

# Fightback

MNDA Norwich & Waveney Branch Newsletter  
Issue 61 January 2014

## North Elmham Young Farmers raise funds for the MNDA



Rebecca Vick, Charity Fundraising Officer of the North Elmham Young Farmers, has advised us that they are to raise funds for the MNDA over the next year. Our branch chairman Malcolm, wearing the MNDA T-shirt in the photo above, was invited to one of their meetings to explain a little more about the nature of Motor Neurone Disease and to talk about the work of the MNDA.

At their first event of the year, a charity fish and quiz night, they raised over £350.



## Celebrating events in aid of the MNDA

*Thank you all for helping raise awareness of MND and for the funds raised to help people with MND.*



The third charity golf day in memory of Brian Fretter was held at Costessey Golf Club on August 23, 2013. The event, organised by his wife Sue and their son Darren, was very successful and raised over £900 for the MNDA. The winner with 34 points was Paul Heath, nearest the pin was Darren Fretter-Hall and the longest drive was by David Littlechild.

Brian, a keen sportsman, died in September 2010 aged 62.

Left to right: Darren Fretter-Hall, Paul Heath and Sue Fretter.

When Anna Kitson and Georgie Sadler were offered the opportunity to join a group walking up Snowdon they jumped at the chance. In Anna's words, "We started going to the gym to get fit



and doing long walks at the weekends. We decided that we would like to raise money for a local charity and as my friend's father had died of MND and my mum works for the charity this was our first choice. We set up our just giving site, gave our work cafes and restaurants money boxes and set about collecting money. Our employers Aviva also gave us £500 to put in the pot. The corporate responsibility team at Aviva gave us a signed Norwich City shirt so that everyone who sponsored us would go into a draw to win it, to help us raise more money.

It took us 5 and a half hours to walk up and down Snowdon, a lot of food, drink and blister plasters but was very rewarding to do it and raise awareness and money for the Norfolk branch of the MNDA." £1378.37 was raised in total.



Ross Brown was responsible for a lot of the hard work that went into organising and comparing the second Ann Franklin MNDA awareness concert at Newport Club Hemsby on the 11 October. They raised a fantastic £2622.65 taking their total since starting the concert in 2012 to £5723.65. Thanks to all who were able to attend and generously support this year's concert. The concert also served to raise awareness of MND with a touching speech from Ann's friend Colleen who described how it has impacted on Ann's life over the last seven and a half years. Malcolm Chubbock also made a short speech giving details of the work done by the MNDA to support people living with MND. It is important to reflect on the day to day support people need not just from the MNDA but also from family members, support staff and friends.



The money raised will be used to good effect. We would like to join Ross and Ann in thanking all the people who helped – the staff at the venue, the performers, the people who sold raffle tickets, carried buckets and sold entrance wristbands. More photos and details can be found on the website <http://mndawarenessconcert.wordpress.com>

The Stall at the Colney Woodlands Burial Park Christmas Charity Day on Sunday 3 November raised £223.45. The parent company Bibbyline Group will match the amount raised. We were grateful to the other stall holders for signing up to the MND Charter.

The joint winners of the Round Britten Quiz, organised by David O'Neale, were Julian Gibson and Brian Parker. The final total raised was £282.

Berenice, on the right, correctly guessed the name of the bear at the Hoveton Motor Show. Here Cilla is presenting her with Fred, the bear, at the Wortwell meeting. Unfortunately the flash did not work as well as sometimes!!



## Future events in aid of the MNDA

Each month, branches of the Nationwide Building Society choose three local projects that support members of the local community. Customers of the building society then have the month to vote for their favourite charity and the winning charity receives £500, whilst the other two nominees receive £100 each. We have sent nominations to the branches in Norwich and Wymondham and are waiting to hear if we have been successful.

Malcolm has been in contact with Norwich Football Club in the hopes that we might join the National Office Campaign 'Football v MND'. We would like them to commit to using a page of their match programme to feature Mark Maddox's story. Ideally we would love a 'bucket collection' too – we may yet need volunteers.

