

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 71 August 2016

Freephone number for MND Connect 0808 802 6262

Events in aid of the MNDA

9th June 2016 Cheque Presentation Karen Grapes ran the 2016 London Marathon in memory of family friend Ryan Harman who had MND. During her training Karen ran over 450 kilometres and, on the day, completed the marathon in 4 hours 25 minutes and 21 seconds.

Sponsors helped Karen raise over £550 for the MND Association. She approached her employers, Roys, for help in increasing the total amount raised. They donated £200 from their *Making a Difference Locally* fund.



The photo shows Ed Roy (managing Director) and Karen Grapes (Roys Dereham store manager) presenting a cheque to Malcolm Chubbock (Chairman of the Norwich and Waveney Branch of the MND Association).

11th June 2016 Sue Heal's Silence Speaks Event Jim, my late husband, began to lose his voice soon after diagnosis. Although as a family we could still understand him, it took careful listening and concentration to take in what he was saying. In due course the MNDA loaned him a Lightwriter and, for a long time he was able to use this to communicate quite well. He used to ask us to say what we thought he was going to write as soon as we knew, since it would save him the tiresome process of typing the whole thing out. This was important because after a while he could only use the little finger on his left hand – he was right handed. We noticed the frustration he experienced when his shorthand was not understood or, in company, when the conversation had moved on before he had finished typing his input – we knew to wait!! In due course Jim developed frontotemporal dementia and was unable to spell and later to recognise the words he wanted – after 6 years plus of struggling to communicate he entered a phase, which lasted over a year, when he could only communicate by blinking – and this wasn't very reliable.

And so it seemed that a sponsored silence of just 8 hours should be easy enough. But my nearest and dearest know that although by nature I am shy, I love to talk and sometimes find myself talking too much – the Branch Committee will attest to that! My sister's reaction was, “Ha, ha! Good luck with this one”.

I signed up, and made arrangements with the Virgin Money Community Lounge in Norwich to stage my silence in public so they could confirm that yes, I really had been very very quiet! I took the branch spring roll, 300 leaflets provided by National Office, and two collecting

buckets to the lounge. Then on Saturday the 11th June, wearing my Silence Speaks t-shirt, I went along and got set up. I was asked to brief staff on what MND is, why the silence was significant and generally to enthuse them. They needed no help from me to become enthusiastic supporters – they were brilliant – especially Robbie who gave me coffee within minutes of my arrival, clearly a man with telepathic skills! At 09:11 I began my silence.



I handed everyone a leaflet as they went into the lounge – most people took one, and the manager assured me he saw many reading them. It was an excellent event on the awareness raising front. The hardest part was responding to children with their quick-fire questions – can you speak?, why aren't you talking?, and so on. Indeed there were several adults who wondered if I was able to speak; I had to point to my t-shirt and the sign that said, "I'm doing a sponsored silence". One man asked if I could hear, well "yes" but I had to write my answer! I nearly came unstuck when I handed a leaflet out and realised it was upside down; I just

wanted to say "sorry". Some parts of speech are instinctive. I began to realise how difficult it is to lose the ability to speak – and that was in 8 hours not the 6 years plus that Jim had experienced. I held a bucket and hoped that many of those using the lounge would make a donation on the way out – we collected £99.87.

As it was the Queen's birthday weekend the staff at the Virgin Money Lounge hosted a birthday tea with cucumber sandwiches, scones and cream available for a donation. They also provided a raffle. The proceeds of £233.36 were split between the MNDA and the Virgin charity of the year, Heads Together, giving us £116.68.

Online my sponsorship reached £260, and offline sponsorship reached £72. To date the total from all sources, including Gift Aid, is over £500. The manager of the Lounge applied for and achieved matched funding for the first £400. Thank you to everyone who supported me.

Who will take on the *Silence Speaks* challenge next year?

9th July 2016 Fundraising event at Lowestoft Football Club Judy Burns-Thomson was delighted to receive cheques to the value of £2,742.59 from Linda Tipper at the Cherry Lane coffee morning on 27th July. Linda later wrote, "The evening was a real team event, without the help of all my family and friends it wouldn't have been such a great success. Lots of people have helped me to obtain as many raffle prizes as possible, 118 in all which was a fantastic response from all individuals, retail shops, tea rooms, hotels, pubs, photography studios, local crafts, bakery and bespoke cupcakes. I was truly overwhelmed by everyone's generosity."



I would like to say a BIG thank you to my daughter for donating money that paid for the children's entertainer as well as my son for DJ'ing with a friend's boyfriend who was over from Barbados. All people that helped make this evening into a fun filled family night for which I

will be forever grateful. I think everyone young and old thoroughly enjoyed themselves and helped raise funds for a fantastic charity that is obviously close to my own heart.”

