

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 63 June 2014

Celebrating events in aid of the MNDA



Inner Wheel Club of Watton held an afternoon of fun and music on 4th May, 2014 featuring the West End Waiters who were performing their 100th concert. The event raised £930 on the day, but with donations trickling in afterwards Pam Challand, their president, was able to send our branch a cheque for £1000. Over the years the West End Waiters have raised over £10000 for the MNDA, £2875 of this has been raised from February 2013 to January 2014. We would like to thank them for their tireless support. June, who is responsible for the music and Brenda, the narrator, are pictured in the centre with Lesley on the right. Malcolm Chubbock attended the event and took the photo.

Rebecca Vick, of the **North Elmham Young Farmers**, sent an update on their fundraising efforts for the MNDA.



The Young Farmers organised and completed a charity bike ride on Bank Holiday Monday 26 May 2014. The event raised £160.87. It looks like they had the right weather for cycling. It was good to see so many MNDA t-shirts being worn to help raise awareness of Motor Neurone Disease.

The following weekend they had a stall at a fete and raised a further £80. We await with interest the results of their fundraising at an Open Farm during the first weekend in June.

The branch is grateful for their continued support.



The Puree Challenge: Helen Wilson and Amy Shaw are final year student speech and language therapists at the University of East Anglia. They were aware that people think speech and language therapy is all about communication, but chose to highlight the importance of their work for people with progressive neurological conditions who may develop swallowing difficulties (dysphagia). We are very grateful that in doing so they chose to raise money for the MNDA by taking on the Puree Challenge. From 5th to 9th May they ate a pureed diet and drank thickened fluids. This meant all their food was lump free and their drinks thickened using a specialist starch based powder to give it a honey like consistency. They hoped to gain insight into what life is like for people living on modified diets and how it affects daily living.

It was interesting to follow their twitter feed to see which issues were highlighted. Both Amy and Helen found the challenge more difficult than expected; their energy levels dropped, and whilst food tasted the same they found the texture and appearance tended to put them off even before they started eating. The photo on the right was posted on 7 May with a comment “Pureed sausage, beans & cheesy mash, the most normal(ish) dinner so far!” was enjoyable as it was closest to the texture they were expecting.



Amy and Helen noted more planning was needed for shopping. The time taken to prepare food was greater and there were difficulties keeping each part of the meal at the same temperature – a microwave was a must, as if that wasn't enough more washing up was generated! These factors add to the difficulties faced by people living independently with a progressive neurological condition. It was also more difficult to socialise – it is not so easy to have a drink or to eat out – you can't just pop out for a sandwich, salad or bottle of water for lunch.

One of the serious problems encountered was managing to drink enough and remain properly hydrated. When asked towards the end what they were most looking forward to eating – the reply was, “Actually all I want is a glass of water”. If you would like to read more about Puree Challenge then visit <http://www.mndnorwichandwaveney.org.uk/news.htm>

Amy and Helen's JustGiving page showed that £522.11 had been raised by 24 May. If you would like to support The Puree Challenge you can still donate £1 by texting "PURE59 £1" to 70070 or you can visit <https://www.justgiving.com/teams/thepureechallenge> to support the Puree Challenge and the MNDA. The JustGiving page is open for donations for 3 months after the event (so it will close on 09/08/14); there is still time for people to donate!

A 60's Dance was held at Lingwood Village hall on Saturday 12 April 2014. Thank you to David Cox and Mick Patterson for organising the dance, and to those who supported the event. Thanks are also due to Shirley Basey-Fisher for presenting the branch with a cheque for £1343.45 and providing us with a photo taken on the night.



The Three Peaks Challenge: On Friday 13 June 2014 Anthony Blakemore together with his brother Craig and friend Chris Cooper began the challenge which involved climbing the three highest peaks in England, Wales and Scotland! They began with Ben Nevis in Scotland (1344m), followed by Scafell Pike in England (978m) and finished with Snowdon in Wales (1085m) – all within 23 hours 45 minutes. Anthony was raising money for the MNDA in memory of Jim Heal. You can still sponsor him via his webpage at <http://uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserProfilePage.action?userUrl=Anthonyblakemore&isTeam=true>



Future events in aid of the MNDA

Norwich Motor Show at the Norfolk Showground: Saturday 19th and 20th July 10am-4pm. Admission is £5 for adults with children and parking free. Please come and support us!

