

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 60 September 2013

I'm not sure but this may be the first time we have been able to open an issue of Fightback with a picture of Queen Elizabeth II awarding an MBE to a local member of the MNDA. David O'Neale, author, musician and community organiser, collected his MBE at Windsor Castle on Friday 19 July 2013 and is pictured here with his wife Hilary.



Since moving with his family to Bridgham 25 years ago David has been active in the community and, despite his diagnosis of motor neurone disease, continues to engage people in the area to carry on the tradition of making a difference to their community.

On Tuesday 10 September we had our first informal gathering at Notcutts Garden Centre. It was a very relaxed and friendly occasion and provided an opportunity to meet up with others and share experiences. Malcolm had asked David to bring his MBE to show us. We also got to see the effectiveness of an iPad as a communication device.



It was particularly good to see Daniel McColl on his new TGA Eclipse electric scooter funded by the branch to assist his mobility.



This summer Terri Johns retired from the Neurological Outreach Service that she set up 17 years ago at the Norfolk and Norwich University Hospital. Many of us have fond memories of Terri and a deep appreciation of the kindness and support that she gave to us over the years. We would like to wish her every happiness in retirement. Rachael Rendell says, 'Terri is really well and enjoying her retirement'.

Debbie Davey has been appointed to replace Terri, and Michelle Green has just moved to South Norfolk to join Shelagh Smith.

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.

Mark's Marathon for MNDA written by Mark Buckingham.



My father was diagnosed with MND in August 2011 and as the disease took over I decided I wanted to raise some money for the MNDA.

I chose the London Marathon as I knew this was televised and my father would be able to watch it at home. After 4 months of training I was ready for the big day. I started off well and felt surprisingly comfortable and was pleased to see my mother and other family members at mile 7. I stopped and gave mum a kiss. But at mile 11 my right calf seized up and needed some help from a spectator to stretch it out. I carried on, a little slower

and was lifted when I saw my family again at mile 14. This time I kissed them all. I had to stop two further times to get my leg seen to by St John ambulance, but I wasn't giving up. At mile 21 I saw my family again, but no time for kisses - I was on the home straight! Over the last few miles thoughts of my father kept me going and I completed the 26.2 miles in 5hrs 45mins. Not great but not bad for a 50 year old first timer. I raised £3,800 for MNDA. And my son Joe did the mini marathon too. Unfortunately my father passed away a few months before so couldn't see it but I know he was there with me.

Ann Franklin's Coffee Morning: The coffee morning on Friday 6 September at the Barn Room in Hemsby was a great success raising £220.10. The photo on the left shows Ann with the pre-loved jewellery that they sold, together with Wendy's mum, Judy, who was selling raffle tickets. They also sold books and of course yummy cakes and tea/coffee/squash. The photo on the right shows Wendy (mum of Ross Brown who is organising the concert) who baked many of the cakes you see in front of her and arranged the morning. There was also a raffle with some lovely prizes. Ann says, 'people seemed to enjoy themselves, judging by the chattering going on!'



James Skilleter: In the tenth anniversary cricket match in memory of Richard O'Flaherty on Sunday 23rd June, the friends of Richard XI comfortably beat Ashby Sunday by 8 wickets. The photo shows James receiving the shield from the Ashby Cricket Club Chairman, Tim Tidsdale.



Ashby batted first and lost their skipper early on which set the tone as wickets tumbled at regular intervals to a strong friends bowling attack which saw the home side all out for 99.

With plenty of time in hand the friends team got off to good start in reply when the score was on 48 when the first wicket fell, James Skilleter being caught with 20. The experienced Andy Franks hit the ball hard to all parts of the ground and got the friends team within touching distance of their target with an excellent crafted 54. Lewis Brawn saw the friends team home.

After a splendid tea, a raffle took place and together with match fees and donations, a total of £244 was raised for MND.

The event was pleased to have Richard's brother Chris in attendance, who is also suffering from the illness, who enjoyed and acknowledged those who came and remembered his brother.

Norwich Motor Show 10/11 August: The weather was good on both days. Cilla (right) and Judy



(left) manned the stall with Malcolm. The cakes almost sold out on the first day with the cupcakes, brownies and muffins proving very popular. Thank you to those who baked for the event. Sweets in the jar and name the teddy generated some interest. The name of the teddy, Fred, was guessed by a person living locally whose father had died of MND. The final sum raised will be announced in the next issue. It was good to have the opportunity to raise awareness of the disease.

Bec's big bike ride: Beccy Roberts finished her cycle across the United Kingdom on 8 September having covered around 100 miles a day, completing the 2500 mile round trip in just 29 days. She passed through 45 counties and covered a distance greater than the Tour de France. We had hoped to provide a local welcome in Hempsall on the 6 September but were thwarted by the lack of mobile phone signal!!

Beccy lost her mother Ellie to MND last year, aged 63, just 18 months after being diagnosed. Frustration at how little is known about the condition drove her to want to do something extraordinary to spread the word, while celebrating her own mobility. We would like to offer our congratulations on her amazing achievement to raise funds and spread the word about the disease.