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

### Donations

- Lizzie Parsons - £40
- Noel Godfrey - £20
- Total received in lieu of gifts for the silver wedding anniversary of Joan and Bob Curtis - £133.30
- Mrs. D. Mulley, donation in lieu of sending Christmas cards - £150

### Fundraising

- Lisa Daniels and friends cycled the equivalent of 50 miles on a Turbo trainer at the Forum. Proceeds from collection boxes - £241.01
- Oliver Reek, aged 10 years, completed a 1 mile cycle swim at Hewitt School, Norwich - £307
- Sale of Christmas goods at Wortwell Branch meeting - £332.25
- Anne Gillett sale of Christmas goods at her coffee morning - £115
- Anne Gillett coffee morning - £155

- Collection box from The Salon, Thorpe - £28
- Anna Kitson Aviva collection boxes - £82.37
- Edna Rudd proceeds of a coffee morning/afternoon tea at Blakeney Church Rooms on 21 August - £365
- Proceeds of a cycle ride/pub crawl on 14 August by Amar Rudd and friends in memory of Carol Kumar - £1000 (funds to go to MND research)
- Mary King sale of hagstones - £291
- Mary King sale of fruit and veg. - £300

### Donations in memory of

- Professor Michael Sanderson - £492
- Ian Basseby-Fisher - £1364.10
- Ghislane Hartland - £20
- Jim Heal - £250
- Mary Joy Harris - £225
- Kathleen May Teevin - £810
- Alexander McKillop - £1000

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

**Red Flags:** The MNDA has been working with the Royal College of General Practitioners (RCGP) on an early diagnosis Red Flags tool for MND. The tool has been endorsed by the RCGP and carries both the Royal College and Association logos.

The purpose of the tool is to raise awareness of MND with General Practitioners and to help them to make an accurate and speedy referral to a neurologist rather than to another professional. It is also useful to other healthcare professionals who may be the first to notice the signs of MND in a patient. The tool, which explores the symptoms of MND under the four headings limbs, bulbar, respiratory and cognitive, has been launched and is ready to be used as widely as possible.

The value of it lies in:

- removing uncertainty for the person experiencing symptoms
- allowing for care and support to start as early as possible
- enabling the person with MND and their carer to plan for the future
- increasing the window of opportunity to research into, and better understand, the condition

Articles will be appearing in professional journals over the coming months with the aim to keep the profile of Red Flags high. As members we can help by sharing the tool with the healthcare professionals that we come into contact with and by encouraging them to share it with their colleagues. The more people that are aware of MND the better chance we have to help those living with this condition and their carers.

A copy of the Red Flags tool can be downloaded at [www.mndassociation.org/redflag](http://www.mndassociation.org/redflag)

**The Living with Motor Neurone Disease Guide** can now be accessed online at [www.mndassociation.org/publications](http://www.mndassociation.org/publications)

**The 24<sup>th</sup> International Symposium on ALS/MND** took place from 6-8 December in Milan. Over 950 people, from 34 countries, registered to hear the latest findings from leading scientific and clinical experts, delivered via a wide range of presentations, satellite meetings and discussion groups. A number of presentations from up and coming young researchers, several funded by the association, displayed not only the scope of new research being carried out, but the strength of the 'next generation' of scientists and clinicians joining the MND field. A number of key research areas were discussed on topics ranging from neuroimaging and genetic testing to support cells and clusters. The abstracts for research papers were published online and can be accessed through the research section of the MNDA website. Alternatively you can go directly to the symposium reports at [mndresearch.wordpress.com](http://mndresearch.wordpress.com)

**Westminster launch for the report *A matter of Life and Death: a picture of palliative care services for people with MND in England*:** The report was launched following an audit of Primary Care Trust provision last year. The audit found that only 15% of PCTs knew how many people with MND were living in their area and that many didn't prioritise palliative care.

The report was welcomed by the National Clinical Director for Neurology, Dr David Bateman. Dr Bateman said it is his ambition to ensure everyone with MND could access high quality care no matter where they live. A person living with MND who had spent three weeks in hospice care over the last 18 months welcomed it as a break for his family, a break from the routine for him, and provided a number of opportunities for staff in the hospice to become accustomed to the latest changes in his condition. He made the point that a hospice is NOT just a place to die.

The MNDA will be using the report to influence the provision of services for people with MND at a local level.

