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The first time I became aware of the MND Association was six years ago when I saw an Awareness Month poster as I was travelling to work. The poster stopped me in my tracks and I was immediately hit by the power of the campaign and devastating nature of the disease. This is why MND Awareness Month is a particularly important time for the MND community, providing us with a month-long opportunity to demonstrate the impact of MND to the general public.

Each year the challenge is on to create something new that will command attention. This year our campaign #MyEyesSay has generated a huge amount of focus on MND and I would like to thank everyone involved, especially Gemma, Dave and Vivienne, who bravely shared their own personal stories.

We know how important raising awareness is for people with MND in helping to reduce the feeling of isolation many experience. We also raise awareness to support campaigning activities and are indebted to our volunteer Campaigns Contacts who, together with staff, help lobby and harness support, focused on ensuring both the NHS and local and national governments meet their responsibilities. This is vital because, though we support the NHS by providing funding to our 21 care centres/networks and specialist practitioner roles, we don’t provide clinical services or hands on care ourselves. Rather, support activities are designed to complement statutory services and offer help that is not available on the NHS or from local authorities.

During 2016, we provided over £1 million in support grants to fund equipment for people with MND to help improve their quality of life, alongside grants specifically for carers, children and young people. In addition, I am very pleased to announce that we have a new service to help ensure people affected by MND are getting the welfare benefit support they are entitled to (page 17).

When I look at the ways in which we have supported people affected by MND in 2016, it is encouraging to see how much progress has been made. On page 20 and 21 is an illustration which shows the work we have funded in 2016. This has only been possible because of the vital support of our members who are committed to doing everything possible to help people living with MND. Thank you for all you do to support us.

Sally Light
Chief Executive
Our Awareness Month campaign in June – #MyEyesSay – highlighted real stories of people living with, or bereaved by MND, in order to raise the profile of the disease and the work of the Association. This year we focused on the eyes, both to share the reality of the disease and to underline their importance for some people living with MND. More than 80 per cent of people will experience communication difficulties and so their eyes can become an increasingly important way to communicate.

Posters featuring Gemma Middleton and Dave Solomon, both living with MND, appeared across England, Wales and Northern Ireland on the National Rail network, London Underground and buses, together with a dedicated interactive website, social and traditional media as well as celebrity support.

Before her diagnosis of MND in June 2016, Gemma was climbing the career ladder as an environmental consultant. She had run a marathon and loved figure skating. Gemma continues to work but has moved back to her hometown near Worksop and is planning her wedding to fiancé Joe. Gemma and her friends and family have been fundraising for the MND Association since her diagnosis and have raised thousands through walks, runs, charity balls, rugby matches and various other events.

Gemma came face to face with her own eyes on a giant poster at Sheffield train station when she was interviewed on ITV Calendar. Gemma said: “I wanted to get involved with Awareness Month as not many people know about MND, especially the fact it can affect anybody. I want people to know how devastating the disease is, in the hope one day we will find a cure. My friends have been taking and sharing pictures of my posters around the country, so to see it so large was amazing and a little bit strange.”

Dave and his wife Paula met at their local running club and married soon after his diagnosis of MND. Their poster message read: ‘I used to run marathons, but with motor neurone disease my eyes might be all I can move’.

Dave said: “I want people to understand that when you have MND you have to figure out what you can do, not dwell on what you can’t do. It doesn’t stop you from going out and having fun. I got involved in Awareness Month because I’ve had so much help from the MND Association and if I could just help one person out there I will feel like I’ve put something back.”

Posters around Dave’s hometown of Northampton also captured the attention of the media with the couple interviewed on BBC Look East and ITV Anglia as well as appearing in local newspapers and on radio.

Chris James at the MND Association said: “We never underestimate the courage it takes for people to share their stories. Gemma and Dave’s posters were seen by thousands so a huge thank you to them both.”

Patrons of the Association Stephen Hawking, Benedict Cumberbatch and Eddie Redmayne also appeared on posters around some of the major London rail hubs.

Our dedicated #MyEyesSay website www.mndeyes.org shares more about
Gemma and Dave, as well as introducing Vivienne whose husband Tony died in 2016. Together they describe the devastating impact of MND on their lives. The website also includes a short animated film about MND and an interactive challenge for people to use their eyes in a knowledge quiz.

We asked people 'If your eyes were all you could move, what would you say with them?' and hundreds did just that with some really powerful and inspiring messages on Facebook and Twitter.

We had lots of interaction with the posters and then a huge buzz around Global MND Awareness Day. More people viewed our campaign website than last year and we reached more than 2.5 million people through Facebook alone in June.

Going Global – June 21

BIRMINGHAM was the focus of a day of activities thanks to the donated use of outdoor media eye-shaped screens around New Street station and the city centre. People shared personal messages and had their own eyes featured on the giant screens together with those from our patrons Benedict Cumberbatch, Eddie Redmayne and Stephen Hawking.

Local volunteers and staff from the MND Association were joined by the Lord Mayor of Birmingham Councillor Anne Underwood and special guests Dave and Paula Solomon from the #MyEyesSay campaign.

Sally Light, chief executive of the MND Association said: “It was an amazing day with so much support from the public for what we were doing. It was wonderful having the backing of the council and Network Rail which gave us access to hundreds of people on the day and even more as we shared our messages across social media too. Huge thanks to the team at Ocean Outdoor who donated their screens for the day and made it possible.”

VIP and volunteers shine a light on MND

OUR patron Eddie Redmayne turned the Coca-Cola London Eye ‘blue and orange’ to raise awareness of Global MND Awareness Day. The London Eye joined other iconic landmarks lighting up in the colours of the Association, including the Blackpool Tower, Emirates Spinnaker Tower in Portsmouth, Gateshead Millennium Bridge, Norwich City Hall, Stockport Town Hall, MediaCityUK, Manchester Town Hall, Royal Border Bridge in Northumberland and the NOMA Earth Tubes in Manchester.

Our amazing supporters took up the challenge to illuminate MND where they lived and caught the attention of the local media too. Trustee Charlotte Layton and Alison Sykes were interviewed on BBC Radio Manchester and the huge number of North West landmarks involved was also covered by ITV news.

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We have always placed great value on the quality of our information and it appears other countries do too, with our resources being adapted to reflect how their own health care systems work. Pablo Aquino, Association Secretary for the ALS Association Argentina said: “After successfully translating and adapting your Living with MND guide in 2014, we decided to do the same with your guide for carers. The contents are being adapted to local laws in Argentina, and other Spanish-speaking countries can then do the same if they wish. We want to thank the MND Association for giving their permission.”

Our new patient record, Understanding my needs, has proved very popular in the UK and is now being adapted by the MND Association of South Australia. People with MND can record their needs on this resource, to help inform hospital and care workers about suitable care. Local nurse Jerry Packer, MND Adviser and Registered Nurse said, “It is our hope to use your booklet to help initiate local and national policy change on MND care. “You are pioneers in MND care and support, and it is wonderful to see your willingness to support other associations around the globe with your information provision.”

New MND drug licenced in USA to mixed reviews

At the beginning of May, the Food and Drug Administration (FDA) in USA announced that they had licenced a drug called Radicava (also known as edaravone) for the treatment of MND. This is the second drug that alters disease progression the FDA have licenced (riluzole being the first drug more than 20 years ago).

The drug was given to 69 people with ALS (the most common form of MND) by intra-venous infusion, another 68 people received a saline intra-venous infusion instead, as a comparison group. People were given six cycles of the drug. In each cycle they received the infusion every day for nearly two weeks, and then a two week break. In total, people were on the drug for around six months. The people who took part in the study were very carefully selected based on their early MND symptoms. It is estimated that this would be equivalent to approximately 7% of people with MND in Europe. The effects of the drug were measured by a comparison of any changes in symptoms between those who received the drug and those who didn’t. A small but statistically significant beneficial effect of edaravone was seen.

While it is exciting news that a second drug has been licenced to treat MND after two decades of failed drug trials, it is currently uncertain what this means for people with MND. Questions remain about how much difference it would actually make and how many people with MND would see an effect. There are also question marks over whether there is enough evidence to licence the drug in Europe (according to regulatory requirements). These are questions that we are actively discussing with neurologists at the moment.

We will be providing updates on edaravone in future editions of Thumb Print. We will post edaravone articles on our research blog too (www.mndresearch.wordpress.com search ‘edaravone’).

If you have any questions about this, please contact the Research Development team on research@mndassociation.org or 01604 611 880.
Championing the Charter

As we celebrate the first birthday of our Champion the Charter campaign, the number of councils across England, Wales and Northern Ireland that have adopted the MND Charter has reached 44. And it’s all thanks to our fantastic volunteers.

Ealing Council passed an official motion to adopt the Charter in April. West London and Middlesex Branch Vice Chair Kapish Narda, who successfully led the campaign for adoption said: “This will directly lead to better services and care for families impacted by MND. I look forward to working with Ealing, and other West London Councils, towards further progress in effective provision of patient care.”

“It’s important that councillors demonstrate our determination to work together when vulnerable groups need our support.”

Charter adoption has opened the door for the branch to meet with the Council’s Director for Adult Social Care to discuss services for people with MND and how they can be improved.

Ealing Councillor, Fabio Conti said: “The council is well placed through its Health and Wellbeing Board to work with partners to ensure that work can be done not only on the care of people with MND, but to help promote the condition in order to get more people diagnosed early.”

Credit Suisse partnership goes from strength to strength

Our partnership with Credit Suisse continues to grow and the total raised so far at the time of writing is a wonderful £300,000 towards the three programmes of work in Care and Research.

Over the last couple of months we have seen senior directors walking around the office in fancy dress outfits for Easter, raffles and the team trekking the Sahara Desert returned home tired but jubilant after raising over £35,000. We were also joined by Sir Chris Bonnington who came along and hosted an evening about his incredible life as a mountaineer and his connection to MND. We are now entering the busy part of the year with lots of activities planned. We have Dragon Boat racing, Lands End to John O’Groats run, a Bangor Rally and a Theory of Everything film screening attended by Felicity Jones and Timothy Hawking all of which are helping us continue our support for people living with and affected by MND now and in the future.