6th August 2016 Malcolm, our chairman, was invited to a barbecue hosted by the Horsford Bowls Club to mark the end of the outdoor bowls season. Over the course of the year the club held a variety of events to raise money for the MNDA. Malcolm attended one on 21 April at which plants, garden produce, books and bric-a-brac were available for sale.

At the barbecue John Bugg presented Malcolm with a cheque for £1,000 to be used in support of people living with Motor Neurone Disease in the Norwich and Waveney area. We are very grateful for the support of the club.



20th August 2016 Eileen Clarke, on behalf of Pulham Market Methodist Church, has been a fundraiser for a variety of charities over the years, each time working with a band of helpers. She chose to support the Norwich and Waveney Branch of the MNDA to receive £1,160.67 from her final event before she retires from fundraising. Eileen had known Malcolm's brother John, who died of MND in August 1997. Malcolm gave a short talk on MND and the work of the branch at the conclusion of one of their events just before the raffle was drawn. The event was held at the Pulham Market Memorial Hall. The photo shows Malcolm thanking Eileen and all her helpers for supporting MND.



3rd September 2016 Tennis for Life coach, Donna Andrews, ran the Quorn Family Tennis tournament for older juniors aged 11-18 years old to play tennis with a parent. The event was hosted by Norwich High School, the proceeds went to the Norwich and Waveney Branch of the MND Association and the Norfolk and Norwich Association for the Blind (NNAB).

The winners, Esme Dickinson and dad Nathan, were victorious and go on to a regional final on 25th September. Donna (left) gave a cheque for £50 to Judy Burns-Thomson (right), who attended to support the event on behalf of our branch. The weather was perfect and some great tennis was enjoyed.



Future events in aid of the MNDA

Saturday 29th October 2016 Inspire Races Steeplechase The Steeplechase is a fun obstacle based race with over 50 obstacles every 5km. If anyone enjoys muddy runs and is interested in taking part in the event then follow the link to the website to sign up. Inspire Events will donate £35 per person to the MND Association.

<http://www.inspireraces.co.uk/steeplechase-info>

If a mud run is not your idea of fun but you would like to help out at the Steeplechase then please get in touch with Judy Burns-Thomson (contact details at the back of the newsletter). The event is being held at Blackwater Farm, Great Witchingham (the same venue as last year). Any volunteers will need to arrive by 9:30am and should be finished by 1:30pm.

Volunteers are needed to take a bucket collection, this is usually most effective left until nearer the end of the event when volunteers stand at the gates as the cars leave. Ideally Ian, the event organiser, would also like up to 20 volunteer marshalls who would be posted at different points of the course to do jobs such as help direct runners and hand out water. Ian's wife Jodi, along with family and friends, is taking care of the cake sale. The event was very enjoyable last year, and volunteers were given tea/coffee and excellent cakes whilst we counted the money.

Sunday 30th October 2016 Charity Football Match Carly Block is organising a Charity Football Match in memory of her father Mitchell, who died from MND in October 2015. A 10:30am kickoff between teams from Wenhaston and Halesworth, at Wenhaston Playing Field, Hall Road, Wenhaston, will be followed by a barbecue and raffle at Chinny's Sports Club, Norwich Road, Halesworth IP19 8BX. There will be a bucket collection throughout, with all proceeds from the event being donated to the Norwich and Waveney Branch of the MNDA.

Sunday 6th November 2016 Christmas Charities Fair This is a free drop-in event from 10am -2.30pm at GreenAcres, Watton Road, Colney, NR4 7TY. The branch has been invited to have a stall; we will be joining other local charities in the Woodland Hall selling crafts, gifts and Christmas cards. Refreshments will be available at Jackie's Sunday tea-shop. We hope to see you there!

It would be good to have a variety of crafts and wares to sell, though not food items. If you have anything suitable to donate to raise funds for the branch please contact one of the committee.

Future events providing information

3rd November 2016 Assistive Technology and Wheelchairs Event Matthew Hollis, Communication Aids Coordinator, has arranged an event open to all – particularly people living with MND, their families and carers, health and social care professionals, Association Visitors and Care Service Navigators. The event will take place at Ashlar House, 23 Eastern Way, Bury St Edmunds, Suffolk, IP32 7AB (www.ashlarhouse.com).

This is an opportunity to find out more about Augmentative and Alternative Communication (AAC), Environmental Control (EC) and Wheelchair options. The day will feature presentations from care professionals and service providers; information on voice banking; exhibitions from the leading AAC, EC and Wheelchair suppliers; opportunities to find out more about service delivery and how the MND Association can help.

