

# Fightback

MNDA Norwich & Waveney Branch Newsletter  
Issue 64 September 2014

## Celebrations!

Chris and Emily O'Flaherty got married at Hunters Hall, Swanton Morley on July 25th. There were around 85 guests both friends and family. Everything went brilliantly. It was a sunny day and lovely relaxed atmosphere. Thundermetal Entertainers (friends of Emily) brought an extra dimension to the day with stilt walking and a fire show. The photos will give you a feel for the day.



The Norwich and Waveney Branch of the MNDA would like to congratulate Chris and Emily on their marriage and wish them every happiness.

By the time you read this Emily and her Dad Peter will have completed a sponsored climb of Pen-y-Ghent in Yorkshire on September 9th raising funds for the MNDA. Chris and Annette will be based in the local hotel raising awareness and hopefully getting donations. We hope you will visit the Just Giving site to read more about Chris and his family as well as to make donations, the web address is [www.justgiving.com/PeterandEmily-Smith52/](http://www.justgiving.com/PeterandEmily-Smith52/)



## Celebrating events in aid of the MNDA

**MND Awareness day at Marks & Spencer Norwich:** As mentioned in the last issue of Fightback the staff organisation at the Norwich Branch of M&S have chosen the MNDA Norwich and Waveney Branch as their charity of the year. On 21 June the branch was invited to have a display with information about the disease, and made Sue K. Cilla and me (Sue H.) very welcome. We were pleased that during our time in the store many people came to talk with us, some sharing their experiences with friends or relatives living with the disease. We held a collection bucket, which was pleasingly heavy towards the end of the afternoon. Meanwhile there were collection buckets on the food tills and collection tins at tills elsewhere in the store.





The schedule of staff events has already begun. Included was a session of leg waxing, it seems the male members of staff with hairy legs were happy to take the pain to support a good cause! The photo shows Ben Godfrey being watched by his mother, June and others. More photos are available on the branch website.

By early August around £2880 had already been raised in memory of Noel Godfrey, the latest figure is £4100; they are on course to reach their target of £5000 this year.

Nearer Christmas we may be asking for volunteers to pack bags at the food tills. Please email Judy or Sue K. if you would be interested in helping.

**Richard Cattermole** completed his 75km circular cycle ride through Suffolk on 22nd June with an average speed of 21mph; this made him third fastest in his group. So far his efforts have raised around £500 for the Suffolk Fundraising Group.

### **Norwich Motor Show at the Norfolk Showground 19-20 July 2014**

Early on Saturday 19 July Cilla and Malcolm arrived the Norfolk Showground to set up the new branch gazebo. It was not quite as described in the shop – it did not just 'pop-up' – and ideally needed four people to put it up. With a little ingenuity and brute force the final score was Gazebo nil, Cilla and Malcolm one! However, given the heat and intensity of the sunshine it was good to have the shade both for us, the helpers, and for the cakes and quiches that we were trying to keep cool and edible!!

The attendance that day was low – it was very hot, and our position towards the back of the showground away from the craft stalls and beyond the motors meant that our cakes did not sell as quickly as we had hoped – though once again cheese straws proved popular.

On Sunday, the weather was promising early in the day and attendance was good. However, towards the end of the show the skies darkened and there was a cracking thunderstorm with plenty of rain. Fortunately Cilla and Malcolm managed to dismantle the gazebo and get things packed away before everything became too wet, except maybe themselves?



Our attendance at an event like this always has two aims, firstly to raise awareness and secondly to raise funds for the branch. Sunday provided more opportunities for the former though on both days we were successful in gathering lots of signatures for the MND Charter. The stall raised £109.50 through the sale of cakes, plants and Christmas cards.

Thank you to all those who helped on one or both of the days, especially to Cilla who masterminded the event and to Hilary (a friend of Sue H.) who was roped in to help on Saturday whilst she was on a 'relaxing' weekend away in Norfolk! Again thank you to all who baked to stock the stall – we were well provided for on both days and appreciated the support.

Cilla is already planning for next year – watch out for the date in August 2015!!

### **“Bake-it” event September 6**

Ann Franklin and her friend Wendy Brown held a ‘Bake It’ Event on 6<sup>th</sup> September in The Barn Room in Hemsby. You can see from the photo that there were a lot of cakes donated for the afternoon!

