Out of this world
Patrick wins top award for ground-breaking design

Little Isla walks 500 miles
full story page 7

Symposium success in Orlando
full story page 4
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They say that ordinary people can do extraordinary things and I think it is a saying which particularly rings true when talking about those who are affected by MND.

It is a disease which is savage, indiscriminate and cruel – it destroys lives and it takes away the things that we all take for granted - the ability to walk, use our arms and even speak.

But in the face of such adversity, some people affected by MND find a way to not just cope, but to achieve incredible things.

When MND robbed Patrick Joyce of the ability to walk and use his arms he tried to find a way of harnessing modern technology to enable him to move his wheelchair using only his eyes.

His invention was entered into the Hackaday Prize alongside a thousand other entries from across the world and in November it was announced that he had won the Grand Prize – a truly inspiring achievement.

The pages of Thumb Print are always full of stories of people whose lives have been touched by MND in some way, but refuse to let it win, whether they are inspired to raise money, or fight back by raising awareness.

Together, one day, I am confident that we will beat MND and I feel this even more strongly having recently returned from our International Research Symposium. In the meantime, I hope the stories of the incredible people featured in this magazine, and all those whose lives are touched by this devastating disease, will continue to inspire you.

Sally Light
Chief Executive
MORE than 800 researchers and clinicians from 30 countries attended the Association’s International Symposium on ALS/MND held in Orlando, Florida in December.

It is the largest scientific and medical conference specific to MND research and care in the world and gave leading researchers the opportunity to plan future work and share knowledge in person.

The Association’s 26th Symposium attracted delegates from Australia, Japan, South Korea, India and Denmark.

Dr Brian Dickie, Director of Research Development at the Association and Programme Coordinator said: “It’s a huge effort to plan the Symposium and every year it gets bigger and better. The science and the level of global collaboration is mind blowing and so many new researchers are coming on board from similar fields to enrich the experience we already have.

“It’s been a fantastic meeting and the feedback has been very positive. Many delegates have said they are looking forward to getting back to their laboratories and teams with renewed energy and enthusiasm for 2016.”

A wide range of research was presented during the three-day event, including respiratory management research, MND genetics, clinical trials, cognitive change and biomarkers.

The final word of the Symposium went to Bernard Muller, who after receiving a diagnosis of MND over five years ago set up his own biotechnology company to develop therapies for MND.

“The science and the level of global collaboration is mind blowing and so many new researchers are coming on board.”

He spoke about how this generation of patients can be the driving force behind new approaches in drug development.

The Symposium also recognised some of the work which is being done into MND research around the world.

Dr Gareth Miles, from the University of St Andrews, was the recipient of the Instituto Paulo Gontijo award, given to an outstanding young MND researcher.

The Association funds part of Gareth’s research, and his team have been able to grow motor neurons in a dish from stem cells to try and work out what goes wrong with them in MND.

Over 300 posters were also presented.

The posters, which are similar to advertising posters, are a good way for researchers to present findings from on-going work, or for PhD students beginning their career in MND research to illustrate their work to peers for the first time.

Every year poster prizes are presented to the best scientific and clinical posters. The scientific award went to Rosie Clark from the University of Tasmania, for her poster looking at what happens during the course of MND to a type of cell called interneurons which connect motor neurones to the central nervous system.

Dr Rebecca Broad from the University of Sussex won the clinical poster prize for her work on a new imaging technique which looks at the density and organisation of parts of motor neuron cells, called neurites, within the brain tissue of people with MND.

The Association is funding Rebecca’s research into this new technique, which could potentially be a biomarker of the future.

To read about some of the research discussed at the Symposium visit our research blog at www.mndresearch.wordpress.com
News of the Symposium spread on social media – here are selection of the best tweets

The ALS Association @alsassociation
Excited to be hosting so many great orgs dedicated to fighting ALS at the #alssymp! Stay tuned for Ask the Experts!

Brian Dickie @DrBrianDickie Great work by @mndassoc Fellow Jon Cooper-Knock on new potential pathway involved in C9orf72 ALS. Potential new treatment target? #alssymp

Belinda Cupid @BelindaCupid Lots of interest in palliative care research priorities poster at #alssymp @PeolcPSP @mndresearch @sabinebest

MND Association @mndassoc
A standing ovation for @BernardusMuller after an inspirational speech finishes the Association’s #alssymp #MND

MND Research @mndresearch
Congratulations to 2015 #alssymp poster prize winners – Rebecca Broad from @SussexUni and Rosemary Clark from @UTAS.

The ALS Association @alsassociation
A BIG thank you to all our colleagues for their hard work for a successful #alssymp 2015! Looking forward to Dublin already!

MND Association @mndassoc
And just like that the @MNDConference Team are packing up ready to go home – another successful #alssymp #MND

Ammar Al-Chalabi @AmmarAlChalabi
Just on my way home after the best #alssymp ever! (It is my 21st). Outstanding quality of science and presentations. Well done @mndassoc

Paula Maguire @paulamaguireMND
@mndassoc @mndconference Sounds like lots of interesting new things came out at the #alssymp Lots of positivity too. Keep up the good work.

Sally Light @sallylight17 And it comes to an end #alssymp Thank you for being here, or following on line. Thank you @alsassociation for being great hosts.

The story of an extraordinary life

A

N autobiography detailing the life of one of the Association’s founders, Dr Frank Clifford Rose has been published.

By Any Other Name talks about Dr Rose’s life, from his time as a medical student, when his interest in MND began, to his time as a Patron of the Association from 1979 to 1990.

The book’s foreword, which is taken from an article published in The Times in 2013 describes him as being ‘well ahead of his time’ and says that many thousands of patients gained enormously from his novel approach to the collaborative treatment of neurological conditions.

He died on 1 November, 2012 aged 86.

The book is available to buy or download from Amazon.

Steven’s fundraising goes up a gear

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NTREPRENEUR Steven Smith is planning to go even further in his bid to raise money for the Association by organising one of the biggest Rave and Ride events ever seen.

To add to the excitement, it is hoped that world records will be broken. The event will see individuals and teams of indoor cyclists riding along to music provided by DJs from across the UK and beyond.

The event on 14 May will be held at Stoke Park Bucks, and it is hoped it will push Steven’s fundraising total to over £160,000. For more information visit www.raveandride.com

View our updated statistics

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HE Association has updated the statistics we use when talking about MND and promoting our work.

Among the information which has been updated is the statistic regarding a person’s lifetime risk of developing MND which is up to 1 in 300.

Other facts which have been revised include the number of people diagnosed with MND each day and information surrounding life expectancy.

For more information please visit www.mndassociation.org/what-is-mnd/brief-guide-to-mnd
Filming My Father: In Life and Death, which charted the devastating impact of MND on one family, has won a prestigious award.

The moving documentary, which was broadcast on Channel 5 in March, told the story of Steve Isaac who was diagnosed with MND in February 2010.

It was filmed by Steve’s son, Fraser, who was trained in camera skills to make the film as intimate as possible, alongside director, Liz Tucker.

Liz won the broadcast journalist of the year award at Medical Journalist’s Association Summer Awards and the film was also highly commended in the Domestic Current Affairs Category at the Association of International Broadcasting awards in November.

The international jury described the film as: “A thoroughly poignant and personal insight that drew the viewer into the drama of a family dealing with the slow decline of a father through motor neurone disease. It felt extraordinarily personal and intimate.”

Inventor wins top award for ground-breaking device

A

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inventor, who is living with MND, has won a prestigious competition with a device which enables wheelchair users to control their wheelchair using only their eyes.

Patrick Joyce, 46, won the Grand Prize in the Hackaday Prize for his Eyedrivomatic, which uses Eyegaze technology.

It is the work of Patrick and his team, which includes Steve Evans, who is also living with MND, and film maker David Hopkinson.

