

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 58 March 2013

The West End Waiters at the Swanton Morley open meeting.

The West End Waiters kept us amused with a repertoire that included music from Gilbert and



Sullivan, and Flanders and Swann. They adapted 'There's a hole in my bucket' for the group, gave an amusing rendition of 'The Pheasant Plucking Song', the ladies performed some sketches and a duck or two were added to the mix! Here you see them with Chelsea Pensioners' hats reminiscing about the girls they once knew!

The group have been raising money in aid of the MNDA for some time now for which we are grateful. If they are performing near you they are well worth going to see.



Lindsay Goward, our new Regional Care Advisor, also attended the open meeting. Her background includes spending a number of years with the Multiple Sclerosis society developing regional services, training professionals around neurological conditions and supporting the society's branches. She has also been a manager in an advice charity for older people and has worked for a charity working with children with disabilities.

Lindsay lives in West Norfolk with one son. She is looking forward to her role within the MNDA working with volunteers to improve and develop services for people living with MND in East Anglia. We look forward to working with her. Lindsay can be contacted on 08453 751829 and by email at lindsay.goward@mndassociation.org. Lindsay works on Tuesday, Wednesday and Thursday as part of a job share arrangement with Liz Cooper.

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 Franklin family and friends raised £1,624 with a cycle ride, from Cley in North Norfolk to Ness Point in Lowestoft, which was spread over two days in July 2012. Jeremy arranged for the Waveney MP, Mr. Aldous, to meet the group at Ness Point. An article in the Lowestoft journal, written by Ann who has a slow developing form of MND, helped spread awareness of the disease and the work of the Association. Ann used a battery powered trike and some pedalling to cover 11 miles.

From left to right Jeremy Woodruff, Linda Nolan, Mr. Aldous at the back, Max, Ann and Barrie Franklin, and Barry Hipwell.



Arctic to the Med: the final sum donated to the MNDA was £1,496. The remainder was raised for a cancer charity.

From left to right Fred Edwards, Freddie Martin and Alex Mansbridge

Future events in aid of the MNDA

We hope you will be able to support one or more of the following events:

- A concert is being performed by members of Bridgham and Harling Band at St. Peter and St. Paul Church, East Harling on Friday 26 April 2013 at 7:30pm. Payment on the door £6. All proceeds to the MNDA. More information is available from the organiser George Lawn on 01953 717493.
- Milton Keynes Marathon 6 May 2013. Phillip Laurier, pictured on the right, will be running in aid of the MNDA and would be glad to receive sponsorship – he hopes to be at the Eaton meeting, so look out for him! (Phillip also completed the Norwich half marathon last November).



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

Donations

- Proceeds of raffle at a Craft Fayre organised by Hilary Webster, a friend of Ann Franklin, £112.00
- Donation in lieu of sending Christmas Cards from SMT Motors - £50.00
- Late donation to Keeble Family Bungee Jump -£ 10.00
- Clive Gladding £50.00
- Money raised by Dereham Rotary at Xmas Tree Festival - £20.00
- Donation in lieu of sending Christmas Cards in Jackaman's office - £40.00

- Mary King, sale of Hagstones - £159.25, miscellaneous sale - £135.95
 - Bibbyline Group cash matched proceeds from the Colney Woodland Burial Event - £526.06
 - Fakenham Church Christmas Tree Event - £355.82
 - The Lingwood Family - £45
 - Gift aid transfer from National Office - £281.02
 - Lucie Legg - £662.85
- ### Donations in memory of
- Mr Vic Saunders - £100
 - Mr John Peter Francis - £165.00

My apologies to those who have made donations but whose names have not appeared, and for the absence of a report of the money raised at Swanton Morley – these figures will appear in the next edition.

The branch would like to express condolences on the death of Olive Anthony who died suddenly but peacefully in January, aged 80. Olive was always present whatever the weather helping at the garage table top sales at SMT Motors, Hoveton run by Sue and Stewart Tubby. They, with friends, have been raising money for the MNDA for at least eight years.

Useful tips: Terry Roberts would like to recommend a device called Safesip, which he has been using successfully. It has saved him spilling many drinks even when knocked over, dropped or held whilst coughing and sneezing! It can be ordered online for about £7 plus postage and packing. It is a clear silicone cap (available in three colours) that seals the top of most glasses and other drinking vessels whilst allowing a straw through it to drink.

Directions 1.Fill the glass to about three quarters full with liquid. 2. Make sure that the outside of the glass is dry. 3.Stretch the Safesip over the top and push a straw through the larger hole.

Problems and limitations 1.The device is likely to slide off if any moisture is left between it and the glass. 2. It can be punctured by sharp fingernails. 3. Size of opening on the drinking vessel. 4.Not sure if it will work with a large diameter straw.

Maintenance It can be washed by hand or in the dish washer.

Google Safesip and you will see pictures, reviews and be able to order the item.

