

# Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter  
Issue 79 May 2019

**Sunday 7 April 2019 AGM and Open Meeting at Eaton** by *Simon Perkin*



Despite torrential rain an hour or so before it was due to start, and some rural roads being made temporarily impassable due to flooding, our AGM and Spring Open Meeting at St Andrew's Church Hall in Eaton still managed to be well attended.

This year everyone was given a name badge when they arrived, which it was hoped would help ease interaction and let Branch members find out who they are talking to. Hopefully this worked, but if there were any issues, do let us know.

After everyone had arrived and partaken of teas and coffees, the meeting opened. All the necessary AGM business was taken care of in a very swift and efficient manner, as usual, by Malcolm Chubbock (Chair) and Helen Devlin (Secretary) with all the current Branch Committee members retaining their roles for 2019/20.

Lunch was then served, and any rumbling stomachs were amply silenced by a vast cold buffet spread, prepared and served by Eric from *The Butcher's Shop* in Swanton Morley. In fact, the spread was so vast that many attendees left the meeting with bulging doggy bags and even then, there was still plenty left over!

After lunch we had the raffle, with lots of lovely prizes supplied by generous members and friends of the Branch, which managed to generate a fabulous £130 for the Branch coffers.

This was followed by the presentation of three well deserved long service awards by Lindsay Goward, Regional Care Development Adviser, to Committee Members; Trish Bates, Judy Burns-Thompson and Sue Heal (see pictures). Without their tireless, compassionate and continuing commitment, the Norfolk, Norwich and Waveney Branch would grind to a halt!



There was then some additional time for mingling and catching up with old friends and new, as due to the inadequacies of the rail network, our guest speaker – Richard Cave, was unfortunately delayed. Luckily he emerged unscathed and we were all very grateful that he had managed to struggle in, despite the adverse travelling conditions, as his talk was on a topic that almost all those with involved with MND would find extremely relevant at some point in their MND journey.

Richard is the MND Speech and Language Therapist Project Manager at the MND Association (see picture on the right) and he spoke with great insight and substantial personal experience on the subject of voice banking.



Voice banking is the recording of a set list of phrases, whilst the person with MND is still able to speak (anywhere between 250 and 3500 phrases in fact, depending on the software used). These recordings are then converted to create a personal synthetic voice, that is a close, though not precise, replica of their own, to be used on voice synthesiser programs such as ‘Predictable’.

Richard’s talk centred on the differences between the competing systems currently available for people with MND. His tone was light and often amusing – using recordings of his own voice and some well-chosen football references to illustrate his points. There were also some very useful and pertinent questions from audience members, who either had just gone through or were considering going through the process. Richard was able to put across quite complex technical issues in an easily understandable fashion, and the feeling in the room was that we all came away much better informed about the pros and cons of each system and how they work. He also confirmed that funding is available for voice banking through the MND Association. There is plenty more information available on the Association website for those wishing to pursue this further.

Another genuine highlight of our AGM was a cheque presentation made by Steve Rowe (pictured on the right) to Branch Chair, Malcolm for £8,600.00. Belinda, Steve's wife, gave a very moving speech in which she spoke of attending open meetings with her late father, John Francis. She said that being amongst others facing the same difficulties in everyday life, he found the support and friendship from each and everyone involved with the Association invaluable. When Steve became the Men's Captain at Bungay and Waveney Golf Club, it was agreed that the Norfolk, Norwich and Waveney Branch of the MND Association would be his nominated charity.



Belinda went on to talk about the events that culminated in such a terrific amount of money being raised, including a marathon event, where Steve and the club professional Andrew Collison, played 72 holes of golf in a day, along with 4 other members who played one round each. They started at 05:30 and completed the session at 20:30 in the evening, covering around 26 miles each – quite a day by the sounds of it. Belinda was overwhelmed by the generosity of members and golfers who helped them exceed their own target.

By the time the meeting closed the weather was comparatively pleasant and hopefully everyone arrived home safe and sound. Many thanks to all those who helped set everything up for the meeting and then clear away afterwards – always very much appreciated.

## Events in aid of the MND Association

### Monday 25 February 2019 – Wymondham Lions Meeting

John Wilde, President of the Wymondham Lions, presented Sue Heal with a cheque for £250 for use by the Branch in support of people living with motor neurone disease. The Lions clubs support a range of good causes and charities. On this occasion Cllr Joe Mooney, a Wymondham Lion, nominated us for receipt of a donation. We are very grateful to the Lions for their generosity.

Whilst there Sue was given the opportunity to speak about the work of the Branch and our current campaign Scrap6Months. A number of those present were kind enough to sign our petition asking the government to change the law so that all people with MND are able to access benefits under the Special Rules for Terminal Illness.

### Sunday 10 March 2019 – Morrisons bucket collection

The bucket collection at Morrisons Catton branch raised £157. Our thanks to those who gave up time to collect and to raise awareness of motor neurone disease, and especially to Anne Gillett for organising the event.



## Saturday 27 April 2019 – The Highland Fling Ultra Marathon by Joe Gilbert

The Highland Fling is a fifty-three mile Ultra Marathon. It is one of the busiest and toughest ultra marathons in the UK, taking in steep climbs and tricky terrain. I, together with my running partner Eric, joined around 800 runners at the start line; over 150 did not finish, a record number, mostly due to the weather and terrain.