The event is free to attend. You can register at www.bit.ly/ASSIST16 or phone the conference and events team on 01604 611837 quoting reference CE16ATW11.

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

Donations and fundraising

- Penny Whiteman - £50
- Collection at Wymondham U3A - £35.95
- Mr and Mrs L. Etheridge, collection box - £40
- Alan Buckingham - £30
- Norwich Petanque Club, tournament and raffle in memory of Norman Guest - £250
- Thelma Pointer, open garden for Martham Gardening Club - £73.30
- Nick Loone in lieu of birthday presents - £120
- Bryan and Eileen Chubbock, donations in lieu of presents for Eileen's 90th birthday - £1,413
- Bryan and Eileen Chubbock, garden produce and baking sales - £308
- M. Davison and C. Collins, proceeds of a sale in memory of Sara Davison - £150
- Amar Kumar and friends, fancy dress cycle ride in memory of Carol Kumar - £1,202
- Upton open meeting raffle - £64
- Upton open meeting quiz - £26
- Upton open meeting sale of goods - £24.50

- Halesworth Cricket Club 6-a-side tournament and raffle in memory of Mitchell Block - £435
- Friend of Judy Burns-Thomson - £25
- Horsford Bowls Club - £1,000
- Broadland Agility Dog Club - £250
- Jane Stringer, from the sale of knits at Eileen Clarke's coffee morning - £140
- Mary King, collection box - £270

Donations in memory of

- John Wayland - £1,042
- David C. Strange - £35
- Johan Wetherell - £43.20
- Barbara Wynn and Barry Osborne - £6,000
- Jenwyn King - £1,037.30
- Beth Marie Parfitt - £126.40
- Joyce Margaret Chamberlin - £484.80
- Jane S. Craske - £175
- John Wilton - £75
- Berenice Groves, a donation in memory of her father - £15

Internal transfers

- Interest - £54.52
- Donations through the Charities Trust - £68.15

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

How can we boost branch income? The Norwich and Waveney Branch relies almost entirely on donations from, and money raised by, our supporters. 'Almost' because people living with MND in our area also receive support from National Office in a variety of ways, such as provision of equipment, financial support and use of the Connect line.

Those who attended our AGM in March, and read the accounts, may have noticed that branch income from fundraising and donations is volatile year on year, which means we cannot always do as much as we would like to support the aims of the Association and help people in our area who are affected by MND. If you would like to contribute to Branch funds, you can do so in a number of ways. Donations will be acknowledged in Fightback unless you prefer otherwise, please just let us know.

- Standing order (if you would like to set one up, please speak to Trish Bates, Branch Treasurer); these can be gift-aided where the donor is able to do so
- Sponsored fundraising events (these can be publicised on our website and by branch social media)
- One off donations; these can be gift-aided where the donor is able to do so

- Purchasing Christmas and other merchandise at the Wortwell open meeting
- Assisting at bucket collections – if you would like your name to be added to the list of potential helpers, please speak to a member of the Committee
- Legacies
- Tribute funds

More information at <http://www.mndassociation.org/get-involved/donations/>

If you have an idea for a fundraising event, but are unsure about any aspect, please speak to a Committee member, who can give advice.

If you have raised funds for the branch these can be paid directly into our account. It helps to phone Trish Bates first to tell her money is on its way; she can check it arrives and confirm this for you. However, money comes to us most often in the form of a cheque. Recently our bank pointed out that the name of the branch is written in many different ways. They have allowed us to list the six most commonly used versions and agreed to accept cheques with these names – but nothing else! The first, being the name used by the bank, is the preferred option.

1. MNDA Norwich & Waveney Branch
2. Norwich & Waveney Branch MNDA
3. MNDA (Norwich & Waveney Branch)
4. MNDA
5. Motor Neurone Disease Association
6. Motor Neurone Disease Ass

We remain immensely grateful for all the fundraising, large and small, carried out by branch members and supporters.

The Norfolk and Norwich University Hospital has applied to the MND Association to become the Association's 21st Care Centre If they receive the grant, the hospital will develop an MND Care Network to provide specialist MND clinics across Norfolk. The clinics would be multidisciplinary, having other professionals within them such as dieticians, occupational therapists and members of the respiratory medicine team. An MND coordinator will ensure they work together effectively. This should greatly improve the patient experience. The Care Centre will also work closely with the University of East Anglia to extend the opportunity for patients to participate in research. The grant will be funded by Ice Bucket Challenge money. The hospital should know whether their bid is successful by the end of November. Thanks to Lindsay Goward for this information.

So many initials – AV, CSN, RCDA. Who should I turn to for help?

