

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 70 May 2016

Freephone number for MND Connect 0808 802 6262

Events in aid of the MNDA

15th March 2016. Malcolm was invited to receive a cheque for £2,020 from Mr and Mrs Ablett.



The money was raised at the Charity Football Match in memory of Mitch Block on the 27th December 2015, as reported in the last edition of Fightback. The presentation took place at Chinny's Sports Club, Halesworth.

From left to right - Joe Block (son of Mitch), Malcolm, Karley Block (daughter of Mitch), Sharon Farrow, Sonia Ablett, John Oakley (73 year old goalkeeper), Gary Bennett (Captain of Gaz's Team from Lowestoft), Paul Ablett (Captain of Coffin Dodger Team), and Mac Watson.

All the players signed a shirt, now framed, which will hang at the club. A shield has been made and they plan to make the match an annual event. So far it has one name engraved - Gaz's Team, the winning team for 2015 with a score of 1-0. From left to right the photo showing the signed shirt features Karley, John, Joe, Paul, Malcolm, Mac, and Gary.

My apologies for referring to Halesworth as Halesford in the January edition.



Sunday 13th March 2016. We are grateful to Simon King who ran the Barcelona Marathon for the MNDA in memory of his Grandmother. He raised £812.30 via his sponsorship forms and a further £235 on his Just Giving Page. More details and photos will appear on our website later.

Future events in aid of the MNDA

Sunday 29th May 2016. Phillip Laurier will be running a tough half-marathon on behalf of our branch of the MNDA. Phillip is no stranger to running marathons, he tells me the challenge will be the gradients. The circular route starts and finishes in Buxton, Derbyshire, and passes through some beautiful countryside which should provide some good views if he has to stop and take a breath!

Sunday 21st August 2016. Amie Godfrey is organising the third **Summer Fun Day** from 11am to 6pm at Sprowston Sports and Social Club. More details will appear on the website as soon as they are available.



Shhh!!! Imagine an hour... a day... a week without speech – this is the reality for many people living with MND.

The MND Association are looking for lots of supporters to take on the challenge and sign up for this year's 'Silence Speaks'.

Silence Speaks is more than just a sponsored silence, it's about finding other ways to communicate. Whether you are taking on the challenge on your own, getting your workplace involved or taking part with friends and family, we have all the tools and information you need to help you. To get involved and take part in Silence Speaks, simply visit and register at www.mndassociation.org/silencespeaks or contact

Roger Widdecombe, your Regional Fundraiser, telephone 01908 508398 or email roger.widdecombe@mndassociation.org. Remember to say that you would like the money raised to go to the Norwich and Waveney Branch.

You can also visit the Volunteer Zone on the MND Association website <http://www.mndassociation.org/> to get lots of hints and tips to help with your fundraising.

Supporting Silence Speaks will make a huge difference to people living with MND. We know that more than 80% of people living with MND experience communication difficulties, and for many this can be the hardest part of the disease. So, why not sign up today and 'lose your voice to help others be heard'.

There is also a NEW teacher and youth leader pack for 2016 with lots of ideas and useful resources to engage young people in the event which we would be happy to send to any schools, colleges, universities or youth groups you may have contact with.

The Virgin Money Lounge, 10 Castle Street, Norwich, has kindly agreed to allow Sue Heal to collect money in aid of the branch during her 8 hour struggle to stay silent on 11 June. Sue will be finding out just how difficult it is to communicate using only pen and paper. She will let you know how she gets on!!

It would be good to publicise your Silence Speaks events on our website and feature a follow-up report in the October edition of Fightback.

Thank you for your support to Share the Silence.....

Sponsored Walk to D'feet MND Saturday 16th July 2016. Anne Gillett is organising a sponsored walk on Gorleston Promenade in memory of her husband who died five years ago having bravely suffered with MND. Gorleston Promenade is two miles long and a safe surface for both walkers and wheelchairs to take part. The walk will commence at 2pm. Participants may walk the distance they feel happy with.

Sponsorship forms will be available from the MNDA website, the Coffee Mornings and the Open Afternoon Tea at Upton Village Hall in June. A bucket collection will take place and donations may be made instead of collecting sponsors. Everyone is welcome. Contact Anne if you plan to walk (her contact details are on the last page). We look forward to seeing and walking with the participants.

charity autumn hall

saturday 8th october
2016
marriott sprowston
manor



7pm arrival for paparazzi photo
experience, 7:45 sit down for a
luxurious 3 course meal and then
be entertained by the Tesla Jets
followed by a local DJ until 1am

tickets £50 pp

for ticket info please email thegodfreysfundraising@hotmail.com

mnda

motor neurone disease
association

In memory of Noel Godfrey who died of MND in April 2014

Donations can also be given to just giving page www.justgiving.com/NoelGodfrey

facebook Search "charity ball in aid of Motor Neurone Disease" on facebook for more information

MND Association, Registered England, Registered Charity No. 294354.

