

# Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter  
Issue 76 May 2018

## **We would like to keep in contact with you about our work, but we need your consent.**

You may be aware that the law is changing regarding holding personal data, and from 25 May we will only be able to hold your data if we have your consent. If you are a member or supporter whose details are already held on the MND Association's central database then you do not need to do anything. However, some of our supporters are currently only connected with us as a local branch in which case we have written to you or emailed you asking you to complete a *Data consent form* to comply with the General Data Protection Regulation (GDPR). You should have received this by post or email. If you have already returned a *Data consent form* – thank you. If not, please return it as soon as possible. If we have not received a response before **25 May 2018** we will not be able to contact you again. If you return the form after this date we can add you to our list again.

As before the introduction of GDPR, if at any time you decide that you do not wish to receive further information, or wish to change your contact preferences, please contact our secretary at [secretarymndanorfolkwaveney@gmail.com](mailto:secretarymndanorfolkwaveney@gmail.com), or write to her at the address given on the contacts page.

## **Sunday 8 April 2018 Annual General Meeting**



Forty-six people attended our Annual General Meeting, including people living with motor neurone disease, carers, those bereaved by the disease, volunteers and health care professionals. It was a good opportunity for people to meet and chat. We were pleased to welcome some new faces as well as those who have been attending for a while – including some who have been associated with the branch since its founding in 1995.

The event was part paid for by a grant of £1,000 from the Community Cash 2017 Fund. A final report on the use of this grant is due at the end of July. Thank you to everyone who provided feedback and/or case studies reflecting their appreciation of our open meetings.

The formal part of the meeting began with an introduction and welcome from Malcolm Chubbock our Branch Chair. Following apologies for absence the minutes of the previous



AGM were accepted and, with no matters arising, we moved on to the Chair's report highlighting some of the wonderful fundraising events held by our supporters and expressing thanks to the committee. Malcolm thanked Shirley Basey-Fisher, who is stepping down after serving four years on the committee, for her work with us. We are pleased that she will continue to keep in touch and help

when she can. Two new members were nominated and accepted onto the committee – Jennifer Palmer, and Simon Perkin, pictured on the right with Eileen Chubbock. We are always happy to welcome new faces and would appreciate more volunteers stepping forward to join us. Trish Bates, our treasurer presented the accounts which were formally adopted. With no other business everyone was invited to enjoy lunch!



As usual we held a raffle with plenty of prizes generously donated by supporters, and Association merchandise was available for sale.



Lunch was followed by a short update on the work of the Norfolk MND Care and Research Network given by Dr David Dick, one of the co-directors of the Network and our Branch Patron. He paid tribute to the work of Helen Copsey, who joined the Network as MND Coordinator on 26 June 2017. Having previously worked at the Cambridge Care Centre she arrived with a good understanding of what was needed. Progress has been made with the provision of additional MND Clinics at the Queen Elizabeth II hospital, and the establishment of satellite clinics at Beccles and Cromer.

Chris James, Director of External Affairs at the Motor Neurone Disease Association gave us a very interesting talk about what the external affairs team really do. For those who were unable to attend the AGM or who wish to see the power point again follow the link on the News section of our branch website at <http://www.mndnorwichandwaveney.org.uk>.

In essence every piece of work done by the external affairs team is to try to make a difference for people with motor neurone disease, their families and carers, focusing on four key areas.



1. **Communications and Digital:** Digital includes the main Association website <https://www.mndassociation.org> with a wide range of information, and others set up for specific purposes such as the MND Charter website which concentrated on a particular campaign <http://www.mndcharter.org>. The Association website is currently being redeveloped for launch later this year.

Social media includes a variety of Facebook pages and Twitter accounts. They include <https://www.facebook.com/mndassociation/>, <https://www.facebook.com/mndcampaigns>, and <https://twitter.com/mndresearch> to name just a few – there are many more, which cater for different interests. There is also an online forum for people with MND, family and carers to exchange ideas: <http://forum.mndassociation.org/forum.php>.

Communications involves reactive media handling, for example following the death of Professor Stephen Hawking the team gave 37 media interviews. They provide briefings and train media spokespersons, share personal stories of people with MND, such as Gemma's story in the My Eyes Say campaign June 2017. Personal stories are a very powerful way of supporting applications for trust funding. They prepare our awareness materials, and look after internal communications within the Association.

Chris told us that the Association is doing things a little differently this year, following an extensive review of our approach to awareness raising that began during a session at the Annual Conference 2017 when around 30 people, including people affected by MND, discussed a wide range of issues. (See Fightback September 2017). This year there will be a break with tradition as the Association won't be hosting an Awareness Month in June. Instead there will be awareness raising activities throughout the year with a focus on those who can make a tangible difference to the lives of people affected by MND, such as decision makers and health and social care professionals. Of course we will still recognise Global MND Awareness Day on 21 June – more information will follow on the main website. To read more or watch Chris' vlog visit <https://www.mndassociation.org/news-and-events/latest-news/looking-at-new-ways-to-raise-awareness-of-mnd-and-the-work-of-the-mnd-association/>.