After a long drive the day before and a late night worrying and packing drop bags, the alarm was set for 04:20 – time to force down porridge and nerves before a 06:00 start. The forecast was for cold and rain all day, but it was dry for the start. A brief from the race director and we were off through Milnagavie town centre and then onto the start of the West Highland Way. The scenery was fantastic, initially following forest trails with runnable uphill and downhill. The first 8/9 miles were a dream, relatively flat paths and nice terrain. We were in good spirits, despite my gut issues and bad cramping.

After a kit check we started the uphill of Conic Hill. The sun disappeared and rain started, gradually at first, but as we went further up Conic Hill the rain was getting heavier and colder. Rain jackets were back on but we were already soaked through and cold. We ran as much of the uphill as we could until we hit the really steep slopes to the summit. Power walking replaced running and we both felt good. We hit the top of the hill at mile 18, absolutely soaked and freezing cold. The scenery was incredible despite the rain, Loch Lomond opened up in front of us. The descent started off quite runnable, but then got more gnarly, the rocks turning to large wet slab steps and everyone had to slow down to watch their footing. Once lower down the hill the terrain became more manageable and we pushed on to the next checkpoint. It was mile 20, and I was feeling good as I saw my wife and son waiting for us.

The next section included some really steep climbs, they were absolutely leg draining and kept coming – steep uphill after steep uphill. At this point I started having issues with my shoes, my right shoe was getting really loose and coupled with being so wet the sole was slipping forward on each descent – which made me feel panicky as I worried if my shoes would last to the end of the race. Yet, still we pushed on, running over beaches and more hills, the paths started to be replaced by roots, rocks and mud, and the terrain was starting to punish my legs. The rain was now really heavy and we were running through constant puddles. We reached Rowardennan at mile 27. I moved from sugary sweets to peanut butter sandwiches and Kendal Mint Cake. I put the next 20 miles or so down to Kendal Mint Cake and the sugar hit!



The next section was meant to be really technical, but I didn't know what to expect. We quickly found out – single file, large wet rocks and thin path made mostly from tree roots. We couldn't see what was coming up and followed the line of the runner ahead so as not to trip as we followed the path and ledges with a drop into the loch next to us. The only runnable paths we came across were long climbs, beyond anything we could train for in Cambridgeshire. We had to run-walk most of them, but the thin path, twists and turns, steps up and jumps down, river crossings and bridges were taking their toll. We had both picked up injuries!

Inversnaid came at mile 34 with fantastic views, incredible Marshals, more mint cake and peanut butter sandwiches for my bag – and off we went. The terrain was now getting ridiculously unrunnable. With big rocks to climb up using your hands and rocks to drop yourself down a large drop, and very stiff legs, this section wasn't about running, but finding the most efficient line through the terrain. The technical section went on for what felt like days and when we reached the end of the loch and roots and rocks turned back to grass, steep climbs and puddles I felt mentally and physically exhausted. We were in survival mode.

We emerged from the next checkpoint at 41 miles pretty shattered. Morale was low at this point. I was soaked through and absolutely freezing. We knew we had 7 miles of steep climbing. By now the paths were really muddy and flooded in many places. At one point I thought we had reached a dead end when we arrived at a waterfall, only to realise that it was the path but with water absolutely pouring down it from the top of the mountain. I just wanted to see Jess, my wife and son Leo and have a mental reset, but we were making slow progress. Our energy sapped and limping we were counting down the miles. Finally we came round a corner and I saw a marquee and lots of flags – it was the next checkpoint at mile 46. We both started running towards them. Something as simple as seeing a familiar face can brighten your mood, I was



in awe that they stood out in the soaking rain waiting. I left this checkpoint knowing I'd finish the race.



The next section was slow and this is where I really needed some motivation. I thought of my Mum with MND that I was fundraising for. I thought of my son's chuckle and of our holiday lined up. I thought of all my generous friends who had donated to my justgiving page. From here on I kept getting bursts of energy, or determination more like. I wanted to finish now and get in the car and warm up. We started running faster than we had for a long time, but the finish line wasn't getting any closer. A few last hills as a cruel punishment between us and the finish line to finish off our legs, we were forced to walk a few more times – and then I saw some marshals who told us the finish line was just 500 metres away. A bagpiper stood up when he saw us come round the corner and started to play and emotion came running through me. I had done it in 11 hours 24 minutes and 7 seconds, the toughest challenge in my life – with thanks to Jess and Eric for their support at every stage.

As of 4 May Joe had raised £1,903.75, if you would like to help him reach his target of £5,000 for MND Research visit <https://www.justgiving.com/fundraising/mndmum>.

## **Saturday 27 and Sunday 28 April 2019**

Jemima, John Newport and a team of hardy volunteers held a bucket collection at Notcutts Garden Centre in Norwich. John had been interviewed by Radio Norfolk ahead of the event. Several people at Notcutts said they had heard the early morning Radio Norfolk interview on Saturday. John also had an interview with Park Radio, Diss, on the following Monday. We are grateful to John for creating these opportunities to help raise awareness of MND. Despite the cold weather and plenty of rain all went well. We were delighted by people's generosity; a total of £466.04 was raised over the two days.

We are hoping that Jemima, John and a small team of volunteers will be equally successful when they hold a bucket collection at Thetford Garden Centre on Sunday 12 May.