Medway Council also adopted the Charter in April, following a campaign led by Mid Kent Branch volunteers Sheila Thompson and Joan Simpson (pictured).

Councillor Teresa Murray said: “It’s important that councillors demonstrate our determination to work together when vulnerable groups need our support. I hope that those living with this terrible disease and their families will be encouraged and come forward if they need more help.”

Find out if your council has adopted the Charter and how you can join our campaign at www.mndcharter.org

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NICE guideline on MND, the story so far

The publication of the NICE guideline on MND follows four years of campaigning by the Association. *Thumb Print* talks to three people about the different parts they played in securing the guideline and why it will make such a difference to people with MND.

Alison Railton, Public Affairs Manager

“In 2009 we put in a formal request to NICE to publish a guideline on MND. With a relatively rare condition like MND, national guidance is vital for healthcare professionals who may only come across one or two people with MND in their careers.

“No other condition with a similar patient population had ever secured a NICE guideline so we knew this was going to be a big task. Indeed, we are one of the rarest conditions to have one.

“During the 2010 general election campaign we organised a petition which was delivered to Downing Street. Following the election, the National Audit Office, published a report into how inefficient neurology care was. The report recommended a NICE guideline on MND.
This helped our campaign enormously. We used the findings from the report to call upon the Government to do something about the poor care people with MND were receiving. For us, it became a human rights issue.

“No other condition with a similar patient population had ever secured a NICE guideline so we knew this was going to be a big task.”

“In 2012, we received the announcement we were hoping for. NICE confirmed it would publish a guideline on MND. However there was no indication of timing, so we launched a second campaign to speed up the process. This campaign was successful and NICE brought the guideline forward by several months. In 2013, they set up a development group, made up of health and social care professionals and people affected by MND to advise what should be in the guideline.

“When NICE published a draft in 2015 we quickly set up a survey and invited members to comment. We influenced the content quite significantly and because of this it now includes guidance around the need for a fast diagnosis and provision for social care.”

Hilary Fairfield, Regional Delivery Manager

“We had to find out how the guideline was being implemented so we developed an audit tool, Transforming MND Care. A project group was established including carers and a person with MND to develop the tool. Once developed, it was piloted with five different NHS healthcare teams across the country. It also went to a number of royal colleges and professional bodies. In March, we launched the audit tool nationally and so far over 80 NHS teams have requested it.

“By completing the audit, professionals will be able to identify which aspects of care they provide need improvement. The audit has two parts: the first part is completed by healthcare professionals by analysing clinical records; the second part is through a short survey to be completed by the person with MND. Once the responses to the two parts are combined, it gives a good picture about what care was given, and how it was given. Once a team has completed the audit they are sent a report with suggestions of actions they could make to improve the service. We will also be sharing best practice and celebrating the teams who are doing well. Promoting the guideline to people with MND and their carers is very important. We want people to use the guideline to challenge the care they are receiving. We created a leaflet people could take to their appointments and use it to discuss the care they are getting.

“We are using the NICE guideline to get Clinical Commissioning Groups (CCG) to meet their obligations. For example, in one area where we have been funding a co-ordinator post, alongside part-funding a physiotherapist, we have been able to challenge the CCG and request they take over the funding because the guideline states those services should be available to people with MND.

“Across the country we will be carefully monitoring the difference the guideline has on people with MND. People faced with this most devastating condition need to be able to access care that is co-ordinated, effective and appropriate. We see it as our job to make sure that happens.”

David Setters, person living with MND

“I was diagnosed with MND in September 2012. Fortunately for me, it is the slow progressive type. That meant I was able to work for a further four years, although my wife, Helen, had to give up her job to be my full-time carer to enable me to do that.

“I had met Hilary Fairfield at various regional meetings and she asked if I would like to become involved in the development of the audit tool as a patient representative.

“Having worked in business for a long time I was a little wary of the term ‘audit’. It wasn’t necessarily always a gratifying experience! However, I was persuaded by the group that many health and social care professionals actually welcomed such initiatives to provide evidence that they are already providing the right standards of care, or to help achieve them. So, having welcomed the publication of the NICE guideline, I could see that this was the best way forward to help ensure that the measures became embedded in best practice throughout the country.

“I believe the audit tool will help improve services in both the short and medium term for people living with MND. In the medium term, standards of provision should improve where the audit tool is adopted and in the short term I hope that shortcomings in services are highlighted and solutions quickly found, particularly for those with a more rapid progression.”

For a copy of What you should expect from your care pocket booklet summarising the NICE guideline recommendations contact MND Connect helpline: 0808 8026262 or email mndconnect@mndassociation.org or download via www.mndassociation.org/publications.

For further information please see 11A – NICE guideline on MND.

www.mndassociation.org 9
In order to find effective treatments for MND, researchers first have to understand exactly what causes the disease. Every year, we receive a large number of funding requests from MND researchers for their specific projects. These projects fall into two categories, biomedical and healthcare projects, and usually take form of a PhD studentship or a general project grant. Sadie Vile, our Research Grants Manager, explains the process a research proposal goes through from the moment it is submitted to the Association, and what projects were awarded funding this year.

“Each application is carefully considered by our Research Grants team and specialised Research Advisory Panels, made up of 10 MND scientists and clinicians. The panel is tasked with considering the quality and feasibility of each study – that is, whether the planned outcomes are achievable with the required resources. The Biomedical Research Advisory Panel (BRAP) met this April to discuss 20 applications relating to understanding causes and mechanisms of MND and development of potential therapeutics, to start from August 2017 onwards.

The applications are scored at the end of the meeting and the highest-scoring projects are given to the MND Association’s Board of Trustees for final approval. In this recent round of applications, the BRAP and the Board of Trustees have agreed to fund six biomedical projects at a total cost of £876,000 over the next three years. For an overview of the panel and meetings please visit our website www.mndassociation.org/our-governance For more information on the projects we fund please contact our MND Connect helpline: 0808 802 6262, email mndconnect@mndassociation.org or www.mndassociation/information-sheets for Information sheet E.

The projects we are funding

Dr Manolis Fanto (Senior lecturer at King’s College London)

**Fruit fly model for Annexin gene causing ALS**

Mutations in a gene called ANXA11 are associated with about 1% of MND cases. In order to understand why mutations of this gene affect the functionality of motor neurones, we first need to understand its normal function. Dr Fanto and his team will study at the fruit fly equivalent of the ANXA11 gene and investigate how mutations may damage the neurones. Findings from other studies show that mutations of this gene are likely to lead to defects in autophagy, a process by which a cell gets rid of its waste. If successful, the project may lead to ways of testing potential therapies.

Dr Tennore Ramesh (Lecturer at the University of Sheffield)

**Zebrafish model to identify novel therapy**

Mutations in the C9ORF72 gene are known to lead to death of motor neurones. One of the reasons that this might be happening is because RNA, a structure important for translating our genetic information into proteins, is created with toxic properties. Dr Ramesh and his team will use zebrafish with the C9ORF72 form of MND to test a new therapeutic molecule that is thought to reduce the toxicity associated with C9ORF72 mutations. Using zebrafish is an efficient and inexpensive way to test potential therapeutic compounds.

Panel member Dr Majid Hafezparast, University of Sussex

Dr Chris Sibley (Safra Research Fellow at Imperial College London)

**Identifying new TDP-43 associated RNAs in ALS**

Finding MND biomarkers (ie fingerprints) is crucial to diagnose a patient faster and to reliably track MND progression over time. By establishing a measure that would reliably inform us about the presence of MND and its current stage, researchers can use it in clinical trials to observe improvements after taking a specific drug. Dr Sibley and colleagues identified a specific molecule that they believe is present at abnormal levels in about 98% of people with ALS, the most common form of MND. This project will focus on further investigation of this molecule, which could eventually lead to a development of a new biomarker.
research projects to fund?

Dr Alexander Whitworth (MRC Programme leader at the mitochondrial biology unit, Cambridge)

The role of axonal RNA transport in MND

Correct functioning of RNA, a template crucial for creating new proteins, is important for survival of all cells. However, in MND, mistakes in handling RNA can lead to the death of motor neurones. Dr Whitworth will use microscopic techniques to investigate how RNA moves along motor nerves, as it has been suggested that their excessive length can affect the way RNA is transported along these nerves. These analyses will be first done in laboratory dishes with individual cells, and followed up by investigations of the affected mechanisms in fruit flies. Findings from this study can increase our understanding of what goes wrong in motor neurones and create a platform for new, more effective therapies.

Dr Jean-Marc Gallo (Reader at King’s College London)

Identification of pathogenic mechanisms of C9ORF72

Mutations in the C9ORF72 gene have a negative effect on many normal functions within a cell, leading to development of MND. The aim of Dr Gallo’s project is to investigate which mechanisms cause disruptions in the cells as a result of the C9ORF72 mutation. Dr Gallo will recruit a specialist to use mathematical and computational analyses to work out the most likely mechanisms that are altered in MND as a result of the mutation. Findings from this project will provide more information on the toxic mechanisms involved in MND and could identify new targets for potential treatments.

Dr Han-Jou Chen (Postdoctoral researcher at King’s College London)

Heat shock response pathway for ALS therapy

Dr Chen’s previous work has shown that by increasing levels of the heat shock protein (HSF1), the tendency of the TDP-43 protein to clump together, accumulate and cause death of motor neurones decreases. HSF1 was already found to be reduced in spinal cords of people with MND, suggesting that lack of HSF1 contributes to accumulation of TDP-43. In the current project, Dr Chen will apply a specialised gene therapy technique in a mouse model to investigate the effectiveness of increasing HSF1 levels on reducing disease symptoms. The findings could lead to identification of new drugs that might act on HSF1, giving rise to a potential treatment.
RENOWNED artist Rose Finn-Kelcey, was 68 when she died from MND in 2014. Described as one of the most imaginative and inventive artists of her generation, her work features in national and international collections including The Tate Gallery Collection, The British Council Collection and The Arts Council Collection. Rose remembered the MND Association in her Will, leaving the Association as the residual beneficiary of her estate. Close friend and Artistic Executor of her estate, Andree Cooke, talks about Rose’s diagnosis of MND and how she is fulfilling her promise to keep Rose’s legacy alive.

