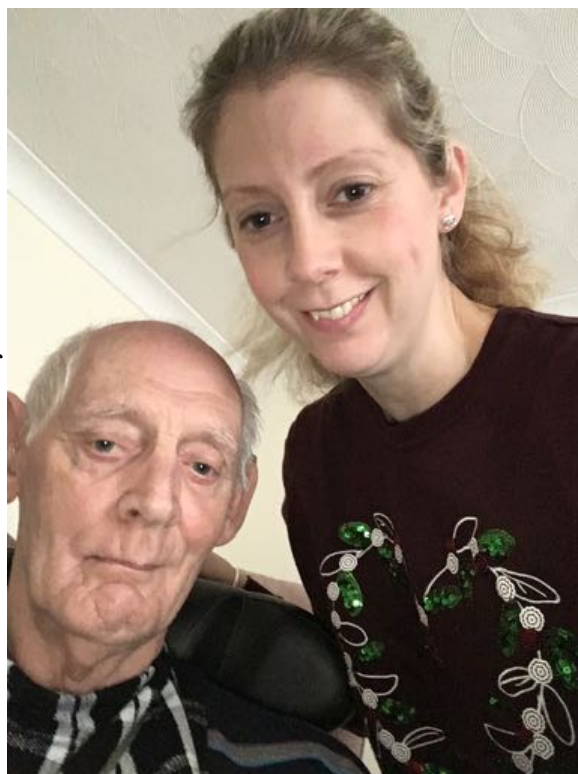
I am running the London Marathon 2022 in my memory of my Dad, Dave Bonney who sadly passed away from MND in May 2019. My Dad bravely battled with MND for nearly two years and he fought to the end. My Dad was a strong, stubborn man who thought that MND was an inconvenience that he had to put up with and that got in the way of the things he really wanted to do – go on holiday, potter around the garden, fix things in the garage and most importantly spend time with his family, his two grandchildren in particular.

I first decided to run the London Marathon for the MND Association shortly after his diagnosis but sadly didn't get a place. After a couple more attempts I got the phone call I was waiting for – an offer of a charity place! And so the training has begun, using my local streets and parks I'm slowly building up the miles. When I'm back home in North Walsham I find running around the local area a comfort as I remember the walks we used to go on together and I always make a point of visiting a boat my Dad restored as part of a local charity. I hope that I can use some of the strength that my Dad had to get me through the Marathon and raise as much money as I can for the MND Association.

www.justgiving.com/Helen-Sia

The photo on the right shows Dave Bonney with Helen, Christmas 2018. Bottom left Helen during a training run in Dave's home town of North Walsham next to a flower planter boat that he restored for North Walsham in Bloom – known to her children as 'Grandad's boat'. Bottom Right Helen after a training run.

We wish Helen well in her training, and thank her for running to support the Association.



Thursday 7 October Wymondham U3A coffee morning

Wymondham U3A will be holding a coffee morning between 10:00 and 12:00 in Wymondham Central Hall, Back Lane, Wymondham, NR18 0QB. Sue Heal will host a stall selling Association merchandise and Christmas cards and be on hand to answer questions about motor neurone disease and the work of the branch.

A reminder – we are still recruiting volunteers!

We included an A5 poster with the last edition of Fightback. If you know of any community newsletters who might be prepared to support us please contact our Area Support Coordinator liz.cooper@mndassociation.org. If you haven't used the poster yet it is not too late – please:

- Put it up on a local noticeboard? Perhaps in your local supermarket, library, community noticeboard, GP surgery or staff noticeboard at work.
- Request additional posters so that you can put up more or pass them on to family, friends or colleagues to put up.

If you would like to print more copies of the poster please email sueheal@btinternet.com or liz.cooper@mndassociation.org who can send you a pdf. Or ask Sue to post you some more.

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

Committee Members: If you are interested in joining our committee please contact liz.cooper@mndassociation.org or phone 01604 800620. We are a friendly bunch and look forward to welcoming you! We meet online every six weeks on a Tuesday evening starting at 6:30pm; meetings are usually finished in under two hours.

