

Fightback

MND Association Norwich & Waveney Branch Newsletter
Issue 73 May 2017

Life of Bryan (with a Y) - Bryan Chubbock, a retired Tivetshall Farmer, released his autobiography with proceeds going to the MND Association!

Bryan and Eileen Chubbock, parents of branch chairman Malcolm, have been attending open meetings and supporting the branch since it began in April 1995. Their eldest son John (pictured in the photo frame) was diagnosed with MND in 1993 and died in 1997. The book documents Bryan's life in farming, and includes stories from the 1940s when he and Eileen started running Walk Farm. We are delighted that he has chosen to donate the proceeds of the book to the branch. It costs £8 and can be purchased directly from Bryan by phoning 01379 676272 or contact Malcolm at malchubbock@hotmail.co.uk. Sales have raised £580 so far.



Read more at <http://www.dissexpress.co.uk/news/life-of-bryan-retired-tivetshall-farmer-releases-autobiography-for-charity-1-7903613>.

19th March 2017 22nd Annual General Meeting

The 22nd AGM held at St. Andrew's Eaton Church Hall, Norwich was attended by 40 people, substantially up on last year's attendance when we had inadvertently chosen Mothering Sunday for our AGM!

Malcolm Chubbock opened the meeting and welcomed everyone. He made special mention of Sally Light, Chief Executive of the MND Association. Malcolm also welcomed Lindsay Goward, our Regional Care Development Adviser, Cllr. Joe Mooney, who has been working with Sue Heal on the campaign that has led Norfolk County Council to support the MND Charter, and Keith and Sharon Lebbell who are involved in the organisation of an event in support of the branch at The Talk, Norwich.

Sally Light is pictured here with Cllr. Mooney.

The minutes of the last AGM were agreed and signed by Malcolm, who then gave his report focussing on the splendid work of many supporters who between them organised fundraising events that made a large contribution to the branch income of £36,809 for 2016. Another significant source of funds came in the form of donations in memoriam totalling £13,813 for the



year. Malcolm noted that since the Norwich and Waveney Branch of the MND Association was formed in April 1995 we have, in the last financial year, surpassed £1 million in fundraising. He expressed thanks on behalf of the branch to all those who have held events, made donations and raised awareness of MND. The money has been used to improve the quality of life for all those in our area who have lived or are living with the disease. Funds have also gone to support a number of research projects as well as helping to fund the essential services provided by our National Office.

Malcolm also paid tribute to those who have lived with MND since the branch was formed, and to their carers and families who have experienced with them the challenges of the disease. On behalf of the branch he thanked the Neurology Nurse Specialists who give support and advice to the families affected by MND. He also thanked the Association Visitors, Care Service Navigators and Regional Care Development Advisers. He concluded his report by thanking the Branch Management Committee for their support during the last year. As editor I would like to add our thanks to Malcolm for his tireless work since the branch began in 1995! He does a huge amount behind the scenes not only to support those with MND, their carers and families, but also the branch volunteers.

Trish Bates had, as always, been meticulous in her treatment of the accounts, which were accepted without question. The accounts are now submitted quarterly to National Office where they are audited, and approved.

The members of the branch committee had expressed their willingness to continue to serve and were re-elected en bloc. However, we would like to welcome volunteers who feel they would like to join us – there is always plenty of work to go round.

Terry Roberts raised a question about the figures for the number of members with MND. Lindsay talked about the process by which our local list is created. Malcolm highlighted the importance of registering as a member of the MND Association, which is free to people with MND and their immediate family. Not only does it give the ability to vote and receive useful publications such as Thumbprint magazine, but it also helps the Association to provide more accurate figures when campaigning for services from the NHS, local and national government. However, as Sally Light later reminded us, the Association will help anyone with MND whether or not they have taken the step to become a member. Sally endeavoured to speak to as many people as possible during her visit.

After lunch Malcolm introduced Sally who gave an interesting presentation on activities carried out by the Association. She spoke of the range of research from the development of the Sheffield Snood (a soft flexible collar to which hard Velcro support pieces can attach) to the vast MinE. MinE is an international genetics project that is analysing DNA from people with MND in great detail. Its goal is to find out more about subtle genetic risk factors, using whole genome sequencing – with a target of analysing 22,500 samples from 16 countries around the world, including the UK. Sally also talked about the MND Register; a research study funded by the MND Association. Its aim is to collect information about every person living with MND. It is thought there are about 5,000 people affected by MND in the UK at any one time, but the true figure is not known. The purpose of the MND Register is to create a database, and the information stored will help plan the care for people living with MND and tell researchers more about what might be causing the disease. To start the process, six or seven Care Centres will be putting people they care for onto the register, in time it is hoped that people with MND can register themselves – there are safeguards to prevent double counting.