2. **Public Affairs:** Work here focuses on building relations with politicians and government bodies, influencing government policy and providing the secretariat to the All-Party Parliamentary Group on MND.

National Campaigning helps ensure our voice is heard by national decision makers. Events such as the Parliamentary Reception held last October, provide an opportunity to build and mobilise our team of campaigners. The Public Affairs team also develop campaign tools and actions – such as the 'Don't let me die without a voice' campaign which resulted in increased funding from the NHS to provide alternative augmentative communication aids. More recently their work has shifted to looking at social care and benefits.

The Local Campaigns team provides the link between local and national campaigning in England, Wales and Northern Ireland. Campaigns Contacts are supported to create change in their communities as they seek to build relationships with key decision makers and healthcare commissioners.

Policy: The team looks to understand Government decisions by considering whether they will have a positive or negative impact on people with MND. They are constantly developing our position and responding to government consultations whilst advising and informing the Association.

3. **VIP and Special Events:** A small team work to put on events such as the recent opening of the Norfolk MND Care and Research Network attended by HRH The Princess Royal. The Association has been very fortunate in that she has attended thirteen events for us over the last four years. These events increase awareness of MND and raise the profile of the Association. Association Patrons include Charlotte Hawkins, Eddie Redmayne, Benedict Cumberbatch and Jeremy Vine who all give generously of their time.

The external affairs team is also responsible for conferences and events, managing the MND Symposium that draws in researchers from around the world, the Association's Annual Conference and AGM, Regional Conferences and Staff Conferences. Finally they manage projects such as speech writing, and publications including Thumbprint, impact reports and annual reports.

4. **Partnership Development:** The team identify new partners that will enable us to support our aims, as well as maintaining, managing and developing existing partnerships. Chris cited two examples. The first was Credit Suisse UK who chose the Association as their Charity of the Year partner for 2017. They hoped to raise £600,000; they ended up raising £763,000 some of which was used to fund the Norfolk MND Care and Research Network. The company was impressed by the Association's ability to help manage events some of which were attended by our patrons. The second was the partnership with the Royal College of General Practitioners to create the Red Flag diagnosis tool. There are other partnerships with professional bodies who help develop training materials, and with other charities with similar aims where there are benefits in providing a strong and united voice in our campaigning work.

In summary, Chris showed a slide drawing in the four strands. Together we raise awareness, communicate our key messages, create positive change and fight for a world free from motor neurone disease. There was time for a few questions before the event drew to a close.

Thank you to Daniel Barnes for taking the photographs on the day.

## Events in aid of the MND Association

### 8 March 2018 Diss Golf Club Presentation

Malcolm Chubbock was invited to attend a cheque presentation at Diss Golf Club on Thursday 8 March. He is pictured here receiving a cheque for £1,900.45 from Mike Doig, Club Captain for 2017; a splendid amount which will be used to help support people living with motor neurone disease. Malcolm appreciated the kind hospitality shown to him on the night, and the opportunity to speak with people who had known his brother John, who died of motor neurone disease in 1997.



During his year as Club Captain, Mike chose the Norfolk, Norwich and Waveney Branch of the MND Association as his Charity of the Year. We are very grateful to Mike for his support. He sent his best wishes "for all the great work you (Malcolm) and other volunteers are doing to help those suffering under the scourge of MND and their relatives".

A number of fund-raising events were held during the year including golf ball raffles at most of the home matches that Diss Golf Club played against a range of golf clubs in Norfolk and Suffolk. There were larger charity raffles at their Seniors Open in May 2017 (which welcomed 90 participants from around East Anglia), and at Mike's Seniors Captain's Charity Invitation Day in August 2017 (which attracted participants from Norfolk and Suffolk). A raffle of a Luke Donald Signature putter within the club raised over £400. Charity donations were received from club members at their various designated charity competitions during the year. We would like to thank everyone involved.

### **Thursday to Saturday 12 – 14 April 2018 Queens Road Sainsbury's Bucket Collection**

Thank you to everyone who held a bucket – we had a team of 20 collectors so that for most of the time we were able to have someone standing at both entrances. Once again it was good to raise awareness and to engage in conversation – often with people who had seen at first hand the effects of motor neurone disease on a family member or friend.

Thank you to the staff at Sainsbury's who made the collection possible, and to all the customers who supported us in raising £594.35.

### **Sunday 15 April 2018 Snap Action was back!**

Thank you to everyone who took part in our action celebrating International Micro-Volunteering day. A message on our branch Facebook page and Twitter account asked people to share the 'What is MND?' animation, which can be found at <https://youtu.be/2QGZKrGih6s>. Together supporters across the country reached 127,280 people online.