“In her final months I was one of Rose’s primary carers. In the twenty years before, I was one of her closest friends. Rose was a hugely creative person and is massively respected in the British art scene, where she is seen as a trailblazer.

“She first started to notice symptoms in July 2013 when she experienced difficulty walking. A visit to her GP did not find anything wrong, but she was getting progressively more and more paralysed and we, her friends, were getting increasingly concerned.

“Rose was scared of hospitals but was eventually referred to the neurology department at Royal London Hospital. By this stage she was already paralysed from the waist down. I had a friend who had MND and I suspected Rose had it too. After some tests the neurologist told me that the disease she had was very aggressive and would be fatal. A few days later we were told it was MND. However, it was clear Rose had an especially rapid form of the disease, and just three and a half months later she died.

“The rapid nature of her disease was very hard to keep up with. Rose was determined to stay at home, despite being completely paralysed and initially very inaudible and eventually having no speech.

“She was very loved and cared for by her friends and we all tried to face MND with her and make her life as comfortable as possible. MND can be an overwhelming disease to manage so a group of us set up a visiting rota system and an online diary to make sure she always had support and company. It was touching when Rose described her friends as the silver lining of MND.

“MND can be an overwhelming disease to manage so a group of us set up a visiting rota system and an online diary to make sure she always had support.”

“I will always remember her last Christmas in 2013. She wanted to celebrate it at home so we got an enormous Christmas tree and organised a party. Even though communicating then was very hard you could see her eyes were completely engaged and showed how much the occasion meant to her.

“Before she died Rose asked if I would be the artistic director of her estate. My job now is to make sure Rose’s legacy continues and to gradually sell her artwork. I am working on her first posthumous exhibition at Modern Art Oxford, 30 Pembroke Street, OX1 1BP to run from 15 July – 15 October 2017 (free entry) and starting to place her pieces in significant collections. We are also trying to get a documentary off the ground and a fundraising campaign for the MND Association, who helped Rose enormously, and who Rose wanted to support long after her death.” www.modernartoxford.org.uk/artist/rose-finn-kelcey
HEATHER Twine received her diagnosis of MND in 2014. Now she has taken early retirement and has become an Association Campaigns Contact to help improve the care for people with MND.

“After three years of symptoms, I was absolutely desperate for a diagnosis. I wanted a label, a name, an explanation, and of course most of all I wanted to hear that there was a cure. I had heard of MND and the slower progressing form, PLS as they had been mentioned at consultations as possibilities.

“However I was actually desperately seeking another diagnosis. So hearing that it was confirmed as PLS, brought a short-lived elation, ‘at last, something definite’, followed swiftly by the deep dark pit, ‘incurable, untreatable, progressive, neurodegeneration – deep joy’. I was alone in The National Hospital, London, so having the Association funded MND Care Co-ordinator, the wonderful Jan Clarke present and able to spend time with me, comfort me and hand me vital Association information was a great blessing. I can recall clutching those leaflets like a small lifeline.

“Six years ago I was a fully fit woman, holding down a high level charity director post, managing a budget of over £20M, and staff group of over 1,000, with an active social life, including aerobics, skiing, tennis, dancing. Now, I’ve taken early retirement, as has my husband, Tony, to become my carer. I use a wheeled walker around the house, and have recently lost confidence to manage outside with two sticks, after several falls. So outside I use a mobility scooter or wheelchair.

“As a Campaigns Contact my message to Government is that this incurable, untreatable, deadly disease devastates lives, destroys families and deserves greater investigation.”

“My voice is slowing and weakening and I’ve voice banked. The inevitability of it all can be quite saddening, and I do have some very down patches. I’m tired all the time and it’s hard to get motivated to do anything much. But inside I’m still the old me. I still think of quick responses in conversations, but can’t get the words out soon enough. I was always a great optimist and mostly I can get back to that glass half full perspective.

“I greatly value the work of the MND Association. Tony and I attended the Parliamentary Reception in October 2016. It felt a bit like being back at work, in a good way. In past roles, I’d have been making the speeches, but it was familiar territory. And so afterwards, it felt natural to ask my MP why he hadn’t turned up, and request a meeting to lobby for the Association. The role of Campaigns Contact was suggested to me, when I let the Association know what I was doing. My first target was getting Somerset County Council to adopt the Charter. A meeting with my local County Councillor went well, and she agreed to help.

“I tend to get fired up about all the possibilities and changes that could be made. In my head I have a full battle campaign to approach all five Somerset District Councils and the local hospitals too, and to go to all the non-adopting South West Local Authorities; but then I take a reality check and realise my very real limitations. One step at a time.

“As a Campaigns Contact my message to Government is that this incurable, untreatable, deadly disease devastates lives, destroys families and deserves greater investigation. The Association does great work, but we need much more awareness generally of what this disease does to people, and much more funding for research, for therapies, for support to help those affected.”
OUR 168 runners each took their places at the start of the London Marathon in April to raise money to support our vital work. Indeed, many of the runners have personal experience of the devastating nature of MND.

John Darby secured a ballot place and decided to run for the Association because his friend Stephen Hadley has MND. John, who has run three London Marathons, decided to give himself an extra challenge by running the marathon dressed as a luna puppet. John said: “The first six miles were fine but I did start to warm up around mile 10 and between miles 15 to 18 I got really overheated, so had to lose the head for a mile! However, with the support of the crowd and the amazing MND cheering post I ran the last four miles without having a breather. Hearing the cheers as I crossed the line was amazing.”

Magazine editor, John-James (JJ) Anisiobi, who confesses to hating running, took a free place in the London Marathon through his work so that he could support the MND Association. John-James, who works as a digital news editor for the online OK! Magazine team, decided to run in honour of his grandma, who has MND.

John-James said: “I decided to give it a go, stupidly thinking it couldn’t be that hard. This is my first marathon and almost certainly my last. I can’t stand running. I do play a lot of sport but it’s all short bursts of energy like boxing and football. I found it difficult to fit in training with my love of drinking scotch and sleeping. My grandma said she’s very proud of me and thinks I’m very brave. I can’t wait to give her my medal.”

James Groves and loved ones helped to raise over £8,000 in memory of his
mum Jenny, who had MND. James said: “My lovely mum Jenny was diagnosed with MND in July 2015. Knowing that she was going to be robbed of the things she liked doing the most, her tap dancing and having a good chin wag, was souldestroying. However in Groves’ family fashion she cracked on with incredible courage, laughing her way through. She loved all the fundraising we were doing as a family for the MND Association. She sadly died in December 2016.

“Running and cycling has been a coping mechanism for me, simply being able to switch off, relax and explore. The training has kept me focused on something over the last few months. I can’t believe how great all the support from #TeamMND has been, it really has been brilliant and I wore my vest with pride, doing my bit for the MND Association.”

ANGELA Newman has raised over £12,000, ran seven marathons and suffered a fractured foot, all as part of her quest to support the MND Association. Just a week before the London Marathon, Angela’s preparations included completing the Brighton Marathon!

She started her challenge in October 2015, having never run a marathon before and with the aim of running seven marathons in seven months, but after suffering a stress fracture in her femur after her fifth marathon, she had to delay her mission until after her recovery.

“With the support of the crowd and the amazing MND cheering post I ran the last four miles without having a breather. Hearing the cheers as I crossed the line was amazing.”

Angela is supporting #TeamMND in memory of her friend Maria’s dad Charlie, and said: “He had seven months of suffering from diagnosis to death, so I felt I would take on a challenge that signified that in some way. Charlie was a wonderful father, husband and grandfather. The London Marathon was my final challenge. What a one to finish on hey!”

BEST friends Stephanie White and Katherine Rigby signed up to the London Marathon after Stephanie’s stepfather, William Fulford, was diagnosed with MND in April 2015. The pair have already raised over £9,000 through hosting a ladies Pamper and Pimms night, a superhero boot camp, a curry and quiz night and a charity fun day.

Stephanie said: “Since learning how cruel and rare MND is we wanted to make a difference somehow. We have all found it hard to come to terms with William’s diagnosis, but throughout he has been so strong and has been our inspiration whilst training during the cold and wet nights. William is fighting MND every day and I know he would do anything to have his life back again, as would all the other people with MND.”

JOSH Younger wanted to run after his company Credit Suisse chose the Association as its charity of the year. Josh said: “MND first came on my radar through the plights of two sportsmen I had followed growing up, South Africa scrum half Joost van der Westhuizen and Rangers defender Fernando Ricksen, and having it as our charity of the year was definitely a motivation to run.” He was joined by colleague Gurpreet Singh, who also ran the marathon for the MND Association.

Every day the devastating nature of MND is matched by the amazing efforts of our fundraisers. Why not find the right challenge for you and join #TeamMND in the fight against MND. www.mndassociation.org/eventsdiary
Without volunteers, the MND Association would not be the fantastic organisation that it has become.

Alun Owen

Without volunteers, the Association would not be the fantastic organisation that it has become. As a volunteer myself, I certainly know this is true. Volunteers are involved in every single part of this charity, from raising money, supporting people with MND and helping to educate professionals.

However, volunteers sometimes have to step back from the work they have been undertaking so there is always a need to find and welcome new people into the MND family. In 2016, we developed plans to help recruit and train more volunteers over the next three years and introduce new volunteering roles related to care and campaigning activities.

As Chair, I am determined to ensure that volunteers continue to be involved in all aspects of our work and that includes helping us to make decisions. As an example of this partnership working, at the AGM there was a workshop aimed at capturing the views of people on some of our future awareness activities, including possible themes for our June Awareness Month. This is in direct response to the views of many that have been shared with me over the last few months.

Our Association is strong because our members, supporters and volunteers are all united behind achieving our vision of a world free from MND. When I see this support it makes me feel proud to be involved with the charity. When my own partner had MND, there was very little I could do to help, but since his death in 2001, I have done as much as I can to work towards achieving our vision. However, I am also keenly aware that whatever we do, sometimes it feels as though it is not enough.