The key to defeating MND lies in fostering strong collaboration between leading researchers around the world, and sharing new understanding of the disease as rapidly as possible. This was the MND Association's reasoning behind the creation of the International Symposium on ALS/MND, which makes a global contribution. The first was held in Birmingham in 1990 and was attended by 50 MND researchers; the 2016 Dublin symposium was attended by 1,100 delegates from 41 countries. The symposia help with our mission for 'a world free from MND'.

Sally then moved on to look at how the Association ensures the best support for people with MND, their carers, families, children and young people affected by the diagnosis. Sally paid tribute to the work of our Association Visitors. She mentioned the focus on quality of life reflected in our equipment loan service, and MND Connect who handle 8,000 calls per year. Health and social care professionals are also encouraged to use MND Connect and the educational modules available on the main MND Association website.

Help the NHS to help you – Sally spoke of the need to drive up the quality of care. The Association part funds MND Care Centres and Networks as research shows that multidisciplinary care can both extend life and improve quality of life. At the moment the centres serve about 3,500 people with MND, this number will increase when new networks such as that in Norfolk (more details later in the newsletter) come into operation.

Campaigning forms another focus for the work of the Association. In 2016, the National Institute for Health and Care Excellence (NICE) published its Guideline on MND – a comprehensive statement of best practice in care after sustained campaigning. MND is the rarest disease to have its own guideline. This was followed by a quality standard that draws attention to specific measurable aspects of good care. An audit tool has recently been produced to allow professionals to bench mark their performance against the NICE guideline. At a local level Campaigns Contacts, with the support of the branch, fight for services to be as good as they can be.

Sally ended her talk with an update on the money raised by the Ice Bucket Challenge – in round numbers of the £7.2 million around £5 million has been spent on research, £1.5m on care with the rest split between campaigning, support and raising awareness.

Coffee mornings

The branch support coffee mornings continue to grow in popularity as judged by the number of people attending. Judy Burns-Thomson sent a photo (shown on the next page) taken at the Cherry Lane Garden Centre during the March coffee morning – they were quite a



a crowd with 14 people attending. This motivated Sue to take the photo (above) at Notcutts in April though numbers attending our coffee morning were a little lower than in March.



Events in aid of the MND Association

24th February 2017 Heritage Quiz and Chips Night

Heritage Wills, Hellesdon, have chosen our Branch as their charity of the year. The first fundraising event organised by their Charity Committee raised £150. Karen Francis of Heritage Wills, Hellesdon, said, "It was great to have Penny and Malcolm on our team and a fun night was had by all". She didn't tell us if their team won!!

They have other events planned such as bakeit!, a car boot sale, a golf day and are trying to source a venue for a Walk to d'feet. Their fundraising year will finish with a Christmas Bingo, followed by a cheque presentation soon after. The details will be added to our branch website.

27th March Wymondham Lions

Sue Heal was invited to give a brief talk about the MND Association and the work of our branch to the Wymondham Lions. She was made very welcome. We are most grateful to them for donating £200 to assist us in our support of people living with MND and carers.

2nd April ASICS Greater Manchester Marathon

David and Cathy Smith's son in law Peter ran the Greater Manchester Marathon, known for being a super fast course, and raised £562 for the Norwich and Waveney branch of the MND Association. We are very grateful for his efforts on our behalf.

Peter wrote on his 'BT mydonate' page that he needed the sponsorship to keep him motivated through 7 weeks of madness as he began training on 19th February. It seemed to work!



1st May 2017 – MK Marathon

Phillip Laurier ran the MK Marathon to raise funds for the Norwich & Waveney Branch of the MND Association. It started and finished at StadiumMK in Milton Keynes.

Future events in aid of the MND Association

Saturday 13th May 2017, 7pm till 12:30am. Charity Night at The Talk

Join us at The Talk, Oak Street, Norwich NR3 3BP. To see the flyer with more details visit our website at <http://www.mndnorwichandwaveney.org.uk/events.htm>.

The event will feature Lowrider, Wypeout and Glamtastics, and is compèred by local comedian Pat Nearney. This should be a great night. All three bands are looking forward to raising some money with lots of good music to suit a variety of tastes. A band member from each band works for Beactive; the leader of Lowrider, Dave Smith, is the Managing Director of Beactive. Beactive are pleased to support and help pay the costs so that more of the money raised can be given to the charities.

Keith Lebell, of Wypeout is raising funds for the Norwich & Waveney Branch of the MND Association in memory of his Godmother who suffered from MND. Keith has raised £28,000 for charity since 1988. Money raised on the night will be split equally between the Royal National Lifeboat Institution, East Anglian Air Ambulance and ourselves. Buy your tickets ahead of the event at a cost of £10 by phoning Keith on 07761 424011. Alternatively you can buy your ticket on the night for £15. There will be a raffle.

Sunday 28th May Skydive by Sheree Page

Sheree is taking part in a skydive to raise money for the branch. If you would like to donate please email shereepage1989@hotmail.com.