### **Wednesday 18 April 2018 release in paperback of *Running Wild: Two horses, friends until separated by an enemy find the way back to each other's company***

Lilia Chippendale was aged 10 when she wrote this short book with her creative writing club at school. It is now available on Amazon, the royalties from each book (about £1) will be donated to the MND Association. Lilia's Grandfather is living with MND in Norfolk – she would love people to buy her book (and so would we).

### **Thursday 3 – Sunday 6 May 2018 Charity Walk**

Paul Ablett and Dale Sankey set off from the roundabout on the Overstrand Road, Cromer, on 3 May to walk to Chinny's, Halesworth where they arrived on 6 May. The walk was in memory of Mitch Block, who died of motor neurone disease. The photographs taken at the start of the walk arrived just in time to make it into this edition of Fightback, thanks to our roving reporter Malcolm Chubbock! Dean Boast, also pictured, drove the back-up car. When Dale was forced to stop because of blisters Dean took over so that there were always two people walking.



## Future events in aid of the MND Association

### Monday 14 – Sunday 20 May 2018 Dying Matters Awareness Week

Each year in May, Dying Matters host an Awareness week which gives the opportunity to put the importance of talking about dying, death and bereavement on the national agenda. This year they will be asking, “What can you do in your community?”.

We will be putting up an information stand at the Norfolk and Norwich University Hospital on Tuesday 15 May, which will remain in place until Thursday 17 May.

The Branch will also have a stand in the atrium at The Forum, Norwich, during the Norfolk and Waveney Dying Matters event on Tuesday 15 May from 10am-2pm organised by The Lord Lieutenant's Palliative Care Forum, in partnership with Macmillan Cancer Support. They say: “The partnership continues to encourage everyone to talk to each other about dying, death and bereavement.” Come and find out about the concept Compassionate Communities, and be present for the launch (around 10:30am) of the new edition of the *'Yellow Folders, Advance Care Planning'* designed to encourage us all to talk to loved ones about their wishes.

### Saturday 26 – Sunday 27 May 2018 Edinburgh Marathon Festival

Phillip Laurier has entered the Edinburgh Marathon, which will be run on 27 May, to raise funds for the Norfolk, Norwich and Waveney Branch. It is the second largest marathon after London!

### Wednesday 30 May 2018 Quiz night at The Avenue

The Avenue, Beatty Road, Great Yarmouth, Norfolk, NR30 4BW, holds a monthly quiz night on the last Wednesday of the month. In May, our Branch will be the beneficiary of the money raised. We hope that those of you living in the area will be available to put together some teams. Phone 01493 843 220 or email [theavenuepubgreatyarmouth@gmail.com](mailto:theavenuepubgreatyarmouth@gmail.com) for more details.

### Wednesday 30 May 2018 St Andrew's Church Hall, Eaton

Eaton Dementia Friends are holding a marketplace event for people to come along and try out some activities, meet other people and find ways in which they can obtain support. Our branch has been invited to have a stand to give information. The event is expected to begin at 3pm and go on until 4:30pm.

### Thursday 31 May – Saturday 2 June 2018 Queens Road Sainsbury's bucket collection

We have been invited to hold the final bucket collection as Sainsbury's Local Charity of the Year. A rota is taking shape with single collectors for most timeslots, but we would appreciate more volunteers coming forward to ensure we have enough people to collect at both entrances. If you are able to help please email [sueheal@btinternet.com](mailto:sueheal@btinternet.com) indicating when you would be available. Many thanks!

### Sunday 10 June 2018 Celebrating Volunteers Day at Norwich Cathedral

Norfolk Community Foundation, together with the Dean of Norwich, are hosting an event in the Cathedral Cloisters to celebrate the role of volunteering. The event will follow the City Service which is to be held in the Cathedral at 11am. Our Branch has been given the opportunity to put up a display about our work. Refreshments will be available, entertainment provided and visitors are invited to bring picnics to enjoy in the Cathedral grounds. The Fayre will be formally opened by the Lord Mayor at around 12.15pm.



**Charity Quiz**  
WEDNESDAY  
30TH MAY  
7.30PM ONWARDS

£3 PER TEAM  
MEMBER MAXIMUM  
OF 6 PER TEAM

FANTASTIC  
RAFFLE PRIZES



motor neurone disease  
association PIC+COLLAGE



## **Sunday 17 June 2018 Ditchingham Estate Open Garden**

The garden will be open from 2pm until 5pm to raise money in support of the Norfolk, Norwich & Waveney Branch of the MND Association. Tea, coffee and cakes will be available for purchase. We are grateful to Sainsbury's Queens Road for agreeing to provide tea, coffee and sugar. If you are able to help by baking or providing small cakes please contact Judy Burns-Thomson by email at [judyburnsthomson@yahoo.com](mailto:judyburnsthomson@yahoo.com) or telephone 01986 948076.