What follows is an attempt to answer the question, with thanks to Liz Cooper.

Association Visitors (AVs) act as the main contact for people living with MND – this includes the person with MND, their family and carers – on behalf of the Association. After diagnosis, and from the time you have agreed that you would like to hear from an AV, they keep in regular contact by phone, email or visits. They offer confidential emotional support and accurate information to enable people to make informed choices.

What they can do:

- Explain the support and services the Association can offer, including the benefits of becoming a member
- Help identify problems as they arise and explore how these might be managed, outlining the sorts of options available and how to access them

- Develop and maintain relationships with the local branch or group
- Refer the family for support from a Care Service Navigator as and when required

Care Service Navigators (CSNs) are usually people who have worked, or are still working, as health and social care professionals. They are likely to have local knowledge of services and support and an understanding of how to access it.

What they can do:

- Support people affected by MND to navigate health, social care and other statutory services, third sector support and to encourage the provision of services that are designed to meet an individual's needs
- Support carers by promoting carers' assessments and making them aware of carers' organisations and services
- Support people to get the best out of personal budgets and other initiatives
- Support and signpost health and social care professionals to specialist training, education and information resources that will help them in their professional work with people living with MND

Funding (known as the Volunteering Fund) was provided to the MND Association by the Department of Health to set up the Care Service Navigator role as a pilot between 2013-2016; this funding ceased in March this year. It was designed to support and supplement the work of existing paid professionals such as the Neurology Nurse Specialists, not to replace them. Following a successful pilot and consultation with people affected by MND, the role of the CSN has been continued as a mainstream service in the East of England supported by local branch funding.

Why two roles? The role of an AV is designed to be long term, the CSN provides short term and task focussed support to people living with MND, their families and their carers.

The MND Association provide training for both roles and ongoing support from the Regional Care Development Adviser. It must be noted that AVs and CSNs are volunteers and as such, these services can only be offered where they are available.

Regional Care Development Advisers (RCDAs) are employed by the Association and in our region the post covers, Norfolk, Suffolk and Cambridgeshire. They recruit AVs and CSNs and provide them with ongoing support and training. They can also offer support and advice directly to people living with MND.

In addition they work with local health and social care staff to improve the services for people with MND and their families locally. They also educate and raise awareness about MND by, for example, organising training and study opportunities for health and social care staff, and working with managers to influence the way services are provided.

What you can expect from your Regional Care Development Adviser

- Detailed knowledge about motor neurone disease and its effects
- Knowledge about health and social services in your area and MND Care Centres
- Free and confidential support and advice that is tailored to meet your individual needs at the time you request it
- Knowledge of how the Association can help you
- Information about the support that is available in your area by Association Visitors and/or support group meetings
- Signposting to other services and other sources of help

- Information about other sources of help, advice and support that may be available in your area
- Acceptance and respect for your choices and wishes

To summarise – if you have an AV they can always advise you and direct you to a CSN where it would be helpful. You can always contact your RCDAs, Liz and Lindsay, directly by telephone or email, though as they job share and work away from the office, you may have to wait a few days for a reply. Their contact details are shown on page 15 of Fightback.

MND Connect is available Monday to Friday from 9am to 5pm and from 7pm to 10:30pm. Call direct on 0808 802 6262 (calls to this number are free from landlines and mobile phones within the UK, and do not appear on itemised bills) or email them at mndconnect@mndassociation.org. They can offer information and support on all aspects of MND, including symptom control, practical management, improving quality of life, clinical research and signposting to other organisations – and to local contacts within the MND Association.

Useful Links Remap presented a stand at the MND Association annual conference. Sue was pleased to speak with Maurice and Neil, both volunteers, and to get an idea of the huge range of problems they have solved for individuals. What came across very clearly was the enthusiasm they have for the work they do – they love solving problems.

Remap is a national charity working through local groups of skilled volunteers to help people with disabilities achieve independence and a better quality of life. They do this by designing and tailor making equipment for their individual needs. This helps them carry out essential daily tasks without having to ask for assistance, or take part in leisure occupations or sports that would otherwise be impossible for them.

They make no charge for the devices they make. If you can't get a commercial product then ask them and they may well be able to help. You can either ask your occupational therapist or other healthcare professional about a referral to Remap. Alternatively you or your carer can also contact them directly. Their website www.remap.org.uk says, "There are no criteria to meet or forms to fill in, it's just a question of whether we have the knowhow".

