

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 68 September 2015

MND Connect Helpline changes its number to 03457 626262

REMINDER - all 0845 numbers have been replaced by 0345 numbers; calls are charged at the same rate as calling an 01 or 02 number, whether from a landline or mobile. Anyone calling the old numbers will hear an automated message asking them to redial, using 03 instead of 08, and will not be charged for the call.

Events in aid of the MNDA

5th Brian Fretter Golf Charity Day for the MND Association: This was held on August 7th at Costessey Golf Course. The sun was shining once again as it has for each of the previous golf days held in memory of Brian. Many people travelled from Leicester to support Sue Fretter and her son, Darren Fretter-Hall, on this special day. With their kindness £1,805 was raised for the Norwich Branch.

Brian was an active golf player, but within a few months of being diagnosed with MND he became wheelchair bound, and died 18 months later. It was Brian's experience of the cruel disease that led Sue and Darren to raise funds in support of the research that they hope might one day deliver a cure.



Paul Heath, Scott Lambert, Darren Fretter-Hall, Sue Fretter, Paul Loomes, Gerry Fowler are pictured above. Thank you to Sue for sending the article and photo.

Charity Motor Neurone cricket match: The annual cricket match in memory of former cricketer, Richard O'Flaherty, took place on Sunday 9th August at the meadow in Ashby St. Mary, near Thurton and raised £390 towards the Motor Neurone Disease Association.

Friends and family of Richard attended the 40 over match which saw Ashby win by 5 wickets. At the end of the match Richard's



brother Chris (pictured) presented the shield to Ashby's winning captain, Rob Beaumont. Our thanks go to James Skilliter for providing the news and photo.

Saturday and Sunday 15th and 16th August Charity Classic Car Show:

Prior to the day Sue K, Cilla and others filled wine bottles with water. They wrapped them and bottles of wine with newspaper – with around 400 bottles this was a huge weight to move around as the stall was set up! Cilla, Malcolm, Trish and Jill set up the gazebo on Friday evening and moved the water into place. The wine and water dip proved popular and, though Saturday was the quieter of the two days, £85 was raised as people tried to win bottles of wine. One happy winner is pictured on the right – there are more photos on our branch website. Sue H was kept busy in the afternoon re-wrapping the discarded bottles of water so that we could maintain the correct ratio between wine and water!



The branch was happy to be donated a number of large cuddly toys, which are featuring in a series of “Guess the name” competitions. Jo could be heard calling people in with, “every home needs a puppy, this one doesn't bark, doesn't need walking, no vets bills...” It worked! Charlotte, pictured with her parents, guessed the name of the dog. Her father asked her to choose, then held her close to the board displaying the possible names. With little pause for thought she placed her hand very firmly on the winning name!

Sunday was much busier. Fortunately this year it was not too hot and not too cold – it was 'just right' and it didn't rain whilst the gazebo was being dismantled! Thank you to all who helped with set up and during the two days – and especially those who supported us by coming over to talk and increase their awareness of Motor Neurone Disease.

More photos of the event can be viewed on the branch website.

Sunday 30 August, 2015 - Sprowston Family Fun Day and Charity Football Match:

Amie Godfrey (pictured on the right with friend Lauren, who was also a massive help) and family organised the second Family Fun Day and Charity Football Match in memory of her father in law, Noel Godfrey, and to raise awareness and money for the Motor Neurone Disease Association.

The event began at 12 noon at the Sprowston Sports and Social Club. Despite the forecast for rain we were relieved that it stayed dry all afternoon, though it might have been nice to have seen the sun and felt a little warmer. There were a number of stalls and activities to entertain. These included Little Jumpers with a bouncy castle, slide, candy floss, popcorn and pocket money toys. The fairground rides looked to be a lot of fun and were a big hit with all the children. Neil Reeve Presentz provided walkabout magic and balloon modelling for all the boys and girls. PappleArt facepainting did a good trade painting the faces of young and young at



heart – Malcolm's face reflected his support for Norwich City as well as Amie being a big kid for the day and having her face painted too! Big Pete's burger van was there keeping us all in tea and coffee – and burgers. Despite the chill of the day Mr Frosty's Ice Cream saw a steady stream of customers. The local police attended, with car, and seemed happy enough to let people try out their sirens. Sprowston Fire Department made an appearance later in the afternoon after a busy morning on call outs. Then after a couple of hours they needed to depart in haste on a yet another call out with their lights flashing and sirens blaring! It was an eventful day for them that's for sure! Peppa Pig and Minion Dave must have featured in many family photos by the end of the day. Amie and friends ran a stall with a tombola and a raffle as well as an environmentally friendly version of the wine and water dip. Avon and Unique products were also on sale.