Future events in aid of the MNDA

The Ann Franklin MNDA awareness concert Friday 11 October 7pm: After last year's success another evening concert with a number of bands is being organised. The Hemsby Singers will start the event (a choir with a wonderful collective voice), there other bands which are sure to get you dancing. There will be a big raffle and a short talk from someone representing MNDA and a short personal statement from Ann. It will be at: Newport Club, Newport Caravan Park, Newport Road, Hemsby, Great Yarmouth, NR29 4NW. From Great Yarmouth take the A149 to Caister, then the B1159 to Hemsby. First right past garage onto Newport Road, The Caravan Park is at the top of the road on the left. Last year they raised £3,101 for the local branch.



Visit <http://mndawarenessconcert.wordpress.com> and/or go to the just giving page: www.justgiving.com/MNDAWARENESSCONCERT to donate or attend on the night.

Christmas Charities Fair Sunday 3 November 10am - 3pm: All are invited to drop in on the annual Christmas Charities Fair at the Woodland Hall at Colney Woodland Burial Park. Ten local charities, including the Norwich and Waveney Branch of the MNDA, will be selling an array of Christmas cards and stocking fillers. It is free to attend, there is no need to book, just call in and see what is on offer. The money raised by the charities on the day will be match funded by Colney Woodland Burials. The Sunday tea shop will be open as usual and there will be a tombola in the Gathering Hall.

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

Donations

- Mr. Clive Gladding, money from a collection box - £33.30
- SMT Motors Table Top Sale on 25 May, 2013 - £1305
- John Garratt. Proceeds of West End Waiters Concerts - £1490
- Mary King, sale of Hagstones - £251.50
- Mary King, sale of fruit and vegetables - £310
- Phillip Laurier, sponsorship money - £90
- Bryan and Eileen Chubbock, sale of produce and donations - £200
- Mrs Susan Coleby, coffee morning at Pakefield Church in memory of her husband Geoff - £300

- Norwich Petanque Club, annual Petanque Tournament in memory of Norman Guest - £156
- Raffle money at Upton - £119
- Charities Trust and interest - £111.41
- MNDA National Office Transfer of £97 from David O'Neale + £94 from the Round Britten Quiz
- £20 from the Summer Raffle

Donations in memory of

- Roy Frederick Sweetingham - £275
- Marion Spalding - £237

Legacy

- Mrs Rosemary Joan Fonseka - £500

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

MND Alert Card: An MND Alert Card is being printed by the Association. It is credit card sized. If a person with MND is admitted to hospital for emergency treatment, the card informs staff they need specialist help. The individual records their name, NHS number and key contacts on the card so that the hospital can access information and make the necessary arrangements as quickly as possible. People living with or affected by MND can order from MND Connect.

Benefit enquiries: We are aware that the Government's general Benefit Enquiry Line has closed. Those seeking information or support on benefits are now advised to contact new helpline numbers for each individual benefit or to visit www.gov.uk. Full details are on the www.mndassociation.org/benefits – but for those who do not have access to the internet here is a list of the numbers that they provide.

Personal Independence Payment (PIP)

Helpline telephone: 0845 850 3322

Helpline textphone: 0845 601 6677

Telephone to make a claim: 0800 917 2222

Textphone to make a claim: 0800 917 7777

Email: not provided

Disability Living Allowance (DLA) or Attendance Allowance (AA)

Helpline telephone: 08457 123 456

Helpline textphone: 08457 224 433

Email for DLA: dcpu.customer-services@dwp.gsi.gov.uk

Email for AA: attendance.allowanceenquiries@dwp.gsi.gov.uk

Universal Credit

Helpline telephone: 0845 600 0723

Helpline textphone: 0845 600 0743

Claim online: search for Universal Credit at www.gov.uk

Email: not provided

For further assistance visit www.gov.uk or contact our own helpline, MND Connect, for guidance:

MND Connect

Telephone: 08457 626262

Email: mndconnect@mndassociation.org

Benefit experiences: The MNDA is a member of the Disability Benefits Consortium which has put together a survey to find out more about people with MND's experiences of the benefits system. We want to make sure that people living with MND respond to the survey so that the Government takes into account their needs and views when developing benefits policy.

If you are able please complete the survey online at:

www.surveymonkey.com/s/BigBenefitsSurvey2013

Keeping care information up to date: Following the launch of the MNDA's new guide, *Living with motor neurone disease* in April the following information sheets and leaflets have been revised and re-launched

9 *Riluzole*

10 *Swallowing difficulties*

18 *Understanding and coping with bereavement*

21 *Physiotherapy for people with motor neurone disease*

22A *Benefits and entitlements*

24 *Communicating about MND to children and young people*

Don't Delay – this leaflet now includes the Personal Independence Payment (PIP).

You can order information from MND Connect or download from the MNDA website.