You can contact Remap by sending them a message through their contact us page, alternatively the local contact details are as follows:

Norfolk Central

Contact Dr Andrew New on 07905 243122 or Mike Lake 01603 744023

Great Yarmouth & Lowestoft

Contact Reg Nicholls on 01493 728050

Suffolk East

Contact Mr M Allkins on 01473 726201/609775 or Quentin Thurtle on 01473 420805

All the details are on the branch website on the Useful Links page.

Annual Conference and Annual General Meeting 10th September 2016

Malcolm Chubbock, Sue and Jo Heal attended this year's AGM at the Radisson Blu Hotel, East Midlands Airport. As on previous occasions there was the opportunity to visit various stands and learn more about the different aspects of the work of the MND Association, and other organisations that



provide support for people living with MND. The photo shows Alun Owen, Sue, Brian Dickie, Malcolm and Professor Dame Pamela Shaw.

There were four learning workshops in the morning.

Malcolm attended a workshop on the new **NICE (National Institute for Health and Care Excellence) Guideline for MND**. The MND Association has put together a patient information tool to help people affected by MND, their families and carers to talk to statutory services about what you should expect. Whilst the NICE guideline is not legally enforceable, it is based on best practice and evidence based research so it is very difficult for the commissioners of your care to ignore the recommendations that NICE make. Information sheet 1A, NICE guideline on Motor Neurone Disease can be found at www.mndassociation.org/wp-content/uploads/01a-nice-guideline-on-mnd.pdf

Sue attended a workshop to learn more about the **MND Register**. This is a relatively new research project that the Association has just started funding. This autumn it will be starting to involve people living with MND. The presenters explained how they keep your data safe with one-way encryption, and how they ensure that people cannot be double counted by generating a unique identifier for each individual based on the data they enter. They then showed a preview of the website so that we could offer our feedback.

Motor Neurone Disease affects about 5,000 people in the UK at any one time, but the true figure is not known as there is no single source of information about who is affected. The purpose of the MND Register is to create a database to collect and store information about every person with MND in the UK. The information will help plan the care for people living with MND and tell researchers more about what might be causing the disease. You can find out more about the register at www.mndassociation.org/mndregister

Jo attended the session on **how to develop successful corporate partnerships**. The workshop gave an overview of corporate fundraising in the UK today, and looked at how National Office could work with branch volunteers to help build a network of potential opportunities. It began by looking at how to research links and how to ensure the right things are asked for when developing successful corporate partnerships within our region.

No one was available from the branch to attend the workshop on **campaigning and raising awareness**. We understand that it looked back at the awareness campaign run earlier this year, what happened during awareness month, and talked about the current campaign Championing the Charter.

As always one of the highlights of the day was the **keynote speech**. This year it was given by **Professor Dame Pamela Shaw from the Sheffield Institute for Translational Neuroscience (SITraN)** where she is a clinician scientist. The title of her speech was Progress in the Understanding of MND and Prospects for New Therapy Development. Her speech can be viewed at <http://livestream.com/eventstreamingcompany/mnda>

SITraN is one example of research laboratories around the world that has a dedicated team of clinicians and scientists trying to solve MND. They work to advance the understanding of the causes of MND and related neurodegenerative conditions and translate that into therapies for patients in the clinic.

In her introduction Prof Shaw commented that every week companies like Pfizer, Astra Zeneca and Biogen are coming to talk with staff at SITraN about how they might work together. They

are also showing a greater interest in the rarer diseases like MND. She thinks academic laboratories working with big pharmaceutical companies will be a positive way forward.

Prof Shaw has noticed that MND is increasing in prevalence as we live longer, rather than dying of diseases like tuberculosis in our twenties and thirties. Whilst much less common than Parkinson's disease and Alzheimer's disease, it is the commonest neurodegenerative disease of younger people and those in midlife. She gave the lifetime risk as about 1 in 400, with 5-10% (depending on the geographic area where statistics are measured) of cases having a genetic origin. Most people have their symptoms for about a year before diagnosis. MND tends to affect people who are more than averagely active. Researchers are now trying to understand why some people have fast and others slow progression of MND.

Prof Shaw noted that MND is a very complicated condition making it hard to find a magic bullet to solve it. Pure scientists or micro-biologists can make important discoveries in the lab, but then get stuck. SITraN has a philosophy of clinicians and scientists working under the same roof so that findings can be taken up to develop gene therapies and drug discovery.

Prof Shaw took us through a history of the research taking us back to 1993 with the discovery of the first gene for MND, the SOD1 gene (which accounts for about 20% of cases with a genetic origin). This led biologists to look at Ribonucleic Acid (RNA) processing as a cause of motor neurone injury. She looked in detail at the role of gene C9orf72 (which explains 40-50% of cases with a genetic origin and some sporadic cases) which was discovered in 2011. At least 30 genes are now known to cause or predispose people to develop MND.