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

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

- Anonymous donations - £60
- Ian Summers, proceeds of coffee morning in his garden - £90
- Christine Widdows, collection box - £12.41
- Eileen Chubbock, sale of garden produce - £41.18
- Diana Buckingham, donation in memory of her husband, Geoff - £30
- Judy Burns-Thomson, proceeds of garage sale - £260
- Donations from Blofield Football Club - £150
- Berenice Groves, sponsor money from her Run21 in memory of her father - £167
- Cawston Triples Bowls League, President's chosen charity - £1,100
- RPJ, donations in memory of Jane Arming - £70
- CFA Sainsbury's - £836.11
- Emergency fund - £255
- Donations in memory of Mrs Laura Mary Lofting - £145
- David Siggins - £80
- Internal transfers
- JustGiving - £25

We are extremely grateful for the donations totalling £20.62, 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.

AmazonSmile: The MND Association received a quarterly donation of £3,307.73 from AmazonSmile thanks to customers shopping at smile.amazon.co.uk or with AmazonSmile turned ON in the app. If you would usually use Amazon then please support the MND Association at no extra cost to you by shopping at [https://smile.amazon.co.uk/](http://smile.amazon.co.uk/).

Thank you for collecting EDP tokens! After weeks of people collecting Cash For Charities tokens from the EDP - 172,544 in total – the £20,000 has been shared across 163 charities in Norfolk and Suffolk. Norfolk, Norwich and Waveney Branch supporters collected 910 tokens, and we received £105.48. You can read more about the scheme at <https://www.edp24.co.uk/news/cash-for-charities-winners-revealed-8291608>.

Eliel Community First Revenue Fund: The Norfolk, Norwich and Waveney Branch was delighted to receive a very generous donation of £500 from the Eliel Community First Revenue Fund supported by Norfolk Community Foundation. This money is available to help fund the operational costs of the branch as we seek to support those living with MND, their family and carers.

Norfolk Community Foundation is an independent, registered charity that bridges the gap between those in need and those who can help. As part of a national movement of Community Foundations, Norfolk Community Foundation is working together with local philanthropists to make a difference to lives in Norfolk www.norfolkfoundation.com.



News from National Office

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

Fundraising News: If you are interested in organising a fundraising event or simply raising some funds there is information at <https://www.mndassociation.org/get-involved/fundraising/>.

If you would like to talk to someone about your fundraising please phone 01604 611860.

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

Benefits Advice Service: 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.

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

You can make a difference to our MND Association information content, from the comfort of home. All you need is internet access, with an email account.

We'd love to welcome you to our User Review Group, if you are:

- living with motor neurone disease (MND) or Kennedy's disease
- an unpaid carer, former carer or family member providing support.

What happens if I join? Once you've given consent for us to use your feedback, you'll be asked for input to new projects and major revisions, or to review drafts as these become available. You choose tasks as convenient to you and respond through short, easy surveys.

You can directly influence our content and even share your experience in anonymous quotes to help others affected by the disease. Your invaluable insight can genuinely make a difference, to help improve our wide range of award-winning print and digital resources.

To join or find out more, email: infofeedback@mndassociation.org. Thank you!

Campaigns

#United2EndMND: The United2EndMND research petition closed on 6 July with 110,700 signatures. Thank you to everyone who signed, shared and promoted it.

The petitions committee scheduled a Westminster Hall debate on MND research in Parliament on 12 July led by SNP MP Martyn Day. Twelve politicians from across the political spectrum emphasised that the figures often cited by the Government for MND research represents a broad spectrum of neurological research, often with no tangible link to MND. They made clear that a boost to MND research makes practical economic and humanitarian sense. Five of the MPs who contributed to the debate shared their personal connection to MND. At the end the then Care Minister, Helen Whately, committed to further meetings with the United to End MND coalition – MND Association, MND Scotland and My Name's Doddie Foundation. We hope this commitment will be honoured by the new Care Minister, Gillian Keegan MP, appointed on 16 September.