£320 was raised and 33 signatures were collected for the MND Charter! There was a queue at 2.30 when it started and it was a real success as all the tables and chairs were full.

Thanks to Thelma Pointer and her 3 friends who had been out to dinner and saved their dessert and coffee until they got to the Barn Room! Extra special thanks go to Ann’s friend Wendy who does all the organising and her family for helping out in the kitchen and selling raffle tickets. It was extra special as Wendy’s dad had passed away nearly 3 weeks beforehand and the funeral was only the day before but the family were adamant that John would have wanted it to go ahead.



### **Sunday 7<sup>th</sup> September, 2014 Charity Family fun day at Sprowston Sports and Social Club**



We would like to record a huge thank you to Amie Godfrey (centre) and family, especially Ben (Amie's husband and the late Noel Godfrey's son) and June (Noel's widow), and friends who put on a wonderful family fun day. One of the highlights was a football match in memory of Noel Godfrey who was a keen footballer and referee. The game raised £320 as participants paid to

play! Ben is the last one on the right hand side of the back row in the orange kit. T. Gill & Son Ltd. builders and Anglian Home Improvements kindly sponsored each kit. This helped them pay for them to be made, and they can use them for all future events and charity matches they plan to organise. The sponsorship was a great achievement as Noel worked for Anglian Home Improvements for many years and retired from T Gills when his MND got progressively worse. 4Sports in Dereham made the kits and even personalised the kit bags! They were brilliant!



The weather was perfect for the event that began at midday and continued on until 7pm. The car park was soon full with an overflow along the road as we were joined by a crowd of hundreds including people of all ages. We were also joined by Roger Widdecombe, Regional Fundraiser, East of England, who said he was proud to support the event. He took a great many photos, including those with Peppa Pig, George and Ben assisting with the Ice Bucket Challenge when

June, Jane and June's niece Hannah Taylor sat for a soaking!



It was hard to choose from the many photos taken at the event, more will be posted on the branch website in the near future. The photo below shows a young supporter, Freddie, (Amie and Ben's son) giving the thumbs up with his granddad Graham McMillan. The cake stall made £140 – the figures are still coming in – a grand total will be announced in the next issue of Fightback. It was a great event for raising awareness of Motor Neurone Disease.



Music was provided by The Tickets. Neil Reeve Presentz made lots of children very happy when he painted their faces. In another area they were entertained by Jake Ace a magician doing tricks and modelling balloons. Anarchy tattoos did spray on temporary tattoos. Sprowston Fire Department made an appearance, happily they were not responding to a fire. Big Pete's mobile catering and Mr. Frosty's ice-cream van kept everyone fed, whilst the bar was provided by the Sprowston Sports and Social Club.

The MNDA stall manned by Cilla, and Sue H. assisted by Malcolm was pleasingly busy with people willing to buy their Christmas cards and puddings early. Nearly 70 people showed their support by signing the MND Charter.

**The Ice Bucket Challenge:** The ALS Ice Bucket Challenge began in the US; in the UK people began taking the challenge for the MND.

Thank you to friends and family members who have supported the Ice Bucket Challenge helping to raise awareness of motor neurone disease, including Malcolm and Judy from the committee and Brian Cloke's daughter pictured with her friend taking a very cold challenge in the North Sea. I am not going to try to give a complete list – it would be so easy to miss someone unintentionally; we really appreciate the support of everyone.



We are grateful to Chloe Smith for supporting the Norwich and Waveney branch of the MND by taking the Ice Bucket Challenge and inviting a member of the committee to watch – Judy went along as the branch representative. Chloe nominated the Duke of Cambridge, Network Rail Bosses and Jeremy Goss to take the challenge. Her challenge can be seen on YouTube. For those who have access to the internet and missed the article in the EDP but would like to read it just search for EDP24 Chloe Smith. We would also like to thank Jo Fuller (Neurology Nurse Specialist) for organising a mass bucket challenge where a group of 15 including neuro nurses, physiotherapists and occupational therapists were soaked courtesy of the Lowestoft Fire Station South – they survived regular buckets, three large buckets from the roof top and a hose! For our friends in Suffolk who may be reading this I am adding a link to YouTube where the Morris Men of Little Egypt (in Glemsford) take the Ice Bucket Challenge [https://www.youtube.com/watch?v=9QmBGlfEe\\_g](https://www.youtube.com/watch?v=9QmBGlfEe_g)

Perhaps we should also add our thanks to Tesco who have so far donated £20,000 from the profits made selling ice; they nominated Sainsbury's, Asda and Morrisons to do the same!