Research following the discovery of the SOD1 gene showed how multiple mechanisms contribute to injuring motor neurones. Since then researchers have used cell models, animal models and human disease bio-samples to model the disease in the laboratory and test potential therapies. This experience has informed research into the role of other genes. She considered gene therapy and approaches to knocking down SOD1, which is not appropriate for all genes, and the role of drug therapies such as riluzole.

To better understand the research surrounding the SOD1 and C9orf72 genes it is worth following the live-stream of her talk which is beautifully illustrated to explain clearly the points that she makes.

Prof Shaw suggested there was value in considering the different subtypes of MND, just as had been done with breast cancer, as it was clear that some subtypes have responded well to Riluzole whilst others have not. She then described several different research projects in models derived from human skin cells to grow motor neurones. As an example we looked at the role of the support cells – astrocytes and microglia – some of which become toxic to motor neurones. This has led researchers to think that some promising treatments might come from looking at how to support the support cells. Additionally, the models have been used to screen drugs that might be useful in the treatment of MND. This has been aided by pharmaceutical companies allowing the use of their drug libraries. The researchers have found that different drugs work better in different subtypes, and it is hoped that this will eventually lead to personalised medicine.

Prof Shaw said the Association should be proud of their network of care centres; they work together sharing monthly telephone conferences, pushing forward projects and joining forces to gather information that will allow the promotion of better care for patients. Treatment and good clinical care through a care centre rather than an ordinary neurology clinic affects the average life expectancy by more than 9 months whereas Riluzole affects life expectancy on

average by 3 or 4 months (though some do better). Good clinical care also makes a difference to quality of life; the clinicians at SITraN look at symptoms reported by people with MND and work to develop new solutions – such as the Sheffield Snood (a collar to support weak neck muscles).

In 2010, a NICE guideline was issued in relation to non-invasive ventilation which changed clinical practice; research had shown that its use really does improve quality of life helping people sleep better, giving more energy during the day and a better appetite. Hopefully the new NICE guideline for MND will help improve standards of care even further.

Prof Shaw gave an overview of recent research, much of which has already appeared in Fightback and/or Thumbprint. In August, funding began for A Multicentre Biomarker Resource Strategy in ALS (AMBRoSIA) which is based in Oxford, London and Cambridge. Its remit is to search for biomarkers of MND. A biomarker is a naturally occurring molecule, gene or characteristic that can be identified and, in this case, is unique to MND. AMBRoSIA will recruit 900 people with MND to take part. In addition, 450 people without the disease will also be recruited, for comparison (the control group). The control group will consist of 135 first-degree relatives of people with MND (parent, sibling or child), and 315 people with no family link to the disease. Participants will donate blood, skin and urine samples on a regular basis. Where possible, cerebrospinal fluid will also be collected.

The research blog gives more information, and notes that the study is still being set up so researchers are not collecting samples yet. However, if you have MND and are interested in taking part you can register your interest by joining the MND Association research list by emailing research@mndassociation.org. When they are ready to start collecting samples they will send a letter to everyone on the list explaining what to do next. There is more information on the research list at <http://www.mndassociation.org/research/mnd-research-and-you/get-involved-in-research/mnd-research-list/> As usual there is more from the research blog in this edition of Fightback.

News from National Office

Help stop the changes to Attendance Allowance! The MND Association has joined forces with Parkinson's UK and Carers UK to help stop the government devolving responsibility for the Attendance Allowance to local authorities. Some of our members and supporters have completed an e-action to encourage their MPs to attend an event on 18 October to help protect the benefits of older people diagnosed with MND in the future.

If you or someone you know claims Attendance Allowance and would like to help us tell MPs why it is important please email campaigns@mndassociation.org before the 18th!

Do you know someone living with or affected by MND who would make a great campaigner? Alice Fuller, Campaigns Manager (East) and Team Leader has asked us to publicise the following:

We're looking for people affected by the disease in East Anglia to help us to raise awareness amongst decision makers and campaign for better services.

Campaigns Contacts are members of our branches and groups, but also supported by the national campaigns team, to raise awareness and create change at the local level. They are the driving force behind our national and local campaigns, spreading the word about campaigns and mobilising other people to take action.

Find out more from a short video about the role at www.mndassociation.org/campaignwithus or contact Alice on 0207 250 8452 or at alice.fuller@mndassociation.org for an informal chat.

Care Information Update The following revised information sheets have been released:

10A Benefits and entitlements – Information on the range of benefits and entitlements that people living with or affected by MND may be entitled to. It includes details of the criteria to qualify and guidance on how to apply

12A Driving – An explanation of what is required when someone has been diagnosed with MND, with details of concessions such as blue badges

12B Choosing a vehicle – Information on how to select an appropriate vehicle to meet the needs of someone with MND.