Saturday 3rd June 2017 Bucket Collection at Notcutts

We are delighted to be able to hold a second bucket collection at Notcutts, watch out for us if you are shopping there on the day.

Friday/Saturday 9th/10th June 5th Morley Beer Festival & Fun Day

Are you starting to plan your summer? Early Bird Tickets are now on sale for the 5th Morley Beer Festival & Fun Day. Morley Village and Sports Hall, Golf Links Rd, Morley St Peter, Wymondham NR18 9SU (not Swanton Morley).

A paradise for beer lovers and featuring music artists *The Vagaband* (Glastonbury) on Friday Night, *Cawston Band* (Award Winning Band & Norwich Beer Festival) on Saturday night & Wymondham College band *Tuesday Club* (BBC Introducing & Waterfront) on Saturday afternoon. Two days of real ale, craft beer, cider, brilliant music, England v Scotland Qualifier on the big screen, food including on Friday night the *Proper Pizza Co.*, camping & fabulous family entertainment for a fun family day out on Saturday afternoon.

They are raising much needed funds for two local charities the MND Association Norwich & Waveney Branch and the 1st Attleborough Scout Group of The Scout Association.

Early Bird Tickets: Day £2.50 or Weekend £4 Children under 18 FREE www.ticketsource.co.uk/event/178499 or from Kett's Books Wymondham NR18 0UQ or Wolf Brewery Norwich Road Attleborough NR17 2LA, tickets will cost more on the day. To reserve your camping pitch please email info@morley-village.co.uk. Camping Fees £3 per person per night, accompanied under 18's FREE. Showers & toilets provided. Payment for camping will be collected on the day.

The main sponsors are David Morter Garage Services www.davidmorter.co.uk & Victoria Marquees www.victoriamarquees.co.uk.

The branch will be hosting a stall on 10th June from 12 noon till 6pm. We hope to see you there – watch for updates on Facebook <https://www.facebook.com/MNDANorwichWaveney/> and <https://www.facebook.com/events/1439457049408786/>.

Thursday to Sunday 15th – 18th June 2017 Bucket Collection

Sainsbury's at Queens Road, 1 Brazen Gate, Norwich, NR1 3RX have kindly offered us a four day slot during June, MND Awareness Month. We are very grateful to a team of willing

volunteers who have already come forward to ensure that we have the event covered. If you missed out and would still like to collect I am sure it would be appreciated if there were two buckets rather than one. Contact Sue Heal by email at sueheal@btinternet.com.

Saturday 24th June Vintage Tea Party from 2pm - 6pm

Linda Tipper is holding a tea party at her home 52 Gorleston Road, Lowestoft, NR32 3AQ. The event includes cream teas and delicious cakes, craft stalls, live music with local DJ, a children's entertainer from 5pm and a brilliant raffle. Linda's email for enquiries and tickets in advance lindatipher50@hotmail.com.

Sunday July 2nd Outlaw Half Holkham.

Lucie Gillett will be taking part in the triathlon that includes a 1.2 mile swim, 56 mile bike ride followed by a 13.1 mile run – three loops round the Holkham estate! Lucie is completing this half iron man in memory of her father Frank Gillett who died from MND. If you are able to support her please visit <https://www.justgiving.com/fundraising/Lucie-Gillett1>. Thank you!

Sunday 23rd July 2pm-5pm. Open Garden and Flamenco Show in aid of the MND Association and Cancer Research.

The event will be held at Hall Farmhouse, Clippesby (past Clippesby Hall Holidays), the home of Rod and Thelma Pointer. To get there turn off the B1152 at the Clippesby Hall sign – they are opposite Hall Farm Barns – there is plenty of parking. Thelma was the former proof reader and Fight Back editor for many years – the name seems to have morphed into Fightback at some point in its history! Live Flamenco music and dancing by Sueños Flamencos will begin at 3pm. In addition there will be plants for sale, wood and up-cycled pallet crafts and a raffle. There is also a new woodland walk and 20 flower borders to enjoy.

Entrance £5 which includes tea and cake. Children come in free. Do not be put off by inclement weather, if it rains you can still enjoy the event which will then be held in the barn.

Sunday 6th August Run Norwich

Richard Jones will be completing the run in support of the MND Association. More details will appear on our website soon, including a link to his fundraising page.

Saturday 16th September Never Lose Hope ... Charity Ball

This must be the most exotic event we have featured in Fightback. Hannah Chippendale is organising a charity ball in Zurich, Switzerland, to raise money for the Norwich & Waveney Branch of the Motor Neurone Disease Association. Follow her Facebook page to keep up with all the news regarding the event – it is already featuring the Willow and Pearl Multiway Dresses. It promises to be an amazing night with lots of great Silent Auction and Raffle Items donated from both local and international companies and individuals as listed below. If you cannot attend but would still like to support the MND Association you can donate directly on Hannah's Just Giving page (as of 19th April £2,151.81 had already been donated) and also bid on Silent Auction Items. For the silent auction, once the full list is out it will be posted on Facebook ahead of the event, please just send an email with your maximum bid and the item number, to the event email on the poster before 11th September 2017.