The debate is available on Youtube at <https://www.youtube.com/watch?v=SgE1JfFr120> or as a transcript at [https://hansard.parliament.uk/Commons/2021-07-12/debates/04DC38FB-44C5-4876-BE27-4531040E8228/MotorNeuroneDisease\(Research\)](https://hansard.parliament.uk/Commons/2021-07-12/debates/04DC38FB-44C5-4876-BE27-4531040E8228/MotorNeuroneDisease(Research)).

On July 12, a Spending Review bid was submitted to the Government. It urges the Government to ring-fence £50 million over five years, in the spending review expected towards the end of the year from Chancellor Rishi Sunak. The money would be used to establish an MND Translational Research Institute.

Campaigns Contact, Sue Heal, wrote to MPs George Freeman, Duncan Baker, James Wild, Jerome Mayhew and Peter Aldous with a summary of the Spending Review bid asking them to write to Sajid Javid MP in support of our bid. A number of replies were received from Lord Bethell, Parliamentary Under-Secretary of State for Innovation. His response cited figures for Government expenditure on MND Research that included generic neurological research. At present it is believed the Government invests less than £5m a year in targeted MND research, which is less than that invested by charities.

Sue had a letter published in the EDP on Monday 13 September under the headline *Join our campaign to fight MND*, which encouraged people to join the #United2EndMND campaign.

Sue also wrote to a number of MPs asking them if they would submit questions to BEIS (Business, Energy and Industrial Strategy) calling on the Government to invest £50 million in MND research.

Whilst their questions were not chosen it was encouraging to hear similar questions during oral questions on 21 September. Martyn Day MP asked: "... Will the Secretary of State now commit to support this spending review bid?" Jason McCartney MP and Karl Turner MP both asked the question "If his Department will increase spending on research into motor neurone disease." Jason McCartney also asked: "...Will the minister please commit to meeting the MND Association to discuss this funding proposal further." Karl Turner made the point that "we need to act now, Minister, now to increase research funding into this devastating debilitating and life limiting disease." In response to each question Kwasi Kwarteng, the Secretary of State for Business, Energy and Industrial Strategy referenced £15.9 million spent over the last fiscal year by UK Research and Innovation on MND research and funds provided for charities supporting medical research. More positively he agreed to a meeting with the #United2EndMND consortium.

Christine Jardine MP drew attention to the need for **targeted** research. She said: “He has already mentioned the research, but the key to the £50 million over five years is that it is not spread over other research—it is completely targeted on motor neurone disease. Will he take that to the Government and bear that in mind please?”

On the same day, two high profile sports personalities, Stephen Darby, former professional footballer and former Leeds Rhinos player, Rob Burrow, delivered a patient letter to 10 Downing Street. The patient letter, signed by around 400 people living with MND – including several living in Norfolk, asked the Government for increased targeted funding into motor neurone disease research. Rugby union legend, Doddie Weir, was supposed to join them, but had been pinged by the Covid App and had to self isolate!

The hand-in was a great opportunity to attract media attention and keep momentum up for the United to End MND campaign. The event was timed to happen ahead of the Spending Review (27 October) to try to influence the Government to listen to our call for increased funding for targeted MND research. The activity was reflected on our branch social media.

You can read more about the day at <https://www.mndassociation.org/rugby-legend-rob-burrow-and-former-footballer-stephen-darby-take-call-for-research-funding-to-no-10/>.

For more information on the United To End MND campaign please visit <https://www.mndassociation.org/get-involved/campaigning/take-action/united-to-end-mnd/>.

Update on the Scrap6Months campaign: After three years of campaigning by the MND Association, we have secured a victory! The UK Government has listened and is set to scrap the unfair six-month rule barring many terminally ill people from fast track access to benefits.

As many of you will know, the Special Rules for Terminal Illness (SRTI) process is the fast-track pathway for claiming benefits, meaning people do not have to go through a long and stressful assessment. In response to the Scrap 6 Months campaign led by the MND Association and Marie Curie, the UK Government has pledged to expand the SRTI criteria from 6 months to 12 months. This will make it easier for people with a terminal illness (including those with MND) to access the support they need quickly and easily.

