

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 59 June 2013

Malcolm, Cilla and Sue H attended the Regional Discussion Forum chaired by Mark Todd, chairman of the board of trustees of the MNDA. Sally Light, chief executive, gave a presentation highlighting some achievements of the MNDA during the last financial year.

- 430 Connect calls per month
- Approx 320 active Association Visitors (1200 people with MND)
- 900+ people at Chicago Symposium
- 8,000 Charter signatures
- Wheelchair and volunteer grants (£1m)
- Biggest ever Christmas appeal (£160k) & 2012 London Marathon (£260k)
- Achieved a balanced budget

Sally's presentation was followed by a lively discussion of some of the issues faced by groups and branches. Of particular concern to the groups is how money raised locally is spent. As a branch we have greater control of our finances than would be the case if we were a group, but still operate within the guidelines agreed as an association to ensure that the needs of everyone living with MND can be met regardless of where they live or where the money is raised. It was interesting to see that there was a good balance between money spent locally and money spent from National Office to fund research and the back-up needed to provide services like Connect.

Celebrating events in aid of the MNDA



One of Sally's first announcements was the news that the MNDA garden had just been awarded a gold medal at the Chelsea Flower show. This provided an opportunity to raise awareness of the disease through publicity on television, radio and across the web. The cost of the creation of our garden was covered by the generosity of five sponsors and did not cost the Association any money. It was co-created by Martin Anderson, one of our founders, and Jacqui Setchfield.

I am grateful to Peter Willsher, who attended the show, for taking the photo especially for use in Fightback.

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

- Phillip Laurier, who ran the Milton Keynes Marathon on 6 May emailed to say that he completed the run in 4 hours 44 minutes and 20 seconds on a very hot day! He is looking forward to giving the branch a nice cheque when he has collected the money from all his sponsors.
- The Bridgham and Harling Band performed in East Harling on 26 April and raised around £650. Sadly no one took a photo in the church so I have used one that David provided showing the band playing for the Diamond Jubilee in Bridgham – appropriately it shows David on the last occasion that he was able to conduct.



Future events in aid of the MNDA

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

Round Britten Quiz: As part of the Britten Centenary celebrations, David O'Neale has devised a 'Round Britten Quiz'. If you think you know your way around Britten, or want to have some fun finding out more about him, then do have a go at David's quiz. The prize is £20. The cost is a donation of at least £1 for each entry, with all proceeds going to the Norwich and Waveney Branch of the Motor Neurone Disease Association. Money can be given to Pat or Malcolm at Upton. There is plenty of time to complete the quiz as the deadline for entries is 22nd October. Have some fun and support a good cause. To enter the quiz go to www.familiarfields.org and make a donation on the Just Giving page which David has created then download the quiz sheet. The minimum donation via Just Giving is £2. Completed entries should be sent to David O'Neale, Mill House, Bridgham, Norfolk NR16 2RS.

Norwich Motor Show 10/11 August 10am-4pm: The show is organised annually by Wroxham & Hoveton Lions Club, on a non-profit making basis with all proceeds being distributed equally between the East Anglian Air Ambulance and SSAFA. Fortunately the Norwich and Waveney Branch of the MNDA has been offered a pitch to raise awareness and funds. The main fundraiser will be a cake sale on the Saturday. In addition there will be 'guess the number of sweets in a jar' and 'guess the name of the doll' competitions. Cilla Godfrey, who will be heavily involved in manning the stand, would appreciate as many cakes as possible. If you are able to bake a cake, small cakes or cookies and could bring them to the Upton open meeting on 5 August that would be appreciated. Please wrap and label them so that they are ready for freezing – Cilla has plenty of space. It would be helpful if you could include a list of ingredients (not the whole recipe!). Many thanks in anticipation of your help.

Admission is £3.50 for Adults with Children and Parking Free.