The Norwich and Waveney Branch has been invited by the organisers of the Wroxham & Hoveton Lions Club to host a stall at the Norwich Motor Show to raise awareness of Motor Neurone Disease. The stall will be manned by volunteers from the branch - thank you to those who have already volunteered - if anyone else would like to join us please contact Cilla Godfrey on 01362 637580.

Last year Cilla and her team sold cakes in aid of the MNDA. Based on the experience gained she is asking people to cook 'tray bakes', sausage rolls, cheese straws, savouries that can be eaten 'on the go' and small cakes - cup cakes were very popular. If you are able to provide food for sale please contact Cilla. Where possible, if you are not able to deliver food, she will arrange for its collection.

More details of the regular features at the Motor Show can be found on the Norfolk Showground and Wroxham & Hoveton Lions Club websites. <http://www.norwichmotorshow.co.uk>
<http://www.norfolkshowground.co.uk/events/detail/206/norwich-motor-show>

Richard Cattermole: On the 22 June 2014 Richard will have completed a 75 km circular cycle ride through Suffolk villages starting and finishing at Elmswell near Stowmarket. Hopefully you will still be able to sponsor him through his webpage at <http://www.justgiving.com/Richard-Cattermole1>

Sunday 7th September, 2014 Charity Family fun day at Sprowston Sports and Social Club in memory of Noel Godfrey. The fun day is due to start at 12 noon and run until 9pm; we hope it will be an action packed day and raise lots of money with your support! Subject to Sprowston FC's fixtures the day may include a football match. Amie Godfrey, Noel's daughter-in-law recently turned 30 and had a party. A charity bucket which went round family and friends with a request for donations raised £52.69 to kick start the fundraising.

Phillip Laurier: A reminder that Phillip will be running the Inverness Marathon on 28 September. We hope you will continue to support him with sponsorship.

Lions Scooter Club of Norwich: have nominated us as their charity of the year. We look forward to publicising and reporting on their fundraising events.

Marks & Spencer: The staff organisation at the Norwich Branch of M&S have chosen the MNDA Norwich and Waveney Branch as their charity of the year. This means that the proceeds of any staff fundraising will be donated to our branch. There may also be the opportunity for our members to undertake fundraising activities within the store, bag packing etc. The first bucket collection took place on Saturday 14 June with another planned for the 21st. A schedule of staff events is already taking shape!

Waitrose Wymondham: selected us to participate in their Community Matters Initiative for the month of June – nicely timed for the MNDA awareness month. By posting green tokens in the MNDA box we should receive a share of their £1000 monthly charitable donation.

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

Donations and fundraising

- June and John Garratt, West End Waiters Concerts - £300
- Hingham Methodist Church - £40
- Dereham and District Metal Detecting Club proceeds of a charity rally - £150
- Luke and Jane Broom-Lynne have donated a cheque from Dillie Keane Ltd - £250
- David Cox and Mick Patterson proceeds of 60s dance at Lingwood - £1343.45
- PLG Taverham - £30
- AVIVA Collection Box - £35.34
- Norfolk Tennis & Squash Club Collection Box - £33.34
- Mrs E M Digby, making and selling teddy bears and selling walnuts - £70

- SMT Motors, table top sale in April - £670
- Raffle at the AGM - £103

Donations in memory of

- Sara Davison - £60 + donations of £8793.81 presented by Michael as above
- Mrs. Isabel Maria Bellamy - £181.60
- Mrs. Isabel Maria Bellamy - €30
- Mr. Jack Edwards - £491.79
- Mrs Kathleen May Harvey - £172.85
- Mrs D. Bauckham made a donation in memory of Edward and her father - £30
- Mr David Henry Swanson - £589.70
- Sarah Baragwanath - £70