The announcement on 8 July is welcome, however, we will continue to put pressure on the Government to ensure the rules are changed at the earliest possible opportunity. We will also campaign for further improvements to support people living with MND. We would like the Government to address our call for the end of the maximum 3-year award length, and replace it with a lifetime award with the possibility of a light touch review after 10 years. For those who have faced the requirement to reapply for their benefits after three years we recognise the need for a dedicated helpline for those who are able to use the SRTI.

The success of the campaign was reported in the Eastern Daily Press: <https://www.edp24.co.uk/news/health/norfolk-campaigners-hail-benefits-victory-for-terminally-ill-8135206>.

See more at: <https://www.mndassociation.org/scrap-6-months-campaign-victory/>



Act to Adapt: In September last year we launched our Act to Adapt campaign to push for accessible homes and a fairer and faster system for delivering housing adaptations for people with MND.

The aims of the campaign in England are 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

Since the campaign launched, we've raised awareness of the challenges that people with MND face. However, a year on, councils are still failing to provide the support they need. Recent data received from councils in England in response to a Freedom of Information request shows that there is still significant variation in the quality of support available across the country.

Phase 2 of the Act to Adapt campaign, launched on 30 September, includes an interactive Act to Adapt housing map providing easy access to the information. Find out what the adaptations process is like in your area and if your council is meeting the housing needs of people with MND. Most local councils in the Norfolk gave information about their adaptations process, we are still waiting for Breckland and King's Lynn and West Norfolk to respond.

Access the map at: <https://ecampaigns.mndassociation.org/page/88773/action/1>

Please use the associated e-action to contact your councillors, share this information and invite them to our councillor event on 16 November. This virtual event will set out what still needs to be done to make lives better for people with MND who must adapt their homes or move to accessible housing.

Please continue to share your experience of accessing home adaptations by visiting <https://www.mndassociation.org/get-involved/campaigning/take-action/act-to-adapt/>.

“Keep Your Promise Boris”: As members of the Care & Support Alliance the Association asked supporters to take part in the “Keep Your Promise Boris” campaign. The campaign asked PM Boris Johnson to honour his manifesto promise to fix the social care crisis – as we read often in the press there are funding pressures and workforce shortages. Sue Heal emailed eight of the Norfolk and Waveney MPs, Jane Lewis, Chair of the King's Lynn Support Group emailed the remaining two. Whilst we received replies it is clear there is still work to do.

You may have seen the Government recently announced its long-awaited plans to increase funding for social care and bring about wider reform. An increase to funding, which will be financed through a levy on National Insurance contributions, will see an extra £5.4 billion for Social Care over the next 3 years.

The Government also plans to change the way that individuals fund their care so that:

- No one in England will have to pay more than £86,000 in care costs over their lifetime
- The state will cover care costs for people with assets under £20,000
- People with assets between £20,000 and £100,000 will have to make a contribution to their care, but can also get means-tested support from the state.

The Government also plans to propose further reforms as part of a White Paper later this year looking at issues such as choice, integration and workforce. Whilst the announcements relating to social care are a start, a lot of the new funding will initially be directed to the NHS rather than social care, so there remains a need for new short-term funding. The proposals don't as yet address the level of unmet care needs, the quality of care or workforce conditions. Additionally the needs of unpaid carers have not been addressed.

As part of the Care and Support Alliance the Association will be looking at the reforms and continuing to pressure the Government for more immediate funding for social care.

NHS Continuing Healthcare (CHC) is a package of care arranged and funded by the NHS available to people who have been assessed as having a ‘primary health need’. To be eligible for NHS continuing healthcare, you must be assessed by a team of healthcare professionals. The team will look at all your care needs and relate them to: what help you need, how complex your needs are, how intense your needs can be and how unpredictable they are.

Your eligibility for NHS continuing healthcare depends on your assessed needs, and not on any particular diagnosis or condition. If awarded NHS CHC, you will be supported to plan your care. If your needs change then your eligibility for NHS CHC may change.