I am also aware that we are not reaching everyone with MND – and that is something we must never accept. As the only national charity supporting people with MND and funding research, we can never be happy that we are doing enough. MND may be rapid, but with your support, so are we and we will continue to fight this dreadful disease as strongly as we can.

Earlier in this article I mentioned the MND Association’s actions in response to members’ views. So if you are a volunteer reading this, I want you to feel able to share your views, opinions and ideas. Our charity simply wouldn’t exist without you. Here is my email address alun.owen@mndassociation.org Please feel free to contact me at any time.
Benefits:
Are you accessing all you are entitled to?

After receiving his diagnosis of MND, William Rosser, 61 had no idea what benefits he was entitled to. The Association referred William to our new welfare benefits advice service, to help him navigate the system and understand all the benefits he could apply for.

William said: “This service has made a huge difference to me. It has meant I have gone from merely surviving to having enough money to make the most of my life. The advice I received has seen my yearly income triple. This money has meant I can now afford to get out of the house more, pay for taxis, save towards a mobility scooter and put some money aside for when my care needs increase.”

“This support has given me back my independence and the ability to plan ahead.”

We knew a support service to help people with MND access benefits quickly could have a huge impact for people. The Ice Bucket Challenge enabled us to fund a pilot project in Greater Manchester where our partner, Citizens Advice Manchester, helped families apply for benefits to which they were entitled. We extended the pilot to the East Midlands, where people with MND had access to a dedicated telephone service provided by Leicester Community Advice and Law Service. During a six month period, 102 people secured benefits worth £234,700. The project has made substantial progress in increasing benefit income for people living with MND and helped to relieve financial worries.

As a result of the success of both pilots we are increasing the scale and reach of the service for people affected by MND, with the creation of our new benefits advice service across England, Wales and Northern Ireland in partnership with Citizens Advice Cardiff and Vale and Advice NI.

Speaking about the advice he received, William said: “The person I spoke to was really friendly and completely put me at ease. I was advised to apply for PIP (Personal Independence Payment) enhanced, universal credit and a care grant. I would never have applied for these by myself.” Our service is available by telephone and email, with an additional web chat facility available in England and Wales that can be accessed via our website.

Benefits:
Are you accessing all you are entitled to?

Money raised from the Ice Bucket Challenge helped us to develop a new welfare benefits service

MND Benefits advice (free to call)
0808 801 0620
England and Wales
0808 802 0020
Northern Ireland

The service will outline the benefits a person is eligible for and will explain how they can be claimed. It can also arrange for help completing forms to be provided locally if required and for additional support to be given, where there are particularly complex issues or appeals against decisions.
Following a diagnosis of MND it can sometimes be difficult for people to know where to turn. Our Association Visitors (AVs) are visiting, calling and emailing people affected by MND everyday, providing local support. Driven by a desire to help people live with a diagnosis of MND, Thumb Print speaks to two AVs in very different areas about their own unique reasons for volunteering.

MARIE Holmes from County Down decided to volunteer as an AV two years after her husband George died from MND. Marie talks about her role as an AV and how it is not as bleak as people expect it to be.

Marie said: “My husband, George, died from MND six years ago. It took a long time for George to get a diagnosis and by the time it was confirmed we already suspected it was MND.

“I came to rely and appreciate the knowledge of the MND specialist nurse and a social worker. Their knowledge and support helped us greatly and this is what motivated me to volunteer as an AV. Two years after George’s death I retired from teaching and thought, why not use what I know to help others.

“Visiting feels very much like you are visiting friends. You will usually be asked a few things to do with MND, like setting up a power of attorney or adaptations. However, for the rest of the time we just chat about their lives, their family and any important events coming up. It is a huge honour to be invited into people’s lives like this.

“Living in a rural area does mean you end up spending a lot of time travelling. Sometimes I can travel 40 miles before I get to the person I see. It also means that it can be very hard for people with MND and carers to meet up with one another. To help with this, we have set up support meetings where people with MND and their carers/family can meet for afternoon tea regularly. They have been a huge success, with up to 24 people with MND and their carers attending. We now have five support groups, and one for past carers.

“My role as an AV has helped me to cope with George’s death. Out of something bad, I have been able to do something good. I never thought being an AV would bring as much pleasure into my life as it has. You get to meet so many wonderful people and be part of their lives. If you are thinking about becoming an AV, be prepared to spend happy and fun times with some very special people, it is not as bleak as you may imagine.”

RAMILA Lad has been an AV in Luton for six years. With no experience of MND Ramilia shares how hearing an interview on the radio inspired her to contact the Association.

Ramilia said: “I was listening to the radio and heard someone from the MND Association talking about the role of an AV and how they needed more volunteers. I had never heard of MND before and was struck at what people with the disease had to face. I knew immediately I wanted to help.

“The training was mind blowing, but it made me feel well equipped to support people. I currently support four people. I
adapt what I do to meet their individual needs and wishes. I much prefer visiting people's homes than supporting them over the phone. By going to their home you build up a bigger picture of their life, their family and how they are managing with the disease. Doing this role in a town like Luton means that I rarely have to travel over 15 miles to see someone.

“I had never heard of MND before and was struck at what people with the disease had to face. I knew immediately I wanted to help.”

“Lately I am supporting more people who don’t speak English. That can provide additional challenges for them when they are accessing care. There is a very different attitude within the Asian community to illness and disease. I find many don’t wish to talk about it, which means they do not get support from their own community. With Asian families, I find I often end up supporting the carer as much as the person with MND, along with other members of the family.

“Being an AV has put me in touch with so many wonderful people and it has enriched my life enormously. I am so glad I heard that radio interview all those years ago. MND is a devastating condition, but I am proud to be part of the charity helping to support people.”

GENEROUS volunteers have already collectively donated 26 years of their time following the launch of our STRONG volunteer recruitment campaign earlier this year.

More than 70 people have pledged time so far – and we’re grateful to all of them. One is Victoria Brown, who has a special reason for participating – her mum was diagnosed with MND just a few months ago.

Victoria shares her MND journey and raises awareness of the disease by blogging – a great way of volunteering. Here’s her story:

“The long Easter weekend felt even longer than usual for my family and me. That was when my mum was diagnosed with MND.

“Everyone reacts differently, but I found that I had to let my emotions out and tell people what we were going through. Two weeks after the diagnosis, I started Daughter of MND, a blog which gives me a platform to honestly discuss what it’s like living with and caring for someone with MND.

“My blog will be there to document the difficult days, and the painful emotions, but also the hope we can find and the strength we can draw from others.”

“Initially, I wasn’t thinking about raising awareness. I was trying to find a way to cope with some of the raw emotions that come with a diagnosis of MND – fear, panic, stress, grief. In my first blog, I said it felt like the world had fallen from under my feet. That first post received so much attention from an incredibly strong and supportive community, and it was then that the impact my blog could have became apparent.

“Raising awareness is already so important to me. I thought I knew what MND was, but the reality of the disease was not something I’d ever thought to try and understand. My sister had never even heard of it, and now it’s something we must deal with every day.

“It’s especially important to me that people realise MND is really an umbrella term, not just a synonym for ALS. My mum has progressive bulbar palsy (PBP), like one in four people with MND. I had never heard of it. All types of MND are similar, but PBP starts particularly with speech and swallowing issues and is very quick to progress. In talking about hers and our journey in this new chapter of our lives, I hope readers will be able to understand a bit more about how this terrible disease impacts everyone.

“Looking ahead to the future is quite difficult, and my blog will grow and develop as I have new experiences, side-by-side with my mum. We are already planning to do some fundraising, including a bake sale and taking Mum’s beloved pug on a ‘dog jog’. I’m looking for opportunities for laughter and joy – because we won’t let MND take our happiness for however long we have left.

“My blog will be there to document the difficult days, and the painful emotions, but also the hope we can find and the strength we can draw from others.”

You can read Victoria’s blog at daughterofmnd.wordpress.com

For more information about STRONG against MND, visit the website www.strong.mndassociation.org

Left to right: Victoria’s mum, sister Hannah and Victoria – the day before Victoria’s graduation last year.
What we have achieved in 2016 together

**Care**
- £1m funding for support grants
- Introduced Carers Grant up to £500, awarding 230 carers £93,000 in grant funding
- Prescription for the Powered Neuro Wheelchair shortlisted for an innovation award by HSJ
- 1,500 pieces of equipment loaned
- Pilot scheme to increase access to welfare benefits
- Supported 200 children and young people and provided £48,000 grant funding
- 26,000 pieces of care information issued and 41,000 publications downloaded
- Care forum 3,200 members

**Campaigning and Raising Awareness**
- After four years of campaigning...
- NICE guideline on MND
- 26,000 pieces of coverage on TV, radio, press and online
- 500 pieces of coverage on TV, radio, press and online
- 4,500 health and social care professionals attended our training events

**We raised £17m**
- Established 4 new MND specialist roles
- mndconnect responded to over 8,400 requests
- £1m funding for support grants
- £1.1m grant portfolio funding 88 projects
- £1.7m and 1,500 samples to Project MinE
- Secured commitment ahead of Wales and Northern Ireland assembly elections from 115 candidates to be champions for MND
- 100 supporters met 57 MPs including three Ministers from the Department of Work and Pensions
- 4,500 health and social care professionals attended our training events
- 225 people with MND supported by our Communications Aids Co-ordinator
What we have achieved in 2016 together

We approved 29 grants with a value of £1.1m

We raised £17m

Volunteering

Recruited 64 new Association Visitors (AVs) making 322 AVs supporting 1,098 people with MND

Established new care volunteer roles to provide more support to people living with MND:

- Care Service Navigators
- Information Assistants
- Support Meeting Co-ordinators

Number of campaign volunteers increased to 29

374 new volunteers recruited

Research

We approved 29 grants with a value of £1.1m

2 new genetic discoveries made, leading us closer to understanding the causes of MND

Establishing MND Register

Provided funding to MIROCALS, clinical trial to enable the involvement of more UK based participants

Funded two new healthcare research projects to help improve symptom management and support for people with MND

June Awareness Month

500 pieces of coverage on TV, radio, press and online

21% increase in visits to our website

2,900 awareness posters across England, Wales and Northern Ireland

LEGACIES
TRUSTS
BRANCHES
AND GROUPS
CORPORATE SUPPORT

Awarded £2.3m grant to Project AMBRoSIA to help develop a faster process for diagnosing MND

Contributed over £1.7m and 1,500 samples to Project MinE

Largest ever International Research Symposium in Dublin

100 supporters met 57 MPs including three Ministers from the Department of Work and Pensions

Supported 200 children and young people and provided £48,000 grant funding

26,000 pieces of care information issued and 41,000 publications downloaded

4,500 health and social care professionals attended our training events

500 pieces of coverage on TV, radio, press and online

Increase in visits to our website 21%
CHARLIE Hammerton and his pet ferret, Bandit walked the length of Hadrian’s Wall in three days to raise funds for the Association and St Elizabeth Hospice, Ipswich. Widely believed to be the fastest man and ferret team in history, they tackled the 84 miles in memory of his mum Jan, who died of MND just weeks earlier.