Internal transfers

- Interest - £52.92
- Charities Trust - £32.14

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

The Annual General Meeting The 19th Annual General Meeting of the Norwich and Waveney Branch of the MNDA was held on Sunday 27 April at St. Andrew's Church Hall, Eaton, Norwich. The meeting was attended by around 40 people. After the formal business of the AGM we enjoyed a hot lunch prepared by the outside caterers from Swanton Morley Butchers and Delicatessen. A number of photos taken on the day can be viewed on our website.

We were pleased to welcome **Barbara Howe** as our guest speaker. Barbara has been a trustee for the MNDA for six years. She has worked in the NHS for more than 20 years and has an extensive knowledge of both planning and delivering health services. In one of her roles she was lead commissioner for neurosciences in London and was a member of the reference group that developed the National Service Framework for neurological conditions. She is currently working for the National Team for NHS England and is responsible for planning specialised services at a national level.

Barbara gave us a short introduction to the MNDA's recent achievements, and plans and priorities for 2013-16.

One of the key developments she talked about was the announcement that NICE (National Institute for Health and Care Excellence) has agreed to lay down standards for the care of people living with MND. They will be producing a clinical guideline on MND for use by the NHS in England and Wales by 2016. The significance of this is that once NICE have agreed guidelines for the care of people living with MND all hospitals will be expected to deliver such care.

Barbara also highlighted the development of the population based clinical register. This register of all people in England, Wales and Northern Ireland with Motor Neurone Disease (one already exists in Scotland) will take several years to develop. It has the potential to become an important resource for research.

As an association we are already involved in lots of laboratory based research. There is now a push to increase the amount of research into care issues – those things that will help people living with the disease now and in the future to limit their symptoms and improve their quality of life. Barbara gave current examples of care research – the work in Sheffield on saliva management and the development of an MND collar.

If you would like to read more about Barbara's talk and/or to view more photos please visit our website at http://www.mndnorwichandwaveney.org.uk/agm_2014.htm

Michael Davison presented cheques and cash generously donated in loving memory of Sara by his friends and colleagues who between them contributed the fantastic sum of £8,793.81. The photo on the right shows Michael making the presentation to Cilla Godfrey, one of our committee members.





Michael attended the AGM with his son Adam and mother-in-law Jean.

Michael told us a little about Sara at the meeting and later sent an email which provided the basis for the following article.



Sara is pictured on her wedding day, 20 February 2009. She was diagnosed with MND in July 2011. The disease progressed very quickly with Sara being wheelchair bound from October 2011, losing her speech in December 2011 and being unable to eat from November 2012. Michael says, "Sara was such a gregarious, fun loving and fit, and wonderfully attractive lady and so sadly taken on 7th February this year". Her funeral was held on what would have been their 5th Wedding Anniversary. The disease has had a huge impact on the lives of those that loved Sara especially her mother Jean, her two step sons Adam and Tom and of course Michael her husband. This has been a tough journey for all the family.

Michael paid tribute to the help that Sara and her family received from the Norwich and Waveney branch. This included a contribution towards a stair climber. In 2012, Michael and Sara had planned a holiday; at the last minute it became apparent that more care would be required than planned. The branch contributed towards the cost of an additional carer to accompany them. Michael said, "This support has been excellent both financially and also the warmth it left me with as Sara's main carer in not thinking you were on your own."

Yet, despite the difficulties, as a family they made things happen with Sara having two cruises in the time she was living with MND. They continued going to watch Norwich City play as season ticket holders until her passing. Somehow Michael was able to keep working and the children kept visiting despite the adverse circumstances. Sara had a great team of carers managed by Michael using a Personal Health Budget, this was challenging but represented an improvement on the use of agencies with high staff turnover. It is good to reflect that they live on knowing they could have done no more.