## **Zoe Anderton's debut harp CD - 25% of sales go to Motor Neurone Disease Association**

Zoe Anderton's debut harp CD is raising money for the MND Association, donating 25% of the sale price of her CD in memory of her friend David, a Norfolk musician who died of MND in 2014. David was a member of our Branch and raised funds for us with a Round Britten quiz, reflecting his musical interests! Details on how to order the CD can be found at <http://www.zoeanderton.co.uk/cd.htm>.

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

### **12 June, Quiz night at Birkbeck Hall**

Brown & Co are hosting a quiz on June 12 at the Birkbeck Hall, Great Hospital, Bishopgate starting at 17:30 for 18:00 to raise money for the MND Association. Malcolm has been invited to say a few words at the start about motor neurone disease and the work of the Branch.

### **Saturday 15 June, 10.00 am – 12.45 pm Walk to D'feet MND**

The King's Lynn Fundraising Group have organised a Walk To D'feet MND. It isn't really a sponsored walk, its aim is to increase awareness of MND, so no preparation needed. Although of course they would never refuse sponsorship if someone arrives with donations! They would like to know in advance if you plan to join them so that they don't set off without you. Contact Julian Gamble, [linnet1968@gmail.com](mailto:linnet1968@gmail.com).

Meet at the King's Lynn Football Ground car park in Tennyson Road (PE30 5PB) at 10:00 to set off at 10:30. It is recommended that you arrive about 10:00 to park, not too early, due to parkrun beforehand. The route is an easy, flat, 4 mile circular walk via The Walks, London Road, the river, quay and through the town back to the Football Ground. Suitable for families and wheelchairs. T-shirts & balloons are provided!

### **21 June, Global MND Awareness Day**

Come and meet Jemima (pictured) and John outside The Forum in Norwich between 09:00 and 17:00 – she will be parked under the awning and adorned with MND Association bunting!

Sue and John have a permit from Norwich City Council to hold a bucket collection and will be raising awareness of motor neurone disease. We hope to see you there – if you would like to hold a bucket then please contact Sue Heal. We are inviting the newly elected Norwich City Councillors to come and spend some time with us – we will use the opportunity to talk to them about our new local campaign on housing.



As in previous years Norwich City Hall will be lit in blue and orange to mark the occasion, though being the longest day of the year the best view is always late in the evening after dark. Once again we are very grateful to the Culture and Events Officer at Norwich City Council for his support and for arranging the lights.

### **Saturday 22 June Plant Sale & Coffee Morning at The Scout Hut, Blakeney, NR25 7PG**

The King's Lynn Fundraising Group invite people to join them from 10:00 for teas, coffees, cakes and a raffle as well as hundreds of plants. The Scout Hut is next to the Village Hall at the junction of the A149 Coast Road with the B1156 Langham Road, adjacent to the car park (free parking). Contact Jane Lewis [janelewis321@btinternet.com](mailto:janelewis321@btinternet.com).

### **Sunday 28 July, 10:30 – 13:00, Bike for Brian, Watlington PE33 0HA**

The King's Lynn Fundraising group have organised an eight mile sponsored bike ride and invite members of the Branch to join them. It starts from The Angel, Watlington PE33 0HA and follows a pretty flat, family friendly, circular route on quiet roads via Magdalen, Stow Bridge and Runcton Holme. The entry fee of £5.00 includes an MND Association t-shirt and barbecue with hot dogs or burger afterwards. Registration from 10:00, ride begins at 11:00. Contact [janelewis321@btinternet.com](mailto:janelewis321@btinternet.com) 01263 740962, or [janet.walker16@btinternet.com](mailto:janet.walker16@btinternet.com).

### **August 2019 – Jemima's road trip West**

Plans continue to evolve for Jemima's road trip. Having brought Jemima to Norfolk for repairs and got her back on the road John Newport initially thought to drive her from John O'Groats to Land's End. However, although she is back on the road and is making short local trips, it has been decided that her age renders the long trip too much of a challenge. So after a summer focusing on fundraising for the Norfolk, Norwich and Waveney Branch, Jemima will be returning back from Norfolk to Wales and the home of John's friend Norman, a prominent barrister and vintage car enthusiast, who died of MND in 2016. If a minimum of £8,000 can be raised in sponsorship (to meet John's original fundraising target for MND research) and if an escort can be arranged, John would plan to drive Jemima back to Wales, hopefully collecting donations along the way. Otherwise, Jemima will be transported back home. John can be contacted on [jv.newport@btinternet.com](mailto:jv.newport@btinternet.com).

Read more at <https://www.mndassociation.org/get-involved/volunteering/volunteer-zone/news-2/jemima-the-car>, or follow her on Facebook <https://www.facebook.com/Jemimas-Challenge-for-MND-Research-325038154884021/>. To donate visit <https://www.justgiving.com/fundraising/John-Newport1?>

### **Sunday August 4, 12:00 – 23:00, Bannaroo festival 2019 at The Banningham Crown**

The Branch have accepted an invitation to host a stand at the festival. The Crown has very kindly offered to waive the usual charges and entry fees, and to provide volunteers with food on the day. We will sell Association merchandise to raise funds for the Branch and use the opportunity to raise awareness of MND and the work of the Association. Please contact Malcolm if you would like to help on the day.

The Crown describes itself as a traditional 17th Century timbered inn on Colby Road, Banningham, Norfolk, NR11 7DY – not far from the A140. It is hosting its second Bannaroo music festival with an amazing line up including *One Night of Queen* performed by Gary Mullen and the Works, for more details and to buy tickets visit <https://www.bannaroo.co.uk>.