Visit <https://ditchinghamestate.com/hall/garden/> to appreciate the beauty of the grounds.

## **Friday 7 September 2018 Bungay & Waveney Golf Club Charity Tournament**

Watch the Branch website for more details nearer the time.

## **Tuesday 18 September 2018, Health and Social Care Professionals – please save the date for the education conference!**

The MND Association national education conference for health and social care professionals will take place at the Hilton Metropole, Birmingham. Registration will be available soon via the Education page at <https://www.mndassociation.org/forprofessionals/professional-education-and-development/study-days/>.

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

- Anonymous donations - £73
- Great Yarmouth Side Winders Scooter Club, proceeds of raffle - £17.54
- Goodies Farm Shop, collection box - £43.01
- Catlin Insurance Company - £298.50
- The Lady Hind Trust in support of an event being organised by Paris Back - £1,000
- Paris Back's Bounder and Cad Event - £2,365
- Raffle at Eaton AGM - £126
- Sale of Merchandise - £83.42
- Betty Flood, in lieu of birthday gift to her son Scott Copey - £40
- Deborah Simpson, donation - £20
- Louisa Hopson, donation in memory of Barry Norman - £20
- Carole Saunders, donation in memory of her husband Vic - £100
- Stephen & Christine Harris in memory of cousin Jeremy Duncombe - £40
- Donation from Alan, brother of Diana in memory of her husband Geoffrey Buckingham - £20
- Pat Goose in memory of Dorothea Menai - £316
- AG Jarrold, Sarah Baragwanath Tribute Fund - £200

### Donations in memory of

- Elaine Crabbe - £1,000
- Betty Ramona Dorleen Smith - £50
- Linda Margaret Tipper - £934.48
- Beryl Anne Pearson - £430.82

### Internal transfers

- Interest - £35.23
- Donations via Sainsbury's from the Charity Aid Foundation - £155.72
- Donation from Elizabeth Goodson - £9.76
- Gift aid - £5

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

## **The beginnings of a local MND Research Program by Dr Ratko Radakovic**

Early in 2018, researchers at the University of East Anglia started to build the foundations for people to take part in motor neurone disease related research. With the support from the Motor Neurone Disease Association and Motor Neurone Disease Scotland, this has now been made possible. Prof Eneida Mioshi, Dr Ratko Radakovic, Ms Kaitlin Dudley and Ms Carmel Moore (pictured below), have been working on a way for people with MND and their families to be involved in research to further understand this illness and eventually help with development of coping strategies and interventions.



This new Motor Neurone Disease Research Program and Pathway now has a core study which looks at lifestyle, thinking and behavioural changes in people living with MND and their families. The **CHANGE-MND study** looks to determine the changes that occur in everyday life, wellbeing, motivation, quality of life and functioning for people living with MND, as well as their families.

The research team aims to visit individuals and their families at their homes so they can take part in research with more ease and in a comfortable, familiar environment. Participants will then be interviewed and asked to provide information about themselves, their motivation, wellbeing, quality of life and functioning. In parallel to this, the research also interviews family members of people with MND, to look at the wellbeing and quality of life, as well as services being used by the family. Following the initial visit, the researchers would follow up and interview the participants every 3 months for up to a year. With this the research aims to create a more complete, practically-driven picture of the changes that may occur with people living with MND and their families. Information about the study can be found via this link:

<https://www.uea.ac.uk/health-sciences/research/projects/change-mnd>

Within the CHANGE-MND study there is also a collaborative study with the University of Edinburgh funded by Motor Neurone Disease Scotland that looks at the impact of motivation, or in some cases apathy or demotivation, for people living with MND and their families, called the **CIAMND study**. Information about this study can be found via this link:

<http://www.mndscotland.org.uk/research/research-we-fund/apathy-in-mnd/>

The research program and pathway works in harmony with the recently opened Norfolk MND Care and Research Network, and works hand in hand with Ms Helen Copey, the Network Coordinator and Principal Investigator on the study, to integrate research into the care pathway in a helpful and accommodating way for people with MND and their families.

If there is anyone interested in participating in the CHANGE-MND study or any other impactful research please email [mnd.research@uea.ac.uk](mailto:mnd.research@uea.ac.uk) and one of the research team will get back to you.

## Norfolk Family Carers

In the last edition of Fightback we featured Carers Matter Norfolk. Funding from Norfolk County Council and NHS Clinical Commissioning Group Partners enables it to offer free advice on 0800 083 1148 or via <http://www.carersmatternorfolk.org.uk>. The service is available from 8am to 8pm Monday to Friday, 4pm to 8pm on Saturday and 8am to 12noon on Sunday.