<https://www.facebook.com/NeverLoseHopeCharityBall>

<https://www.justgiving.com/fundraising/NeverLoseHopeCharityBall>

Sponsors / Auction and Raffle Donations come from Kimi Räikkönen; Willow and Pearl Multiway Dresses; Caroline Dyer-Smith Photography; Hotel Café Royal London; The Savoy Hotel London; Abbot's Oak Country House; Hotel Cavour Milan; Renaissance Zurich Tower Hotel; Sarah Huber Singer and Songwriter; Alessi; EconmarketBio and many more to come...

If you have anything you are able to offer for either the Silent Auction or the Raffle then Hannah would love to hear from you.

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

Donations and fundraising

- Linda Turner, donations from giving talks and craft demonstrations - £174.20
- Diana Buckingham, donation from Diana's brother Alan in memory of Geoff - £15
- County Hall Short Mat Bowls Club, Christmas Raffle - £101
- Raffle at Eaton Open Meeting - £132
- Sales of merchandise at Eaton Open Meeting - £28
- Wymondham U3A, retiring bucket collection at their AGM - £66.34
- Wymondham U3A, speaker's cheque donated to the branch - £60
- Wells War Memorial Club in memory of Nigel Parr - £349.26
- Aubrey & Shirley Ampleford, donations in lieu of Golden Wedding presents - £340

- Lucie Gillett in memory of her Father Frank Gillett - £50
- Anonymous - £60
- Kessingland Over 60s donation from Christmas Event - £100

Donations in memory of

- Thelma Hazel Shorter - £484.82
- John Freeman - £86.30
- Rita Jeanette Ablitt - £175
- Geoffrey Fiddler - £1,825
- Russell Keith Boldero - £185.67
- John Joseph Rudrum - £555.57
- Stephen Craske - £195
- Joan Elizabeth Longstaff - £669

Internal transfers

- Interest - £25.44
- Donations through the Charities Trust - £41.02

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

Norfolk and Norwich University Hospital becomes the MND Association's 21st Care and Research Network

The Norfolk and Norwich University Hospital will operate as the hub for this new care and research network. There will also be clinics at Queen Elizabeth Hospital, King's Lynn and James Paget University Hospital, Gorleston. Helen Copsey has been appointed as Motor Neurone Disease Care Network Coordinator and anticipates starting work on 26th June. Dr Dick is the lead neurology consultant. He is joined by Dr. Muhammad Rafiq from Sheffield Institute for Translational Neuroscience. The clinics will also work closely with the University of East Anglia to extend the opportunity for patients to participate in research. We are excited to see the start of this new venture for Norfolk.

The stories behind the eyes

Throughout MND Awareness Month the Association will be telling inspiring stories of real people living with MND; the 'Story Behind the Eyes'. Look out for our posters from 1st June across England, Wales and Northern Ireland at railway stations, on the London Underground and on buses. The Association also has special access to the Birmingham Media Eyes – three eye shaped screens – on 21st June, MND Awareness day. We will be sharing ways in which you can get involved on our Facebook page and on Twitter.

Chris James, Director for External Affairs, said: “*While primarily an awareness campaign, it is also an opportunity to engage more people in becoming potential fundraisers or volunteers for the MND Association. Better awareness grows our voice to make our campaigning more effective and we know this activity helps people affected by the disease feel that they are neither alone nor forgotten.*”

News from National Office

Message from Sally Light

Sally wrote to Trish, our treasurer, thanking her for sending the Branch's annual transfer. The funds raised help cover the cost of services provided by National Office for people living with MND in our area. In addition the money helps fund more ground-breaking research to help improve our understanding of the causes of MND and to find new treatments. Sally concluded her letter by saying, "We believe now more than ever that a world free from MND is possible and we can only achieve this with your continued support. Your impact is being felt in so many different ways and I really can't thank you enough."

MND alert wristband are now available!

The branch now has a small supply of wristbands, ask your Association Visitor for one, or order from the care admin team by email careadmin@mndassociation.org or call 01604 611812.

This simple silicon band can be worn by a person with MND, at all times if required. It is designed to let emergency and hospital staff know the wearer has MND. It carries a clear caution to let emergency teams know that oxygen therapy may put someone with MND at risk (as they are more likely to retain carbon dioxide if they have breathing problems). A web address on the wristband directs professionals to more information about urgent and acute care support for MND, as they may be unfamiliar with the condition.