There were nearly 1,000 entries for the competition and the top prize was the choice of either a trip to space or $196,000.

Patrick, a former artist who was the face of the Association’s 2010 Awareness Campaign Incurable Optimism, said: “I’m pleased we won. I would love to go into space, but Eyedrivomatic was a team effort and sadly we can’t all squeeze into one seat on the spaceship, so we’ll take the money. Personally the money comes at an opportune moment as our house is too small and we couldn’t afford to move.”

Patrick explained that the idea for the device had come about due to personal experience of being reliant upon a wheelchair.

He explained: “I was originally a sculptor, my mind has always worked well in three dimensions, so 3D design came easily to me. I’ve enjoyed fiddling with electronics since my childhood, so when I became disabled, it was natural to find solutions to the problems I faced.

“Steve and I both have MND. We both have electric wheelchairs, but while I still have some movement in my fingers and am just able to operate mine, Steve only has his eyes left and until Eyedrivomatic, had to rely on his carer to operate his.

“We both also have Eyegaze equipment, which is becoming increasingly available. As I don’t actually own the wheelchair or Eyegaze, my idea was to make something which would interface with the user’s chair-mounted computer and physically move the joystick. Crucially, this would mean not making any modifications to the loaned hardware and could work with any wheelchair and Eyegaze combination.”

The result was Eyedrivomatic – a two-part system featuring a ‘brain box’ and an electronic hand to move the wheelchair’s joystick. Patrick and his team were announced as the Grand Prize winners of the Hackaday Prize, organised by Hackaday, a website for aspiring engineers and inventors, at a ceremony in San Francisco on Saturday, 14 November.

Since winning the award the Eyedrivomatic has appeared in several newspapers including The Mail and The Times and attracted coverage online and on TV. To find out more visit www.eyedrivomatic.org

Award for poignant film

Fraser Isaac, his father Steve and mum Debbie, pictured during filming
FOUR-year-old Isla Grundy is walking 500 miles to raise money for the MND Association – and has already made some celebrity friends along the way.

Inspired by The Proclaimers’ hit song I’m Gonna Be (500 miles), Isla has pledged to walk 500 miles in memory of her Grandad, David, who died from MND in June 2015.

Isla, her mum Kirsty and dad Richard were even lucky enough to meet The Proclaimers when they visited Bradford in October as part of their tour.

Kirsty said: “Back in July I contacted The Proclaimers’ agent wondering if there was any chance we could meet them. I didn’t hear anything until the Thursday before they were due to perform in Bradford when their agent asked if we would like to go along to the soundcheck in Bradford on Saturday afternoon.

“They sang five songs – it was just like our own private gig. Afterwards they came down and had a little chat with us, they were really friendly, really nice.”

Isla, who lives in Pudsey, Leeds will complete the 500 mile challenge by taking part in small walks during the year to raise awareness of the disease as well as vital funds.

At the time of going to press, Isla had raised £2,208 and covered 216 miles.

Isla’s proud mum, Kirsty said: “My father-in-law, David, was diagnosed in June 2013 and soon afterwards my brother-in-law, John, decided that he wanted to run, cycle and swim 10,000 km in a year – starting in July 2013 and finishing in 2014.

“My husband and I have taken part in runs, as did Isla when she did a little run in Sheffield last September. My other brother-in-law went teetotal to raise money and altogether we have raised over £8,000 for the MND Association.

“Isla doesn’t really understand why she is doing it yet – she was only three-and-a-half when we started, but it is nice for us all to do something positive.”

You can take part in a walking event whatever your age! If Isla has inspired you to take part in a Walk to D’Feet* MND event, or to organise your own, visit www.mndassociation.org/walktodfeet or call our fundraising team on 01604 611860.

*WALK TO D’FEET is a trademark of The ALS Association and is used with permission. All rights reserved.

Fleck Ditchburn is determined not to let MND win.

After being diagnosed with the disease in March 2009 he has tried to live as normal a life as possible, despite losing the use of his limbs.

Thanks to some clever computer software, the 66-year-old former ICT teacher from Cumbria has even managed to continue one of his great loves – painting.

He said: “I have never thought, ‘Why me?’ It is important to remain as positive as possible. I feel very well and healthy – I feel good so I try to do as much as I can.

“The disease prevented me from painting in water colours, which is something I really enjoyed. As I gradually lost the use of my limbs so ended the ability to paint, which was frustrating because my next challenge was Ashness Bridge in Cumbria.”

Not to be beaten, Fleck found some software which turned the computer into a canvas to paint on. He also developed a device which allows him to control the mouse via a straw in his mouth.

Fleck and his family have also done a huge amount to raise money for the Association, including a mountain pull, which saw Fleck being pulled and pushed up Skiddaw, the fourth highest mountain in England.

He said: “MND is not the end – I believe it means Must Never Despair.”

Fleck’s motto?

MUST NEVER DESPAIR
Film stars take on new leading roles

In 2014, Benedict’s Ice Bucket Challenge video played a huge role in raising £7million, securing over 5.6 million views to date on our YouTube page alone and generating global media coverage.

In May 2015 Benedict, and his wife Sophie, attended a VIP dinner at Buckingham Palace alongside Professor Hawking, which was hosted by our Royal Patron, HRH The Princess Royal.

Benedict said: “As part of my research into Stephen Hawking I worked with the Motor Neurone Disease Association who introduced me to two people who had MND at very different stages.

“They very generously allowed me to film them and were remarkably brave in their frankness and honesty about how it started and what they’d felt emotionally and physically.”

In 2014 and 2015, Eddie made Ice Bucket Challenge videos in support of the Association.

Eddie Redmayne, 33, undertook similar research as part of his Oscar-winning role as Professor Stephen Hawking in the BAFTA-nominated BBC drama Hawking.

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Benedict and Eddie take on the role of Patron, while Taron becomes an Ambassador.

39-year-old Benedict has been an Association Ambassador since 2008. He carried out extensive research into MND to prepare him for his role as Professor Stephen Hawking in the BAFTA-nominated BBC drama Hawking.

In April 2015, Eddie visited an MND clinic in London to show his Oscar statue to one of the people who helped him understand the difficulties of living with MND, Glenn Phillips.

“These people were incredibly receptive, and really kind.

“All the understanding they gave me went into the film, and there’s no question that we couldn’t have done it without the help we had from everyone. Being an MND Association Patron tops off the life-changing experiences I had making this film, and learning about the devastation of motor neurone disease along the way.”

Actor, Taron Egerton, 25, is now an MND Association Ambassador.

Taron lost his grandmother to motor neurone disease in 2003 and in February 2015 he organised a fundraising screening of his hit film Kingsman: The Secret Service in his hometown to support and benefit the South West Wales Branch.

Taron said “I’ve been lucky enough to have had some amazing success with my first film Kingsman: The Secret Service and if some of that success means I can help raise awareness of motor neurone disease then I will do all I can to help. My gran was a formidable woman and to have her taken from us so quickly by MND was an awful shock for my family. I’ve already worked with my local MND Association branch to put on a big fundraising event back in my home town so I’m really excited to become an Ambassador for the MND Association.”

Association Chief Executive, Sally Light said the actors’ support had bought global attention to MND.

She said: “We are thrilled to be working with our new Patrons and Ambassador, and are incredibly grateful for their support.”
ICE BUCKET CHALLENGE HITS THE SMALL SCREEN

The impact of the Ice Bucket Challenge is continuing to be felt with the Association’s communications team supporting filming in laboratories in London and Oxford recently.

Huffington Post, the news and entertainment site, has commissioned a new web docu-series starring Game of Thrones actor Sophie Turner.

Turner, who plays Sansa Stark in the hit HBO series which airs on Sky in the UK, will host the 10-part series called #PowerShift sharing stories from around the world where social media has been harnessed to effect change.