Norfolk Family Carers, the operating name for Norfolk Carers Support, no longer receive Council funding for adult carers, but continue to help people access services and organise practical support, manage finances and learn about grants, and make sense of options such as finding paid care. All profits from their fee-based services are reinvested in their charitable work. They have been supporting family carers in Norfolk since 1993 and can be contacted on 01603 219924 or by emailing [info@norfolkfamilycarers.org](mailto:info@norfolkfamilycarers.org). You can visit their website at [www.norfolkfamilycarers.org](http://www.norfolkfamilycarers.org) to read about their services.

## News from National Office

**11-17 June 2018 Carers Week** this year's theme is 'Healthy and Connected'. The aim is to raise awareness of the different ways caring can affect the health and well-being of carers. Visit <https://www.carersweek.org> to find out if any events have been organised in our area. During the week, the contribution of the UK's 6.5 million carers will be celebrated and there will be opportunities to access support, advice and information.

**Improving MND Care Survey Results 2018.** Thank you to everyone who completed the survey last year, whether sharing your experiences as a person living with MND receiving care, or as a carer giving insights into looking after someone with MND. The key findings help shape the Association's plans and help focus our efforts.

### Key insights from people living with MND

- The support offered by social care for people with MND is perceived as consistently worse than health care. For those that answered the question "overall I am satisfied with the care I receive" only 63% felt this for Social Care vs 86% for Health Care.
- A wide range of Social Care problems were identified in the survey. For example, only 45% of people know how to access an advocate.
- There is a lack of awareness of voice banking. Based on the responses, 40% of those people who had not banked their voice were not aware they could do this. Hence the new trial of Voice Banking Volunteers.

In response the Association will continue to support NHS services to use our Transforming MND Care Audit Tool to benchmark and improve their services for people with MND.

### Key insights from carers

- Carers for people with MND spend a very high proportion of their time caring. More than half of carers (59%) spend more than 50 hours per week caring. That's more than an average week's full time job.
- Many carers are not getting carer's assessments. Only 38% have been assessed or are in the process of being assessed.
- Nearly half of carers receive no benefits at all.

The Association is continuing to promote our MND Costs campaign to raise awareness of the financial burden on families affected by MND. We have made grants available to help carers to improve their quality of life and will continue to engage with Government to hold them to account in the development of a carer's action plan. In the meantime you can receive help applying for benefits, or check what is available to you by using the Benefits Advice Service which is free to call on 0808 801 0620.

The full Improving MND Care Survey Results are available to read at <https://www.mndassociation.org/wp-content/uploads/Improving-MND-Care-Survey-Results-2018.pdf>.

Watch out for the 2018 Care Survey!

**Voice Banking Volunteers.** The Association is piloting a new Voice Banking Volunteer role in seven areas of the country, with two volunteers being recruited in each area. We are keen to ensure that people with motor neurone disease have the opportunity to create their own personalised synthetic voice as early as possible. Our closest area is Buckinghamshire and Bedfordshire. If you know someone in the area who might wish to get involved contact Matthew Hollis by emailing [communicationaids@mndassociation.org](mailto:communicationaids@mndassociation.org) or call 01604 611767.

**New and revised care information sheets.** Download information sheets at <https://www.mndassociation.org/about-mnd/information-resources/> or order copies from the care admin team by calling 01604 611685 or by emailing [careadmin@mndassociation.org](mailto:careadmin@mndassociation.org). People living with or affected by MND can order direct by contacting the MND Connect helpline on 0808 802 6262 or emailing [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org).

**Information sheet 3A MND care centres and networks.** An outline of the services provided by MND care centres and networks as part funded by the MND Association.

**Information sheet 10E – Work and MND.** This sheet looks at how to continue working for as long as possible, or leave in a way that feels right for the person with MND or Kennedy's disease, or their carers.

**Information sheet 14A – Advanced Decision to Refuse Treatment (ADRT) and advance care planning.** The sheet explains how to use an ADRT form, and explores how advance care planning can help guide those involved in delivering care.

**Web app for Eating and drinking guide** is designed for use on smart phones and tablets (I have tried it on a MacBook and it works well) and has been launched to accompany the Association's Eating and drinking guide. The web app including all of the easy-swallow recipes and a summary of the information sections can be found at <https://www.mndassociation.org/eatingwithMNDapp/>. More information about swallowing, eating and drinking can be found at <https://www.mndassociation.org/about-mnd/living-with-mnd/eating-and-drinking/>.

**Research we fund 2018** is the first new information sheet to be released as the Association updates the range of Information Sheets on all aspects of MND research.

**Website revamp.** If you are interested in helping test new designs please let Abi know by emailing [abigail.stafford@mndassociation.org](mailto:abigail.stafford@mndassociation.org).

**Tell us your personal story.** Personal stories bring to life how motor neurone disease affects the people living with it and their families. They also encourage people to support us in different ways like volunteering, campaigning or fundraising.