A new guide on eating and drinking with MND has been launched. It is presented like a cookery book and contains a range of easy-swallow recipes along with information and tips. Download the guide at <https://www.mndassociation.org/wp-content/uploads/Eating-and-drinking-with-MND-final-web-PDF-2017.pdf>

What you should expect from your care is a small pocket sized booklet featuring key points from the NICE guideline on MND to help open discussions with professionals about treatment and care. The aim is to help people gain better outcomes at appointments and raise awareness for the new guideline. It can be downloaded at

<https://www.mndassociation.org/wp-content/uploads/What-you-should-expect-from-your-care-NICE.pdf>

Two professional publications have been updated

Managing saliva problems in MND can be downloaded along with numerous other resources for professionals at <https://www.mndassociation.org/forprofessionals/publications-hscp/>

Nutrition reading list can be downloaded at

<https://www.mndassociation.org/wp-content/uploads/px024-mnd-nutrition-reading-list.pdf>

New care information sheet

1D – *How we may use your information*, which provides details of why we ask for people's information, and how it is used. The sheet also explains how the association protects confidentiality and people's rights.

Updated care information sheets

2D – *Progressive muscular atrophy*, which contains details about this rare form of MND, ways to manage symptoms and how to access further support.

5A – *Riluzole*, which explains how the drug works, with guidance on how it can be obtained and administered.

7A – *Swallowing difficulties*, which provides information to help people with MND manage concerns about swallowing difficulties, saliva, coughing and choking, should these occur.

This information sheet is endorsed by the British Dietetic Association, and has been translated into a range of languages.

You can download information sheets at <http://www.mndassociation.org/life-with-mnd/publications-pabmnd/information-sheet-range/> or order hard copies from the care admin team by calling 01604 611685 or emailing careadmin@mndassociation.org.

If people living with or affected by MND wish to order direct, they can contact the MND Connect helpline by calling 0808 802 6262 or emailing mndconnect@mndassociation.org.

NICE Guideline – Audit Tool

On 2nd March the MND Association launched *Transforming MND Care*. This is a free to use Excel-based audit tool developed by the association in collaboration with people living with MND, carers and health and social care professionals. It enables health and social care professionals to see how well their service meets the standards set out in the NICE guideline on MND and plan for improvements. It is also a practical way commissioners, service managers and other decision makers can improve compliance with the guideline. Professionals can access this at www.mndassociation.org/transformcare.

Ice Bucket Challenge – What has it funded?

The Ice Bucket Challenge benefited the Association with donations of £7.2m. As at the end of 2016 £4.9m has been spent across the four key areas

- Research - £4,235,000
- Care - £373,000
- Campaigning and Raising Awareness - £207,000
- Volunteering - £98,000

Benefits Advice UPDATE

Following our successful pilot work the Association has now established a benefits advice service for people with and affected by MND in England and Wales. The service is available by telephone, email and webchat.

Telephone: 0808 801 0620 (free to call)

Email and webchat: www.mndassociation.org/benefitsadvice

The service is provided in partnership with Citizens Advice Cardiff and Vale and will:

- Help users identify the benefits they may be eligible to claim and how best to claim them
- Deal with complex benefits issues, including appeals against benefits decisions

The service was launched on 24th April. As part of the development of the service the association is now looking at how best we can help people who cannot use the phone, email or webchat complete benefits applications at home and how we can make the service available to people who do not speak English or Welsh. Depending upon where you live and your circumstances they may be able to arrange a home visit to help with the completion of forms.

Enter our Summer Raffle for a chance to win £4,000

To take part in the Association's Summer Raffle online visit www.raffleentry.org.uk/mnda or call 0345 601 6936 to order your tickets. Alternatively, if you would like to order raffle tickets to sell at events, or to friends and family, please email raffle@mndassociation.org. Taking part in our Summer Raffle can make a huge difference to people living with MND and their families – plus you could win a prize. Sadly the newsletter will reach you after the 50 soft toys that were available as early-bird prizes, for those entering before 5 May, have already been won!

1st prize: £4,000

2nd prize: £500

3rd prize: £200

Plus 20 runner up prizes: £25

The raffle closes Monday 12th June 2017 and winners will be drawn on Monday 19th June 2017.

Campaigns

Parliamentary Reception Tuesday 6th June 2017 in London postponed.

The announcement of a snap general election on 8th June means the reception needed to be put on hold. Parliament is dissolved in the run up to the election, this means that seats in the House of Commons become vacant and there will be no MPs. National Office will be contacting all who were due to attend to let them know that the reception is no longer going ahead on 6th June.

Our annual parliamentary reception is a key event in the MND calendar. It is a great opportunity for people with MND, their families and carers to meet MPs and tell them first-hand about the issues they are facing and raise awareness of MND – this is particularly important after a general election when we may see new MPs who have little or no experience of MND. Therefore, the Association is planning to hold the reception post-election, the new date is set for 17 October.

Thank you to everyone who had already invited their MP. MPs are much more likely to attend if people from their local area are present. Sue Heal plans to attend in her capacity as Campaigns Contact. We expect to be invited to send three other representatives, with priority given to people with MND. Contact Malcolm if you would like to attend – he will need to register our representatives soon after the new date is announced. Those who have already expressed an interest in attending will be contacted nearer the time to check whether they still wish to attend.