The Association is leading some work with the Continuing Healthcare Alliance; as always we are looking to improve people’s experience accessing care.

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>

Local MND Research Update

The FACTOR-MND project continues to recruit carers of people with motor neurone disease. *By Eneida Mioshi*

FACTOR-MND is a research project, sponsored by the University of East Anglia, aiming to understand factors affecting the wellbeing of carers of people with motor neurone disease.

Findings from this study will better inform future non-pharmacological interventions and enable tailored information for families, services, as well as training for Association Visitors and healthcare professionals. Your time will greatly contribute to this goal.

The research team is targeting MND family carers in this study. They must be a relative currently supporting someone diagnosed with motor neurone disease, have capacity to consent for themselves and be at least 18 years old. We are recruiting carers throughout the UK.

There are 82 questions in total which are mostly multiple choice, and some background questions. It is estimated that the survey takes 30 minutes to complete. All data will be anonymized.

There are two ways to complete this survey:

- ONLINE: via this weblink <https://uea.onlinesurveys.ac.uk/factor-mnd>
- PAPER AND PEN: questionnaires can be posted to the address of your preference, together with a pre-paid return envelope. Just email us on mnd.research@uea.ac.uk

If you would like more information or to ask for a pen and paper packet, you can either ...

- Email: mnd.research@uea.ac.uk
- Call on 07825 863389

Thank you for your support!

The Norfolk MND Care and Research Network continues to recruit people diagnosed with motor neurone disease to the MND Register. The MND Register provides a valuable database to collect and store information about every person with MND in England, Wales and Northern Ireland. It helps in the planning of care for people living with MND and tells researchers more about the causes of the disease.

<https://www.mndassociation.org/research/get-involved-in-research/mnd-register/>

Research *by Aidan Nicholson*

Therapy

Masitinib, recent trial shows that given early in ALS extends life – July 2021

Treatment with the investigational oral therapy masitinib can extend lifespan when given early during MND. Patients treated with masitinib lived about two years longer than those with a placebo. Results have shown that masitinib tended to be more effective in patients with relatively mild disease. In a study on patients with mild to moderate disease a treatment dose of masitinib led to longer median overall survival of 69 months compared to 44 months in a placebo group. Further analysis suggested that masitinib reduced can offer a substantial survival benefit when treatment starts before severe loss of functionality. Masitinib is designed to inhibit certain enzymes called tyrosine kinases, blocking the activity of several immune cells involved in inflammatory and neurodegenerative processes. In addition to MND, the drug is being evaluated as a potential candidate for the treatment of multiple sclerosis, Alzheimer's disease, asthma, COVID-19 and types of cancer.

See more at: <https://alsnewstoday.com/news-posts/2021/07/20/masitinib-early-use-extends-survival-phase-2-3-trial-analyses/>

Phase 3 Trial of Ultomiris brought to an early halt – August 2021

Alexion Pharmaceuticals is stopping further work on Ultomiris (ravulizumab) as a potential treatment of MND based on data from the CHAMPION-ALS Phase 3 clinical trial. This is due to a lack of Ultomiris's efficacy in a pre-specified interim analysis. No new safety concerns were identified, and the therapy's safety profile was consistent with that previously reported. Ultomiris is a monoclonal antibody designed to block the activity of complement protein 5, one of more than 20 blood proteins forming part of the body's complement immune system. The complement system enhances (or complements) the ability of the body's white blood cells to identify and neutralise potentially harmful bacteria and viruses entering the body. Ultomiris has been approved for use in two rare blood conditions caused by over-activation of the complement system. Uncontrolled complement system activation can trigger inflammation that can contribute to diseases such as MND. By suppressing the complement system, Ultomiris was thought to be able to reduce neuroinflammation and slow MND progression. However, although Ultomiris has been stopped, the C5 protein is still a target for future treatments to be developed.