Charlie said: “The hospice was brilliant with my mum and I also want to support the work the MND Association does to make sure that no one has to go through what Mum did in the future.”

The intrepid pair raised more than £3,500 and featured on the radio, TV and in print across the length of the route, in Lincoln, where Charlie works and in their home town of Ipswich.

Charlie said: “It’s been an emotional rollercoaster with a few tough moments; my ankle was so sore at one point I had to take my boots off and walk barefoot for about four miles! But I’ll always remember the amazing landscape and the welcome from all the people we met along the way. Thanks to the media coverage lots of people recognised us en route and Bandit has loved all the attention.”

“The hospice was brilliant with my mum and I also want to support the work the MND Association does to make sure that no one has to go through what mum did in the future.”

There are so many unique and wonderful ways to raise funds for the MND Association. For some ideas take a look at www.mndassociation.org/fundraising
“Rule one of starting a movement – don’t know you are starting a movement”

**LETCHWORTH Walks to d’feet MND**, headed by Claire Pedrick, have already raised more than £16,000 after just four of the 12 planned 13.6 mile walks around the Letchworth Greenway.

Claire was inspired to take action after family friend John Gray and neighbour Pete Jackson were diagnosed with MND. After leading 10 people on the first walk, she promoted the walks locally and increased the number of walkers to 60 in April, including John’s wife Margaret.

Claire said: “Many people don’t know what to do when someone is faced with such a devastating diagnosis. We have had stuff happen in our family and wanted to stand together with our friends. It needed to be local, free and easy and make enough noise that people would want to come too. It is overwhelming how many people want to walk with us. We are here for the long haul. I told my husband, we can do something.”

Claire told her local newspaper, *The Comet*, she was astonished at how the movement had grown since she first had the idea to walk the Greenway in January. She said: “It’s absolutely extraordinary. I set a target of £12,000 thinking if I brought another nine people on each walk we might raise £1,000 each time, but we’ve smashed that! We only came up with the idea about two weeks before the first walk in February. At first I was just going to walk the Greenway, then we had coffee one day and that turned into 12 walks, one each month, then into inviting everyone to come along as well. We just talked to everybody we knew.

“What I hadn’t realised at all was that so many people would want to come and that they’d want to come back. So, rule one of starting a movement … don’t know you’re starting a movement! “We start each time from The Fox at Willian. They’ve been brilliant and let us put a collection pot on the bar and use the car park as a meeting place. It’s a real hodgepodge of people, we have participants from every decade, including some in their 60’s and a five month old baby. It’s an amazing way to spend a Saturday.”

Further walks are planned for 5 August, 9 September, 7 October, 11 November, 2 December and 6 January 2018. At the time of going to press, the walks have so far raised over £20,000.

To find out more take a look at justgiving.com/claire-pedrick and to register email claire.pedrick@gmail.com

**Successful formula turns into yearly event**

**Les Alderson** was a devotee to Ashington Football Club in Northumberland before he died of MND in 2013. After he was diagnosed with MND, his family and friends wanted to do something to show Les how much they cared. They embarked on runs, walks, and many different fundraising activities for the MND Association. They then decided to organise a family fun day and football match due to Les’ love of football.

The first Les Alderson Celebration Day was held at Ashington FC in July 2013 in memory of Les. The day was such a success that it is now held every year, with a successful formula in place for a wonderful yearly event to celebrate Les’ memory and devotion to the club.

The celebration day includes former England cricketer and club manager, Steve Harmison’s Ashington XI competing with the Bedlington Terriers XI for the Les Alderson Memorial Cup. There’s also a junior game, various stalls, face painting, bouncy castle, live music and fundraising throughout the day.

Now in its fifth consecutive year, it has raised a whopping total of over £14,500 since it began. Nicola Shotton leads up the team at the club who organise the event every year and regularly competes in a series of gruelling running events to raise money.

She said of the day: “With a great team of volunteers, we have managed four successful years and hope to continue in years to come to help support and raise funds for the MND Association in memory of Les.”

Lee Anderson who was on the 2016 winning team, collecting the trophy from club chairman Ian Lavery MP with Nicola, Les Alderson junior and the rest of the Alderson family.
It’s not just the physical and emotional impact of MND that can be hard. Which is why we’ve made tackling the financial impact of MND a key priority.

Read about the ways we’re campaigning for improved financial support and services for people living with MND, their carers and families.

Find out how you can get involved in our new MND Costs campaign.

LIFE with MND is tough enough without being pushed into financial hardship – but according to our new research report, that is what’s happening.

People are spending significant amounts of money trying to maintain their quality of life and independence – from home adaptations and care to specialised wheelchairs and vehicles. On average, MND costs someone and their family nearly £12,000 a year. For those of working age, and particularly those living with children, that figure is likely to be even higher.

The MND Costs report was produced for us by Demos, a cross-party think-tank, who surveyed nearly 800 people living with MND and bereaved carers.

Researchers heard from people and families who are wiping out their savings to get support, or going without because they can’t afford it. Almost half say the financial support they receive is inadequate. And nearly a quarter of people are not receiving the disability benefits they’re entitled to.

Financial support to help with aids, equipment and housing adaptations is being provided too late, in some cases after the person has died. And many bereaved carers and families struggle to cope financially after their loved one has died, because there’s little money left. Our new campaign – launched on 21 June, Global MND Awareness Day – is aimed at changing this picture. An essential first step is to raise awareness of the issues and get as many people on board as we can, to create positive change.

Please get involved by sharing the report with your MP, and urging them to take action. To join the campaign and read the full report, go to www.mndassociation.org/mndcosts

Vivienne’s husband Tony was eventually diagnosed with MND in January 2013 after having symptoms for around 18 months. He died surrounded by his family in 2016 but never met his grandchildren born just months later. “MND is devastating but the financial impact is crippling. If you can’t move your legs or walk you’ve got to adapt your house. You want to move into a bungalow but you can’t because it could take too long to sell up and do that. So you have an extension built and even then it’s not quick enough. We had to use our pension, so that’s our pension gone and that will have an impact later on in life.

“When Tony died we were all in limbo. You didn’t know whether you should forge a new life or to carry on with campaigning and raising awareness; could I be around other people with MND? But I do it because the impact on your family is huge. No other family should go through what we’ve been through.”
The unpredictable nature of MND makes it hard to plan and cope financially.

Lack of awareness around bereavement forms of MND.

The financial impact is particularly hard on working age adults, especially those with children.

Lack of awareness around bereavement benefits, and not enough support for many people bereaved as a result of MND – particularly working age parents.

The financial impact increases as the disease progresses, creating a mounting financial burden on those living with more slowly progressing forms of MND.

MND has had a massive financial impact on me and my family. Before my diagnosis I was living in a first floor property with steps, so I had to be rehoused because I couldn’t manage them. I am in a more suitable property now but the rent and council tax is higher. From heating to clothing everything costs more, but you have to be positive and keep going.”

Robert was 57 years old when he was diagnosed with MND. He has a close family, all living near his home in North Wales, and was looking forward to retirement with his wife Jane.

On the day he was diagnosed Robert was told to ‘retire tomorrow and enjoy yourself because you have only two years to live.’ That was in summer 2014. He admits he struggled to come to terms with the diagnosis and then had to cope with the stigma of claiming benefits. “I didn’t know what PIP (Personal Independence Payment) was – I thought it was something out of an apple and I didn’t really want to claim. I had never claimed for anything in my life.

“But as someone else explained it to me, all through your life for 43 years you have paid tax and National Insurance and you have never claimed before and your National Insurance is like your pension pot that you have been paying into. Now, because you need it most in your life, you are just drawing down on it, and your National Insurance is like your pension pot that you have been paying into. “I don’t think she has come to terms with losing dad so suddenly on top of the diagnosis. Still today she writes down that she misses my father. He did everything for her, all the financials... everything.

“Mum has some savings – about £3,000 – but that will start to tick down, so where I can I am helping out, but there will come a point when that money runs out and we just hope we sell her house by that time and we can plug the gap (primarily in care home costs) with that money.

“Just over a year ago we came home to spend more time with my father and my mother and to let them get to know the children again. But now my father has died and my mother is unrecognisable really. It’s heart breaking.”

MND – particularly working age parents.

Relief from reassessments

June’s snap general election was an opportunity to help politicians understand a key problem with financial support that affects many people living with MND.

With your help, we ran a campaign urging parliamentary candidates to commit to scrapping benefit reassessments for people with MND, if they were elected.

An incredible 700 supporters took action and 607 candidates pledged their support. Of those candidates who pledged their support, 50 are now MPs. Thank you to everyone who took part.

Reassessing people with MND for disability benefits is pointless. The reassessments are unnecessary, cause avoidable stress and anxiety for people with MND, and are a waste of public money.

The last Government announced in October 2016 that people with ‘severe and lifelong conditions’ in the support group of Employment and Support Allowance (ESA) would be exempt from reassessments for that benefit. This is still to happen and we will be lobbying the new Government to uphold this commitment.