Produced by Broad Bean Media, it will be aired on all 15 global editions of the Huffington Post as well as being syndicated to partners on its AOL On Network.

The filming around the impact of the Ice Bucket Challenge included a day interviewing Jakub Scaber, a Lady Edith Wolfson Clinical Research Fellow at the Nuffield Department of Clinical Neurosciences, University of Oxford. Jakub explained the background to some of his research and how the IBC raised awareness of MND to the wider global research community too.

Meanwhile Cactus TV is making an hour long documentary on celebrity and social media presented by Sophie Ellis Bextor. The documentary is for the UKTV channel Watch and will be airing in January.

The heavily pregnant singer and musician first travelled to Wakefield to meet with Paula and Robert Maguire and learn about the very start of the Ice Bucket Challenge in the UK. She also met researchers at the King’s MND Care and Research Centre where she interviewed Director Professor Ammar Al-Chalabi and found out the wider implications of the IBC.

Professor Al-Chalabi said: “We discussed the power of celebrity and the way the multiple Ice Bucket video by Association Patron, actor Benedict Cumberbatch really made such a difference to the speed with which the phenomenon took off back in August 2014.”

He said that he explained the research they did and the benefits that the Ice Bucket Challenge had brought to his patients.

We are delighted to report that Sophie gave birth to Jesse Jones a healthy baby boy just a few weeks after the filming.

LIQUID RILUZOLE NOW AVAILABLE TO MND PATIENTS

A liquid form of riluzole has now been made available in the UK.

Because MND can cause problems with swallowing, some people choose to crush their riluzole tablets to take them. The motivation behind the development of Teglutik® was to meet this clinical need for a liquid form of riluzole when the tablet form proves too difficult to swallow.

A couple of our MND Care Centres have had the opportunity to look at Teglutik and are positive about the benefits it may bring.

Rachael Marsden from the Oxford Care Centre said: “This is a very welcome development; the tablet form of riluzole has always been difficult for some patients to manage, hopefully being able to request it as an oral suspension will improve some patients’ experience of taking it.”

The decision as to whether the drug is prescribed lies with the patient’s care team, but it is hoped the drug will make taking riluzole easier for patients in the future.

from our chair

The start of a new year always offers a time for reflection and for me, the start of 2016 has been no exception. As 2015 drew to a close I know many of you were deeply saddened to learn of the deaths of three members of our MND family.

Campaigners Mark Samson, Eric Rivers and our colleague and friend, Trustee Lena Marsh all lost their battles with MND towards the end of the year and my thoughts are with their family and friends at this very difficult time.

The work they did to raise awareness of this devastating disease, in spite of everything they were going through personally, should inspire us all to come together to do everything we can to beat MND for good.

So, as we start 2016, and perhaps consider our resolutions for the year ahead, let us all resolve to go a little bit further and push a little bit harder in memory of Mark, Eric and Lena and all the other members of our family who live with the impact of MND every day.

I look forward to working with you all in 2016.

Alun Owen, Chair, Board of Trustees
After 25,000 miles, 1,676 days, 23 hours and 25 minutes it was the moment Sarah Outen had been waiting for.

A triumphant return to London, kayaking under the welcoming arms of London Bridge, having survived everything from a near miss with Hurricane Joaquin in the mid-Atlantic to weeks and months of isolation.

While it was a moment the 30-year-old had thought about and longed for often during her incredible journey, the emotion of the experience was probably the one thing she had felt least prepared for.

She said: “I had a fantastic two weeks on the final leg cycling and kayaking from Falmouth to London. My family and friends were nearby and it was great being on familiar territory.

“I wanted to raise money for charities which were personal to me. I had a friend whose mother had died from MND.”

That final kayak into London was very surreal. After a four and a half year journey - plus a year and a half of planning it beforehand - it was odd to think that it was all coming to an end.

“I felt very warmly hugged by everyone who was there at the home-coming. There were tears, lots of grinning, happiness and an overwhelming sense of gratitude.”

Sarah’s London2London Via The World journey started in April 2011 when she left London on board her kayak, Nelson, and headed down the River Thames towards the English Channel and on to France.

The aim was to loop round the planet using a rowing boat, bike and a kayak, while raising money for a number of charities – including the MND Association – and sharing her story with children around the world at the same time.

The journey was borne out of a previous challenge which saw Sarah row across the Indian Ocean in memory of her father, Derek, who died in 2006.

She said: “I wanted to raise money for charities which were personal to me. I had a friend whose mother had died from MND and I am also friends with Patrick Joyce who is living with MND. It is a terrible, devastating disease and I wanted to do something to help.

Sarah described the logistics of planning the journey as ‘complex’ and said it involved cutting through lots of red tape and paperwork as well as enlisting the help and support of fixers around the world.

One of the most dramatic moments of the journey came in October when she was forced to call for an evacuation from her rowing boat, Happy Socks, as mountainous seas and treacherous conditions whipped up by Hurricane Joaquin, closed in.

She said: “I heard a forecast that the hurricane was coming right over where I was heading, so a swift decision was taken to evacuate before it arrived. It was so widespread that tankers and other carriers...”
of the world!

Sarah cycles into China having crossed the border with Kazakhstan.

were already starting to turn away. There was really no other safe option."

It was during her time at sea that she was totally alone and she found her day-
to-day life was dictated by the weather.

“I heard a forecast that the hurricane was coming right over where I was heading, so a swift decision was taken to evacuate before it arrived.”

She said: “My days at sea were about eating, sleeping and rowing and maintaining myself and the boat. It was quite a simple life really. There was liaison with shore as well as interviews with classes of children back home who wanted to interview me about my experiences. On tough days it was great to be able to talk to the children and tell them my tales of life at sea.”

On land, Sarah met countless people along the way who she said were mostly extremely friendly and interested in what she was doing.

“The people I met were so inspiring as were the amazing sunsets,” she said.

Among those waiting for her as she arrived in London was her fiancée Lucy, who she plans to marry in June. As for the future, the couple have plenty of plans.

She said: “In the short-term, I am about to start writing my book, Dare to Do, and I would also like to make a documentary, as I filmed most of the journey. Lucy and I also want to open an adventure farm to teach children about farming and the outdoors and I would also love to get into broadcasting.

“For now though, it’s all about meeting up with my friends and family.”

Raise a mug to Pete

PUT together two of the nation’s favourite pastimes – making tea and taking selfies – and you have a recipe for fundraising success.

Since being launched in September, the #SelfTea4MND campaign has raised almost £7,000 and has proved to be a hit on social media with hundreds of people – including celebrities such as Chris Ramsey, Jeremy Vine and Eamonn Holmes – posting pictures of their ‘selftea’ on social media.

As well as being simple to take part in, the campaign has a serious side as it highlights the difficulties some people living with MND face with swallowing, eating and drinking – things we all take for granted.

#SelfTea4MND was started by fundraiser Pete Collins, who lost his father to MND six years ago and his auntie to the disease a couple of years later. The family has raised money for the Association ever since, reaching an incredible £76,000.

During the Christmas period, the #SelfTea4MND campaign took on a very festive twist with fundraisers taking a selfie with their mugs in front of their Christmas trees.

Pete said he had been overwhelmed with the response and thanked everyone for taking part.

If you would like to join in the fun simply make a cup of tea, take a selfie and make a donation using the Textgiving or Justgiving website. Text TMNDS5 £5 to 70070 or visit www.justgiving.com/Tea4MND and then nominate your friends and family to get involved.

However you do it, make sure you send your pictures to Thumb Print and we’ll publish a selection. You can contact us at editor@mndassociation.org.

Sarah cycles into China having crossed the border with Kazakhstan.