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

Donations and fundraising

- Carole Saunders - £20
- Diana Buckingham, donation in lieu of birthday present - £40
- Amie Godfrey, collection box at Mad Moose Public House - £20.15
- Sue Childs (Store Manager), collection box at Factory Shop, Harleston - £52.83
- Thelma Pointer, in lieu of leaving present for Sue Kitson - £100
- Halesworth, further money from the Football event - £40

- Raffle at Annual General Meeting - £79
- Kim Gaze - £20
- Mary King, sale of hagstones - £124.50

Donations in memory of

- Graham Keeler - £515
- Arthur Bloomfield - £600

Internal transfers

- Interest - £76.11
- Charities Trust - £54.52
- National Office - £106.72

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

Snap Action: Snap Action was launched on 4th April. It enables people to take part in short snappy actions which require no long term commitment, but which combined together can make a huge difference. Our initial actions are based on awareness raising, fundraising and campaigning activities and most will take no more than two minutes to complete. The actions will change regularly. Follow the link from the branch website – volunteering page, or visit <http://www.mndassociation.org/get-involved/volunteering/snapaction/>

Care information update

The following new publications have been introduced

- **Motor neurone disease checklist.** A form to help people to manage their condition and think ahead with MND. An action plan is included to help list areas for discussion with an appropriate health and social care professional.
- **Information sheet 10F – Your rights to social care.** Includes details of people's right to social care in England, Wales and Northern Ireland. Being aware of these rights can help you get an assessment, and access support and information.
- **So what is MND anyway?** Our guide to help support young people aged 13-18, who are close to someone with MND. More information was provided in the Spring edition of Thumb Print.

The following publications have been updated

- **Caring and MND: support for you.** Our main guide for carers, revised and redesigned. This guide can help people supporting someone with MND to think about their own wellbeing in the caring role and how to access support as a carer.
- **Understanding my needs.** A revised form to help people living with MND record their needs. This can help care workers or hospital staff provide appropriate care, according to the person's wishes.

You can download these publications from www.mndassociation.org/publications or order printed copies from MND Connect on 0808 802 6262.

Research

Stem Cells were in the news in January, but a little too late to make the last edition of Fightback. Recent stem cell trial results from a MND study in Israel, and a Panorama programme on stem cell treatment trial for multiple sclerosis, have raised the profile of whether stem cells could be a possible therapy for MND.

Sara Bolton wrote an article posted on the MND Research Blog on 20th January looking at the results from these two trials, and what they mean for people living with MND.

<https://mndresearch.wordpress.com/2016/01/20/stem-cell-trials-in-the-news/>

Pesticides linked to increased risk of MND. Dr Feng-Chiao Su and Dr Eva Feldman led a group of researchers from the University of Michigan looking at the possible links between exposure to environmental toxins (found in pesticides) and motor neurone disease.

The study took 156 people with amyotrophic lateral sclerosis (ALS, a type of MND) and 129 healthy 'control' participants from Michigan, USA. They completed questionnaires on their occupational history, gave blood samples, or did both. The levels of 122 persistent (long half-life) environmental pollutants (including organochlorine pesticides) were tested for in the blood samples. The blood tests could pick up exposure to pesticides years ago.

“The results from the questionnaire indicated that exposure to pesticides at work during any point of a person's life is linked to an increased risk of MND. Blood samples showed that concentrations of five environmental pollutants were also associated with increased risk of developing MND.”

There are many different types of pesticide. The researchers found that it was a group of older pesticides that increased the risk of developing MND. These pesticides are known to stay in the body for many years after entering it. Their effects are well known, and have led to a ban on the use of several pesticides of this type, such as DDT.

“Modern pesticide use is strictly regulated and the chemicals used do not last as long in the body as the old type. The new types of pesticide could not be picked up in participants' blood samples, and so we do not know if they present a risk factor for MND.”

Dr Belinda Cupid, Head of Research at the MND Association said, “It's unlikely that any single factor on its own will cause MND and the results in this research paper aren't a 'eureka' moment. But the evidence that exposure to pesticides is a contributory risk factor towards getting MND is stacking up and I'm sure will be the focus of future research.”