### **Saturday 5 October MND Association Commemorative Service**

The Cambridgeshire Branch of the MND Association presents a multi-faith commemorative service and reception at Peterborough Cathedral to celebrate forty years of the Association.

The service starts at 16:00. The service is free, but there is a small charge of £10 per head for the reception, which includes a buffet and hot drinks. All tickets must be booked in advance, you can book your ticket by emailing Simon at [cambridge@mndassociation.org](mailto:cambridge@mndassociation.org).

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

- Anonymous donations - £160
- Chris Liles, proceeds of raffle at Norfolk Stag Owners meeting
- Frances & John Fairbrother, donations in lieu of presents for their Golden Wedding Anniversary - £340
- Anne Gillett, table top sale - £35
- Paul and Wendy Muncilla, sale of surplus bread - £50
- Susie Meadows, birthday fundraiser - £45
- Pakefield PCC - £150
- Sale of Association merchandise - £53.80

- Hatch Brenner, donation - £200

### Donations in memory of

- Mr White - £530
- David Cossey - £212
- Sylvia Dear - £341.10
- Minnie Jennings - £100

### Internal transfers

- Interest - £79.72
- We are extremely grateful for the donations totalling £121.76 which have been made to National Office for transfer to the Branch.

*My apologies to those who have made donations but whose names have not appeared, these figures will appear in the next edition.*

## **News from National Office**

**40th anniversary raffle:** For £1 a ticket you could win a fantastic £5,000! If you would like to request tickets to sell to your friends and family, you can call the raffle hotline on 0330 002 0342 or email [raffle@mndassociation.org](mailto:raffle@mndassociation.org). Alternatively you can take part online at <https://www.raffleentry.org.uk/mnda>. Closing date 2 July, draw date 9 July.

*Please do not feel under any obligation to take part and note, players must be over 16 and entry is open to UK residents excluding Northern Ireland, Guernsey and the Isle of Man.*

**Jersey holiday bursaries:** The Jersey Branch of the MND Association are offering holiday bursaries for people with MND and their families who would like to visit the island. Financial assistance may be given in part or in whole towards the transportation cost of sea ferries, air fares or accommodation. You can find out more about the bursary, and how to apply by visiting the Jersey Branch page on the Association website at <https://www.mndassociation.org/getting-support/local-support/branches/channel-islands/jersey-branch/>.

**Carers Week 10-16 June:** The theme this year is 'Getting carers connected' whether that be to financial support, practical support, via technology or to friends, family and the wider community. The week aims to raise the profile of the role of caring and to recognise and celebrate the contribution carers make, and to highlight the challenges carers face. You can find more on the Carers Week website at <https://www.carersweek.org/>.

**JustGiving have removed the 5% fee they charge charities for each donation:** Supporters looking for a fee free fundraising platform to ensure that we get 100% of the donations made can use JustGiving. <https://www.justgiving.com/>

**Doddie Weir Foundation hits £2m research target:** My Name's5 Doddie Foundation has committed £1.4m towards MND research which will be awarded to MND centres of excellence across the UK. The charity, which was launched in 2017 after Scotland rugby star Doddie Weir announced he is living with the disease, has now donated £2m to MND research including support to the MIROCALS trial (more information under the Research heading).

In addition, the Foundation has given a total of £350,000 to the MND Association and MND Scotland to fund grants that help pay for adaptations to homes and fund respite for carers. Our thanks go to the Foundation for their continued support, some of which has already been used to support people in our area, and for their commitment to MND research.

**Updated information sheets:** Download information sheets at <https://www.mndassociation.org/about-mnd/information-resources/> or order copies from the care admin team by calling 01604 611685 or by emailing [careadmin@mndassociation.org](mailto:careadmin@mndassociation.org). People living with or affected by MND can order direct by contacting the MND Connect helpline on 0808 802 6262 or emailing [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org). A number of sheets have been re-worded and made clearer so it is always worth looking at them online to ensure you access the latest version of each sheet.

**Two new information sheets:** Pain may be experienced with MND due to problems with movement and mobility. 6C – Managing pain has been written to help support people with MND, and may also help people with Kennedy's disease. P11 – Pain in motor neurone disease is written to assist health and social care professionals who provide support.

**Could you help review the Association's information?** Are you living with MND? Are you supporting someone living with MND or have you previously been a carer? Do you have a few hours to spare? Then we need your help!

You could get involved in a range of exciting projects and help develop the information provided by the Association. What will it involve? You will make a difference from the comfort of your own home by giving feedback about our existing and new publications and digital resources. Who do I need to contact if I would like to take part? Please email volunteering [volunteering@mndassociation.org](mailto:volunteering@mndassociation.org) or ring 0345 6044 150.

**Live streaming the National AGM.** After careful consideration, the Association has decided not to provide live-streaming of this year's Annual Conference and AGM. Having reviewed the costs and the number of people making use of the live stream, it was decided that the money can be better spent elsewhere. However, the keynote speech presented by leading MND researcher Kevin Talbot, will still be filmed and made available to view at <https://www.mndassociation.org/videos/> after the event. Updates from the AGM which will be held on 13 July, will also be available on Twitter under the hashtag #AGM19.

**Improving MND Care Survey.** The survey was launched in March after the last issue of Fightback was sent out and sadly will have closed by the time you read this. However, we would like to thank everyone who was able to follow the link on our Facebook page to complete the survey. The information gathered will provide valuable insight into the experiences of people living with MND and their carers, and help to shape the future priorities and activities of the Association to support MND care. We look forward to seeing the results.