Access to PIP

The All-Party Parliamentary Group (APPG) on MND has run an inquiry into access to Personal Independence Payment (PIP) for people with MND. Its findings will be reported later this year, and we will use the evidence to campaign to ensure access to PIP is improved for people with MND.

PIP is a benefit for people under 65 to help pay for the extra costs of living with a disability or health condition. We know anecdotally that people with MND can find it hard to access PIP in a timely way and an estimated 800 people with MND are currently waiting to be transitioned from Disability Living Allowance (DLA), which is ending, onto the new benefit PIP.

The MND Costs report shows:

- Not enough financial support is available to help people cope with the immense costs of MND.
- Lack of awareness of what financial support is available to people with MND, and a stigma about applying for disability benefits.
- Financial support that is too slow to access, means-tested and overwhelmingly complex to apply for.
- The unpredictable nature of MND makes it hard to plan and cope financially.
ND is a complex condition and requires a co-ordinated approach to care. Research has shown that a multi-disciplinary approach can increase life expectancy and, as part of our plans to enable as many people as possible access to this support, we have expanded our MND Care Centre Network.

Following a review of local provision across the country, we recently opened our 20th MND Care and Research Network in Sussex and will be opening our 21st in Norfolk later this year.

Our network has come a long way since we opened the first centre at King’s College Hospital in 1993, headed up by consultant neurologist Prof Nigel Leigh. Prof Leigh, is in the unique position of having been director of our first centre and is currently director of the latest addition to the programme. Thumb Print speaks to Prof Leigh about the development of the programme and how care for people with MND has evolved.

“When I was first appointed as consultant neurologist at King’s College Hospital in 1989 there was no special service for people with MND. However, I had been working alongside a small team consisting of a social worker, physiotherapist and an occupational therapist at St George’s Hospital and saw how crucial this integrated approach was for people with MND.

“At St George’s I had also started to work on the basic science of the disease. It was through being involved in research that helped the establishment of a service for people with MND at King’s. Our philosophy was always that you combine the very best care with the very best research and never separate the two. At King’s we were involved in one of the first major trials for MND. We were also awarded a grant from the Medical Research Council (MRC) to do research on brain imaging. My research fellow, Dr John Kew and I found a room in the basement of King’s, where we started to see patients. It wasn’t long before we managed to acquire a dedicated suite of rooms in the University Department where we could see the patients more comfortably and were able to work more formally with other professionals.

“There has been extraordinary progress in our understanding of MND. However, the problem remains that we have so far made little progress in terms of treatments.”

“Establishing an MND Care Centre Network without the support of the MND Association would have been very difficult and much less ambitious. There probably would have been major centres like King’s and Sheffield, but not centres throughout the country.

“In my view, the biggest advance in
patient care over the last 25 years goes beyond genetics and far beyond Riluzole. It is the co-ordinated, multi-disciplinary approach to care that has without doubt changed the patient’s experience. It hasn’t cured MND, but compared to what it was 30 years ago when I started my consultant life, it has totally transformed care. Back then, you were told to send patients home to die. As a neurologist it shocked and appalled me and I remember thinking, we must do better.

“Now 28 years from when I first moved to King’s I am helping to set up the Association’s 20th MND Care and Research Network in Sussex. This is a slightly different model than the one we have at King’s. Sussex covers a wide geographic area, with no centrally-based MND service. However, there were some excellent teams across the region. After a review we decided a network would best support our patients. We will have a physical centre in Brighton where research will be conducted, but our co-ordinator will be supporting teams throughout Sussex.

“There has been extraordinary progress in our understanding of MND. However, the problem remains that we have so far made little progress in terms of treatments. It is a real challenge because whilst there is understandably tremendous pressure from patients to prescribe drugs, as clinician scientists, we have to remain committed to the highest level of scientific rigour. We are treating our patients in this generation, but we have to consider future generations. There are ethical and political issues and we must guide a course between rigour, compassion and understanding of the urgent desperation of patients.

“The MND Association Care Centre Network programme has made a huge difference to the way people see and understand the co-ordinated approach. No professional can work in isolation, and it puts patients where they belong, firmly at the centre of their care.”

Co-ordinated, expert care is also available at local neurological services. This year we are going to be expanding the high standards of our MND Care Centre Network model across England, Wales and Northern Ireland by creating a network of affiliate, multi-disciplinary teams that may be based in a number of settings such as community services, local hospitals or hospices. We will work closely with these teams and, when they have achieved an agreed standard of care based on the NICE guideline, they can apply to become an MND Association affiliate. Our aim is that the majority of people with MND should have access to more effective multi-disciplinary support close to their home.

The latest care information

**Eating and drinking with MND**
Proving popular since its recent launch, this ‘cookbook’ offers information on nutrition, tips from other people with or affected by MND, and lots of easy-swallow recipes. There are even a few surprise recipes from celebrity chefs.

**7B – Tube feeding**
We have updated our information sheet to include details about the new web platform MyTube by SITraN research centre. The MyTube resource includes video clips of people with MND talking about their decision making and life with a tube www.mytube.mymnd.org.uk

**1C – Where can I find the information I need?**
To help people search for MND information, following diagnosis. This information map is also available as an online resource at: www.mndassociation.org/in fmap

**7D – Voice banking**
This information sheet accompanies 7C – Speech and communication support, providing more detail on how people can bank their voice, for future use on voice apps.

**3D – Hospice and palliative care**
Exploring the varied benefits that hospice and palliative care can bring to quality of life, from diagnosis onwards.

**8C – Withdrawal of ventilation**
This information sheets explains what to consider when thinking about future care and the option to withdraw ventilation, if wished. Please be aware this sheet covers end of life decision making.

You can download our publications at: www.mndassociation.org/publications or order printed copies from our MND Connect helpline: 0808 802 6262, mndconnect@mndassociation.org
RESEARCH isn’t just about finding a cure for MND. It also helps discover new ways to improve the lives of people living with MND, and those who care for them. A substantial amount of our research investment is in this area.

We recently joined forces with charity Marie Curie to fund three palliative and end-of-life care research grants, all aimed at investigating how best to support people with MND and their carers. Between us, we will invest £450,000 over the next three years in these three projects:

### Improving management of excess saliva and secretions

Around half of people living with MND have problems with excessive drooling, creating both physical and psychological discomfort. At the moment, there are lots of different ways to treat this symptom, with practices varying across the UK. Prof Chris McDermott and his research team at the University of Sheffield plan to recruit 500 people with MND from 17 centres across the UK to investigate current approaches to managing excess saliva and assess which are most effective.

### Learning from people with MND to improve palliative care

It’s important to know how people with MND, their families and carers feel about the palliative support they receive. Dr Kate Fleming and her team at the University of York will examine previous studies that interviewed people affected by MND about their opinions on current palliative care. Their findings should inform and improve current care services.

### Adapting existing carers’ support tool for families affected by MND

Carers play a central role in palliative care. Making sure they are getting enough support is paramount for providing the best end-of-life care to people with MND. Prof Gunn Grande and Dr Gail Ewing will collect opinions from carers and healthcare practitioners to develop a ‘Carer Support Needs Assessment Tool’, so carers of people with MND receive well-planned long-term support. This is a joint project between the University of Manchester and the University of Cambridge.
If we are to achieve our vision of a world free from MND, while also providing the best possible care and support for people affected by this cruel disease, then we must continue to raise the substantial income to meet the costs involved.

We rely on voluntary donations of which legacies are a vital source, accounting for almost a third of our total income over the last decade. Without legacies, we could not maintain the same high level of investment in research or the breadth and quality of our care and support services. So we are asking for your help, to ensure we can continue our fight against MND, by leaving a legacy to the MND Association in your Will.

More information can be found at: www.mndassociation.org/legacies.

Alternatively, call fundraising on 01604 611860 or email legacies@mndassociation.org

Please remember people with MND in your Will.
MARIE'S husband James was receiving poor care from his care home who were not equipped to meet his complex needs. The local NHS and the Care Quality Commission got involved and moved James to a different home. Due to the original care home's cancellation policy, Marie was faced with the prospect of paying for a further 28 days care. James' NHS Continuing Healthcare (CHC) package had agreed to pay for the new home but would not pay the cancellation fee. This left the family facing a bill of almost £4,000. Marie shares the couple's experience with Thumb Print and tells how a call to MND Connect secured James' care and rescued the family from a deeply traumatic situation.

“My husband James was diagnosed with frontotemporal dementia (FTD) in 2004 and then, six years later (2009) he received a diagnosis of MND. The shock was huge. We were devastated. We were told the prognosis wasn’t good, but seven years on I feel so lucky he is still here.

“Now my very active, 18 stone, power lifting, scaffolder husband, who was just 57 when he was diagnosed with FTD, is now unable to talk, doubly incontinent and needs constant support to eat, move and wash.

“After his dementia diagnosis I looked after him at home for seven years. The dementia would make him very aggressive and it was becoming increasingly difficult to care for him at home. He would often disappear and I wouldn’t know where he was until the police would find him and bring him home. I was so exhausted and tired.

“One day, on verge of a breakdown I phoned up the mental health team telling them I could no longer cope. James was admitted to hospital where they assessed him. He moved into a care home but sadly the care deteriorated year by year. The home just couldn’t meet his needs. James hardly ever left his room, would be lying for hours on a wet bed, surrounded by left over plates. I visited daily to care for him, but it was heart-wrenching to see him like this. My proud husband was just left to sit in his room for hours on end. I took photographs and showed them to the Care Quality Commission (CQC) and the
providers of his CHC funding who were shocked and agreed to move him to a different home.

“I found out a new care home, Woodland View, was being built nearby. They did an assessment and confirmed they were able to meet his needs.

“When we moved James into Woodland View he was naturally apprehensive. However, the carers really helped James settle and took the time to get to know him. CHC funding had not come through yet so I paid for the first week in the new home because I wanted him in a better place as soon as possible. It was then I was informed that I would also need to pay the old home one month’s notice, nearly £4,000.

“It is hard to put into words how distressing this was. When James got ill and could no longer work we lost everything. We exhausted our savings and lost our home. To try and raise the money to pay the old care home I sold my jewellery and anything I had that was of value. I could only raise £1,000.