See more at: <https://alsnewstoday.com/news-posts/2021/08/24/alexion-stopping-ultomiris-als-phase-3-trial-lack-benefit/>

Dosing of SLS-005 to begin in phase 2b/3 trial – August 2021 (America Based Trial)

A new Phase 2b/3 trial is testing experimental therapy SLS-005 (trehalose), designed to prevent protein clumping in cells, in adults with MND by the end of September. SLS-005 is administered directly into the bloodstream and consists of autophagy-promoting sugar molecules found in plants, fungi and bacteria called trehalose. Autophagy is the process by which cells breakdown and recycle old or damaged proteins/components they no longer need preventing their potentially toxic accumulation. MND is characterised by the toxic build-up of several proteins such as TDP-43 and SOD1 in nerve cells and preclinical studies have shown that SLS-005 promotes the clearance of these proteins, delaying MND progression and preserving motor neurons and muscle fibre size. Additionally, SLS-005 can cross the blood-brain barrier which is a highly selective membrane or covering around the brain that prevents circulating microbes and harmful molecules from reaching the central nervous system. The inability for therapies to pass the blood-brain barrier is a common obstacle that has been overcome with SLS-005.

The study is part of the HEALEY ALS Platform Trial led by Harvard Medical School located only in the US.

See more at: <https://alsnewstoday.com/news-posts/2021/08/12/seelos-sls-005-dosing-healey-als-platform-trial-arm-expected-start/>

Arthritis treatment eases MND inflammation in trial – August 2021

Actemra (tocilizumab), an approved treatment for rheumatoid arthritis, was found to be safe and well-tolerated to reduce a key marker of inflammation in MND patients with evidence of systemic inflammation in a Phase 2 study. The study's results did not demonstrate that Actemra could slow MND disability progression however these encouraging results have warranted a future larger trial to occur to find the potential benefits of this therapy in MND patients. Actemra is an injectable medication which reduces inflammation by blocking a protein called IL-6. Although it remains unclear whether inflammation plays a role in MND onset, it has a clear role in disease progression which makes anti-inflammatory therapies attractive approaches for treating MND. However, although theoretically Actemra should work in a Phase 2 study, researchers observed no clinical benefit when patients with MND used the treatment. However, researchers are further studying the results and the underpinning science in order to find a clinical use of this hopeful treatment.

See more at: <https://alsnewstoday.com/news-posts/2021/08/05/arthritis-therapy-actemra-eases-signs-inflammation-als-phase-2-trial/>

Aetiology

TP73 Identified as a new genetic risk of sporadic MND – August 2021

Rare mutations in the TP73 gene responsible for regulating a cell's life cycle, may put a person at greater risk of developing MND. This finding was discovered after a genetic analysis of nearly 2,900 sporadic MND patients and in analysis of zebrafish. TP73 is a family member of the tumour suppressor gene TP53 which provides the instructions to create p53, a protein. P53 has two main forms; TA-p53 and delta-N-p53. TA-p53 activates target genes that promote cell death. Delta-N-p53 suppresses both TA-p53 and p53 (the protein coded by TA-p53), which is also required to regulate cell division and death. In the nervous system, p53 is mainly present in its delta-N-p53 form which promotes nerve cell survival by preventing TA-p53 and p53-induced cell death. Researchers testing the mutations of TP73 found that the mutated delta-N-p53 protein could no longer bind to p53, being unable to prevent it from inducing cell death. However, by identifying the mutations as a risk factor it provides a new target for researchers to work on treatments to delay or stop MND.

See more at: <https://alsnewstoday.com/news-posts/2021/08/11/rare-mutations-tp73-gene-potential-risk-factor-sporadic-als/>

Cholesterol, TDP-43 and MND – August 2021

Recent studies report that cholesterol metabolism defects may account for some of the neurological damage that occurs in MND and other diseases which involve the protein TDP-43. As cholesterol is crucial to nerve cells, restoring its metabolism may be a new avenue for future MND treatments. Cholesterol is a fatty substance that is critical in many parts of the body, but of relevance to MND, cholesterol is the major component used to make myelin sheaths. These sheaths are a coating that wrap around nerve cells, helping send electrical signals more effectively, damage to this sheath can lead to neurological problems. In recent cell and mouse experiments, mutations in the TDP-43 gene were looked at in relation to its effect on oligodendrocytes. It was found that a lack of TDP-43 caused some of oligodendrocyte's gene expression to be turned off ultimately leading to neurological symptoms.