This year's event was planned to be a joint reception with the All-Party Parliamentary Group (APPG) on MND. The APPG was to launch the results of a report into access to Personal Independence Payment (PIP) for people with MND at the reception. Thank you to everyone who took part in the survey looking at access to Personal Independence Payments for people living with MND that will have been used to inform the report.

New campaign launching soon

Later this year, the Association will be launching a new campaign to ensure that all people with MND, their families and carers get the financial support they are entitled to, at the right time, and according to the right rules. This campaign will be backed up by strong evidence from the APPG Inquiry into PIP and the financial impact of MND research carried out by independent think tank Demos. The research is showing that MND creates a huge financial burden on people with MND, their families and carers, and that often local and national governments are not providing adequate support to help people cope with the added costs the disease brings. We will add details to our branch website, Facebook and Twitter when they are available.

Take Action!

Continuing Healthcare (England only): People with MND are missing out on vital continuing healthcare (CHC) when they most need support. If you have not already helped us to put pressure on the Government and the NHS to improve the system please email your MP and Clinical Commissioning Group by visiting <http://e-activist.com/ea-action/action?ea.client.id=138&ea.campaign.id=58532> and help us raise these concerns.

The Association has responded to worrying plans to cut NHS care in Leicestershire, Leicestershire and Rutland. Those outside the area can read more about the issues and if interested can add their support to an e-campaign. <https://www.mndassociation.org/news-and-events/latest-news/proposed-cuts-nhs-continuing-healthcare-leicestershire/>

Champion the Charter: one year on

It's been just over one year since we launched our *Champion The Charter* campaign, and we are delighted to announce that a total of 44 councils have adopted the MND Charter as of 28th April.

Norfolk County Council supports the MND Charter by Sue Heal

The Charter went to the full Norfolk County Council meeting on 10 April and was ratified by a unanimous vote. Once again Cllr Mooney spoke for the motion and made clear the importance of supporting the MND Charter with its statement of the respect, care and support that people living with MND and their carers should expect.

On Friday 31st March a group of representatives of the MND Association in Norfolk met with James Bullion, the Executive Director of Adult Social Care, and Sera Hall, Acting Director Integrated Commissioning, to discuss ways in which we can work in partnership with the council. Thank you to everyone who contacted us to share their story, either as a person living with MND or as a carer. We were delighted with the outcome of the meeting. Both James and Sera had clearly read the MND Charter and thought about its implications for people affected by MND. James began by mooted the idea of a Social Worker who would take the lead on MND. This was taken up by Sera who thought there would be a willingness to have staff who championed the needs of people with MND and their carers.

There was agreement that many staff would welcome the opportunity for further training. We gave them links to the online training provided on the main MND Association website. Lindsay Goward and I are looking forward to further meetings with Sera Hall to work out the logistics for training courses.

Both James and Sera were concerned to hear of instances where the response to need had not been met in a timely manner. Where there had been an issue with a personal budget James offered an apology, and agreed to look into what might be done to improve the service offered. Sera went further in asking if this particular issue could be used as a case study in staff training.

James has also asked for us to feed through to him areas of concern as they arise. As he said, no one goes into social work to do a bad job! In particular he has asked Shirley Basey-Fisher to report any difficulties with social services care being put in place.

After the meeting James Bullion tweeted, "Great to meet @mndassoc today @NorfolkCC @Norfolk ASSD to go through issues. Nothing like hearing users to build understanding." We felt very encouraged by the meeting and hope to develop a good working relationship with Adult Social Services.

If you live in Norfolk do get in touch with Sue if you would like to share your experience of services and/or to help ongoing efforts to ensure people living MND and their families get the support they need, when they need it.

More detail about what the MND Charter means in practice can be found on our National Office website at www.mndcharter.org.

Research

If you want to get involved in research you can look here for the latest opportunities: <http://www.mndassociation.org/research/mnd-research-and-you/get-involved-in-research/>.

Families for the Treatment of Hereditary MND (FaTHoM)

Martina Slapkova <https://mndresearch.wordpress.com/2017/02/20/families-for-the-treatment-of-hereditary-mnd-fathom/>

Scientists from the University of Oxford have set up FaTHoM, an initiative to bring together the community of families affected by inherited forms of MND. The first event, in April 2017, was a meeting led by Professor Martin Turner and Professor Kevin Talbot, where experts spoke on key issues affecting such families. It was open to any person living with an inherited form of MND, and close relatives of those who have been affected by inherited forms of MND. We will post updates on Facebook and the branch website when we learn of future meetings.

New urine-based biomarker opens a gate to improved tracking of MND

Martina Slapkova <https://mndresearch.wordpress.com/2017/02/23/new-urine-based-biomarker-opens-a-gate-to-improved-tracking-of-mnd/>

Researchers from Flinders University, Australia and the University of Miami have discovered a protein called p75 that can act as a biomarker to track disease progression in people with MND.