## Campaigns

**Scrap6Months campaign update:** In the last edition of Fightback we announced a new video, Michael's story, showing why our Scrap6Months campaign is so important for people with MND and their families. In March, the Association launched Jack and Rose's story, which we shared on Facebook. You can find it at <https://www.youtube.com/watch?v=X7pV903j8NI&feature=youtu.be>.



It is very moving so you might need tissues to hand! It demonstrates clearly why we need to continue our Scrap6months campaign until a change is written into law.

The good news is that the campaign is already making progress. The Association has engaged with the Department of Work and Pensions (DWP) to bring about changes to their guidance for medical professionals when deciding if their patients should access the Special Rules for Terminal Illness (SRTI) fast-track for welfare benefits. The guidance now makes it clear that the benefits fast-track is not only for people living with terminal cancer. It also recognises that providing a prognosis is not an exact science and needs to be based on the 'balance of probability'. It makes clear that clinicians can start conversations with patients about accessing support using the SRTI.

The Work and Pensions Select Committee, chaired by Frank Field MP, have also shown an interest in the issue and sent out a press release on 30 April which you can read here: <https://www.parliament.uk/business/committees/committees-a-z/commons-select/work-and-pensions-committee/news-parliament-2017/chairs-comments-special-rules-for-terminal-illness-17-19/>.

The changes in guidance represent an important step forward. However, we still believe that the legal requirement for “a reasonable expectation of death within six months”, which is not appropriate for complex and unpredictable conditions such as MND should be removed.

As of 3 May, 12,865 people had signed the Scrap6months petition, calling on the Government to Scrap6Months and make benefits more accessible for people with MND and other terminal illnesses. This is an amazing figure showing the benefit of working collaboratively with another charity, Marie Curie. We would like to thank everyone who has signed so far, and all those who have asked their family and friends to sign too. Don't be afraid to ask your GP or other health and social care workers to sign too! We are anticipating that the petition will close soon before being 'tidied up' for presentation to the Government. Sign online at <https://e-activist.com/page/33936/petition/1> or use a paper petition sheet to collect signatures from family, friends, colleagues and neighbours. You can contact Sue Heal (01953 606569) if you need one posting to you, or use the tear out copy in the recent edition of Thumbprint.

**The All-Party Parliamentary Group on Terminal Illness** is seeking evidence on the legal definition of terminal illness. The inquiry is being coordinated by Marie Curie. Please share your views at <https://e-activist.com/page/33639/petition/1>.

**The All-Party Parliamentary Group (APPG) on Social Care:** On 26 February, eight APPGs came together in Westminster to discuss working-aged disabled people and the Social Care Green Paper. The APPGs were MND, Disability, Autism, Eye Health and Visual Impairment, Learning Disability, Deafness, Mental Health and Parkinson's.

The Care and Support Alliance (CSA) which represents over 80 charities and organisations, including the MND Association, was also in attendance together with volunteers, service users and three people living with MND.

The APPGs are writing to Matt Hancock, Secretary of State for Health and Social Care to request a meeting to discuss the issues raised. The Green Paper on Social Care has yet to be published, but we are hopeful that due to lobbying from the Association and from the CSA, it will address the social care needs of both working age adults and older people.



## **Follow up on the decision of the Norfolk Clinical Commissioning Groups to adopt the MND Charter:**

On March 12, Helen Copsey, Dr Mamutse, Jean Lindsay (neurological nurse specialist), Lindsay Goward and Sue Heal attended a meeting of the Planned & Unplanned Care Clinical Network chaired by Dr Linda

Hunter to discuss the information which might usefully be circulated to GPs. We looked in some detail at the pre-referral pathway and how GPs could use the Red Flag tool to identify people who should be referred to a neurologist for assessment to see if their symptoms were caused by motor neurone disease. The four Clinical Commissioning Groups (CCGs) represented at the meeting accepted in principle that this should happen within four weeks. We are hoping that West Norfolk CCG will adopt the same timeline to ensure that everyone within Norfolk is treated consistently in line with best practice.

Helen Copsey provided an update on the work of the Norfolk MND Care and Research Network. Helen, Lindsay and Dr Mamutse made a strong case for the provision of a neurological nurse specialist to work out of the Norfolk and Norwich University Hospital – a gap that has existed since the last summer. Whilst those present at the meeting were clearly sympathetic there are many more hurdles to surmount, and a huge amount of work behind the scenes, if kind words are to translate into this much needed appointment.

**North Norfolk District Council:** Despite efforts over an eighteen month period we had been unable to arrange an appointment to meet with any of the North Norfolk District Councillors. Thanks to Care Service Navigator Trish Moore, we were finally offered a meeting on 22 March with Sarah Bütikofer, Leader of the Council.

Sue was able to attend and spoke with Sarah about the MND Charter and its importance in detailing ways in which local councils can best support people living with MND. It was agreed that a motion in support of the Charter would be added to the agenda at the second council meeting after the local elections that took place on 2 May.

**Housing adaptations:** Have you or someone you know struggled to get home adaptations? The Association would like to use people's real stories and experiences to support our campaigning work on accessible housing and adaptations for people living with MND. This could include using your story or a quote on the website, or in reports, leaflets, social media and/or national and local media. There is no guarantee that we will use your story, but we will acknowledge all submissions. If we are able to use your story we will follow up with you and share how we will use your story or quotes to ensure you are happy with the content.