**Have your say:** On an associated topic the MNDA is supporting a new survey enabling people to have their say in setting future research priorities for palliative and end of life care. It welcomes feedback from those living with MND, current or bereaved carers, their families, and frontline social and healthcare professionals or clinicians. Dr Belinda Cupid, our head of research, said, “We are asking for your help because we want to improve care, support and treatment for people in the last few years of their lives. We know that many people have important questions about care, support and treatment, and we want to find out what they are. It is an area that is currently under-researched and this ground-breaking research will be invaluable to help guide our future priorities.”

The survey was developed by the Palliative and end of life care Priority Setting Partnership, led by Marie Curie Cancer Care, and brings together a large number of organisations involved in palliative and end of life care research. The project is independently overseen by the James Lind Alliance, a non-profit making initiative, which is funded by the National Institute of Health Research.

You can complete the simple survey online: [www.palliativecarePSP.org.uk](http://www.palliativecarePSP.org.uk)

Over the phone: 020 7091 4153

By post – request a paper version with freepost return envelope either by phoning 020 7091 4153 or emailing [PeolcPSP@mariecurie.org.uk](mailto:PeolcPSP@mariecurie.org.uk)

The deadline is 30 April 2014.

**MNDA Charter:** Our MND Charter, calling for improved support for people with MND and their carers, has been signed by 13,600 people. The more public support we get, the harder it is for decision-makers to ignore the MND voice. Share the link to our Charter [www.mndassociation.org/3minutes](http://www.mndassociation.org/3minutes) Alternatively ask for one of our new freepost MND Charter signing cards.

**Our first ever television advert,** featuring TV presenter Nick Knowles and Eric Rivers, who has MND, is being broadcast on popular TV channels and is showing in cinemas (thanks to the support of Pearl & Dean). The creation of the 60-second advert is thanks to the friendship which began when the DIY SOS team, led by Nick Knowles, turned up on the doorstep of the Rivers family in Enfield, London in November 2011. Eric's family friends had contacted the show.

Nick said: “Eric is about the bravest and most honourable man I know, a fine husband and great Father. It is an honour to work with him to bring this terrible condition to the attention of a greater audience. I hope others will be motivated by Eric's words, as I was, to get involved or offer what financial support they can to the MNDA”.

Douglas Graham, our Director of Fundraising said, “We are delighted that we are able to spread awareness of MND by reaching so many people in this way and we are very grateful to Eric, Nick, and his production team, for making the advert. It is powerful and poignant and is clearly connecting with television and cinema audiences.” The advert, includes a text-to-donate number and more than 450 texts had been received in the first half of December.

To find out more and view the advert visit [www.mndassociation.org/drtv](http://www.mndassociation.org/drtv)

## **Branch News**

**Thank you:** Liz Cooper and Pauline Matheson asked us to convey their thanks for the invitation to share information about the Volunteering Fund at our Wortwell Meeting in October. They appreciated our help and support in accommodating the focus group sessions and wished to extend their thanks to all the people affected by MND who took part. They hope to attend a future meeting to update us on the project.

**Next Open Meeting:** 12:45 pm Sunday 2<sup>nd</sup> February 2014 at Swanton Morley Village Hall, Manns Lane, Swanton Morley, East Dereham, NR20 4PX

**Advanced notice of the Annual General Meeting:** Sunday 27 April 2014 at St. Andrew's Church Hall, Eaton.

**The next meeting at Notcutts:** We would like to invite carers and people living with MND to an informal get together at Notcutts on the ring road in Norwich on 15<sup>th</sup> January, 2014. Again it will be an opportunity to sit and chat with people who have been through or are currently involved in caring – there is no agenda. Unlike the open meetings where refreshments are provided anyone attending will need to pay for their own tea or coffee and snack. Let us know if you are hoping to attend and if you think there are other venues we might try. Following a suggestion at the last open meeting we did approach Waitrose with a view to using their coffee shops. They were very apologetic that they were unable to accommodate us. However, they are happy to support us through the 'green token' scheme and invited us to put in a request. This has been sent to the Wymondham Branch, though we will approach others during 2014.

**Meetings at the Louise Hamilton Centre:** A room has been set aside for people living with MND and their carers between 10:30am and 12:00 noon. Please note the change in times from the events last year. The Louise Hamilton Centre is in the grounds of the James Paget Hospital. The list of dates for 2014 is given below, though reminders will be posted in future editions of Fightback. Judy Burns-Thomson asks anyone who is thinking of attending to give her a call first in case it is necessary to make any changes – her contact details are included on the back page.