The protein, p75, initially supports the growth of neurones during embryonic development, its levels decrease significantly after birth. Throughout our lives, p75 only reappears in higher levels when the body detects injury of the nervous system, and shows its presence in urine. Urine samples from 54 people with MND were compared to those from 45 healthy 'control' participants and levels of p75 protein were observed. The amount of p75 was significantly higher in people with MND compared to healthy controls.

31 people with MND were followed up and the levels of p75 were tracked. Their urine samples showed a stable increase of p75 levels each month. This means that the further the disease has progressed the greater the amount of p75 found in the urine. The significance of this result is that a biomarker measurable in urine is easier to collect than blood or cerebrospinal fluid, and may mean that people with MND are more likely to take part in a clinical trial.

Palliative Partnership with Marie Curie

Dr Belinda Cupid <https://mndresearch.wordpress.com/2017/03/22/new-research-projects-agreed-to-help-improve-palliative-and-end-of-life-care/>

On 22nd March Marie Curie and MND Association announced the co-funding of three new research studies that aim to improve the quality of palliative and end of life care received by people with MND. There is growing recognition that palliative care for people with MND should begin as early as possible, the research could improve the lives of people affected by MND - around 5,000 in the UK at any one time.

- Professor Chris McDermott's study will look at the problems associated with excess saliva and how the symptom can best be managed. Information on how excess saliva is treated and how well the treatment worked will be collected from many multidisciplinary clinics in the UK including MND Association Care Centres.
- Dr Kate Fleming will look at research studies that have asked people with MND, their families and carers how they feel about the palliative care they have received and what is important to them. Her work will tell us what has worked and what we still need to find out. As well as highlighting research priorities it will help improve current palliative care services so that people with MND and their families can get the best support possible.

- Professor Gunn Grande and Dr Gail Ewing, recognising the central role that carers play in palliative care, will collect their opinions and experiences at three MND Care Centres. They aim to use these to develop a tool to enable them (the carers) to better coordinate support for themselves and the person living with MND. The aim is to ensure that carers have well-planned long-term support that reflects their changing needs over time.

This is especially exciting news for us as this is the first time the Association will be co-funding research projects with another charity. With a total worth of £450,000 across the three projects, each charity is contributing £225,000. We are hopeful that these projects will improve the lives of people with MND, their carers and family.

Funding for Gut-sy MND research announced

Dr Belinda Cupid <https://mndresearch.wordpress.com/2017/03/29/funding-for-gut-sy-mnd-research-announced/>

In March the Reta Lila Weston Trust announced funding of £1.2m for one of our trustees, Dr Nikhil Sharma and colleagues at the Leonard Wolfson Experimental Neurology Centre. The LWENC is run jointly by the National Hospital for Neurology and Neurosurgery and University College London. In his four-year project, he will investigate whether changes in the bacteria living in our guts (microbiota) could affect the progression of MND.

Researchers have found a link between the bacteria that live in our guts and cells called microglia. Motor neurones are supported to conduct messages from our brains to our muscles by a group of cells known as glia. This research focuses on a particular type of glial cell known as microglia, which help regulate the function of the motor neurones. Scientists already know that in the early stages of MND microglia help protect motor neurones, however as MND progresses their role changes and they become toxic to motor neurones. This study aims to find out whether the balance of gut bacteria in MND could be linked to changes in microglia. They will explore the possibility that changes to gut flora could slow the progression of MND in patients.

Finding a reliable association between the gut and motor neurones would open up a new avenue of investigations into the causes of MND. Results of the study are expected in 2021.

Epi Epi Epi, Oi Oi Oi

Sarah Thompson, 13th April <https://mndresearch.wordpress.com/2017/04/13/epi-epi-epi-oi-oi-oi/>
This article looks at an epidemiology study designed to identify risk factors for MND from a person's lifestyle and the environment they live in, and to look at how these interact with a person's genes. Between 2009 and 2015 data was collected from just over 400 participants, half with MND (mainly recruited from the DNA bank study) and the other half serving as controls. People were asked to complete two surveys – one written and one in the form of an interview with a nurse. They asked a wide range of questions from employment and residence history, smoking and alcohol intake, to medical history and hobbies. Blood samples provided the genetic information and the questionnaires the environmental information; these have now been combined in a static data base that can be analysed by researchers. Dr Ammar Al-Chalabi's lab in King's College is the first group to begin working with the data base. This field of research is very important because if we can find risk factors of a disease, we can either try to avoid them or use appropriate treatments.

What is the deal with magnetic fields?

Marina Slapkova <https://mndresearch.wordpress.com/2017/03/30/what-is-the-deal-with-magnetic-fields/>

A recent paper describing a study at Utrecht University that explored the connection between occupational risk factors and MND has sparked interest, especially in the media. It reviewed and studied five occupational exposures that had previously been suggested to be associated with developing MND (specifically, amyotrophic lateral sclerosis). These factors included exposure to electromagnetic fields, electrical shocks, solvents, metals and pesticides.