Chris Wade, Director of Engagement at National Office emailed volunteers to say, “We are delighted to announce that the income received so far from the Ice Bucket Challenge is just over £6 million.” (This is the equivalent of our income from 48 London Marathons in a normal year). He goes on to say, “This has been an historic fortnight. Last year we received an average of 13,000 donations in a month, from the ice bucket challenge alone we have now had over 750,000 donations. Challenges are still being held and money continues to pour in. We are so incredibly grateful to those of you who use social media and have helped us to spread the word and raise awareness of MND, and are also grateful to all of our supporters for their donations.

“Now that the rush has started to subside, we will be starting the task of deciding how to best spend this money. It is not difficult to spend £6 million quickly; it's much harder to spend it well, therefore we are not rushing into decisions without proper consideration and without dialogue with stakeholders including members, volunteers, staff, trustees and international colleagues.

“However, this unexpected bonus of £6 million does allow us to immediately bring forward certain projects that were already in the pipeline and to fast-track new ideas.

“For instance, we are currently in the process of awarding seven new research grants, totalling over £1 million, to UK research teams for studies aimed at understanding the causes of MND, the processes that lead to motor neurone degeneration and the development of new approaches to treating the disease. Many of these grants will run for up to three years, so the incredible generosity from donors to the Ice Bucket Challenge means that we can be sure of sufficient funding available for the lifetime of each award.

“We have also noticed an increase in volunteering enquiries and applications over the last couple of weeks and we will be seeking to capitalise on the raised awareness of MND with volunteering recruitment efforts.

“If you still plan to hold an Ice Bucket Challenge and would like any resources, please contact the Volunteering Team on 0845 6044 130 or email [volunteering@mndassociation.org](mailto:volunteering@mndassociation.org)

Donations made to the Motor Neurone Disease Association are used to fund the 3 main pillars of our work in support of people with MND and their families: Details of the breakdown are available on the MNDA website

- undertaking research to find the causes of the disease and a cure
- providing care and support for people with MND and their families
- raising awareness to ensure people with MND are recognised by the wider society

National Office makes the point that where we jointly fund research with other organisations (such as the Medical Research Council), for every £1 we put in they often match this with another £2 or £3. Wherever the money is spent you can be assured that it will be spent in the best possible way and have a huge impact, and that it is truly appreciated. Thank you!!!

Thank you to National Office staff who worked until gone midnight over several days (including the bank holiday weekend), and still managed to complete their normal work!

**MND Association AGM Saturday 13 September:** Cilla and Sue H. attended this year's AGM and Annual Conference at the Radisson Blu East Midlands Airport. The theme for the day was 'One Organisation'. The main speaker was Ammar Al-Chalabi, Professor of Neurology and Complex Disease Genetics and Director of King's MND Care and Research Centre at King's College Hospital, London. They hope to present a report in the next issue of Fightback.

## **Future events in aid of the MNDA**

**Firewalk 13 December:** Vici Bailey intends to complete a Firewalk challenge at Sprowston Sports and Social Club at 1pm in aid of the MNDA. She would welcome support! More details will be available on the branch website when they are available.

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

### Donations and fundraising

- Anthony Blakemore Three Peaks Challenge in memory of Jim Heal - £435
- Barbara Winner donation - £125
- Inner Wheel of Watton concert with West End Waiters - £1000
- Cilla Godfrey no uniform day at Central Booking - £22
- Gordon Public House collection - £70
- Aviva Collection Boxes - £55.70
- Mary King sale of Hagstones - £245
- Langley with Hardley Social Club donation due to Club closing down - £780
- Liza and Emma Daniels donations at school fete - £34.36

- Brian and Eileen Chubbock proceeds of garden produce and scones - £200
- Raffle at Upton Open Meeting - £78
- Waitrose Community Matters Initiative - £394