12C Travel and transport

12D Planning a holiday

13A Sex and relationships: information for people living with MND

13B Sex and relationships: information for partners of people with MND

You can download any of the information sheets by following the link 'Our information sheets' at www.mndassociation.org/publications. This will provide you with the latest version of each sheet at all times. For hard copies of information sheets, contact the Care Admin team:

Telephone: 01604 611812 or 611685

Email: careadmin@mndassociation.org

If people living with MND wish to order direct they can contact the MND Connect helpline. The team provide support and directions to further assistance:

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

Carer's Grant The Carer's Grant was introduced to support those who commit their time in supporting someone with MND. The recent carers' survey highlighted that MND carers provide more hours of care each week than the average for carers across the UK.

The Grant is available to the non-paid carer (19 or over) of a person with MND to allow them to take a break from their caring duties. The maximum any individual can receive is £500 in any one year.

Application forms are available at <http://www.mndassociation.org/getting-support/>; you will need to scroll down to the bottom of the page to find the link.

Research During Awareness Month the MND research blog highlighted some of the research the Association funds as part of its 'Project a Day' series. Some days there were several posts so I will not summarise them all here! The blogs covered the five areas in which the MNDA funds research: looking for the causes of MND, new models of MND, diagnosing and tracking disease progression, healthcare research and developing treatments.

Read all the blog posts by visiting www.mndresearch.wordpress.com/category/project-a-day.

What follows is of particular interest in that the second post detailed research that has been commissioned at the University of East Anglia (UEA) in Norwich. Some people with MND develop an increasingly recognised form of dementia, known as frontotemporal dementia (FTD). The care information sheet 9A 'Will the way I think be affected' looks at this in more detail. The main symptoms of FTD include alterations in decision making, behaviour and difficulty with language (cognitive change).

Is frontotemporal dementia different when found with MND? Posted on 6th June by Sara Bolton.

It appears that the relationship between MND and FTD is not well understood. Prof Julie Snowden and PhD student Jennie Saxon at the Cerebral Function Unit in Salford (University of Manchester) are working to establish whether MND combined with FTD is subtly different to when FTD is found on its own.

Sara wrote, “People diagnosed with FTD-MND, with FTD alone, and those with no form of dementia will be asked to perform a series of short cognitive tasks. These will test things including a person’s ability to recognise emotions, draw inferences about the thoughts of others, their ability to concentrate, organise actions and understand language. The findings from this study will hopefully offer the potential to improve identification of those people with FTD who are also at risk of developing MND, leading to improved care and quality of life.”

Research on the best practical support for people with cognitive change Posted on 7th June by Belinda Cupid.

To help support people with MND who have symptoms of FTD, and their families and carers, we need identify or confirm the symptoms and then to find ways to help manage them.

The Edinburgh Cognitive and Behavioural ALS Screen (known as ECAS) is used to detect symptoms of cognitive change. It is a series of tests that are quick to do and are specific to MND. However, there is no agreement on how best to manage them if they are present.

The MND Association has agreed to fund Professor Eneida Mioshi and Professor Michael Hornberger, both based at the University of East Anglia in Norwich, to develop a toolkit (a set of tools for guidance, clinical care, and information) to help both healthcare professionals and people with MND be better equipped to work and manage these symptoms. Once the toolkit is ready it will be tested to see if it is useful and practical, and whether it makes a difference to people with MND and their carers.

Protecting motor neurones against oxidative stress in MND Posted on 14th June by the Research Development Team

Prof Kay Davies and PhD student Matthew Williamson’s study involves finding out more about the role of the Oxr1 gene. Previous research has shown it may protect motor neurones from something called oxidative stress. Matthew has discovered a part of the gene which acts like a switch and turns on the function of the gene. Next step is to develop drugs which can flick this switch on to boost Oxr1 levels.

Developing a blood test for MND by linking changes in the brain and spinal cord Posted on 21st June by Belinda Cupid

MND Association grantees Dr Andrea Malaspina and Dr Ian Pike (Blizard Institute, Queen Mary University of London) and Prof Linda Greensmith (University College London) are currently working on a project to find biomarkers. These would help to diagnose MND rapidly and track how it progresses over time. People with MND have been helping the researchers by regularly donating blood and spinal cord fluid samples.

Dr Malaspina is looking at whether proteins present in tissues relevant to MND are also detected in the blood of people with MND. Is what we see in blood representative of what’s happening to motor neurones affected by MND? If it is, it will be practical to check on a day to day basis – it is much easier to take a blood sample than a sample from a lumbar puncture!