The researchers used a database of over 120,000 people that were a part of The Netherlands Cohort Study on diet and cancer. This register was set up in 1986 and only included people who were 55-69 years of age. Out of the whole register, 158 people (88 men and 70 women) died of ALS – these were the cases whose data were used for the analyses.

The participants were asked detailed questions on various topics, including lifestyle, dietary habits and previous occupations. Specific for this study, the researchers focused on the type and nature of companies the participants had worked for, their job title and time period of employment. They then looked at occupational exposure using a job-exposure matrix, which looks at the harmful factors for specific occupations. Further calculations relating to the time period of each employment and the number of paid jobs before joining the database gave an 'exposure score' grouped as background exposure (no exposure at work), low and high for each of the five potentially harmful factors.

The main finding revealed that men who were exposed to high levels of extremely low frequency magnetic fields (ELF-MF) at work were twice as likely to develop ALS compared to those with lower exposure levels. Due to the low number of women working in high ELF-MF jobs, the analysis was only done on men. Any profession that involves working closely with high-voltage electricity appliances is a likely to lead to exposure to ELF-MFs.

Dr Brian Dickie (Director of the Research Development team of the MND Association), sums up: *“The results suggest that exposure to high levels of extremely low frequency magnetic fields is associated with an increased risk of developing MND. However, this only becomes apparent when relatively large numbers of people are studied, indicating that any such effect is a very subtle one. It does **not** mean that exposure causes MND.”*

Suffolk Invitation

Suffolk drop in support meetings 2017

The Suffolk Group invites members of branches bordering Suffolk to their support meetings. MND Association representatives and nurse specialists will generally be on hand to advise.

Meetings in **West Suffolk** will be held at Hawstead Village Hall, The Green, Hawstead, IP29 5NP on the following Wednesdays, times vary as shown below

5th July 2017, 2-4pm

6th September 2017, 2-4pm

1st November 2017, 12-2pm *

***light lunch to be provided in November so an idea that you are coming would be helpful.**

If you would like to attend please email Janet Oliver on ooliverjanet@btinternet.com or contact West Suffolk Neurological Nurses by telephoning 01284 748848.

The Ipswich support groups will be held at The Atrium, St Elizabeth Hospice, Ipswich on the following Mondays between 5pm and 7pm:

19th June

21st August

16th October

18th December

For the Ipswich meeting please contact Kate Barber on 01473 707962.

Suffolk MND Association contacts are Janet Oliver 01359 241084 and Liz Cooper 03453 75 1827. Suffolk Direct (for access to social care services) call 0808 800 4005.

Branch News

Open Meeting: Sunday 11th June, between 2:30pm and 5:30pm (note the new time). The branch is hosting an afternoon tea at Upton Village Hall, Upton, Norfolk, NR13 6AU. Helen Copsey, the newly appointed Motor Neurone Disease Care Network Coordinator will attend and give us an update on the new MND Care Network for Norfolk.

Advance Notice: Open Meeting on Sunday 19th November from 12 noon for 1pm until 4:30pm at Wortwell Community Centre, Tunbeck Close, Wortwell, Norfolk, IP20 0HS.

Open Meeting Survey: Thanks to everyone who completed our survey on branch open meetings. The consensus seems to be that we are doing broadly the right thing. We will take the responses into account when planning future open meetings.

Coffee mornings

At Notcutts coffee shop: The next coffee morning will be held on Wednesday 17th May from 11am to 1pm. As usual we hope that many who are currently caring for, or who have previously cared for, people with MND will be able to attend an informal get together. Of course people living with MND are always welcome. Refreshments can be purchased in the coffee shop.

Advance notice of 2017 dates for Notcutts, Daniels Road, Norwich, NR4 6QP

June 14 th	July 19 th	August 16 th
September 20 th	October 18 th	November 15 th

At the Cherry Lane Garden Centre: The next coffee morning will be held on Wednesday 31st May between 11am and 12 noon. It is an informal gathering for people with MND and their carers.

Advance notice of 2017 dates for Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU

June 28 th	July 26 th	August 30 th
September 27 th	October 25 th	November 29 th

Website: www.mndnorwichandwaveney.org.uk We are always happy to add information about events you are planning in support of the Norwich and Waveney Branch of the MND Association (and would welcome content from the Suffolk Fundraising Group).

Facebook: @MNDANorwichWaveney

Twitter: @MNDANorWave

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 30th September for the October edition.

Useful Numbers

Regional Care Development Advisers share an email address

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

Care Service Navigators

Jo-Ann Dawson 07872 161747 email jo-ann.dawson@mndassociation.org

Trish Moore 07813 094 820 email 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 helen_devlin@tinyworld.co.uk, or write to her at the address given on the back page or write to Norwich and Waveney Branch, c/o MND Association, PO Box 246, Northampton, NN1 2PR.