The raffle prizes were announced at the end of the afternoon with many happy faces going home with some of the amazing prizes that were generously donated. 1st Prize was a signed NCFC shirt followed by over 30 other prizes and vouchers that were up for grabs in the raffle.

Cilla, Malcolm, Sue and Jo manned the Norwich and Waveney Branch stall to raise awareness of MND, and were pleased by the number of people who came to talk, guess the name of the Bear – and to buy their Christmas cards early! Sadly no one guessed the bear's correct name so it will re-appear at the Christmas Fair at Colney on 1st November.

The football match began at 2pm and seemed to be enjoyed despite the casualties! Good job the local first responders were on hand to assist those in need.



Thank you to everyone who took part, and to David Willis who took the photographs. Next year's event is already in the diary at the same venue on Sunday 21st August 2016.

Note the new polo shirts and fleece in the photo of Cilla, Amie, Jo and Sue H. – these are available to order. Let Sue Kitson know if you are interested in purchasing one.

Future events in aid of the MNDA

Royal Scottish Country Dance Society Annual Charity Dance 26th September, 2015: We are very grateful to the society for deciding to donate the proceeds from the tombola to our branch of the MNDA.

Coffee Morning Sunday 27th September: Carol and Arthur Bloomfield are hosting a coffee morning from 10:00 to 13:00 at School Cottage, Howe Green, Howe, Norfolk, NR15 1HD. Although this is a drop in event it would help with catering if they had a rough idea of numbers so if you know you are going please email arthur.bloomfield@btinternet.com Alternatively just turn up on the day!

MND Afternoon Tea Fundraiser Saturday 3rd October: Lindsey, a physiotherapist, recently spent some time working at Priscilla Bacon Lodge. Here she was inspired by a person living with MND to raise money for the association. Join her and others at Whitwell and Reepham Station, Whitwell Road, Reepham, Norfolk, NR10 4GA, from 12:00 till 17:00. It should be an enjoyable day out for the whole family!

Tickets are £12.50 per person, which includes: a train ride with the diesel engine, followed by a selection of sandwiches, cakes, scones, and cup of tea or coffee. Other alcoholic and nonalcoholic refreshments can be purchased from the sidings bar.

Please Note: Trains will be running throughout the event however during busy periods you may be required to have your Afternoon Tea before your train ride.

Book now at <http://whitwellstation.com/motor-neurone-disease-afternoon-tea-fundraiser/>

Wheelchair users can access the train from an alternative platform. However, because of the width of the carriage doors passengers must be able to step onto the carriage and mobilise to their seats. If you require support for this or other special requirements please notify the organisers on the form when booking.

Christmas Charities Fair Sunday 1st November: Greenacres Woodland Burials, Colney will be hosting the fair between 10:00 and 14:30. All are welcome at this drop in event. As usual local charities are invited to hold table top sales of their Christmas cards, merchandise and craft items. There are always gifts and stocking fillers on offer. This year the Norwich and Waveney Branch of the MNDA will be joined by, amongst others, Cat Chums, The Big C, East Anglian Air Ambulance, Scotty's Little Soldiers, East Anglian Children's Hospices, The Raptor Trust, and The Hamlet Centre Trust. There will also be a tombola in the Gathering Hall in aid of Nelson's Journey. We hope to see you there!

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

Donations and fundraising

- Joan Heal - £5
- Mad Moose Public House, Unthank Road, Norwich via Amie Godfrey - £85.29
- Upton Get Together, raffle and donation - £86
- Bryan and Eileen Chubbock, collection box - £205
- Sale of goods - £14.10
- Mary King, sale of hagstones - £159
- Phillip Laurier, sale of MNDA goods - £6
- Phillip Laurier - £35 received in sponsorship for the Great Yarmouth half-marathon
- Thelma Pointer - £10
- Berenice Groves - £20 in memory of her father

- Cromer and Sheringham Operatic Society, collection buckets at Cromer Pier shows - £463.16
- James Skilleter, cricket match in memory of Richard O'Flaherty - £390
- Amie Godfrey, proceeds from the Sprowston Family Fun Day - £1,048.92