Michael does not intend to give into self-pity. He plans to run the London Marathon on 26th April 2015 (assisted by his brother Neil!). He already has a guaranteed place to raise more money for the MNDA with a target of £3,000. Neil ran the London Marathon in 2012 raising £3000. Robert Swann, a good friend, and his daughter Laura raised £1000 having completed the great South run in October 2012. Further sums were raised by Michael's company holding baking days and his neighbour selling raffle tickets for a quilt made by her sewing club. He also made donations instead of sending Christmas cards in 2011. This will take the total raised by Michael, friends and family to over £16,000 for which we are most grateful. We will add details of how you can sponsor Michael to our website when they become available.



We would like to welcome **Esther Cockram**, pictured on the left, who has joined the team of Neurological Nurse Specialists at the Norfolk and Norwich University Hospital. She attended our AGM along with Rachel Rendell one of our well-established neurological nurses.

A History of the Branch: Towards the end of the meeting Brian Cloke, a retired committee member, approached me and we got chatting about the history of the Norwich and Waveney Branch. I started attending meetings in 2006 with my late husband Jim, so had little idea of the background of the branch. I thought that I was not the only one in that position so asked if he might find time to write a personal history of the branch. I am very grateful to him for the following article and hope that you find it as interesting as I do.

Attending the 19th Annual General Meeting my mind wandered back to the beginning of our Norwich and Waveney Branch and some of those lovely people who have helped the branch along the way and who have contributed in no uncertain manner to the raising of the large amount of money announced by Malcolm at our Branch AGM.

At our early committee meetings I can remember three nurses, a policeman, a journalist, a corporation gardener, a dentist, an Orcadian dancer, a psychiatrist and a car sales manager. We elected the policeman to be chairman to keep us in order and he is still keeping the Branch in order. It seems that at each Annual general Meeting, as again this year, Malcolm has appealed for someone to take over the Chair. Malcolm has done such a fantastic job running the Branch that each of us felt that we would be totally unable to do anywhere near such a good job as he does, and so no one comes forward and the same again this year.



Julian Smith (on the left), lately news editor of a local radio station, with his journalistic skills made light work of starting up Fight Back so that we could communicate with our branch members. It has been so useful for many years and now how marvellous to find that in this digital age we have progress to adding a website. I was away on holiday when Julian received his diagnosis and I still recall clearly asking him when we met what the diagnosis meant? "It means that you have no time to waste standing around, so go and buy me a pint Clokey." Once he had his drink he did his best to explain MND.

How did we arrive at our committee decisions on how to spend the money as it came into the branch? It was always after democratic discussions and having two patient members there giving their particular point of view helped enormously.

It is one of my regrets that so few patient members have felt able to come onto the committee. It was from one that I learnt the perils of being over keen to use the newly delivered riser recliner chair. His description of how well the chair can lift one up so that falling face first onto to the living room carpet can be accomplished with ease.

We were unsure in the early days of how to find somewhere for the committee to meet in order not to waste valuable branch funds on room hire. We were enormously grateful to Sue Kitson who said "Meet at my place." Whilst most of us have lost count of the number of Branch meetings held there, Malcolm might have some of the idea of the hundreds. Sue must have served up even an even larger number of cups of teas to the committee. As for the plants which are presented to Sue at our AGMs there must be a jungle behind her home in Harvey Lane. There was Jimmy who used to travel to committee meetings on a moped, braving the traffic from one side of the City to the other and I can never remember him being late. When Branch funds were tight in our early years I remember how grateful we were to Mr and Mrs Chubbock, Malcolm's parents, for their coffee mornings held at their home at Pulham. How hard they worked to raise what were by any standards enormous sums of money for Coffee. Money from the sale of hag stones began to appear in the Branch accounts and still do. Thelma, our Orcadian dancer, coming to our meetings from the Broadlands the other side of Acle held plant sales, tea sales and dancing programmes to augment branch funds. These items made such a difference to what help could be given to our members. (Brian Cloke 2014)

News from National Office

MND Awareness Month, June 2014: Raising awareness informs policymakers and means people living with MND receive the best possible care.