Pete Collins pictured with his #SelfTea4MND mug.

www.mndassociation.org 11
Jean Worker, a talented embroidress, poet and supporter of the South and East Somerset Branch of the Association, died from MND in June. In this tribute, her husband John describes how they met and the happy life they shared together.

Jean was born on 20 January 1928 in Srinagar, India. Her father, a Londoner, was an architect working for a Maharajah.

The family returned to England in the early 30s to live in Ealing, West London and early in the Second World War they moved to Surrey in an attempt to escape the bombing.

I had been a chorister in the church at Belmont, Surrey since 1938. In 1942, four girls from the local private school started coming to the services in full view of the choir. One of them was particularly pretty and caught my eye immediately. A year later, I met the girls at a confirmation class and we were briefly introduced by the vicar.

It was not until April 1944 that I plucked up the courage to deliver a note to her house, asking if she would care to come for a walk with me. Happily she agreed.

On reflection, later that evening, I realised how much I liked her, so much so that if I wanted to have any chance of marrying her I had better pull my socks up and pass my General Schools Certificate exam, which was three months away.

We met every fortnight or so and mostly discussed my studies. To my astonishment, I passed the exam with several credits.

In 1945, I volunteered to join the Merchant Navy. After preliminary training, I was posted to a troopship in Avonmouth Dock, which then sailed for far eastern operations against Japan.

I was away for a year, during which time we corresponded frequently, see poem right. Later that year, Jean went to the Royal School of Needlework in London to study embroidery and dressmaking and qualified as an embroiderer.

I left the sea in 1946 to study quantity surveying which led to further separation when I obtained a post in Persia with the Anglo-Iranian Oil Company to earn money for our marriage.

We married in January 1952 – Jean made her own wedding dress and I helped turn the handle on the manual sewing machine, but never saw the completed dress until the day.

After changing jobs and locations several times, my work on the railways brought us to York in 1959 where we settled with our three children.

It was there that Jean’s embroidery career really blossomed. She became a member of the York Minster Broderers, working on repairs and vestments for the clergy and she studied for additional qualifications at York University.

In 1987, when she was aged 59, Jean noticed that her index finger would not straighten easily and she began falling over for no reason. In 1988, she was diagnosed, with 90% certainty, of having motor neurone disease.

I promised to look after her for as long as she needed and for as long as I was able. Now that Jean is at peace, free from the ravages of the disease, I can honour her wish by picking up my own life again.

It has been a great privilege to have her as my wife and life-long friend for 71 years, she will be sorely missed.

Goodbye

Poem to John – written by Jean in 1945

Goodbye – oh how I hate that word, Today our ways must part; You to sail the ocean blue I my career to start

And as you sail the seven seas Will you think of your home sweet home Of the life you left to serve your land By riding o’er the foam?

Will you think of the services at St John’s? Will you think of the Downs so wild? Where you walked alone like Kipling’s car Where you played when you were a child.

Will you think of your home in Belmont Road? Of the games you played with your brother? And he of course will remind you of Sis And also of father and mother.

Will you think of the little things of life, That to you have a meaning rare? And last of all will you sometimes think Of a girl with curly hair?
My name is Monica, I was diagnosed with MND on the 31 July 2013.
My world came crashing down around me, it was the worst day of my life. I still can’t believe this has happened to me. I have an amazing family and carers - they keep me going.
I feel very blessed to still be alive. My family keeps me going, I see them every day, they take it in turns to come and see me. The first thing I noticed was that I started limping, I would fall over and then my right hand started twitching.
As the days, weeks and months went by I became progressively worse and the only part of my body I could move was my head and my left thumb.
I am so grateful to be alive. I am still here and I don’t intend on going anywhere for a long time. My family, myself and my carers will continue to fight this war until we win this battle. I would not wish this terrible disease on my worst enemy.
I am very lucky to have the carers I have, they will do anything for me. They always listen to what I have to say, and they act on it.
One of the worst things about this illness is when I have to wear a face mask to help with my breathing. No-one can understand me when I am wearing the mask.
I get so frustrated about it, but I manage to keep my cool. It is not anyone’s fault and it is really hard watching my carers and family doing my housework. I was so house proud, at least I can talk or use my computer to communicate with everyone. I know I am lucky to be able to talk and eat, I feel very blessed. I eat and drink very well, the only thing is I have to remove my mask often when I’m eating and when I’m having my medication.
My brother Keith is an incredible man. Keith has always been the one to take me to all my hospital and doctor appointments, there was never a day when Keith could not take me, I always come first. Thank you for what you have done for me and my family, I love you from the bottom of my heart, I know you will keep up the good work.
I have two amazing daughters, Natalie and Shona. We have always been very close, they are my rocks, they are with me most days, they are so strong, but I know deep down they are struggling to come to terms with the fact they are going to lose their Mum, but we don’t talk about that, only positive things. They keep me going, bless them, I love you girls more than you will ever know.
I have also been blessed with two amazing granddaughters Jada and Saraya. We are very close and I see them all the time. They are the reasons I have to keep going.
My family are my soldiers, we will keep fighting this dreadful war together. Having MND is like being behind bars in prison, watching the world go by, and there is nothing I can do about it. I hope one day soon, they will find a cure for this dreadful disease.
I try not to think about it too much otherwise I will get upset. I just take each day as it comes.
I have met some amazing people since I became ill, I would not have met them if I did not have this dreadful illness, so there are some positives.
I just want to mention a few people who have had a major impact on my life, first the most amazing woman in the world, who happens to be my Mum. If it was not for my Mum, I would not have those amazing holidays abroad so thank you. Thank you for being you, I love you unconditionally.
My brother Keith is an incredible man. Keith has always been the one to take me to all my hospital and doctor appointments, there was never a day when Keith could not take me, I always come first. Thank you for what you have done for me and my family, I love you from the bottom of my heart, I know you will keep up the good work.
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I hope one day soon, they will find a cure for this dreadful disease.
Whatever plans you all have, just do them, because you don’t know what’s around the corner. There is no warning.

“Having MND is like being behind bars in prison, watching the world go by, and there is nothing I can do about it. I hope one day soon, they will find a cure for this dreadful disease.”

Mum-of-five Monica Seville’s loving family regard themselves as her foot soldiers in her battle with MND. Since her diagnosis they want to grab every minute they can with her and make sure her Reading home is filled with fun and laughter. Here, thanks to her Eyegaze, Monica pays tribute to her wonderful family and talks about her life with MND.
A MOTOR-racing fan, who is living with MND, met two Australian racing legends at Silverstone.

Craig Sarson, 53, who also lives in Silverstone with his wife Miriam, was invited to the home of British motorsport on November 1 to watch the final of The Walter Hayes Trophy – a race weekend which features Formula Ford 1600 cars.

Craig was diagnosed with MND in August, having experienced symptoms for around 18 months.

Australian racing driver, Chris Davison and his brother, Richard, were on hand to show Craig and his sons, Damien, Thomas and Martin around the garages and pit lanes and helped to spread awareness about the work of the MND Association by running logos on their cars during the race.

Craig explained: “Being diagnosed with MND was a bombshell, it has changed everything. I hadn’t even heard of it until I was diagnosed. I am now in a wheelchair and have had to pass my business over to my sons.

“I have lived in Silverstone for over 30 years and have spent a lot of time going up to the circuit. We had a brilliant day on Sunday, it was very interesting.”

Drivers Chris and Richard were also promoting Racing4MND – a fundraising website set-up by former racing driver, Neil Cunningham who is also living with the disease, while another driver, Neil Tofts, chose to offer his support as his friend Phil Newby has MND.

Chris said: “Both my brother Richard and I are in our 60s and our real racing days were many years ago. But we have always harboured a desire to race overseas at some stage in our lives, and this was the year.