Donations in memory of

- Mrs King - £400
- Raymond Osbourne Purdy - £85
- Mr Keith James Bass - £388.65
- Mr Geoffrey Rix - £240
- Mr Clive Gadding - £298.86

Internal transfers

- Interest - £52.68
- Charities Trust - £40.89
- National Office Transfer of Gift Aid from Alex Georgescu's walk - £33.75

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

MND Charter: Following the report '*33630 reasons to feel proud*' in the summer edition of *Thumbprint* we were pleased to hear from the campaigning team that Prime Minister David Cameron has issued a reply. In a letter addressed to Sally Light, Chief Executive of the Motor Neurone Disease Association, he thanked her for delivering the MND Charter to Downing Street and wrote as follows:-

“Anyone who has witnessed someone suffering with MND knows that patients can experience a rapid decline in their health, losing their mobility and their ability to speak. It is vital that the NHS responds rapidly to this changing level of need and NHS England's neurosciences service specification sets out what providers must do to deliver high quality specialised care and support equity of access for patients with MND.

Over the past year, NHS England has been working closely with the MND Association to ensure that new funding for the National Augmentative and Alternative Communication (AAC) aids service has been distributed in a fair and consistent manner. AAC aids are important in addressing quality of life and independence by restoring communication for those who cannot communicate using speech. A nationally commissioned service represents an important step forward. I am delighted that NHS England has identified funding of £15 million per year from 2015/16.

It is also important to ensure that there is clear guidance on best practice in support of people with MND and the Department of Health has asked the National Institute for Health and Care Excellence to produce a clinical guideline for the diagnosis, treatment and care of patients with MND. We expect this guidance to be published in February 2016.”

He finishes by saying, “I hope this letter offers you some reassurance of the steps the Government is taking to improve care for those with MND.”

NICE (National Institute for Health and Care Excellence) published the draft guideline on MND on 1st September: This long awaited guideline came about following several years of campaigning by the Association and its supporters. The NICE guideline, when published in its final form, is designed to improve health and social care by making recommendations to health and social care professionals on how best to treat and care for someone with MND. Not everyone will have the time to read the full draft guideline (over 300 pages long), or possibly even NICE's short version (only 48 pages) though of course you are very welcome to – the short version is very readable. However, hopefully some of you will take the opportunity to look at the questions written by the MNDA that ask your views on key parts of the guideline. Feedback needs to be given by **30th September** at <https://www.surveymonkey.com/r/mndguideline2015>

<https://www.nice.org.uk/guidance/GID-CGWAVE0680/documents/motor-neurone-disease-full-guideline2>

<https://www.nice.org.uk/guidance/GID-CGWAVE0680/documents/motor-neurone-disease-draft-guideline-nice2>

Ice Bucket Challenge anniversary: The MND Association is supporting the anniversary of the Ice Bucket Challenge through the #Last Summer campaign, launched during MND Awareness Month in June. As you know in a few weeks last summer the association raised £7.2 million to help fight MND. This represented a huge financial boost enabling the association to bring forward a number of key projects. This summer we look back to last year and say thank you to everyone who took part in the phenomenon. This time last year many people living with MND

felt isolated with a lack of knowledge among the public about their disease and how it affects them on a daily basis. Awareness of MND and the work of the Association have never been greater. A number of people locally have commented that they no longer need to explain their condition, they say they have MND and people have heard of it!

The Ice Bucket Challenge generated 910,000 donations, with 533 new direct debits set up. In terms of awareness raised there were 1 million views of Stephen Hawkings' Ice Bucket Challenge, 700 additional MND Charter signatures and 8,000 new Twitter followers.

However, despite the participation and generous support of thousands of people last summer there is still no cure for MND and we still need your help. If you would like to support us again this year you can make a donation or organise a fundraising event to help raise money. Alternatively if you would like to do the ice bucket challenge again you can find further details on the National Office website. <http://www.mndassociation.org/ibc> You will also find an interesting video made by Professor Ammar Al-Chalabi talking about important research funded by the MNDA.

If you would like to watch something that might make you smile visit 'The Ice Bucket Challenge - Thank You! #LastSummer' on <https://www.youtube.com/watch?v=hKsjBlfCtrk> Alternatively visit our branch website where you can see Malcolm Chubbock being dowsed last August! <http://www.mndnorwichandwaveney.org.uk>

By working together: The MND Association provided one-to-one support for 1,314 people with MND and 479 carers. The MND Connect helpline responded to over 6,000 calls. £230,000 was spent on lending out specialist equipment. Support grants totalled £662,000. The Association supported 65 research projects with a total research portfolio of £8 million. This is in addition to work raising awareness of the rights of people living with MND. The success of the film, *The Theory of Everything* took awareness of MND to a new global audience.