Better understanding also means more fundraising. Put simply, that means we can back more crucial research into the causes of MND, to bring us closer to finding a cure.

People with MND tell us that spreading the word can be a powerful way to keep their voice, when their own might be getting fainter... That is why this year our June awareness campaign has been based around the theme VOICE. Thanks to some amazing sponsorship the MNDA has had public awareness far beyond our charity budget on the National Rail network and London Underground. Fronting the 2014 Voice-themed Awareness Month have been Charlie Fletcher a 29-year-old vibrant filmmaker from Peterborough and Mark Samson, 56-year-old IT enthusiast and professional from Camberley in Surrey.

Depression - asking the right questions: A NEW national survey about depression has just been launched.

'Depression: asking the right questions' is being supported by the Association as this is an important area of research that may affect people living with MND, their families, friends and healthcare professionals.

The survey aims to identify the top ten unanswered questions about depression, including depression in relation to MND, highlighting them as research priorities for action.

Depression affects 1 in 10 adults in any year. Current researcher suggests some people with MND may experience depression, but this is no greater than the general population.

People who experience emotional lability (known as pseudobulbar effect) may be more likely than others with MND to experience depression.

We would like to know what questions people living with MND, their families, friends and clinicians have about depression. Anyone who has experience of depression can take part by completing a 10-minute survey at www.depression.arq.org

Gene discovery brings new hope: Following our 'year of hope' fundraising appeal last month, an international team of researchers including two funded by the Association, have identified mutations in the Matrin 3 (MATR3) gene as a cause of the rare inherited form of MND.

The MATR3 protein is commonly found in the nucleus or 'control centre' of the cell and is involved in the processing of RNA (the cell's copy of DNA that is responsible of making new proteins).

RNA processing has been previously associated with other inherited MND mutations (eg TARDBP and FUS). The MATR3 mutation also affects this process, adding more evidence to the role of abnormal RNA processing in MND.

Dr. Brian Dickie, our Director of Research Development, said: "This research has opened up a new avenue for MND researchers to explore. Identifying the MATR3 gene is the first step, now we need to find out how common it is and importantly how this mutation causes MND.

"The international team of researchers have already begun to answer the latter, highlighting RNA processing, and the cell's ability to make new proteins, as an important area of future MND research."

Thanks to this recent gene discovery, this year is fast becoming a year of hope for MND research, with researchers around the world working towards our vision of a world free from MND>

Read more on the research blog: www.mndresearch.wordpress.com

TDP43: Research published in June 2014 gives us new clues as to why one protein called TDP43 may cause motor neurones to die. MND Association grantee Professor Chris Miller has shown that TDP43 loosens the vital tether between two cellular compartments.

Within any cell there are lots of compartments that work together to maintain its normal functioning. Some of them are implicated in MND, specifically the mitochondria – the cell's battery - and the 'ER' or 'endoplasmic reticulum', which is where proteins are made and recycled. Professor Chris Miller, based at the Institute of Psychiatry, King's College London, has identified the physical 'tether' or 'scaffold' that brings the mitochondria and ER together and allows chemicals to pass between them. Perhaps more crucially he and his colleagues have found that TDP43, a protein already known to go wrong in MND, loosens this tether. The search is now on to find drugs to restore the strength of this link.

Belinda Cupid, MND Head of Research said: "These findings pull together several different areas of research that have been linked to causing MND and that's what makes it really exciting. It's a bit like finding a straight-sided jigsaw piece and really important for seeing the bigger picture. It's especially welcome that we have this news during our June MND Awareness Month." To read more visit the news section of the MNDA website.

The Spring Conference: was filmed this year and can be watched online at <http://new.livestream.com/eventstreamingcompany/mnda>

Book now for the MNDA AGM: We hope that some of our branch members will attend this year's AGM and Annual Conference on Saturday 13 September at the Radisson Blu East Midlands Airport. The theme for the day will be 'One Organisation'. The main speaker will be Ammar Al-Chalabi, Professor of Neurology and Complex Disease Genetics and Director of King's MND Care and Research Centre at King's College Hospital, London.