Using a small number of samples, they have been able to show that their idea and their approach is likely to work. The analysis can spot the samples from people with MND from those from healthy ‘control’ participants. They have also been able to separate the samples from different people at different stages of disease progression: those characterized as having a ‘fast’ or ‘slow’ rate of progression. The third comparison that they have been able to do is to separate samples from the same person, where the samples have been taken three months apart.

Analysis of a much larger numbers of patient samples to confirm that it is possible to make these comparisons is underway. Please visit www.mndassociation.org/alsbiomarkerstudy if you are interested in donating samples for this research project.

Using Surface Electromyography (EMG) to see if fasciculations can be used as a biomarker for MND Posted on 24th June by the Research Development Team

When motor neurones in the spinal cord become damaged they can spontaneously discharge electrical impulses that cause small groups of muscles to contract. These contractions, known as fasciculations, are a common symptom of MND. Research suggest they might be a good marker of motor neurone health. Fasciculations in people with MND are different to benign fasciculations, which can occur in people without the disease and are generally harmless.

The project is led by researchers Prof Chris Shaw and Prof Kerry Mills, Dr James Bashford is using technology called surface EMG to collect data on the site and frequency of fasciculations in different muscles in people with MND. James and the team hope to show that fasciculations in those with MND have a unique 'fingerprint' which can be accurately identified and tracked. Data collected will be compared to other information currently used to track the progression of MND. They hope “surface EMG might provide a more sensitive way of measuring the disease progression than previously used methods”.

Ultimately it is hoped that a wearable garment with surface EMG can be designed. It could be used to assess people in their own homes. This could be used to identify positive drug effects rapidly, which would help in future clinical drug trials.

Ice Bucket Challenge funds gene discovery in MND research One of the research projects that benefitted from the Ice Bucket Challenge money was Project MinE, an international initiative which aims to sequence 15,000 MND genomes. The MND Association has contributed over £1.5m and approximately 1,400 samples from our UK MND DNA bank towards Project MinE. The project has discovered two genes, NEK1 and C21orf2, which contribute towards the risk of developing MND.

New genetic discoveries tell us more about what causes MND – Part 1.

Posted 26th June by Belinda Cupid followed by Part 2 on 27th June.

Prof Ammar Al-Chalabi was one of the lead researchers. The research found that people who have a rare variation of a gene called C21orf2 are at an increased risk of developing MND. C21orf2 gene variations may contribute to why people who don't have a family history get MND. The genetic variations interact with lifestyle and environmental factors to cause MND. The research also tells us new information on how many of these gene variations there might be, and how much each of them adds to the risk of getting MND.

New genetic discoveries tell us more about what causes MND – Part 2.

Researchers found that variations in the NEK1 gene contribute to why people develop the rare, inherited form of MND. Variations in the NEK1 gene were also found to be one of the many factors that tip the balance towards why people with no family history develop MND. As usual, more research is needed into the role of NEK1 in MND, and hopefully develop new treatments.

Branch News

Open Meeting Sunday 20th November 2016, from 12 noon for 1pm at Wortwell Community Centre, Tunbeck Close, Wortwell, Norfolk, IP20 0HS. Join us for a Christmas lunch, and buy your Christmas cards, puddings and a few of your presents. Alun Owen, chair of the board of trustees, will be our speaker as we celebrate 21 years as a branch.

Advance notice Sunday 19th March – the Annual General Meeting will be held at St. Andrew's Eaton Church Hall, Church Lane, Norwich, NR4 6NW. We are really pleased that Sally Light, CEO of the MNDA, has agreed to be our speaker.

Coffee mornings

At Notcutts coffee shop, Daniels Road, Norwich, NR4 6QP: The next coffee morning will be held on Wednesday 19th October 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. There is no coffee morning in December.

Advance notice: 16th November 2016 at Notcutts, Daniels Road, Norwich, NR4 6QP.

2017	18 th January	15 th February	15 th March	19 th April	17 th May	14 th June
	19 th July	16 th August	20 th September	18 th October	15 th November	

At the Cherry Lane Garden Centre: The next coffee morning will be held on Wednesday 26th October between 11am and 12 noon. It is an informal gathering for people with MND and their carers.

Advance notice: 30th November 2016 at Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU. There is no coffee morning in December.

2017	25 th January	22 nd February	29 th March	26 th April	31 st May	28 th June
	26 th July	30 th August	27 th September	25 th October	29 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 or Suffolk Fundraising Group of the MNDA. Thanks to Mike Searle, our webmaster, who continues to support us and without whom there would be no website.

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 31st January for the February 2017 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

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*