The Association use personal stories in a variety of ways, such as in appeals for funding, in education or training materials, in reports and in our campaigning work. They are looking for more people to share their story. In particular, they are looking for people who have:

- Had recent experience at one of our MND Care Centres or Networks in the last six months or so – they say: ‘especially Norfolk’.
- Had an Association Visitor who has supported them, either recently or over several years.

Send your personal stories by email to [communications@mndassociation.org](mailto:communications@mndassociation.org).

**Support Volunteer Project.** Support volunteers provide information and emotional support to people affected by MND. They include Association Visitors and Care Service Navigators. Over the next two years the Support Volunteer Project will look at how the Association could provide an even bigger, better volunteer support service to people affected by MND. They would welcome your ideas for improvements and would like to hear from you by 1 June 2018.

Phone: Call 01543 415121 to speak with Project Manager, Tim Atkinson

Email: [svproject@mndassociation.org](mailto:svproject@mndassociation.org)

Post: Support Volunteer Project, MND Association, PO Box 246, Northampton, NN1 2PR

For more information about the project visit <https://www.mndassociation.org/get-involved/volunteering/support-volunteering/support-volunteer-project/>.

**Cards for Good Causes.** Last year Cards for Good Causes helped raise almost £27,000 for the Association – Norwich is amongst the pop-up shops generating the highest sums. If you are interested in helping out this year, please register your interest by emailing [volunteering@mndassociation.org](mailto:volunteering@mndassociation.org).

## Campaigns

**The MND Costs Campaign** continues, if you would like to get involved visit: <https://www.mndassociation.org/get-involved/campaigning-influencing/mnd-costs-v2/>.

The MND Costs report showed the huge financial impact that MND has on people living with MND and their families, and the crucial role of welfare benefits in supporting people.

Working on benefits has remained a key part of the work of the National Campaigns team, and has been followed up locally.

In the last edition of Fightback we reported on the meeting with Sarah Newton MP when an open letter signed by 8,000 supporters, including a number in Norfolk, was delivered. It called for a solution to prevent existing **Employment and Support Allowance (ESA)** Support Group claimants from having to go through a final reassessment before qualifying for the new Severe Conditions Exemption. The minister replied on 13 March, you can read her letter at <https://www.mndassociation.org/wp-content/uploads/Minister-reply-March-2018-MfDP.pdf>. We are pleased that the Minister has asked her officials to look into the issues raised, but disappointed that there is no reference to an imminent solution for the existing Support Group claimants. If you, or a member of your family, was in receipt of ESA before 29 September 2017 please contact MND Connect on 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) where someone will take your details and put you on a contact list for further information. A further meeting with the Department took place in April to discuss the ESA exemptions and work is ongoing.

**If you are part of this group and are sent an ESA50 form for reassessment, you can contact the Association's Benefits Advice Service on 0808 801 0620 for help completing it.**

**All Party Parliamentary Group (APPG) on MND meeting on 21 March to discuss access to the Personal Independence Payment (PIP) benefit for people with MND.**

The APPG Chair, Madeleine Moon MP and eighteen other MPs attended and discussed the findings of the APPG inquiry into PIP. They agreed urgent action was needed to improve PIP for people with MND, including removing the need for people with MND on the highest rate of PIP to be reassessed. Read more about the meeting at <https://www.mndassociation.org/news-and-events/latest-news/mps-hear-powerful-statement-on-pip-experience-at-appg-meeting/>.



Sue Heal sent an email to each of the eight MPs representing our Branch area inviting them to attend, sadly none were available. However, the Rt. Hon. Norman Lamb MP wrote to Esther McVey, Secretary of State for Work and Pensions, on our behalf asking her to respond to our serious concerns about the benefits system.

Peter Aldous MP asked for a meeting to discuss the issues prior to his pre-arranged meeting with Sarah Newton MP. The meeting took place on 10 April at his constituency office in Lowestoft, and was attended by Sue, Judy Burns-Thomson and Martin Burnell. We were very grateful to Martin for sharing his personal experience of the benefits system with Peter. At the end of the meeting we left the MP with a list of recommendations and a request for his support.



- People with MND claiming Disability Living Allowance should be transitioned to PIP at the same rate unless they request an assessment.
- People with MND on the enhanced rate for PIP care and mobility components should be exempt from further reassessments and granted indefinite awards. We asked if he could write to the Minister (Sarah Newton MP) making the case for people with MND to be granted indefinite awards once they are on the highest rates of PIP.
- People with MND should not be called for a face-to-face assessment unnecessarily.
- Ask the Department of Work and Pensions to review their guidance on the Special Rules for Terminal Illness (SRTI) and DS1500s to enable greater flexibility in how the definition is interpreted and applied.