Wheelchair Charter launched: In July the Wheelchair Leadership Alliance launched a Wheelchair Charter as part of a new campaign *Right Chair Right Time Right Now*. The MND Association is a member of the Alliance and has signed up in support of the Charter. Karen Pearce, Director of Care (South) said, “Wheelchairs can be a lifeline for many people with MND but some people experience long waits to access a suitable wheelchair. This is unacceptable for a rapidly progressing condition like MND. We welcome the publication of the Wheelchair Charter and hope it will lead to higher quality services for everyone who needs a wheelchair.”

Our fundraising promise: You will undoubtedly be aware of the recent media coverage of fundraising practices in the charity sector. The Association does not use any of the organisations at the centre of these allegations. Douglas Graham, Director of Fundraising, has outlined our fundraising promise to reassure everyone who supports the MND Association about the high standards we strive to ensure are integral to all our fundraising activity.

- We make sure we comply with all aspects of charity law by rigorously adhering to the Institute of Fundraising Code of Practice and the legislation on data protection
- We do not undertake any cold calling
- We do not share the details of our supporters with any other organisation
- Should you wish not to receive fundraising communications then all you have to do is tell us and we will make sure you are no longer contacted in this way. All our fundraising communication contains this option to opt out

- We receive very few complaints, but when we do we take them very seriously, investigate them thoroughly, report them to our Board of Trustees and take appropriate action
- We are especially careful when communicating with people with MND who are also supporters
- Finally, and probably most importantly, the MND Association is part of the MND family and our most important value is putting people with MND, their families and carers at the heart of everything we do. Everyone in the MND family wants a world free from MND and at the Association we want donating, fundraising, and supporting the MND Association in any way to be a positive experience so we will always treat supporters fairly and with respect, and would never intentionally see to pressurise them in to giving.

Thank you for your continued support. It is only because of you that we can fund research, provide care, campaign and raise awareness. We will never forget that.

If you have any questions please contact our Fundraising Team on 01604 611860 or email fundraising@mndassociation.org

Publications update: Up to half of all people with MND may experience some changes in how they think and behave. For many, the changes are usually subtle and have little or no effect on daily life. For others, the effects may be more apparent and intensive support may be needed.

To help people understand how these changes may affect them, the Association has updated the following information sheets:

- Information sheet 9A – Will the way I think be affected?
- Information sheet 9B – How do I support someone if the way they think is affected?
- Information sheet 9C – Managing emotions.

The information booklet for professionals, which has information on the effects of cognitive changes, how to detect them and how to support people and their families: Cognitive change, frontotemporal dementia and MND booklet.

All of these resources can be downloaded from the main MND Association website, ordered on 01604 611812 or by email careadmin@mndassociation.org

Research

Formaldehyde exposure and increased risk of developing MND: A study published on 14 July in the Journal of Neurology, Neurosurgery and Psychiatry highlights the link between increased exposure to formaldehyde and an increased risk of developing MND. The study in the USA was conducted by Andrea Roberts and colleagues at the Department of Social and Behavioural Sciences at Harvard. The study found that people who regularly came into contact with high levels of formaldehyde had an increased risk of developing MND. The only occupation where this link was found was funeral directors.

This is the first time formaldehyde has been identified as a possible cause of MND, Further studies are needed to confirm the results from this study, because jobs involving exposure of high levels of formaldehyde are uncommon and MND is a rare disease. Read more at:

<https://mndresearch.wordpress.com/2015/07/15/formaldehyde-exposure-and-increased-risk-of-developing-mnd/>

Endomicroscopy lighting the way for a diagnosis: At present there is no diagnostic test for MND, and diagnosis is usually determined through clinical observations and by excluding other

diseases. This process frequently takes several months. By developing an effective diagnostic test for MND, it will be possible to diagnose MND earlier and put in place effective care and support sooner. It would also be possible to start treatment with riluzole earlier. Professor Richard Ribchester and colleagues at the University of Edinburgh have recently been awarded funding from the MND Association to develop a new technique that allows them to view the connections between the motor neurones and muscles, by inserting a tiny, powerful microscope – a microendoscope. They are also working to discover suitable fluorescent dyes to be used with the microendoscope. Read more on the MND research blog for 29 July:

<https://mndresearch.wordpress.com/tag/prof-richard-ribchester>

Results from the UK clinical trial of diaphragm pacing in MND/ALS (known as DiPALS) were published on 31 July in the journal *Lancet Neurology*: DiPALS was the first randomised clinical trial of diaphragm pacing in MND and aimed to find out whether or not diaphragm pacing was beneficial when added to the current standard treatment of non-invasive ventilation (NIV), compared to NIV treatment alone.