Wednesday 29 January

Wednesday 26 March

Wednesday 28 May

Wednesday 30 July

Wednesday 24 September

Wednesday 26 November

It is hoped that some dates can be agreed at the January meeting for some informal get togethers at garden centres in the East of the region for the intervening months.

**Newsletter Editor:** Thank you to all who have sent photos and stories for inclusion in this edition of the newsletter, particularly as it came at a very busy time for many. The next deadline for receipt of articles is Friday 7 March 2014 for the March edition.

The newsletter should be available to view online on the MNDA website. Follow the links to Getting Help, Local Support, Branches, East Anglia and finally click on the Norwich and Waveney Branch. The direct link is [www.mndassociation.org/norwichandwaveney](http://www.mndassociation.org/norwichandwaveney)

**The Chief Executive's Appeal:** This is a way for branches to make a donation to a specific area of the work of the MNDA. In 2012 our branch was amongst the 45 branches and groups who between them contributed £298,500; the largest ever response.

This is the difference it made:

- **Equipment Loan Service.** As a result of the donation of £71,000 to this fund the association was able to purchase 45 new riser-recliner chairs to replenish the equipment loan scheme and a further 34 chairs to go directly to individuals who were in immediate need. The National Office support services team (covering equipment loan and financial support) were able to negotiate with suppliers to get lower cost deals on these chairs to ensure best value for money.
- **PhD Student Programme.** £54,000 was directed to this area of need. Brian Dickie, our Director of Research, said: "This boost was extremely welcome and timely. We expected to fund around three new projects from the autumn 2012 grants round, but the quality of the proposals was so high that we ended up funding five. The projects cover research ranging 'from bench to bedside'. The laboratory studies involve the study of motor neurons in cell culture (including new stem cell models) and the creation of zebrafish models of MND. The

clinical studies involve the development of a new ultrasound technique to aid the diagnostic process, and investigating new ways of analysing MRI scans to help predict how the disease is likely to progress.”

- Building on the Chromosome 9 discovery by supporting a project to investigate the inability of motor neurones with this genetic cause to deal with a build up of damaged proteins – a common feature of MND. The Cardiff researchers have already helped to develop a genetic test for the C9orf72 form of MND for use within the NHS. They have also developed a way of assessing how much C9orf72 protein is being made within cells and where it is located. Their work using post-mortem human tissue indicates that levels of the functioning protein are reduced in the brain and spinal cords of people with MND. They are collaborating with research teams in Oxford and London to try and understand how these protein changes can disrupt the normal function of neurones, leading to their degeneration. £85,000, almost half the cost of this project was funded by the branches.
- Trustees' Discretion – a further £88,500 was donated which was then allocated as opportunities arose to make the biggest difference for those affected by MND.

**The money raised from the 2013 appeal will support the following important projects.**

- Funding a National Register for MND. This is a programme that aims to aid understanding of where MND occurs across the country, the natural history of the disease (how the disease manifests and progresses in different individuals) and the 'real world' impact of the care and support offered. The development of this register will also form the foundations for future large-scale clinical research programmes, including genetic, epidemiology and biomarker studies. The initiative will build on two successful regional registers that have been in existence in England for several years and will be created to complement similar initiatives in Scotland and the Irish Republic.
- Supporting adaptations to property. The MNDA is getting many more requests for adaptations to property to support people with MND to achieve a better quality of life. We are unable to support extensions to property or major structural changes, but can help with for example fitting a wet room, or funding the installation and first six months' rental of a washer dryer toilet, provide support for installation and rental of stair lifts, or widen doors for wheelchair access. The support services team are able to negotiate lower costs on our behalf.
- Campaigning and awareness. The new MNDA Strategy, which sets out our plans and priorities for the next three years includes, for the first time, Campaigning and Awareness as the third pillar of our programme alongside Care and Research. At this time it is crucial that we keep the needs of people with MND and their carers at the forefront of the minds of those designing services and making decisions that will influence services for years to come. Recent surveys have shown that people living with MND want the association to do more to raise awareness of the condition, both with the general public and the health and social care professionals. An example of this sort of work being the Red Flags check-list referred to earlier in Fightback.
- Trustees discretion. This money can be used wherever they determine the need is greatest.