### Donations in memory of

- Roger Ackling - £50
- David O'Neale MBE - £1,903.85
- Barry Norman - £611.63
- Noel Gerard Godfrey - £1,681.18

### Internal transfers

- Interest - £56.43
- Charities Trust - £26.90

*Stop press: Ice Bucket Challenge reaches £6.8 million (13 September update)*

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

**Open Meeting at Upton** On Sunday 10 August we held a branch open meeting at Upton Village Hall where about 30 people enjoyed a hot lunch prepared by the outside caterers from Swanton Morley Butchers and Delicatessen. Brian Cloke captured the atmosphere in the following article that he emailed to me; we would like to thank him for his kind words.

“What You Missed at Upton!

Upton is a little off the beaten track. It is close to Acle and easy to find if coming from Norwich, one turns left into Acle and left again, and then take the road to South Walsham. Upton is sign posted to the right about a mile along that road. Of course, if like one committee member, you turn right in Acle and carry along the ever narrowing Norfolk roads you will find yourself heading towards Reedham Ferry. However, she arrived safely at the meeting and was able to give us her warm smile. Now if like me you come the other way from South Walsham there is the dauntingly named Hanging Hill Lane on the left shortly before the left turn to Upton. Hanging Hill Lane? For those that know the flat land around Acle it is hard to imagine anything resembling a hill. After all this is Broads Country. “Rise” might be more appropriate. “Hanging” I assume took place on this rise and using high ground for the gibbet would have made it visible for some way around and to, quote the French General, provided a means “To encourage the others.”

Talking of hills, a proper one, 694 metres tall, was mentioned at the meeting. Member Chris O’Flaherty came along and told us the lovely lady with him was his new bride, Emily. (Applause all around.) Peter, his new father-in-law, stood up to say that he and Emily are intending to climb Pen-y-ghent to raise funds. For the uninitiated this uncomfortably large hill is a few miles north of Settle in the Yorkshire dales. Sponsorship will be welcome and with sore feet to show for it.

I thought that I had arrived early but entering the Village Hall the tables were laid with chequered cloths, cutlery in place and tumblers waiting for the fruit juice or water which had been provided. Almost before I could sit down there was a committee member asking if I would like either tea or coffee and bringing a cup of tea to the table as I sat down. After announcing that the caterers were ready to serve, committee members delivered the loaded plates to the tables, then offered second helpings, before serving a choice of puddings followed by tea or coffee. Having cleared away they were very grateful to the caterers who washed up! I am sure everyone who was present would like to thank them all.

As if to top that one former lady committee member told me that whilst she did not miss the drive to the meetings on a cold winters night she missed the members themselves.”

It was not a large turnout, perhaps due to the awful weather forecast, but we were pleased to welcome three families who travelled from Suffolk.

## **News from National Office**

**Review of staffing:** Earlier in the summer National Office embarked upon a review of the Association’s staffing structure. This was to enable us to benefit from closer alignment with the NHS *Strategic Clinical Networks (SCNs)* for our care and campaigning teams in particular to have better access to key health care professionals and decision-makers.

To achieve the best outcomes for people affected by MND, the new staffing structure is built into 4 regions, each comprised of a cluster of SCNs. This means that all staff are to be linked to a *Regional Delivery Manager* who has responsibility for ensuring all our employees work in a joined-up way in supporting people with MND in their region.

The Volunteer Development Coordinator for the East of England is Neil Penson.

**A new online directory of services for the East of England** is being launched on 1<sup>st</sup> October. It can be found at <http://mndsupport.org>

**Don't let me die without a voice:** On 9 Sept. the MND Association launched a new campaign, 'Don't let me die without a voice', calling on the next Government to ensure that all people living with MND get timely access to appropriate communication support. They urge us to write to candidates standing in the general election to commit to working with us on this important issue.

Later in the campaign National Office will be collecting experiences with communication aids.

80-95% of people living with MND will experience some loss of speech. Too many people experience significant delays in getting the right communication equipment, leaving some people with MND to die without a voice. This is unacceptable.

We need your help to change this.