“Things changed dramatically in my life in February 1988, when my wonderful wife Jan suffered a very severe stroke, leaving her with major disabilities for life. Her situation made me very aware of people who are afflicted with major health problems, and I like to help where I can.

“My daughter Claire, who now races historic Formula Ford cars with us, has developed a stroke awareness initiative called FF/FAST, and with the support of the Australian Historic Racing Group, many of our historic Formula Ford cars are running her FF/FAST stickers.

“As I had become aware of the Racing4MND program through Neil, an old racing buddy, I thought our visit to Silverstone may give us the opportunity to repay the support we have had over the years by carrying the MND Association logos on our cars.”
PEOPLE living with MND were given the chance to view Augmentative and Alternative Communication (AAC) products at an event organised by the MND Association.

Held at the Queen Elizabeth Foundation Mobility Services Centre in Carshalton, Surrey, the event gave those with MND, their families and health and social care professionals the chance to find out more about AAC provision and how the system should work.

Liam Dwyer, who is living with MND, also talked about his personal experiences.

Those who attended had the chance to participate in focus groups about voice banking and ideas and innovations, both of which supplied some interesting points to be considered in the coming months.

The event was well attended, with more than 90 people registered and the feedback on the day was very positive. It is the Association’s intention to run similar events throughout the country, with the next planned to be held in Darlington on 17 March.

If you are experiencing issues with communication aid provision, or have a positive experience you would like to share, please contact our Communication Aids Co-ordinator, Matthew Hollis, on 01604 611767 or email communicationaids@mndassociation.org

A personal view by Liam Dwyer

“Volunteering comes in many forms but what I find very rewarding is campaigning.

“Although we are still only a small group, we are steadily growing in numbers. Campaigning and raising awareness is one of the three pillars of the MND Association’s mission, alongside improving care and support, and funding and promoting research.

“For just over two years I have been involved in Augmentative and Alternative Communication (AAC) provision for people with MND, campaigning and working with NHS England alongside MND Association colleagues.

“Losing my speech is by far the worse thing for me about this disease but it is not the end. If you read the APPG report, Condemned to Silence you may have seen that Surrey and Sussex were among the most concerning areas in England for AAC provision.

“My own experience started in July 2014 when I was told I could not have an assessment. I then asked for another assessment in March this year and was approved for my communication aid equipment in August. For someone like me with a slow form of MND that is acceptable, but we need to get it right for those who have a rapid form of this devastating disease.

“On Thursday, 1 October, a group of people with MND, alongside MND Association staff, met with the NHS England office for Surrey, Sussex and Kent where we were given an updated report on what is happening in Surrey and Sussex. Dr Donna Cowan and her team at Chailey Heritage Clinical Services (CHCS), the AAC specialist centre for Surrey and Sussex presented a very pleasing report.

“The main points showed that the average waiting time from referral to first assessment was 30 calendar days and from assessment to delivery of equipment was 22 days. Although it is always possible to improve a service, when you look at these facts you can see how well the team has performed in a short time.”

Hair-raising challenges raise more than £2,000

IFTEEN-year-old Ella Colgan bravely went for a dramatic change when she decided to raise money for the MND Association.

Ella, from Sunderland cut her long wavy hair off after being inspired by a family member who has recently been diagnosed with MND.

She has raised £695 and said that she likes her shorter style so much, that she has decided to keep it.

When Matt Goodchild was challenged to grow his beard during a year away travelling, he decided to do it to raise money for the MND Association.

Matt’s auntie, Rosemary Garrod is living with MND and Matt decided that having his head and beard shaved on his return would be a good way of showing his support.

In September, a beard and head shaving night was held in Suffolk, raising more than £2,000 and Rosemary went along on the night to help.

For more wonderful fundraising feats turn to pages 34, 35 and 36
When MND strikes at the heart of a family, everyone within it, regardless of their age, are affected. Thumb Print meets two families who have been touched by MND and are now using their experiences to help improve the lives of other members of the MND family by becoming volunteers.

**United in our fight**

**Brian makes short work of raising £10,000**

After spending a year sporting a bright and colourful array of shorts to raise money and awareness for the MND Association, you might expect Brian Jackson to be looking forward to pulling on some warm trousers!

Not so, according to the 72-year-old grandfather from Sheffield who decided to take up the unusual challenge after losing his wife Chris to MND in 2012.

Brian has spent the entire year wearing shorts and, as Thumb Print went to press, he had raised an incredible £10,000.

He explained: “I’m not really looking forward to pulling on my trousers, I’ve really enjoyed wearing the shorts.

“It hasn’t been particularly challenging, but it was important for me to raise awareness and I believe I have done that.”

As well as wearing ordinary shorts, Brian has had some help from a seamstress to create some fancy shorts for special occasions. During the year, he wore hearts on Valentine’s Day, white shorts during the Wimbledon fortnight and a pair featuring the Scottish Saltire on St Andrew’s Day in November. He has also turned his hand to volunteering by becoming an Association Visitor for the South Yorkshire Branch of the Association.

To sponsor Brian visit www.justgiving.com/BareLegsBrian

**Jack makes short work of raising £10,000**

Jack Batterby may only be ten, but he is still determined to do everything he can to rid the world of MND. Together with his grandad, Geoff, who volunteers with the South Yorkshire Branch of the Association, his mum, Joanne and dad, David, Jack has vowed to raise as much money as possible in memory of his grandmother, Joan who died from MND in 2013.

As well as attending a number of branch meetings alongside Geoff, Jack was also behind MND is Pants – a fundraising twist on Walk to D’Feet – which saw around 50 people take part in the sponsored walk wearing brightly coloured pants outside their clothes.

Jack explained: “MND is pants, so I thought it would be a good way of raising money. I just want to do as much as possible for Nannan.”

Geoff explained that he had felt compelled to support the Association having received financial support for equipment during Joan’s illness.

He said: “I just wanted to help people affected by MND and do everything I could to help find a cure. I also felt as though I could speak from the heart about my experiences.

“It really is a family affair – we all do a little bit to help.”

**Chris Allen decided to support the Association while his wife, Brenda was living with MND.**

In 2007, he took part in a London to Amsterdam cycle ride, which saw him raise over £4,000 for the Association, as well as a coast to coast ride. In July 2007, Brenda
against MND

sadly died aged just 45.

He said: “After Brenda died, I couldn’t speak to anyone about it, but eventually I felt as though I wanted to give something back.

“We used to go to the local branch meetings and after she passed away, I went to a committee meeting.

“My sons were only 18 and 13 when their mum died and my eldest, Daniel, just didn’t want to have anything to do with MND for some time.

“I find that I can empathise with what people are going through and that I can offer them my support. I like to feel that I can help.”

“In 2009, Bradley did a sponsored walk up Mount Snowdon and organised a charity music night in 2010. Daniel is now a member of the West London and Middlesex Branch and earlier this year he did the Three Peaks 24 Hour Challenge.”

Chris is now the Chair of the Clywd Branch and finds volunteering allows him to give something back.

He said: “I find that I can empathise with what people are going through and that I can offer them my support. I like to feel that I can help.”

Daniel explained that The Three Peaks Challenge was the first thing he had done in support of the Association. He also helps organise fundraising events for the West London and Middlesex Branch.

He said: “I felt like I had done something in memory of Mum and that it had given me closure. It was a relief.”

The Allen family, pictured on a trip to Australia in 2006, from left to right, Daniel, Brenda, Bradley and Chris.

If you would like to find out more about volunteering for the MND Association, call 0345 6044 150 or email volunteering@mndassociation.org

Make a date to start fundraising

I T’S the start of a brand new year and time to fill your new calendar and diary with dates to start fundraising.

To help inspire you, the Association’s Community Fundraising Team has published its latest Events Diary which you will find enclosed with your copy of Thumb Print.