“I attended the Colchester and North East Essex Group Christmas meal and just broke down. Someone suggested I call MND Connect to get some advice. I called at 4.55pm. The next day, at lunchtime they called me back to say that it was all sorted. I could not believe someone was helping me. I had struggled and struggled and never thought for a single moment that a charity would step in and make such a difference. The MND Association is amazing, and have saved both mine and James’ life.

“James is so much happier and responds well to the carers at Woodland View, who he clearly trusts. He smiles all the time. After 42 years of marriage that is the most wonderful thing to see. I can’t thank the MND Association enough. You can see they really do care about people with MND and do everything they can to support them when they need it the most.”

Wendy Twydell, Home Services Adviser at Woodland View said: “James is a gentle giant and it is wonderful to see him so settled. After six years of never leaving the home, now he is often out in a wheelchair enjoying the gardens.

“I have never seen a charity step in so quickly to fix a critical situation. I knew immediately I had to start fundraising for them. I have seen how the money is used and the difference it makes. We have also been in touch with the MND Association and arranged for them to do some training at the home so we can make sure we are giving the very best care.”

Left to right: James and Marie Grant (front) Wendy Twydell and Juliet Driver from Woodland View

Mouth care with MND

Taking care of your mouth and teeth is important, but we know, with MND it can be challenging. Here are some tips to help you.

Limited arm strength or movement?
An electric toothbrush may help. Extra-long handled toothbrushes can make it easier to reach your mouth. There are some three-sided toothbrushes available that can brush all sides of the tooth at once.

Swallowing difficulties?
Choose a non-foaming toothpaste (one without sodium laurel sulphate) as these simply dissolve and do not need to be rinsed. If you use a suction machine, this can be used to suck up excess saliva and toothpaste. A toothbrush accessory can be attached to suck up toothpaste and excess saliva.

Difficulty opening your mouth?
Using a bite block or mouth rest in the other side of the mouth will help keep the mouth open for brushing and mouth care, and help to protect carers’ fingers.

Difficulty visiting your dentist?
Regular visits to the dentist are recommended if you can travel. Some dentists have hoists to assist wheelchair users to use the dental chair. Others may have wheelchair recliners so you can stay in your wheelchair.

If you can’t travel, you can be referred to a community dental service by any member of your health and social care team. Community dental services may be able to arrange for a dentist to visit you at home.

Our information sheet 11B – Mouth care has more detailed information about mouth care with MND. We also have a new publication available for dental professionals – Motor neurone disease: a guide for dentists.

You can find our information online at www.mndassociation.org/publications

To order publications, contact our MND Connect helpline on 0808 802 6262 or email mndconnect@mndassociation.org

Continuing Health Care funding

We know NHS continuing healthcare (CHC) funding is a vital source of support for many people. We are working with partners in the Continuing Healthcare Alliance at both national and local levels to ensure that people living with MND receive CHC support. Earlier this year, the Association wrote jointly with other CHC Alliance members to the leads of NHS England’s CHC improvement programme, to call on NHS England to ensure that CHC is funded to a sufficient level, and we have engaged with local proposals for CHC restructuring to ensure that they do not have a negative impact on the support people receive. We will continue to monitor developments in CHC funding and provision closely and to oppose any steps to restrict access or reduce the available funds.

For further information on CHC please see our information sheet 10D – NHS continuing healthcare

We were pleased to be able to help James and Marie in this very difficult situation. As a charity we are not able to fund ongoing care costs. In this emergency case however, we were able to make a one-off payment under our support grant programme.
“Fundraising helps me stay focused and striving to raise even more”
As a fitness instructor and mum, Jo Cole’s life was all about helping others stay in shape, running half marathons and chasing after her young son Harry. But all that changed two years ago, when Jo was diagnosed with MND, just before her 27th birthday.

RIPPED by an “overwhelming feeling that I just had to make the best of a terrible situation”, Jo set up an MND Association Fightback Fund, which now stands at over £13,000, thanks to Jo’s efforts and those of family and friends inspired by her energy.

You may recognise Jo, who along with Harry was the subject of a portrait in 2016 by artist Sarah Ezekiel. Sarah, who is also living with MND, used Eyegaze technology to create Mother and Child for our Shortened Stories awareness campaign.

Jo, who lives in Stafford with nine-year-old Harry and her partner Stuart, talks about coming to terms with her diagnosis, and how her Fightback Fund is helping her stay focused and positive.

“Even though MND has entered my life, it will never change me as a person. I still have a positive outlook on life.”

“I use having MND as an opportunity to appreciate life more and live better. I want to make a difference in fundraising and other people’s lives. For them to know they are not alone.”

“When I left school I was unsure which direction I wanted a future career in. I studied childcare initially, beauty and finally sports. Being a fitness instructor and working in a gym was by far my favourite job.

“In December 2014 I experienced some weakness in my hand and wrist. I started to drop things, but there was no pain so I carried on. I assumed I’d overdone it on the weights. Over the next few months my symptoms worsened. I became concerned when I started to lose my balance. Sensing something wasn’t right, I made a GP appointment.

“The doctor thought I’d had a mini-stroke. But after lots of examinations, doctors told me they didn’t think I’d had a stroke after all.

“It might sound strange, but when I was finally diagnosed in July 2015, I didn’t break down or cry. I’ve always been a strong person and think everything happens for a reason.

“Now my main interests are fundraising for the MND Association, family time, being a footie fanatic – Tottenham Hotspur is my team – my dogs and, just recently, joining in with raising awareness of MND in road races.

“In March this year I took part in the Stafford half marathon along with several members of the Run MND family. It was great fun. I’m so lucky to have such amazing people in my life, and they helped support me the whole way round the course. I’ve now entered four more races for this year, including a full marathon.

“I plan to do the longest zip line in Europe this summer, and maybe even a trek up Snowdon – exciting!

“I found out about the Fightback Fund through an email from the Association and thought that’s fantastic! It’s kind of like my legacy. It was extremely easy to set up and communication is second to none.

“The benefit of the Fightback Fund is it helps me to stay focused and I find myself striving to fundraise even more. I’m extremely proud of this, and have a great sense of achievement. The Association have been amazing and deserve every penny.

“I use having MND as an opportunity to appreciate life more and live better. I want to make a difference in fundraising and other people’s lives. For them to know they are not alone.

“I believe a cure is near and by fundraising and working together we can achieve this.”

To find out more about MND Association Fightback Funds or Tribute Funds, please visit www.mndassociation.org/get-involved/fundraising or call 01604 611864.
Grant funds robotic and furry companion

When Judy Merritt’s husband, John, moved into a nursing home she was very concerned about how he would adapt. When he started to struggle, Tracey Thomas, MND Care Co-ordinator, proposed a rather novel idea, to get John a robotic cat to keep him company. The MND Association stepped in and provided funding so that John could have his cat. Here Judy talks about the difference the grant has made and how John is now calm and happily living in the home.

“During difficult times the MND Association has always been there and now, thanks to them, John and Mr Trump are the best of friends.”

Judy said: “My husband John was diagnosed with MND and frontotemporal dementia (FTD) in 2013, two years after he first went to see a specialist. We were devastated. I looked after John at home for as long as I could. However, it became increasingly difficult for me to care for him. He fell on the stairs a few times and after a particularly bad one, John was hospitalized for a week. When he was released from The Royal Cornwall Hospital, he went into a nursing home.”

“John had always had cats and totally adored them. He especially liked our neighbour’s cat Frankie. Frankie used to spend hours in bed with him and saw him through some very dark days.”

“Due to his FTD, my wonderful and sensitive husband was struggling to cope in the nursing home. We had a meeting to decide what to do and, knowing John loved cats, Tracey suggested the idea of getting John a robotic cat from America to help keep him calm. Tracey contacted the MND Association about the proposal and the Cornwall Branch agreed to fund it.”

“The ginger cat promptly arrived from America and John took to him straightaway and named him Mr Trump. Mr Trump purrs, meows and rolls over. Everyone who comes to see John makes a fuss of Mr Trump and it really helps to break the ice. It has made John so calm and happy. Mr Trump has made such a difference and I am so grateful to the MND Association for funding it. During difficult times, the MND Association has always been there and now, thanks to them, John and Mr Trump are the best of friends.”

If you would like more information on our grants please contact MND Connect helpline:
0808 802 6262 or email
mndconnect@mnassociation.org
Sophie runs for Derbyshire Branch

Sophie Sharp ran a half marathon, raising £2,100 for the Derbyshire Branch after her grandma was diagnosed with MND. Sophie said: “I wanted to do something positive to raise money for the Association. My grandparents both love motorbike racing and when I saw the half marathon on the Silverstone racetrack, I knew that was the event for me. I’m not a runner but gave myself six months to train. I hope one day there will be a cure so no one has to go through what my grandma and my family are going through.”

BBC News presenter marks 30 years

BBC News presenter Nicholas Owen, attended the Reading and West Berkshire Branch’s 30th anniversary event. Nicholas spoke to guests about his personal connection with MND. The event at Englefield House, home of the branch’s patron Newbury MP Richard Benyon, followed a service of music and readings in nearby St Mark’s Church.

One of the organisers Mrs Mary Dodds, helped set up the branch in 1987 when her first husband, Derek Prior, was diagnosed. Mary said: “We decided to mark this special anniversary by sharing our memories and achievements and to look positively to the future together.”

After Derek’s death in May 1990, Mrs Dodds continued supporting the branch which has gone from strength to strength.

Remembering loved ones

Thirty former partners and carers of people from across Surrey who have died from MND gathered at a special annual reunion in the Gallery Restaurant at Denbies Wine Estate in Dorking. The event was organised by Beryl Daniel and Mary Williams, East Surrey Branch Patient Care Co-ordinators. The event is the tenth reunion for former carers and raised £250 for the branch.

Celebrating Dad

Sally and Richard Woods organised a fundraising evening at the Old Cattle Market, raising £6,200 for the Cornwall Branch. Sally’s dad Roger Johns, died of MND and she wanted to mark her 40th birthday by celebrating his life with friends and family at a music, comedy and auction night.