On 25 April, the Scottish Government voted to change the definition of a terminal illness for the purpose of claiming benefits. The new system in Scotland will see someone defined as terminally ill if “it is the clinical judgement of a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual’s death”. We would like to see the same definition in use in England, Wales and Northern Ireland as there are several benefits of applying under SRTI – a person does not have to fill in a long claim form, they avoid a face-to-face assessment, are awarded the highest rate of the benefit and should receive their benefits quickly. Research by the All-Party Parliamentary Group on MND found that just 28% of people with MND claimed PIP under the SRTI. To read more about this change visit <https://www.mndassociation.org/news-and-events/latest-news/scottish-government-makes-it-easier-for-people-with-terminal-illnesses-to-claim-benefits/>.

**Universal Credit** (UC) is a benefit that the Government is introducing to support people who are on a low income or out of work (including people who cannot work because of ill health or disability). It replaces the following means-tested benefits: Income Support, income-related Employment and Support Allowance, Housing Benefit, Child Tax Credit and Working Tax Credit. UC is being rolled out across the UK in stages.

The Association is concerned about Universal Credit and the financial impact it will have on people living with MND and will be publishing a report on UC later this spring. If anyone with MND has applied for Universal Credit and would be willing to discuss this further with the campaigns team, please contact [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) for information.

**Housing Survey.** Campaigns are always underpinned by a strong evidence base. **YOU CAN HELP** us build a clear picture of the accessible housing issues affecting people with motor neurone disease by completing a survey at [www.mndassociation.org/housingsurvey](http://www.mndassociation.org/housingsurvey).

The survey will help provide the information that we need to inform our campaign to push for improvements so that people with MND and their families can access the homes or adaptations they need when they need them. The results will be anonymised, and the survey should take between 5 and 15 minutes to complete. The survey closes on 13 July 2018.

**Monday 5 March meeting with Norwich City Council.** Sue Heal, Malcolm Chubbock and Lindsay Goward met with Alan Waters, Leader of Norwich City Council and Grant Lockett, (Tenancy Services and Income Management), to discuss housing issues. Discussion included applications for council housing from people living with MND, whether they are existing council tenants or not. This enabled us to learn about how the application process should work, how the council deals with applications and where input from the Branch and healthcare professionals could help them better understand people's needs. When applying it is important that people give as much information as they can about their current and future housing needs to enable the Council to deal with their requests appropriately. It is also important that couples put both partners on the tenancy agreement to safeguard the home for the surviving partner.

Discussion moved to Disabled Facilities Grants where we spoke of the need for the process of applications by people living with MND to be dealt with as a matter of urgency.

We asked about building properties that were 'future proofed' for changes in mobility. The Council's aspiration is to build Category 3 (wheelchair user dwellings). However, we learnt that what the Council can build depends on where the funding comes from.

We ended by agreeing that Lindsay would arrange some training for staff working within housing department focusing on how motor neurone disease, and its progression, can impact the type of housing and housing adaptations that might be appropriate.

We plan to arrange similar meetings with other Councils before and after the results of the housing survey have been published in consultation with the Campaigns Team.

## Research

If you want to get involved in research or read more about ongoing research there is always a wealth of reliable information at <https://www.mndassociation.org/research/>. If you wish to talk about getting involved you can contact the Research Development team on 01604 611880.

The information given below is based on the Autumn and Winter Research Newsletters and the MND Research blog <https://www.mndassociation.org/research/mnd-research-blog/>.

**COMMEND Study Update** (Acceptance and **Com**mitment therapy for people with **motor neurone disease**). Recruitment for the first part of the study which focuses on developing an ACT intervention designed to meet the needs of people living with MND has now closed. We will advertise the second part of the study when recruitment opens.

**Project MinE uncovers a new gene KIF5A.** Project MinE is an international project involving MND Research Institutions from five countries, and nine consortia (including MND Association-supported project MinE) that aims to understand the genetic basis of MND/ALS. This recent finding was published in the journal Neuron. Genes such as KIF5A play a key role in ensuring that essential raw materials are delivered to where they are needed most. Mutations of the KIF5A gene lead to inappropriate transport of cargo along the motor neurone. It is also associated with earlier onset (**45 years** vs 65 years) and longer survival (**10 years** vs 3 years).

In two separate analyses, designed to detect different types of genetic risk factors, KIF5A was identified as being linked to MND. You can read more about this exciting new discovery at <https://www.mndassociation.org/get-involved/volunteering/volunteer-zone/news-2/research-updates/>.

**The ALS RAP** is the catchy name for the Amyotrophic Lateral Sclerosis Reproducible Antibody Platform. A collaboration involving a group of universities that make up the Structural Genomics Consortium, working with industry partners alongside the ALS Association, ALS Canada and the MND Association was announced in March. It will focus on providing the scientific community with 'gold standard' antibodies for use in MND research. The antibodies are used to help scientists work out what specific proteins in the body do, whether in the blood, cerebrospinal fluid or motor neurones. In diseases, such as MND, a lot of damage occurs to the proteins in nerve cells, the antibodies are made to stick to one particular protein so that scientists can study them in great detail. They believe the work of the consortium will greatly improve the quality and pace of MND research both in understanding the cellular processes that cause motor neurones to degenerate, and in helping with drug discovery and development. To read more of Dr Brian Dickie's report visit <https://mndresearch.blog/2018/03/09/the-als-rap/>.