### **Branch News**

**Next Open Meeting:** Sunday 19 October 2014 from 12:30pm to 4pm at the Wortwell Community Centre, Tunbeck Close, Wortwell, Norfolk IP20 0HS from 12:30pm. Guest speaker Paul Ray from the Multiple Sclerosis Therapy Centre, Alkmaar Way, Norwich is coming to talk to us about the facilities there and the services they offer – some are open to people living with other neurological conditions. Paul will be accompanied by one of the therapists from the centre.

**Advanced notice of Open Meeting:** Sunday 1 February 2015 from 12:30pm. Swanton Morley Village Hall

Due to popular demand, the **Introduction to Campaigning workshop** will be held in **Norwich** on **21<sup>st</sup> November 2014**. Thank you to those who expressed an interest.

It will be held at Norwich Football Club and run from 0930 -1530, including a break for lunch (which will be provided). The venue is fully wheelchair accessible.

To register for the event, which is absolutely free, please visit: [www.mndassociation.org/news-and-events/events/Campaigning+Events](http://www.mndassociation.org/news-and-events/events/Campaigning+Events)

### **Coffee mornings**

**At Notcutts coffee shop:** 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 at Notcutts on the ring road in Norwich on Wednesday 24 September between 11am and 1pm. Again the morning will provide opportunity to sit and chat – there is no agenda. Of course people living with MND are always welcome. Refreshments can be purchased in the coffee shop. Let us know if you are hoping to attend, but do not worry if on the day things don't go to plan and you are unable to make it – we understand! Our next date is Wednesday 19 November.

**At the Louise Hamilton Centre in the grounds of the James Paget Hospital:** The next two dates for the LHC coffee mornings are Wednesday 24 September and Wednesday 26 November. A room has been set aside for people living with MND and their carers between 11:00am and 12:00 noon. There is no agenda. Tea and coffee is provided.

**Age UK:** Their recent magazine advertised a mini-guide to Great British Accessible Attractions that is available by writing to Silver Travel Advisor/Life, Age UK, Tavis House, 1-6 Tavistock Square, London WC1H 9NA or email [service@silvertraveladvisor.com](mailto:service@silvertraveladvisor.com) They suggested it was useful for people looking for ideas for days out where access is an issue.

**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 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 12 December for the January 2015 edition.

## Useful Numbers

**Regional Care Development Advisers** share an email address

[eastangliarcda@mndassociation.org](mailto:eastangliarcda@mndassociation.org)

Norfolk – Lindsay Goward 08453 751829. Lindsay works Tuesday, Wednesday and Thursday

Suffolk – Liz Cooper 08453 751827. Liz works Monday, Wednesday and Friday

## Care Service Navigators

Isobel McCarthy 07714 077671 email [isobel.mccarthy@mndassociation.org](mailto:isobel.mccarthy@mndassociation.org)

Jo-Ann Dawson 07872 161747 email [jo-ann.dawson@mndassociation.org](mailto:jo-ann.dawson@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.*

### Advertisement:

The Norwich and Waveney Branch has been invited to man a stall. We will be selling MND Christmas Cards and merchandise. Please come and support us.



**CHRISTMAS CHARITIES FAIR**  
SUNDAY 2ND NOVEMBER  
10 AM – 2.30 PM

*Merry Christmas!*

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[facebook.com/colneywoodlandburials](https://facebook.com/colneywoodlandburials)

Please join us in the Woodland Hall for our annual Christmas Charities Fair. Local charities will be selling Christmas cards, craft items and stocking fillers just in time for the festive period – do come along and see what is on offer!

Our Sunday Teashop will be open as normal in the Gathering Hall for homemade cakes and refreshments.

This is a drop-in event – no advance booking is required. For further information please visit our website or contact us on **01603 811556**.

**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](mailto:sue.kitson2@btinternet.com), at Norwich and Waveney Branch, c/o MND Association, PO Box 246, Northampton, NN1 2PR*

If you would like to talk to someone about MND please contact our MND Connect team on 0845 626262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

Visit our online forum <http://forum.mndassociation.org/>

Website: [www.mndassociation.org](http://www.mndassociation.org)

Registered Charity no. 294354

Registered Address: Motor Neurone Disease Association, PO Box 246, Northampton, NN1 2PR

MNDA National Office 01604 250505