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

Donations

- Archant Norfolk - £150
- Mr. Clive Gladding - £50
- Mr & Mrs Hubbard - £60
- Mr Cecil Traveller - £20
- John Garratt. Proceeds of West End Waiters Concerts - £330
- Anne Gillett. Money raised from the sale of Frank Gillett's cards - £25, and other MNDA cards - £17
- Mary King. Sale of Hagstones - £181
- Marriott Sprowston Manor. Proceeds of the Golf Club's fundraising - £250
- Mr & Mrs Middleton. Donations in lieu of presents for Nigel's 60th birthday - £450

- Mrs. K. J. Reeder. Money raised from selling cards made from her own photos - £20
- Sales at Swanton Morley - £20
- Raffle money at Swanton Morley - £130
- Raffle money at AGM - £128.50
- Charities Trust - £41.89

Donations in memory of

- Edward Bauckham - £75
- Geoffrey Buckingham - £880
- Walter Norman Freestone - £120.00
- Geoff Coleby - £300 (raised by Pakefield Wives Group and received in January – my apologies for not acknowledging this money sooner)

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

The branch would like to express condolences on the death of Geoff Buckingham.



Geoff Buckingham passed away in December 2012 aged 76 years after a very brave two years suffering with MND. He spent the last four days of his life in Priscilla Bacon Lodge; the dedicated staff made him comfortable and safe. Diana Buckingham said, 'Malcolm Chubbock's visits to our home were always appreciated'. Geoff had a lightwriter, which they found very useful, and an iPad with a switch box he could operate using his feet, which proved a tremendous piece of equipment for aiding communication. As a family they were unable to fault the care and nursing profession department; the support was there.

Geoff spent all his life in Norfolk apart from National Service (fourteen months in Cyprus). He worked as farm manager and developed a most successful "Pick Your Own" enterprise on an arable farm on the outskirts of Norwich. He took part in rallies around Norfolk the 1970's in a Hillman Imp. He was also a very keen golfer, this plus his love of classic motor cycles made for many trips all over the UK and Continent.

Geoff was fun loving and generous. He will be sadly missed by his wife Diana, sons Glenn and Mark, Jeannie and Sian daughters in law, and four grand children.

Branch News

AGM and meeting at Eaton: The event was attended by 36 members and guests. Dr Dickie gave a talk on the current state of research into the causes of MND and the search for a cure entitled 'Research today, implications for tomorrow'. A number of people were unable to make the meeting yet still wanted to hear what he had to say. He gave a similar talk on 3rd December, 2012 at the Chicago International Symposium which can be viewed on youtube – watching it on the

computer has the advantage that you are able to see the slides that he used as well as hearing the talk. Either google MND Research Today: Implications for Tomorrow. Brian Dickie, which takes you to an MND care site from which you can click on the link to YouTube or go directly with <http://tinyurl.com/mh5g7dg>

Next Open Meeting: 1pm Sunday 4 August 2013 at Upton Village Hall. Richard Bothway-Howard has been booked to talk on 'The Life and Times of George Formby'. David, of Swanton Morley Caterers, will be providing the meal for us.

Advanced notice of a new type of meeting: We are hoping that many carers will be able to attend an informal get together at Notcutts on the ring road in Norwich on 10th September 2013. 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. Of course people living with MND will also be welcome. Unlike the open meetings where refreshments are provided anyone attending will need to pay for their own tea or coffee and snack. If the meeting is felt to be useful then we will try to arrange more dates for next year at venues around the county. Let us know if you are hoping to attend and what you think of the initiative.

Louise Hamilton Centre: A room has been set aside for people living with MND and their carers on the last Wednesday in June between 1:30pm and 3:30pm as a trial. If this proves successful then it will become a regular event. We hope to be able to provide more information in the next edition of Fightback.

The palliative care centre is in the grounds of the James Paget Hospital and was officially opened in April 2013 to serve the residents of the Yarmouth and Waveney area.

Advanced notice of Open Meeting: Wortwell Community Centre 20th October, 2013.

A request: We would really appreciate another member or two joining the committee. It may be that you would like to begin by attending a committee meeting to see if the idea appeals to you? If you are interested then please talk with Malcolm or Sue K.

We recognise that not everyone wants to or is able to make a long term commitment but that many people would like to help if they knew what was needed. If you fall into this category please let us know since there are some one off events, such as at the Showground, where an extra pair of hands or just a presence would be greatly appreciated.

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 20th August for the September 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 <http://tinyurl.com/MNDA-Nch>.