If you would be happy to share your story or can help someone who has a story to contribute please complete the form at <https://ecampaigns.mndassociation.org/page/41068/data/1>. If you prefer a paper copy of the form and consent form please contact Sue Heal or ask your Association Visitor or Care Service Navigator.

**NHS continuing healthcare:** Some people with long-term complex health needs qualify for a free package of care arranged and funded solely by the NHS. This is known as NHS continuing healthcare – sometimes referred to as CHC. It can be provided in a variety of settings outside hospital, such as in your own home or in a care home. To be eligible for NHS continuing healthcare you must be assessed by a team of healthcare professional (a multi-disciplinary team – MDT). The team will look at all care needs and relate them to what help is needed, how complex the needs are, how intense the needs can be and how unpredictable they are, including any risks to health if the right care is not provided at the right time – it is looking to determine whether or not the needs represent a primary health need.

Eligibility for NHS Continuing Healthcare depends on assessed needs and not on any particular diagnosis or condition. This also means that if a person's needs change then eligibility for continuing healthcare may change. The person living with MND should be fully involved in the assessment process, and carers and family members should also be consulted where appropriate.

Clinical commissioning groups (CCGs) must assess a person for NHS continuing healthcare if it seems that it may be needed. For most people there is an initial checklist assessment, which is used to decide if a full assessment is needed. If care is needed urgently, for example if a person is terminally ill, the assessment may be fast-tracked.

The initial checklist assessment can be completed by a nurse, doctor, other healthcare professional or social worker, who has been trained to do so, after consent has been granted. Depending on the outcome of the checklist a person may be told that they don't meet the criteria for a full assessment of NHS continuing healthcare and hence are not eligible or will be referred for a full assessment of eligibility. The purpose of the checklist is to enable anyone who might be eligible to have the opportunity for a full assessment, but does not necessarily mean a person will be found eligible.

More detail about NHS continuing healthcare can be found at <https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/>.

*If you think you may be eligible please talk to someone who can complete the initial checklist.*

On 6 December 2018, a report on the management of NHS continuing healthcare in Norfolk was presented to the Norfolk Health Overview and Scrutiny Committee. The paper referenced data collected by NHS England and included a graph, “which showed that significantly fewer people per 50,000 population are assessed as eligible for fast track continuing healthcare in Norfolk than is the case in England as a whole, or in the NHS England Midlands and East (East) region.” Looking at the NHS England data suggests that the same might be said of people looking to receive NHS continuing healthcare using the standard application process.

Anecdotal evidence suggests that people living with MND are not always receiving NHS continuing healthcare where healthcare professionals and volunteers might have thought they should. Before we can campaign on an issue we need to collect data to support our case. However, before we collect data we need to make sure that it will be secure and compliant with General Data Protection Regulation, and that we have appropriate consent from individuals who are sharing their experiences. If you feel able to help us by sharing your story please talk with your Association Visitor, Care Service Navigator or Lindsay Goward.

## **Local MND Research Update May 2019** *by Dr Ratko Radakovic*

The **CHANGE-MND study** has been recruiting people living with MND and their study partners since January 2018.

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

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

	Recruitment Progress	
	People Living with MND	Study Partners (carers/ relatives/ close friends)
Baseline visit	27	26
1 <sup>st</sup> Follow-up Visit (3 Months)	14	13
2 <sup>nd</sup> Follow-up Visit (6 Months)	8	7
3 <sup>rd</sup> Follow-up Visit (9 Months)	5	4

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

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

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

## Research

If you want to get involved in research or read more about ongoing research there is always a wealth of reliable information at <https://www.mndassociation.org/research/>. If you wish to talk about getting involved you can contact the Research Development team on 01604 611880. The information below is taken from links given in the MND Monthly Research Newsletters, and the MND Research blog <https://www.mndassociation.org/research/mnd-research-blog/>.

**Can you help? The Neuro LTC Study** aims to identify and better understand the factors and events that influence the care needs of people with long term neurological conditions. It is led by Dr Christopher Kipps at University Hospital Southampton. The team is looking for people to take part in two surveys, each takes about 15-20 minutes to complete. The first survey is for patients, carers and people who have cared for someone with MND in the past. It asks about your personal experiences of what affects the care that a person living with MND requires. The second survey is only for people living with MND and asks about the impact of fatigue. You can complete the survey online by following the link at <https://www.mndassociation.org/research/mnd-research-and-you/get-involved-in-research/neuro-ltc/>. If you would prefer to complete it on paper or over the phone, or would like more information, you can contact Sarah Fearn at [neuroltc@soton.ac.uk](mailto:neuroltc@soton.ac.uk) or on 07876818404.

**Drug repurposing – new life for old drugs.** Developing new drugs can cost tens of millions of pounds and take more than ten years – you can read about how clinical trials work in the latest edition of Thumbprint. The good news is that drugs which have already gone through this process are now being investigated as potential treatments for other diseases, including MND, as they have already been found to be safe for use in people. However, pre-clinical tests and clinical trials are still needed – though they may be fewer, less time-consuming and hence cheaper. A safe dose still needs to be established for treating a different disease – in this case MND, some degree of effectiveness must be seen, and clinicians need to understand the benefits and risks before the drug can be made available as a new treatment.

This blog post explains the process and lists the trials taking place in the UK using repurposed drugs. It is worth reading if you are interested in taking part. However, it is important to note that trials have strict inclusion and exclusion criteria so that not everyone is able to take part even if they would like to. Once you have read and considered the ongoing trials it is worth talking with your neurologist to decide which, if any, might be worth following up.