Lectureship for young scientist: Dr Richard Mead, based at the Sheffield Institute for Translational Neuroscience (SITran) at the University of Sheffield has been awarded the first Kenneth Snowman-MND Association Lectureship in Translational Neuroscience. Dr Mead was awarded the lectureship as he has the expertise and knowledge to enable high quality pre-clinical research into MND. His findings will be made available nationally for other researchers. Developing disease models is important for furthering our understanding of MND, and allows researchers to screen potential new drugs for a beneficial effect before they can be given to humans by means of a clinical trial. Dr Mead already has a track record of taking potential new drugs into clinical development and aims to use this knowledge and experience to develop MND-specific drugs.

Prof. Pam Shaw, Head of Neuroscience at SITran, and Dr Mead have recently been awarded one of 15 national Medical Research Council AstraZeneca Compound Collaboration Grants for £283,000.

The MNDA Director of Research, Dr. Brian Dickie commented, “Our understanding of the causes of MND and the reasons why motor neurons degenerate is increasing rapidly and we need more researchers like Dr Mead who are ideally placed to move this new understanding from the laboratory to the clinic.”

Help us reach our 15000 target: Almost 2000 people signed our Charter in June, MND Awareness Month, taking our total over 12000. Please encourage friends, family members, neighbours, health and social care professionals and politicians to sign. This will help create a groundswell of support for the rights of people with MND and encourage decision-makers to ensure the priorities of good care (as set out in the Charter) are realised. The more public support we get for our Charter, the harder it is for decision-makers to ignore the MND voice.

Share the link to our Charter www.mndassociation.org/3minutes

Branch News

Next Open Meeting: 1pm Sunday 20 October 2013 at Wortwell Community Centre. Sandie Bailes was booked to talk on Care and Health Budgets, sadly family illness means she has had to postpone her talk. Christmas cards and large puddings will be on sale. There will be a copy of the MNDA catalogue if anyone would like to place an order for specific items. John Grooms will be providing the catering for us.

Advanced notice of the second meeting at Notcutts: We are hoping that many carers will be able to attend an informal get together at Notcutts on the ring road in Norwich on 12th November, 2013. 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. 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. Let us know if you are hoping to attend and if you think there are other venues we might try.

Louise Hamilton Centre: A room has been set aside for people living with MND and their carers on the last Wednesday in the month between 1:30pm and 3:30pm. Numbers were down a little over the summer – hopefully reflecting people's ability to get out and enjoy the hot weather. The Care Centre is in the grounds of the James Paget Hospital.

Advanced notice of Open Meeting: 1pm Sunday 2 February 2014.

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 10 December for the January 2014 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://www.mndassociation.org/getting-support/local-support/branches/East+Anglia/norwich-and-waveney-branch-260412.htm>.*

URGENT: STOP PRESS

We have a real opportunity to raise awareness of MND and the Association, however, we urgently need your support to make this as effective an event as possible.

Brad Drewett, former Executive Chairman and President of the Association of Tennis Professionals (ATP), sadly died from motor neurone disease (MND) in May this year.

In memory of Brad, Barclays, the title sponsor of the Barclays ATP World Tour Finals have kindly given the opportunity for 34 children, who have been affected by MND, to be a mascot and accompany the world famous tennis players on to the court at this year's tournament, held from 4 - 11 November at The O2.

The mascots will carry a large version of a tennis ball with our logo on and be kitted out in Lacoste gear (the kit and tennis ball is theirs to keep). Thousands of people will be at the O2 and watching the tournament on TV

The MNDA will be providing a press pack and doing all we can to make the most of this event. Any child who is aged between six and ten, who has been affected by a relative having MND can be nominated to be one of the lucky 34, including children, grandchildren, nieces, nephews etc of someone either living with MND or who has lost someone to MND.

They will be mini ambassadors, helping us to raise awareness of MND and the work of the MND Association. As well as undertaking their mascot duties, each child is invited, along with one accompanying adult (if this should be someone with MND this will also include their carer) to attend the whole session for the day, getting the chance to sit back and enjoy both the doubles and singles matches.

The Association has agreed to contribute up to £200 per family towards any travel and accommodation costs and we would encourage branches and groups to further support costs where needed.

Unfortunately there is a very quick turn around on this and that's where your help is crucial.

Branches and Association Visitors have been asked to let as many families who are eligible know about this once in a life time opportunity and encourage them to nominate a child to take part in this exciting experience, by filling out an application form (this will also be available on the MNDA website shortly – probably by the time you receive Fightback!!) and return it by **Friday 4 October**. I (Sue Heal) have a copy of the application form attached to an email that I can forward to anyone who emails me and requests it. Alternatively I can print it out and post it to you – just provide me with a name and address of the person who needs it. My contact details are on the committee contact list.

If you have any queries at all please do not hesitate to contact Ben Sharpe, Senior Corporate Fundraiser on 01604 611876 or by emailing ben.sharpe@mndassociation.org who will be pleased to answer your questions. For full terms of reference please see application form.