There are ideas and events to suit all ages and abilities, from walks and runs to tougher challenges both in the UK and overseas. You will also find full details about how to take part in our Awareness Month campaign, Silence Speaks, which will be held in June.

Last year our fundraisers raised an incredible £3.2 million for the Association to help those affected by MND, their families and carers – together we can raise even more in 2016.

If you have a question or if you would like to discuss your fundraising ideas, please call 01604 611860, email fundraising@mndassociation.org or visit www.mndassociation.org/fundraising

We look forward to hearing from you and welcoming you to #TeamMND

Your fundraising stories:

Please send your stories and photos to editor@mndassociation.org or Editor, Thumb Print, MND Association, PO Box 246, Northampton, NN1 2PR

www.mndassociation.org
When Chris Boon was diagnosed with MND at the age of 35, he was forced to give up one of his biggest passions – carp fishing.

After he died, his father, Peter, decided to follow in his son’s footsteps and take up fishing himself, leading him on a journey to some of Chris’ favourite places.

According to his dad, Peter, Chris Boon had three great passions in his life – his young daughter Hollie, Liverpool FC and carp fishing.

He loved nothing more than travelling to lakes around the country and spending the day landing carp.

But in 2010, Chris was forced to sell all of his fishing gear after he was diagnosed with MND – aged just 35.

Peter explained: “We really didn't know much about MND. Unknown to us he had been researching his symptoms before going to see his consultant, but had not mentioned it to us.

“We told him it would be a trapped nerve and that it was, ‘Nothing to worry about, son.’ The devastating news from Professor Young was that he had MND.

“Our lives would never be the same again and the journey we were to take with our son was nothing but horrendous. It is such a cruel, cruel illness.”

After making the heart-breaking decision to sell his fishing gear, Chris and his fishing buddy Bris, were invited to Linear Fisheries in Oxford, the number one fishery in the country, thanks to Charlie Reece of the Milton Keynes Branch of the Association.

“Now each time I go fishing I feel that Chris is with me. It's as if his passion for carp fishing has taken me over and I absolutely love it.”

Peter explained that the manager of the fishery, Len Gurd and his wife, Fran had both lost loved ones to MND and knew exactly what the family was going through.

Peter said: “Our Chris enjoyed the fishing trip tremendously, especially as Len had arranged for two professional anglers to fish with him. All together they helped our son land what was to be his last large carp.”

Shortly afterwards, aged just 38, Chris lost his battle with MND.

Peter said: “Although we don’t remember much about the funeral, we do remember witnessing a sea of red, as lots of people were wearing Liverpool shirts. He would have loved that. Afterwards we released 38 red balloons into the blue sky, one for every year our son was on this earth.”

A year later, Peter decided to go fishing on the same peg Chris used to visit at their local canal.

He said: “I had never been interested in fishing, not since my teens. I enjoyed the day so much I felt as though I was catching the bug.

“Now each time I go fishing I feel that Chris is with me. It’s as if his passion for carp fishing has taken me over and I absolutely love it.”

In 2014, after meeting up with Charlie Reece again at the Association’s AGM, Peter, Chris’ friend and his cousin were invited back to Linear Fisheries to fish at the spot where Chris had landed his last carp.

Peter said: “Unfortunately, I did not get a catch, but Kevin, my nephew, caught two large fish. For me, just being there on that day was fantastic and very emotional.”

Next, Peter’s journey took him to nearby Orchid Lakes in Oxford where Chris caught a 35lb fish on a peg called Chris’ Bar.

He said: “Unfortunately, again, I came away empty-handed. One of Chris’ friends said, “You’re not as good as him!

“Now I’m just waiting for Chris’ help to catch the big one. Watch this space!”

Following in Chris’ footsteps

Chris, pictured, left at Linear Fisheries in 2011

Chris’ dad Peter revisited Chris Bar on October 2, 2015

Chris, pictured, left at Linear Fisheries in 2011
YOU can help people living with MND by taking part in our annual fundraising and awareness event Silence Speaks. Last year hundreds of you fell silent during Awareness Month and found other ways to communicate, to highlight the speech challenges faced by people living with MND. You also helped to raise an amazing £50,000 at the same time.

This year we want to go even further and are encouraging people of all ages to register their interest now before Silence Speaks is held in June.

Cut out this article as a reminder and visit www.mndassociation.org/silencespeaks2016 or call us on 01604 611860 to register your interest now.

Swimmers take to the sea for fundraising challenge

Swimming the Solent is one of the greatest challenges a swimmer can face and in September a brave group took to one of the world’s busiest shipping lanes to raise money for people living with MND.

Despite having to be cancelled twice due to adverse weather, the swim, which is organised by Tony Bray, with help from Sarah Lannie and Richard Dawson, finally took place with 37 swimmers.

Tony, who is also the Vice Chair of the Shropshire Branch, first swam The Solent as a personal challenge in 2012 and since then it has grown into an annual fundraising event.

In 2013, Tony met Ian Pratt, who is living with MND, and the event became known as the Ian Pratt Challenge in his honour.

Over the past two years the swim has raised almost £50,000.

Tony explained: “It is a huge event to organise as every swimmer has to have a kayaker with them and there also have to be enough safety vessels to evacuate everyone from the water. The Harbour Master has to approve the swim and the risk assessment is at least four pages long. “There are a lot of pleasure craft around and it is a very dangerous shipping channel.

“If you were to go in a straight line, it is a two-and-a-half mile swim, but in reality you actually swim about four because of the currents. To complete it is a massive personal achievement.”

Each swimmer wears a number of wristbands to honour MND warriors – those who are living with the disease – and MND angels – those who have sadly lost their battle.

Once the swim is complete, the wristbands, together with a certificate, are then sent back to the person living with MND, or the family of those who have died, as a reminder that the swim was done in their honour.

So far, wristbands have been sent as far afield as Argentina, Australia, Canada, Ireland, Holland and Germany, South Africa and America.

Tony said he hoped this year’s swim would take place on 25 August.

For more information or to register your interest in a future swim, visit www.swimmingthesolent4mnd.com
Howzat

The Broad Appeal

It has been just over five years since Miche Broad lost her battle with MND. Since then, her husband Chris and stepchildren, Stuart and Gemma have raised £500,000 and funded seven research projects to help find a cure for MND. This is their story.

The Broad family is on a mission. After losing their beloved wife and step-mum Miche Broad to MND in 2010, Chris Broad – together with his son, Stuart and daughter Gemma – has been determined to raise as much money as possible to help find a cure for MND.

In 2011, Chris, a former England batsman, set-up The Broad Appeal, alongside current England cricketer Stuart, and Gemma, a former performance analyst for the English Cricket Board, to generate income for the MND Association.

Since then the appeal has gone from strength to strength, raising an incredible £500,000 in five years providing funding for seven separate research projects.

Justin vows to push on with fundraising feats

“I'LL KEEP fundraising for the MND Association until my ideas dry up – and I have a lot!” – so says Justin Hostettler-Davies who has already raised more than £60,000 since 2010.

His driving force and inspiration is his best friend Gareth Hayes, who was diagnosed with MND in 2010 and died in 2013. Since 2010 Justin has organised and taken part in three major events, Walk4MND, Cycle4MND and Climb4MND as well as volunteering for the South West Wales Branch.

He said: “When Gareth was diagnosed it was a complete shock for everyone – nobody knew what MND was, we had never heard of it. When we found out more I decided to make it my goal to raise awareness – that was just as important to me as the money.”

Justin’s first challenge – Walk4MND – saw him walk the 650-mile Welsh coastal path from Prestatyn to Porthcawl in just 30 days.

In August 2014, Justin took part in Cycle4MND along the 800-mile route from Land’s End to John O’Groats.