<https://mndresearch.blog/2019/03/27/drug-repurposing-harnessing-the-positive-side-effects-of-old-school-drugs/>.

**Preclinical studies show experimental gene therapy successfully silences C9orf72 gene.** This is significant because the C9orf72 gene (chromosome 9 open reading frame 72) is the most common cause of familial and sporadic motor neurone disease (MND) and frontotemporal dementia (FTD). Researchers with uniQure in the Netherlands have completed two preclinical studies designed to establish the feasibility of using miQURE (the therapy) to target a key mutation in the C9orf72 gene. The aim was to lower the accumulation of toxic RNA (ribonucleic acid) clumps and reduce the activity of the mutated gene without causing damage elsewhere. They achieved promising results in both studies, one using cells collected from a person with FTD and the other in a mouse model of MND. The ability to silence the gene may prove to be critical for the future development of effective gene therapies for MND and FTD, and to support the continuation of the research. To read more about this study and to understand the science behind it visit <https://alsnewstoday.com/2019/02/18/gene-therapy-silences-key-als-gene-c9orf72-preclinical-studies/?>.

**Can nerve injury trigger MND?** In some people motor neurone disease appears to develop after a nerve injury, a theory supported by anecdotal evidence. Two articles look at this in more detail. The first is a blog article looking at the evidence surrounding people who engage in intense physical activities. The second comes from some work being carried out at the University of Chicago and reported in Science Daily.

The Association's blog article looks at some studies that investigate the incidence (rate of newly diagnosed cases) of MND in professional footballers and consider the suggested causes.

After reviewing a 2005 study of Italian footballers, that found they were six times more likely to develop MND than the general population, the blog went on to look at a 2009 study that looked at a larger sample of footballers, professional basketball players and road cyclists. The study showed an increased risk for footballers, but the numbers were still small and there was no convincing evidence that the results might not show a random cluster occurring by chance. None of the basketball players and cyclists involved in the study developed MND during the study period, but there was no evidence to suggest that either of these sports conferred a protective effect.

Next came a consideration of the factors, thought to play a part in the development of MND, that footballers are exposed to. Factors included repeated injuries (including heading the ball), high levels of physical activity, potential substance use (such as supplements, medicines, performance enhancers) and possible exposure to environmental toxins such as pesticides. Reference was made to a 2016 review of the evidence by Bozzoni and colleagues. They concluded that the literature suggests there may be an increased risk of MND in football players not seen in other sports professionals. They were not able to rule out a number of risk factors acting together being associated with the disease, but one risk factor alone did not stand out. More studies are needed – and are taking place. Read more details at:

<https://mndresearch.blog/2019/03/08/professional-football-and-mnd-looking-at-the-evidence/>.

Researchers in the USA have shown that a peripheral nerve injury “can start a cascade of inflammation in the spinal cord that initiates and causes the disease to spread in genetically-susceptible animals” in a SOD1 animal model. This could explain how the disease spreads in people who are genetically predisposed to develop MND once it starts from the site of a previous injury and could be what causes the progressive muscle weakness seen in MND. Read more details at: <https://www.sciencedaily.com/releases/2019/02/190220112208.htm?dm>.

For those new to reading about research into the causes of MND, SOD1 is short for Superoxide dismutase and is an enzyme encoded on the SOD1 gene located on chromosome 21. In 1993, it was the first gene identified as a cause of MND and is associated with the familial form of the disease which is thought to cause around 10% of cases of MND.

**Pesticides may be related to faster MND progression.** Although what causes MND is unknown recent research suggests that pesticides and other environmental pollutants may advance the progression of MND. A team, working at the University of Michigan ALS Centre of Excellence in the USA, followed up on their findings from a 2016 study which showed that increased levels of numerous pesticides were found in blood tests of people with MND.

Their more recent study found that increased levels of pesticides and environmental pollutants, such as polychlorinated biphenyls (PCBs), in blood samples from people with MND correlates with faster progression and shorter survival, particularly in those with the highest concentrations. The team plans another study with a new group of people with MND; repeating these results would strengthen their findings. There is a particularly high incidence of MND/ALS in Michigan. Feldman (a neurologist who founded the Centre in 1998) says, “We believe the answer may lie in the fact that Michigan is both an industrial and agricultural state”. Whilst some of the harmful pesticides and pollutants have now been banned they take many years to break down.

Understanding what causes MND to develop will help researchers work towards a cure. You can read more at: <https://www.sciencedaily.com/releases/2019/02/190228093553.htm?dm>.

**Occupational exposure to silica and risk of MND.** The cause of MND is still unknown, but both genetic and environmental factors appear to contribute to the development of the disease. Certain occupations, such as farmers, vets, flight attendants and truck drivers appear to be at an increased risk of MND. Researchers at the University Medical Centre Utrecht in the Netherlands analysed the job histories of 1,252 people with MND and 2,590 age, sex and residency matched controls from five registries in the Netherlands, Ireland and Italy. They wanted to see if occupational exposure to certain toxins such as silica, asbestos, organic dust, contact with animals, polycyclic aromatic hydrocarbons (combustion products) and diesel motor exhaust could increase the risk of MND. Overall the statistics showed a significant association between developing MND and low- and high-level occupational exposure to silica, although this is not the same as saying that exposure to silica causes MND.