**CHANGE-MND Study (Cognitive, behavioural, and lifestyle change in Motor Neurone Disease)** is open for recruitment. Please email [mnd.research@uea.ac.uk](mailto:mnd.research@uea.ac.uk) if you are interested in participating.

**Government clarifies misleading statement:** On 20 March Andrew Lewer MP asked: “With the death of Professor Stephen Hawking in all of our thoughts, can the Minister tell us what steps his Department will take to support research to develop a cure for motor neurone disease?” In answer Jeremy Hunt said: “This disease is a big area of priority for us. In the last year for which we have full-year figures, £52 million was invested into it, and we are currently recruiting for 24 clinical trials.”

The Association wrote to the Secretary of State requesting clarification. On April 19, following a question from Tom Brake MP, Caroline Dineage MP said the figures quoted by the Secretary of State in fact referred to research across all neurological conditions. The response clarifies that the Government spent £4.58 million of research funding specifically on MND and closely-related conditions. More on this story, and a list of research that is being supported by the National Institute for Health Research, can be found at <https://www.mndassociation.org/news-and-events/latest-news/government-clarifies-misleading-statement-on-mnd-research-funding/>.

**Suffolk drop-in support meetings 2018.** People living with MND, families and professionals are welcome. Feeling isolated or unsure about support and services available? MND Association representatives and Nurse specialists are usually on hand to advise over a cuppa.

Meetings in West Suffolk will be held at Hawstead Village Hall, The Green, Hawstead, IP29 5NP on Wednesdays between 2pm and 4pm on 4 July, 5 September and 7 November. Note the times for November 12noon – 2pm, when a light lunch will be provided, so let Janet know you are coming. For more information email [ooliverjanet@btinternet.com](mailto:ooliverjanet@btinternet.com) or phone 01359 241084 or contact West Suffolk Neuro Nurses, Nicky McGreavy or Sarah Ward on 01284 748848.

The Ipswich support meetings will be held in The Atrium, St Elizabeth Hospice, Ipswich on the following Mondays between 5pm and 7pm. For further information please contact Kate Barber on 01473 707962. Dates for the Ipswich meetings are: 18 June, 20 August, 15 October and 17 December.

## Branch News

**Open Meeting:** Sunday 24 June 2018, 12:30 pm – 4:30pm at Upton Village Hall, Upton, NR13 6AU. We are reverting to a lunch time meeting and will be providing a cold buffet lunch. Dr Caroline Barry, Consultant in Palliative Medicine at the Norfolk and Norwich University Hospital, will be our guest speaker.

**Advance Notice:** Open Meeting Sunday 18 November 2018, 12 noon to 4:30pm, at Wortwell Community Centre, Tunbeck Close, Wortwell, Norfolk, IP20 0HS.

### Coffee mornings

**At Notcutts coffee shop:** The next coffee morning will be held on Wednesday 16 May 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 of future dates for Notcutts, Daniels Road, Norwich, NR4 6QP

2018 June 20	July 18	August 15
September 19	October 17	November 21

**At the Cherry Lane Garden Centre:** The next coffee morning will be held on Wednesday 30 May between 11am and 1pm. It is an informal gathering for people with MND and their carers. There is no coffee morning in December.

### Advance notice of future dates for Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU

2018 June 27	July 25	August 29
September 26	October 31	November 28

**Website:** [www.mndnorwichandwaveney.org.uk](http://www.mndnorwichandwaveney.org.uk) We are always happy to add information about events you are planning in support of the Norfolk, Norwich and Waveney Branch.

**Facebook:** @MNDANorwichWaveney

**Twitter:** @MNDANorWave

**Louisa's Facebook page** @fundraising4MND

**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 **30 September** for the next edition.

### Useful Numbers

Regional	Care	Development	Advisers	share	an	email	address
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[eastangliarcda@mndassociation.org](mailto:eastangliarcda@mndassociation.org)

Norfolk – Lindsay Goward 03453 751829. Lindsay works Tuesday, Wednesday morning, Thursday, and Friday morning.

Suffolk – Liz Cooper 03453 751827. Liz works Monday and Wednesday

**MND Coordinator** Helen Copsey 01603 647221 [helen.copsey@nnuh.nhs.uk](mailto:helen.copsey@nnuh.nhs.uk)

**Care Service Navigators** Trish Moore 07813 094 820 email [trish.moore@mndassociation.org](mailto:trish.moore@mndassociation.org)

Gill Newton 07810 750122 email [gill.newton@mndassociation.org](mailto:gill.newton@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 [secretarymndanorfolkwaveney@gmail.com](mailto:secretarymndanorfolkwaveney@gmail.com), 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.