Terry also noticed the 1 litre drinking hydrant bottle with tube mentioned on the MNDA forum; initially designed for sports people it is useful for those with MND who have little use in their hands. The bottle can be attached to a bed, and one can take sips from the tube as and when required. It might be worth talking with your occupational therapist or neurological nurse specialist about the safety of using this device in your particular circumstances.

News from Head Office

New insight into MND gene: An MND Association funded research project at University College London has revealed new insights into the structure and function of an MND gene called C9ORF72. A team has successfully identified the structure of a genetic mistake in C9ORF72. Since the discovery in 2011 that genetic mistakes in this gene can cause up to 40% of cases of MND with a family history of the disease, researchers have been trying to unravel its role in the body, to determine how it could cause MND. Understanding how the gene works, what it looks like and how mistakes may cause MND could assist researchers in the future to identify potential treatments that target the disease. For more information see:

<http://www.mndassociation.org/news-and-events/Press+Releases/2012/quadruplex+C9ORF72>

Disappointing results from drug trial: BIOGEN Idec has announced the news that their drug dextramipexole showed no beneficial effect for people living with MND. Brian Dickie expressed his disappointment, “We had great hopes that the drug would show a beneficial effect, based on the positive data from the earlier Phase II study.” The knowledge gained from the trials can be used to inform future trials and we are glad that the company is continuing to prioritise MND as a disease that can be targeted for treatment. The drug is considered safe to take. Some people in the UK may still be taking it, if so it is recommended that you contact your study centre.

Spring Conferences: focus on current news in both care and research and provide an opportunity to chat informally and network with other people interested in MND. The nearest location for our branch is Cambridge Belfry, Cambourne on 13 April. Delegate fees have been kept at the same rate as last year so that people living with MND and their carers/spouses can attend for free, members £12 and non members £15. Lunch and refreshments are included in the price. You can view the programme and register on the MNDA website or using the form sent out with the winter edition of Thumb Print. Alternatively contact the Conference and Events team on 01604 611837 or email conference@mndassociation.org if you would like a copy of the programme or to talk about the conferences being organised this year.

Explaining benefit changes: People who receive Disability Living Allowance (DLA) may recently have received information about the introduction of Personal Independence Payment (PIP), which will eventually replace DLA.

Anyone who currently receives DLA does not need to do anything at the moment. People living with MND aged under 65 and not receiving DLA should consider claiming it before PIP is introduced as it may be easier to qualify for DLA than PIP in the early stages of MND progression. Apart from some areas of the north of England, where the date is April 8, DLA closes for new claims on June 10. Although DLA may be easier to access than PIP, Head Office still expect PIP to be available to all people of working age.

For people making a claim aged over 65, Attendance Allowance remains available and is not being changed. Eventually everyone receiving DLA will be required to claim PIP instead, but this will take several years. From October 2013, those who need to report a change in their condition to move to a higher rate of DLA will see their claim changed to a claim for PIP. Those who have a fixed term DLA award that ends in February 2014 or later will be asked to claim PIP when it comes up for renewal. Apart from people in those situations nobody receiving DLA needs to take any action until they are contacted by the Department of Work and Pensions (DWP). The DWP has committed to contact people with terminal illnesses only towards the end of the programme, so anyone with an indefinite DLA award is unlikely to have to take any action this year, or even in 2014. If you are asked to apply for PIP you need to complete the form and send it back; there is no automatic transfer from DLA to PIP. The process may involve a face-to-face assessment, though it is anticipated that most people with MND will be able to have their claims processed without this. If you would like further information please contact MND Connect on 08457 626262.

Branch News

Next Open Meeting and AGM: 1pm Sunday 14 April 2013 at St Andrew's Church Hall, Eaton. Dr. Brian Dickie has been booked to give us an update on research into Motor Neurone Disease.

Open Meeting: Advance notice of the date for your diary. Sunday 4 August 2013 at Upton Village Hall. We hope to have entertainment.

Regional Discussion Forums: Sally Light, chief executive, and Mark Todd, chairman of the board of trustees of the MNDA, have arranged a meeting between volunteers and staff in the region. The meeting provides an opportunity for us to highlight issues for people living with MND in our local area, express any concerns and to make suggestions first hand regarding the direction of the Association. Two or three committee members will be attending so please talk to us about issues you would like raised.

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 14 June for the July edition.

Thank you to those of you who responded to my request to accept the newsletter as an attachment to an email. If others would like to receive the newsletter in this format please send me an email – my contact details can be found on the included list of committee members. The paper version will continue to be sent in the normal way for those who prefer it.

The newsletter is now 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 <http://www.mndassociation.org/getting-support/local-support/branches/East+Anglia/norwich-and-waveney-branch-260412.htm>. We have also updated the page with a photo of those members of the committee who were able to attend the Swanton Morley open meeting. We now have the facility to add forthcoming events to our page. If you would like your event advertising please send me the details set out as you would like them to appear so that I can forward them to the Volunteer Liaison Co-ordinator who will do the necessary work to ensure they are added to our page. Allow as much time as possible as this takes time to work through the system.

My apologies to Lindsey Wilkins for misspelling her surname in the last edition of Fightback.