There is no fee for people with MND, their carers/family, or Association Visitors. Those staying the night before can meet our Trustees and Directors at an informal buffet.

The programme is available from July but booking is open now through the main MNDA website.

Branch News

Next Open Meeting: Upton Village Hall from 12:45pm on Sunday 10 August 2014.

Advanced notice of Open Meeting: Sunday 19 October 2014 from 12:30pm. Wortwell Community Centre, Tunbeck Close, Wortwell, Norfolk IP20 0HS.

Coffee mornings 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 Wednesday 16 July. Again the morning will provide opportunity to sit and chat with people people who have been or currently are carers – 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, but do not worry if on the day things don't go to plan and you are unable to make it – we understand!

Louise Hamilton Centre: The next two dates for the LHC coffee mornings are Wednesday 30 July and Wednesday 24 September. A room has been set aside for people living with MND and their carers between 11:00am and 12:00 noon. As with the coffee mornings at Notcutts there is no agenda, the events provide an opportunity for people to sit and chat – tea and coffee is provided. The LHC is in the grounds of the James Paget Hospital.

Bake it: The first of hundreds of bakeit! events planned for this year was held in Normandy, France over the Easter Weekend. Sadly we can't all hold our bakeit! events in such stunning locations. National Office have provided Sue Kitson with bakeit! packs and flyers, contact her if you would like to have some fun whilst raising money for the branch.

300 councillors pledge support: Sue Kitson took part in the MNDA local elections campaign by writing to our councillors and candidates asking them to sign our charter. Whilst we do not know how many signed locally we were pleased to hear from Stephanie Friend and Richard Bearman who told us they had signed the Charter.

Website: www.mndnorwichandwaveney.org.uk We hope that if you have not already had the opportunity to access our website that you will make time to visit it! Mike Searl continues to work hard behind the scenes adding any material that I send him – usually within 24 hours! It continues to be a work in progress so it is worth checking back from time to time to see what has been added particularly to Recent News and Forthcoming Events. Where we have several photos from an event it is usually only practical to use a few in the printed newsletter, however, we can show many more on the website. Similarly where further information is available that might only be of interest to some people, or becomes available after the newsletter has been sent out, we are able to feature it on the website. We have recently added a new page entitled, 'For Professionals' that includes details of courses and forum events for medical and health care professionals.

If your photo has featured in any of the recent issues of Fightback please let me know if you would be willing for your picture to appear in a gallery of scrolling photos.

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 Friday 15 August for the September 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>. Alternatively go directly to our website www.mndnorwichandwaveney.org.uk

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.

Campaigning comes to East Anglia!

- Did you know campaigning and raising awareness is now the third pillar of the MND Association's work, and want to know why?
- Ever wondered what campaigning is all about and what its achieved?
- Want to know how you can get involved in securing real improvements for people with MND and their families?

If you answered YES to any or all of these questions you'll be pleased to hear that a campaigning workshop is coming to Norfolk in the Autumn!

The workshop is aimed at anyone interested in campaigning for change for people with MND. It will explain what campaigning involves and why we do it, and give you some ideas and skills to help you to talk to local politicians and other decision makers.

The workshop is currently being planned and will either take place in Norwich, Thetford or nearby Bury St Edmunds. It will be run in partnership with our branch, and delivered by the Association's campaigns staff. It will be an all day event, probably from 10.00-15.30.

Please register your interest in the workshop by contacting Alice Fuller by email at alice.fuller@mndassociation.org or phone on 0207 250 8452. If you have a preferred location (Norwich, Thetford or Bury St Edmunds) or timing (weekday or weekend) please state that in your response.

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 sue.kitson2@btinternet.com, 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

If you would like to talk to someone about MND please contact our MND Connect team on 0845 626262 or email mndconnect@mndassociation.org

Visit our online forum <http://forum.mndassociation.org/>

Website: www.mndassociation.org

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