Arley Hall celebration raises over £16,500

An evening of fine dining and music in the magnificent surroundings of Arley Hall raised more than £16,500 to support people living with MND in Cheshire.

Viscount Michael Ashbrook, Patron of the Cheshire Branch hosted the event raising £16,500 for the branch. Lord Ashbrook and his wife Zoë, worked with the Cheshire branch committee to organise the evening, designed to be a celebration of the good work of the branch as well as a fundraiser. Following a drinks reception, guests enjoyed dinner, before Dr Brian Dickie, Director of Research Development, gave a presentation about current research projects. The evening finished with a musical performance from the Manchester School of Theatre, led by Ian Chesworth.
Pounding the streets:
Lydia Dower decided to take on a 10k and half marathon after her best friend’s father, Richard Haworth, was diagnosed with MND. Lydia got a team of 19 to take part in the 10k raising over £5,100 for Richard Haworth's Fightback Fund. This brings the total now raised in honour of Richard to over £10,700.

Pub quiz:
The Pheasant pub in Bedford was jam packed when 170 quiz goers attended an event organised by Denise Cardwell. An amazing £1,400 was raised, with further donations expected from matched funding. Denise and her husband Jim, who is living with MND, are pictured with their friend Sharon.

Remembering Syd:
Warren Thompson and Wilmslow Glass raised over £2,000 from their Golf Day, held in memory of Warren’s father, Syd who died from MND in 2015.

Marathon challenge for Team Ian:
Bev Farrow and Team Ian took part in the Windsor and Eton Half Marathon in February, raising around £1,800. The team was created after Bev’s brother-in-law Ian Smith, was diagnosed with MND.

Hair today:
Adriana, 11 had been growing her hair for five years but decided to cut 16 inches off, raising £300 for the Association. The sponsored hair chop happened on what would have been her grandad’s birthday. Adriana said: “Thank so much for all your support and helping me to help others. I feel very proud.”

Pub quiz:

A night to remember:
Michelle Hanslip and Hayley Rudd held a charity ball at Knights Hill King’s Lynn, in honour of Mandy Gamble, sister to Michelle and Auntie to Hayley, on what would have been Mandy’s 50th birthday. Mandy died from MND in November 2015, 13 years after her diagnosis. The ball was a huge success with over 150 guests and raised an amazing £4,700. The pair are aiming to raise even more money with more events planned for the summer.

bake it for MND:
Eleanor Kirlew held a bakeit! cake sale at her work, Centre for the Environment, Fisheries and Aquaculture Science, in Weymouth, raising over £320. Eleanor said: “I have recently been diagnosed and I’ve had fantastic support from the Association so would like to give something back.”

Hair today:
Taking the plunge: Imogen, who has overcome a fear of water to take on a sponsored swim, raising £700. Imogen decided to undertake her epic challenge after family friend, Gordon Lambert (pictured) was diagnosed with MND. Imogen said: “I am very proud because I have overcome my fear and I feel like I have also helped raise awareness.”

It's a goal: Zoe Pilsbury and her family organised a football event and auction, raising over £1,300 in memory of their dad, Philip Latham, bringing Philip’s Tribute Fund to over £4,800.

Doing it for Grandad: Jessica, Grace, Ellie, Elsie and Hallie all raised over £900 for the Association in memory of their grandfather Paul Manning, who died from MND. The family remain committed to raising money and say that it is now the adult's turn after the children did such a fabulous job.

Pedal power: Graham Plain has taken on three gruelling cycling challenges in memory of his mum, Avril who died in 2015. After his first challenge, Paris-Roubaix (nicknamed The Hell of the North) Graham said: “On entering the velodrome in Roubaix and passing the finish line my emotions took over, tears of joy, relief and pride on the realisation of what I had achieved in memory of my mother. The pain was only temporary and well worth it.” To date Graham has raised over £5,000 which includes his employers, Henderson Global generous matched funding of £2,000.

Walk to d'feet MND: Grace Sienko-Eland, 11 organised a 10 mile Walk to d’feet MND in April to honour her Auntie Paula, raising an incredible £560.

Let's dance: Maria Collins along with two friends organised a Zumbathon to raise funds for the Association and two other charities. Maria said: “The event exceeded expectations all round, and we were absolutely blown away by the whole thing.” The group raised £4,100, with £2,000 going to the Association.

Tracing footsteps: Jasmine Jagger organised a Walk to d’feet MND event across The Coleridge Way for her family and friends, raising a whopping £10,000. Jasmine said: “I wanted to raise money for research into MND because Mum was diagnosed with bulbar onset ALS last August. It shocked our whole family. Around my 30th birthday I announced we would walk 50 miles across the English countryside, along with anyone who was willing.

The Association were fantastic and we felt like a team working towards something amazing together. It united my family and gave Mum something to get excited about, she checked our online donation page every day and helped with the planning. Tracing the footsteps of Coleridge and Wordsworth was the stuff of dreams, a beautiful three days filled with laughter, chatter and joy. We learned what friendship and family really means.

When we checked our online page our donations were over £10,000 raised from sheer tenacity to publicise our event and share our challenge with everyone we know.”

Let’s dance: Maria Collins along with two friends organised a Zumbathon to raise funds for the Association and two other charities. Maria said: “The event exceeded expectations all round, and we were absolutely blown away by the whole thing.” The group raised £4,100, with £2,000 going to the Association.
Thank you to our friends and family

My husband Steve, was diagnosed with MND in 2009, having experienced symptoms for two years prior to that.

Since diagnosis, the disease has been progressing slowly but relentlessly and has taken its toll to the point where, having lost his speech long ago, Steve has virtually no movement and therefore no ability to communicate (despite his mind being as sharp as it ever was).

MND has affected our family and those close to us immensely – not least our daughter’s. She was seven years old when this all began and has had to endure the difficulties and changes alongside us. We cannot be more proud of her now as she turns 16 and faces all the challenges life throws her way quietly but determinedly.

Her dad, my wonderful Steve, has been utterly heroic throughout it all. For him this has been, and continues to be, a monumental challenge that he faces and withstands valiantly day after day, without flinching.

I just wanted to take this opportunity to thank all our friends and family for their support and caring messages and MND Association donations. In particular, we have Steve’s work colleagues at Drax Power in Selby to thank for inspiring us to set up the Stephen Halliday Fightback Fund. Their most recent effort, for example, was to take on the Yorkshire 3 Peaks Challenge! The 10-strong team, led by Nickie Garrett, battled through torrential rain and high winds to make it in 10 hrs 45 mins with “thoughts of Steve getting us round.”

We are enormously grateful for their support. Indeed it makes us very emotional to think that they, and others, are still thinking of Steve and his struggles after all this time.

Jill Halliday, Yorkshire

Since writing this letter Steve has sadly died after 10 years living with MND.

Laughter, Tears then MND

I’m Margaret Leader and I have bulbar onset MND. I was suffering for 18 months before my diagnosis. I have written a book, Laughter, Tears then MND, with the help of St Christopher’s Hospice. It tells the story of my family life, the jokes I played, and how I cope with MND. Raising money has been a way to help others living with MND and is something my whole family has got involved in.

My work colleagues did a cake sale and raised £1,000, my son and daughter raised £1,500 by giving up chocolate and my sister arranged with a friend a dance in their sports club raising £2,000. I was especially touched by my daughter’s friend, Andrea, who, despite being ill herself, is running five miles a day for one month raising £1,500.

My son, nephew, son-in-law and four friends are doing the London to Brighton bike ride for MND. Oh and I forgot, my dear friend ran the marathon for MND and another charity, she raised over £1,500 for MND. That’s a total of over £7,500 and the bike ride money is yet to come. I feel touched by everyone’s efforts and would like to say to all of them a very special thank you.

Laughter, Tears then MND
Bravery

TIFFANY Furleger wrote this poem for her grandma, who sadly died from MND in 1996. Despite being just 12 at the time, Tiffany helped care for her grandma and was struck by the bravery and dignity she showed throughout her illness.

Bravery can come on suddenly, Defeat cowardice with a single slice, Overpower fragility in the first round, Take control of weakness.

Bravery is power, Gifted to all through the dark times, It drives you on relentlessly, Your energy, your saviour.

Bravery is support, A defender through the pain, It fights your corner, battles your battles, Temporarily triumphant.

Bravery is is impressive, Overcoming the unexpected, Overtaking the frail, Leaving fear on the sidelines watching in awe.

Bravery is a performance, An act of defiance, A mechanism to cope, Still deserving of an applause.

And you were beautifully brave. Brave to the final beat, the final breath, the final word: ‘I just want to sleep’.

Thumb Print on top of the world

DAVID Browning sent in this photo of his carer, Benn Elliott, on holiday in Dubai. Benn took along his copy of Thumb Print and is seen pictured on the 120th floor of the world’s highest building, Burj Kalifa in Dubai. David said: “Benn has been my main carer for the past seven years and has been my rock in stormy waters. Benn was lucky enough to go on a cruise to Dubai this year and we wanted to share a photo of him with Thumb Print because being in the magazine would make our day!”

Registration is now open for the 2017 education conference for health and social care professionals. This year it takes place at the Hilton Birmingham Metropole on 31 October and there will a focus on practical management of motor neurone disease.

Interested professionals should visit our online registration page for more information and to sign up to attend www.mndassociation.org/edconf17

Education conference

The Motor Neurone Disease (MND) Association
We improve care and support for people with MND, their families and carers, and fund and promote research that leads to new understanding and treatments. We also campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

As a charity we rely on voluntary donations. Our vision is a world free from MND.

Website
www.mndassociation.org

Social media
Online forum
A place for people affected by MND to share experiences and support each other. http://forum.mndassociation.org

Facebook
www.facebook.com/mndassociation

Twitter
@mndassoc

MND Connect
Our MND Connect helpline offers advice, practical and emotional support and signposting to other organisations.

Open Monday to Friday 9am to 5pm and 7pm to 10.30pm.

0808 802 6262
mndconnect@mndassociation.org

Membership
To receive a regular copy of Thumb Print, call 01604 611855 or email membership@mndassociation.org

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