In August 2015, Justin took part in his biggest challenge to date – Climb4MND – which saw him climb the five highest peaks in the UK and Ireland in just three days with a team of 50 other people.

But Justin isn't about to stop there – plans are already in place for more fundraising events in 2016 including Kayak4MND.

He said: “In reality, I think it is a way of coping. I don't think I could stop if I wanted to, I have to keep going.”
Chris recently visited the Association’s head office in Northampton, accompanied by his fiancée Rosemarie Macdonald. Rosemarie has been working alongside Chris on The Broad Appeal, particularly during his long periods away from home working on the Elite Panel of Match Referees for the International Cricket Council.

Chris added: “When I set-up The Broad Appeal I didn’t want to put a target on the amount of money we raised. We are indebted to all of our supporters and friends. We aim to do the same over the next five years, until a cure is found.”

Miche remains very much at the heart of the work the family is doing and her story continues to inspire them. Their lives were turned upside down when she was diagnosed with MND in 2009 after returning home from a trip to Australia where she had been working as a golf tournament organiser. During a night out in Australia with friends, Miche noticed that her speech was slurred. Later she started to suffer with painful cramps in her hands and arms and a tingling sensation in her fingers.

“We are indebted to all of our supporters and friends. We aim to do the same over the next five years, until a cure is found.”

A friend insisted that she should consult the tournament doctor who in turn referred her to a local neurologist. On her return home, she visited Prof Pamela Shaw who diagnosed Miche with MND. Chris cut back his working schedule to care for her, but she sadly died in July 2010.

The Association’s Chief Executive, Sally Light said: “The Association is extremely grateful to the Broad family, their supporters and friends for raising such an incredible amount of money for the Association in memory of Miche. Thanks to them, the Association has been able to fund research projects which will hopefully bring us closer to a cure for this cruel and devastating disease.”
Plan ahead and be prepared

Whether you are living with MND or close to someone with it, it can be reassuring to plan ahead. Here, we look at the ways in which the MND Association can support you. Please note, this article contains sensitive information around end of life provision.

If you are living with MND, planning for the unexpected can be a good way of ensuring that you feel empowered and in control.

The Association has a wealth of information and resources available to help make the decisions that are right for you.

In medical emergencies, contacting 999 will often be the first course of action, but to be prepared for occasions when this isn’t necessary, find out about out-of-hours healthcare services in your area from your GP or healthcare team.

To find out about alternative care arrangements, contact local adult social care services. They can provide an assessment of care needs, which may result in care services being arranged. This will also give the opportunity to find out what can be done in an emergency.

Our resources can also help you plan ahead:

**MND Alert card**
This handy card has space to record key contacts. It can be used to alert professionals that a person has MND and needs specialist help.

**Understanding my Needs**
The Association has just re-launched this document, so someone with MND can record their needs and make it clear how they wish to be cared for by care workers, hospital or hospice staff.

**Motor neurone disease checklist: To help you manage your condition and think ahead**
This checklist has been designed to help people with MND feel more prepared for the challenges ahead and think about ways to avoid urgent situations.

**Information sheet 14A – Advance Decision to Refuse Treatment (ADRT)**
Information about how to refuse or withdraw treatment in specific circumstances, including emergencies. This includes a completed example and a blank form that may be filled in if wished.

**End of life: a guide for people with motor neurone disease**
This guide contains detailed guidance about planning ahead for future care, including preparation for emergencies. Contact MND Connect on 0808 8026262 to order these resources.

**MND Just in Case kit**
We’ve just updated the MND Just in Case kit, which is designed to hold medication that may be needed if someone with MND experiences a sudden change in their symptoms.

The kit must be ordered from MND Connect for a named patient by their GP, who should then prescribe medications to be kept inside. There are two sections: one for medications to be used by a doctor or nurse, and the other for medication which can be used by a carer. The carer must be shown how to use it.

Most people will never need to use the kit, but it is there to provide reassurance if needed.

The following may also be useful:

**Carer’s emergency card**
This card can alert someone to a person’s care needs, if the main carer is unable to provide this support for any reason. These cards are usually available from local authorities, or the local health and social care trust in Northern Ireland.

**Message in a bottle**
A scheme familiar to paramedics, where essential personal and medical details are kept within a bottle in the fridge. Search for message in a bottle at www.lionsclubs.co.uk

**MedicAlert**
This charity sells jewellery which lets emergency medical staff know the wearer has a medical condition. Find details at www.medicalert.org.uk

**We also offer resources to healthcare professionals:**
**Motor neurone disease (MND) in acute, urgent and emergency care**
We’ve developed a new resource for professionals working in emergency care, including paramedics and accident and emergency staff. This document highlights specific actions that may be taken and those that require caution when treating someone with MND.

Download from www.mndassociation.org/publications or order printed copies from MND Connect on 0808 8026262.
Karen turns the spotlight on young people

Doing more for children and young people affected by MND is the task of the Association’s new Children and Young People’s Development Manager, Karen Welsenaer.

Karen, who has worked for the Association since March 2012, started her new role on 30 November and one of her first projects has been to conduct a review of the current services for children and young people.

She said: “The current MND Association strategy 2013-2016 advises that the Association will be doing more for carers, children and young people. This includes improving our information to support children and young people, the way in which children and young people access our services, and ensuring that families receive any benefits and entitlements they are due to help them to enjoy the best quality of life.

“I will be contacting our branches and groups, Regional Care Development Advisors, and Care Centres to find out how many children and young people are affected, as well as other teams across the Association.

If you would like more information please contact Karen via email at karen.welsenaer@mndassociation.org.
Help for people with Kennedy’s disease

Although Kennedy’s disease is not classed as a type of MND, many of the symptoms are similar, which can lead to people being misdiagnosed. Like MND, the disease causes progressive weakening and wasting of the muscles. Unlike MND, it also causes hormonal changes. It is a rare condition, with an estimated 1 in 40,000 people affected.

Most people with the disease start to show symptoms when they are 30-60 years old, but it can appear in older or younger people.

Kennedy’s disease is hereditary and is caused by a genetic mutation that damages the nerves that control voluntary muscle movement and mainly affects men. In rare cases, women may develop symptoms, but these are usually milder.

Not everyone will develop all of the symptoms listed here and some people may only experience very mild symptoms.

The symptoms of Kennedy’s disease in men include:
· fatigue
· twitching and rippling sensations under the skin
· tremors and muscle cramps
· muscle weakness
· growth of breast tissue
· reduced sex drive and problems with sexual function
· reduced fertility
· difficulty swallowing
· slurred speech.

There is now a weekly clinic specifically for people with Kennedy’s disease at the National Hospital for Neurology and Neurosurgery in London. The hospital has also set up a national register of people with Kennedy’s disease.

Joining the register will mean that you can be contacted and kept up to date with the latest information about the disease, new studies, drug trials and other initiatives for people with Kennedy’s disease.

For further information about the register or the clinic, email sbma@ucl.ac.uk or call the National Hospital for Neurology and Neurosurgery on 020 3448 3899.

For more information about managing the symptoms of Kennedy’s disease, see our information sheet 28: Kennedy’s disease. You can get a copy by phoning MND Connect on 0808 8026262 or visiting: www.mndassociation.org/publications

Improving our web pages

Alongside development of our care information, work has commenced on how to improve our web pages for care. Here, we look at progress made during 2015 and future plans.

Our website is an invaluable tool when it comes to communicating information about our work to people living with MND and those affected by it. In 2015, we have improved content on the care pages to make them as easy to use as possible.

We recently added a new ‘publications’ button at the top right of our website home page.

www.mndassociation.org

This allows you to access the main publications page with a single click. Our Useful organisations and internet sites page has been adapted into a simple drop-down menu. This groups different types of support for ease of reference.

www.mndassociation.org/usefulorgs

We have added a new Apps page, as featured in a previous edition of Thumb Print.