The trial results unfortunately show that diaphragm pacing was not beneficial when used in addition to NIV. Read more at: <https://mndresearch.wordpress.com/2015/07/31/disappointing-news-for-diaphragm-pacing-in-mnd/>

Symposium 2015 Destination Orlando: This year's symposium, the 26th, will be held in Orlando, USA on the 11-13 December. It is the largest conference that MND researchers and clinicians can attend, and is organised by the Association. The symposium helps showcase MND research from around the world, allows an exchange of expert knowledge, and improves care practices in MND. The topics being covered this year include sessions on genetic counselling, non-motor symptoms of ALS, cognitive change in ALS, and gene therapies.

Sign up to the research blog at <https://mndresearch.wordpress.com> for daily updates on the presentations. There will also be reports from the symposium on the National Office website.

Miscellaneous

For Professionals: Motor Neurone Disease Study Day at the Riverside Centre in Lowestoft, Suffolk on Friday 27th November 2015 09:30-16:30. To book phone 01604 611837, visit www.mndassociation.org/northsuffolkstudyday or email conference@mndassociation.org. There is more information on our branch website; the programme will be added when finalised.

June Garratt has a Quingo Pick-me up power base chair for sale. It has the ability to turn 360°, as she phrased it 'the chair turns on a sixpence'. There is a one finger control which is currently on the right hand side, but this could be moved to the left. The wheelchair will split into two with the top lifting off to make transport easier. The chair retails at over £2,700, June is asking £1,500. If you are interested please make direct contact with June on 01953 885698.

Thank you to the managers of the **Duke of Wellington** on Waterloo Road, Norwich, NR3 1EG who have put four MND Association collection boxes in their pub. The boxes will be there for six months from the start of September 2015 - we hope their clientele will be generous!

Cards for Good Causes Multi Charity Christmas Shop: 13th October – 18th December at The Forum, Norwich. Open 7 Days a week selling cards for more than 40 charities plus CFGC gifts, gift wrap, traditional advent calendars and lots more. Cards for Good Causes Limited (CFGC) pays the participating charities at least 70p in every pound from card sales. The retained amount covers CFGC's costs of running the temporary charity Christmas shops. Cards for Good Causes Limited is the trading company of the 1959 Group of Charities (Registered Charity No. 249039).

Branch News

Next Open Meeting: Sunday 18 October 2015, 12:30 for 13:00 to 16.00. Wortwell Community Centre, IP20 0HS. Christmas cards and puddings will be on sale together with the usual merchandise.

Advanced notice of the Annual General Meeting in 2016: The AGM will be held at St Andrews Church Hall, Eaton, Church Lane, NR4 6NW on Sunday 6th March from 13:00 to 17:00.

The schedule of open meetings for next year will be discussed at the next committee meeting in September. There will still be time to voice your thoughts before venues are booked. Please phone or email Malcolm or Sue Kitson before October 18 with any positive suggestions regarding the format, catering and location of the open meetings.

Coffee mornings

At Notcutts coffee shop, Daniels Road, Norwich, NR4 6QP: The final coffee morning of the year will be on Wednesday 18 November from 11.00 to 13:00. As usual we are hoping 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.

At the Cherry Lane Garden Centre: The next coffee morning will be held on Wednesday 30 September from 11:00 to 12:00. It is an informal gathering for people with MND and their carers.

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

Wednesday 28 October

Wednesday 25 November

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 MNDA (and would welcome content from the Suffolk Fundraising Group).

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 15 December for the January 2016 edition.

Useful Numbers

Regional Care Development Advisers share an email address

eastangliarcda@mndassociation.org

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

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

Care Service Navigators

Isobel McCarthy 07714 077671 email isobel.mccarthy@mndassociation.org

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

Di-Dann 07870560039 email di.dann@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 sue.kitson2@btinternet.com, 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*