The information is taken from an article posted by Sara Bolton on the MND Research Blog on 10th May 2016. <https://mndresearch.wordpress.com/2016/05/10/pesticides-linked-to-increased-risk-of-developing-mnd/>

Branch News

Sainsbury's. Each Sainsbury's store selects a local charity that it will support for a year. We have sent a nomination to each of the four Norwich branches. The next step is to learn if we will be invited to give a presentation to the store. The store will then decide on a final shortlist of up to three local charities. The short list will then be announced and the public invited to vote in store and through their website www.sainsburyslocalcharity.co.uk. Please watch out for the start of voting and lend us your support. Thank you!

Advanced notice of the next open meeting: Sunday 20th November, 12 noon for 1pm (to allow time to purchase Christmas cards and merchandise) at Wortwell Community Centre, Tunbeck Close, Wortwell, Norfolk IP20 0HS. This year we are planning to host a Christmas lunch.

Thank you! Sue Kitson held the post of branch secretary from the time of the formation of the Norwich and Waveney Branch of MNDA in April 1995 until she retired in February 2016. Initially Sue's husband Mike was also a member of the Branch Management Committee. Every meeting except one was held at Sue's home, including the steering group meeting, until this January. She has hosted a total of 149 meetings over 21 years. As well as being secretary, Sue was present at fundraising and awareness events. The committee made a presentation of some flowers and theatre vouchers to Sue at the last meeting held in her home on 5th January. I think we all appreciated the support and friendship that Sue gave so freely – and all the little things done behind the scenes. One example of many was the fresh flowers on each table at the open meetings, which came from Sue's garden.

Sue in turn expressed her thanks for the gifts; she and Mike used the vouchers to see the Northern Ballet Company's performance of Swan Lake which they really enjoyed.

Our thanks also go to Margaret Heywood who stood down at the Branch AGM in March having served on the committee for many years.



Annual General Meeting. The 21st AGM of the Norwich and Waveney branch of the MNDA was held on 6th March at St Andrew's Church Hall. Firstly, thank you to all those who attended! Sadly attendance was low; we will avoid Mothering Sunday next year. We have to finalise numbers 72 hours ahead of an event. If we know of changes to the numbers attending this can avoid branch funds being wasted on meals that are not eaten. Of course we fully understand that unforeseen events can cause plans to change at the last minute.

The AGM itself was short and efficiently chaired by Malcolm. Helen Devlin was formally elected as the branch secretary, and Malcolm agreed to continue serving as our Chairman. Lindsay Goward presented long service awards to Malcolm and Judy - and left an award for Sue Kitson together with a 'Thumbs Up' rose bush. Isabel Coe, of East Anglian DriveAbility, gave a very interesting presentation looking at all aspects of providing assessment and advice both for drivers living with disabilities and for passengers with mobility difficulties. She threw a few questions out to the audience which made us think! Do you know if it is legal to drive with only one eye? For initial advice and information and to check for your nearest Driving Mobility Centre call 01842 753 029 or visit the website: <http://www.eastangliandriveability.org.uk> or Email: mail@eastangliandriveability.org.uk. A link to East Anglian DriveAbility can be found on our 'Useful Links' page at <http://www.mndnorwichandwaveney.org.uk/links.htm>.

Open Meeting: Sunday 19th June 2016, from 2:30pm until 6pm at Upton Village Hall, Upton, Norfolk, NR13 6AU. We are holding an afternoon tea. Let us know what you think of the slightly different format for the meeting. We welcome suggestions as to how to make our open meetings more relevant and appealing. We are following the Silence Speaks theme during our meeting by holding a 'Silent' themed quiz – we might also include some questions on Father's

Day. The cost of entering the quiz is £1, feel free to gather in teams of up to 4. Yes, we have hit the jackpot and chosen Father's Day for our June meeting. The committee has promised to buy Malcolm a 2017 diary with Mothering Sunday and Father's Day marked in it – though it might have helped if the rest of the committee had noticed the significance of the dates! Fathers, attending our get together is one of the best ways of celebrating your day, we might also have a small gift for you!

Coffee mornings

At Notcutts coffee shop, Daniels Road, Norwich, NR4 6QP: The next coffee morning will be held on Wednesday 18th May from 11am to 1pm. 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.

Advance notice of 2016 dates for Notcutts, Daniels Road, Norwich, NR4 6QP

15 th June	20 th July	17 th August
21 st September	19 th October	16 th November

At the Cherry Lane Garden Centre: The next coffee morning will be held on Wednesday 25th May between 11:00am and 12:00 noon. It is an informal gathering for people with MND and their carers.

Advance notice of 2016 dates for Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU

29 th June	27 th July	31 st August
28 th September	26 th October	30 th 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 7th September for the October 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

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

Di Dann 01328 878 196 email di.dann@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*