To read more about this research visit <https://alsnewstoday.com/2019/03/13/occupational-exposure-to-silica-may-increase-risk-of-als-study-suggests/>.

This research followed earlier work looking at electromagnetic magnetic fields as a potential environmental risk factor for motor neurone disease reported in the MND Blog at <https://mndresearch.blog/2017/03/30/what-is-the-deal-with-magnetic-fields/> and referenced in an earlier edition of Fightback.

**Changes to MIROCALS trial inclusion criteria:** MIROCALS (Modifying Immune Response and Outcomes in ALS) is a joint trial between clinicians in France and the UK that will test a molecule that occurs naturally in our bodies called interleukin-2 (IL-2) as a potential new therapy for MND.

Changes have recently been made to the inclusion criteria of the MIROCALS clinical trial. Previously the trial was only open to people with no prior, or present, use of riluzole. This has now been changed and people who have been taking riluzole for less than one month may now be eligible to take part.

The inclusion criteria for the MIROCALS trial are now:

- Less than 24 months since symptom onset, and
- Haven't been treated with riluzole or have been taking riluzole for less than one month

*Please note that these changes are not yet shown on the website or information sheet. If someone thinks they may now be eligible to take part in the MIROCALS trial they should talk to their neurologist, who will have contact details of the centres involved and should be able to refer them.*

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

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

3 July 14:00-16:00 for an English cream tea                      4 September 14:00-16:00 for a Harvest tea  
6 November 12:00-14:00 for a Pumpkin lunch

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

The **Ipswich** support meetings are held in The Atrium, St Elizabeth Hospice, Ipswich, IP3 8LX on Monday evenings between 17:00 and 19:00 on the following dates:

17 June            19 August            21 October            16 December

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

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

**MND Carers Friendship Group:** This informal group is just for carers and former carers of people with MND. They normally meet up on the third Wednesday of the month for coffee in the café at Tapping House, The Norfolk Hospice at Hillington between 11.00 to 12.30. Do contact Dianne Hepburn if you would like to join them or for more information, [dianne-h@hotmail.com](mailto:dianne-h@hotmail.com) or 07789 281100. Their next meetings are on 15 May and 19 June from 11:00 to 12:30. For further dates please watch the King's Lynn page on our Branch website.

## Branch News

**Open Meeting:** Sunday 23 June 2019 Upton Village Hall, Cargate Lane, Norwich NR13 6AU. We are very pleased that Dr Mamutse, consultant neurologist at the Norfolk and Norwich University Hospital has agreed to be our guest speaker. The title of his talk is 'Symptoms and Management of MND'.

**Advance Notice of Open Meetings:** Sunday 17 November 2019 Wortwell Community Centre, Tunbeck Close, Wortwell, IP20 0HS. Sue and Malcolm heard Dr Kirsten Kelly speak at the Cambridgeshire AGM and were so impressed that they issued an invitation to address our meeting, and were delighted when she agreed. Kirsten is the Association's Research Programmes and Partnership Manager. You can read an introduction to her role here – <https://mndresearch.blog/2017/11/02/introducing-the-research-programmes-and-partnerships-manager/>.

**Coffee mornings** are informal gatherings for carers and people living with MND hosted by Association Visitors and Committee Members. Note there are no coffee mornings in December. **At Notcutts coffee shop:** The next coffee morning will be held on Wednesday 15 May from 11:00 to 13:00. Refreshments can be purchased in the coffee shop.

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

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

**At the Cherry Lane Garden Centre:** The next coffee morning will be held on Wednesday 29 May between 11:00 and 13:00. Refreshments can be purchased in the coffee shop.

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

2019 26 June 31 July 28 August 25 September 30 October 27 November

**Website:** [www.mndnorwichandwaveney.org.uk](http://www.mndnorwichandwaveney.org.uk) We are always happy to add information about events you are planning in support of the Norfolk, Norwich and Waveney Branch.

**Facebook:** @MNDANorwichWaveney

**Twitter:** @MNDANorWave

**Louisa's Facebook page:** @fundraising4MND

**Newsletter Editor:** Thank you to all who have sent photos and stories for inclusion in our newsletter. The next deadline for receipt of articles is **23 September 2019** for the next edition.

### Useful Numbers

**Regional Care Development Advisers** share an email address  
[eastangliarcda@mndassociation.org](mailto:eastangliarcda@mndassociation.org)

Norfolk – Lindsay Goward 03453 751829. Lindsay works Tuesday, Wednesday morning, Thursday, and Friday morning.

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

**MND Coordinator** Helen Copsey 01603 647221 [helen.copsey@nnuh.nhs.uk](mailto:helen.copsey@nnuh.nhs.uk)

**Care Service Navigators** Trish Moore 07813 094 820 email [trish.moore@mndassociation.org](mailto:trish.moore@mndassociation.org)

Gill Newton 07810 750122 email [gill.newton@mndassociation.org](mailto:gill.newton@mndassociation.org)

*Please pass this newsletter on to people who may be interested and together we will fight for our vision of a world free of MND.*

**Disclaimer.** *The views expressed in this newsletter are not necessarily those of the MND Association. The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise. We would like to keep in contact with you about the important work we do. If you do not wish to receive further information, please contact [secretarymndanorfolkwaveney@gmail.com](mailto:secretarymndanorfolkwaveney@gmail.com), or write to her at the address given on the back page or write to Norfolk, Norwich and Waveney Branch, c/o MND Association, PO Box 246, Northampton, NN1 2PR.*