Oligodendrocytes are specialised central nervous system cells which create the myelin sheaths described above. Damage to these cells have been seen as the main cause of several conditions including multiple sclerosis (MS). In cell models, extra cholesterol given to TDP-43 deficient oligodendrocytes allowed them to make myelin more effectively. Therefore, via early identification of TDP-43 deficient oligodendrocytes and the development of cholesterol based new treatments, neurological symptoms of MND and other conditions can in theory be minimised.

See more at: <https://alsnewstoday.com/news-posts/2021/08/16/cholesterol-metabolism-impaired-tdp-43-protein-als-like-disorders/>

Take Part in Research

As part of an initiative to increase the opportunities for people with MND to get involved with research, the MND Association has created a website cataloguing all studies looking to recruit participants. The studies are not always to do with finding new treatments or the cure to MND with others focusing on improving wellbeing, understanding the cause of MND, improving diagnosis methods and more. Most studies are remote based so as long as you fulfil their inclusion criteria and have access to a device you should be able to get stuck in to the joint goal of researching and bettering the quality of life of all people affected by MND.

See more at: <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/>.

Alternatively to talk about getting involved phone the Research Development team on 01604 611880.

You can read more about opportunities to get involved in MND research locally at https://www.mndnorwichandwaveney.org.uk/local_research.htm.

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

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

We are hoping to introduce face to face coffee mornings at some point. Watch the website for details in the New Year.

- **Open online group for carers of people with MND.** The meetings take place on the first Thursday of the month at 11am, and are facilitated by MND Association staff and volunteers. Upcoming dates are 4 November and 2 December. Join on Zoom as follows: Meeting ID: 868 3154 7488 Passcode: 411744. For more information please contact liz.cooper@mndassociation.org.
- **East Region Get Together.** Monthly support on Zoom, these allow you to get peer support, connect with other people with MND and their families. The meetings take place on the third Tuesday of every month from 11:00-12:30. Next event dates are 19 October and 16 November. Meeting ID: 882 1929 8759 Passcode: 113926

Branch News

Save the date: Sunday 7 November 2021 12 noon - 3pm at Wortwell Community Centre, Tunbeck Close, Wortwell IP20 0HS. Everyone is invited to join us for lunch; there is a choice of three main courses served with creamed leeks and broccoli. Dessert, back by popular demand, is Meringue Roulade with rum soaked raisins, oranges in caramel. We will have a selection of Association merchandise and Christmas cards for sale. We would love to see you, but please let us know of your intention to attend. The idea is to have a relaxed social gathering, with the opportunity to meet friends new and old.

Advance Notice of Open Meetings: Usually we would be able to give a date and venue, but in the current climate feel that it is safer to announce this nearer the time. Watch the website!

Virtual Coffee mornings: for carers and people living with MND hosted by Judy and Sue. These are planned for the third Wednesday of each month starting at 11:30am and finishing around 1pm. Feel free to drop in and leave as you please, do not feel you must stay for an hour and a half.

Email judyburnsthomson@yahoo.com if you have not been sent the link by your Association Visitor or Care Service Navigator – or if you fancy joining us just to see what they are like – they are very friendly and relaxed events. Newcomers are always welcome!

Dates for 2021 are as follows: 20 October 17 November 15 December

An update with further dates will appear on the Branch website and in the next issue of Fightback. We will consider the advisability of meeting in person in the New Year.

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 **23 February 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 and together we will fight for our vision of a world free of MND.

Disclaimer. *The views expressed in this newsletter are not necessarily those of the MND Association. The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise. We would like to keep in contact with you about the important work we do. If you do not wish to receive further information, please contact judyburnsthomson@yahoo.com, or write to Norfolk, Norwich and Waveney Branch, c/o MND Association, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ.*