Many apps exist to help manage life with disability or illness, but the choice can feel daunting. This page features a drop-down menu of free or low cost apps to get you started.

www.mndassociation.org/apps

In addition, we now offer various publications in a range of other languages, which can be easily downloaded from our website.

www.mndassociation.org/languages

Our guides Living with motor neurone disease and the award-winning End of life: a guide for people with motor neurone disease are available to download in interactive formats and as separate subject sections.

www.mndassociation.org/lwmnd and www.mndassociation.org/eolguide

Later this year, we will be launching a new version of our guide for teenagers who are close to someone with MND.

Called So what is MND anyway? the guide will be produced in print and in mobile format.

We will look at the results of this project to consider mobile readable formats for other publications.

As part of a wider look at our website and how to make information easier to find, we will be looking to further improve navigation, text content and imagery this year and next.
**Association wins fight to keep specialist nurse**

The decision makers in Bedfordshire have agreed to reinstate a specialist nurse for people with MND and other rare and rapidly progressing neurological conditions following a public campaign.

The Association gave evidence to scrutiny committees at two Bedfordshire councils, challenging a decision made by the Clinical Commissioning Group (CCG) to u-turn on an earlier pledge to introduce a nurse into the area.

Representatives from the MND Association made their case alongside people living with MND in Bedfordshire.

Councillors were moved by powerful testimonies from Alastair Varley and Stephen Rhodes, who both live with MND, on the devastating impact of MND and the vital role specialist nurses play.

Councillors gave their unanimous support to our campaign, and made a strong recommendation to the CCG that it reconsider.

Local MPs also lent their support, having received letters from their constituents. Bedfordshire Clinical Commissioning Group (CCG) said it had made a mistake in reversing their previous decision to fund the post, and pledged to reinstate the post.

The Association’s Rachel Boothman, has been campaigning for five years to see this result. She said: “We’re delighted that the nurse will be reinstated. This will come as a huge relief to local people living with this devastating disease and their families. “More than half of people with MND die within two years of diagnosis – no-one should have to spend that time worrying about who they can turn to in a crisis.”

Alice Fuller, Campaigns Manager for the East Region, added: “This shows why we must not be afraid to use our collective voice and campaign to ensure vital services are not withdrawn from people with MND and their families.”

We expect the nurse to be in post by Spring 2016.

Find out more about our local campaigning at www.mndassociation.org/local-campaigns

**Your views are sent to NICE**

The views of those living with MND have been sent to the National Institute for Health and Care Excellence (NICE) in response to their draft guideline on MND.

After consulting with members, a number of points were raised in response to the draft guideline including:

- The need for stronger language to convey the importance of timely provision of services and for them to include a greater emphasis on anticipatory assessment and provision.
- Clearer information on how having a single point of contact/care co-ordinator for emergencies and out of hours will operate.
- The need for multi-disciplinary care teams to involve the GP of the person with MND.
- Stronger and clearer guidance on palliative care, including early referral for all people with MND
- A greater emphasis on pain problems

We have also recommended that advice be included on dry mouth.

The final version of the guideline is due to be published in February 2016. The Association expects to make it a central part of its campaigning work to improve MND care next year and beyond.

To see a more detailed summary of all the points raised, please visit www.mndassociation.org/nice

**Chancellor delivers ‘disappointing’ Spending Review**

George Osborne delivered a ‘disappointing’ Spending Review for people living with MND in November.

While he increased funding for the NHS, the Association expects that much of the benefit of this will be wiped out due to an underfunded and failing social care system. People with MND may find it harder to access social care as a result.

The Association welcomes the announcement on research funding, however, this represents a better outcome than in 2010 when research funding was frozen in cash terms.

Key announcements of the review, which details how the Government will spend taxpayers’ money over the course of the Parliament included:

- An extra £8.4 billion in the five years to 2020 for the NHS.
- The power for local councils to raise Council Tax by up to 2% to generate funds for social care, plus an extra £1.5 billion from central Government.
- Cuts to Housing Benefit and Universal Credit, a benefit for working aged people, as well as further changes to how the benefits system works.
- A slight increase in funding for research over the next five years.

Details of tougher new rules for the Universal Credit system will be announced in the new year, but the Association expects them to focus more on making sure people move back into work.

The Association will work with the Government to make sure they understand that this is not possible for people with MND once the disease has advanced.
IN 2015 people affected by MND represented the Association at the Labour and Conservative Party conferences for the first time.

The Association attends the main political party conferences each year to raise awareness of MND, build relationships with politicians and make the case for better services for people with MND and their families.

This year we also co-hosted a fringe event on end of life care at the Conservative conference with charity colleagues Marie Curie, Macmillan Cancer Support, Sue Ryder, Hospice UK and the National Council for Palliative Care. Minister for Health Services Ben Gummer MP spoke at the event.

Campaigns Contact for the Manchester Branch Greg Broadhurst, whose grandfather died from MND, joined us at the Conservative Party conference in Manchester and Campaigns Contact for the East Surrey Branch David Setters, who is living with MND, attended the Labour Party conference in Brighton with his wife Helen.

Greg Broadhurst:

**MS Society – Protecting those in greatest need – Welfare**

A very good introduction to my first fringe at conference, a real feeler for how the panel and Q&A process worked. Gave me confidence to look at throwing questions into other fringes.

**Meeting with Macmillan Cancer Support**

It was good to sit with the Association’s Public Affairs Manager Alison Railton and Policy Officer Ellie Munro and be able to compare campaigning tactics with Macmillan Cancer Support on areas of joint interest. It gave me insight into how charities can work together.

**End of life campaign – Joint Fringe with Macmillan, Hospice UK, Sue Ryder and MND Association**

This was attended by myself, Alison and Ellie. A highly thought provoking event, and very pleasing to attend.

The Government need to get end of life care right, the political will across the chamber is there, the public will is there, time for talking is over, we must now act.

**Main Speeches – Iain Duncan Smith and Jeremy Hunt**

No mention by Iain Duncan Smith on how he will protect the most vulnerable, speech concentrated on ‘getting back to work’, nothing on helping those who are unable to work due to their condition.

No mention by Jeremy Hunt on specific funding for social care. He did refer to £10 billion extra in funding, but there was no breakdown, could this include an element for social care?

Help make a difference by joining our Campaign Network. Visit www.mndassociation.org/campaignnetwork for details.
Campaigners fight benefits changes

A major new campaign has been launched against the Government’s proposed changes to the benefits system through the Welfare Reform and Work Bill.

Make benefits work for MND has been launched by the Association amid concerns that people who claim certain benefits including the Employment and Support Allowance and the Carer’s Allowance could be worse off.

We believe it is unacceptable to expect people with MND, who will face rising costs as their illness progresses, to manage with less as a result of the Government’s changes.

Over 450 supporters have added their voice to this campaign so far, by emailing their MP and using social media to spread awareness of the issue.

Our Campaigns Contacts volunteers have been helping to raise awareness of our concerns by meeting with MPs in their local constituencies.

The Association has written to Government ministers and met MPs and Peers in Westminster to make sure they understand the impact of the Bill on people living with MND, and to persuade them to support our changes.

Not only are we working hard to make sure the MND voice is heard, we are also campaigning with other disability charities as part of the Disability Benefits Consortium (DBC) to ensure the Government improves the Bill so it works for all disabled people and their families.

There is strength in numbers and working with the DBC to campaign sends the message that thousands of people are against the changes.

For more information about our campaign and how you can get involved, please go to www.mndassociation.org/campaigns

On 1 December, 20 MPs attended the All-Party Parliamentary Group (APPG) on MND meeting in Parliament to discuss access to benefits for people with MND.

MPs heard from the Association’s Director of External Affairs, Chris James, Policy Officer Ellie Munro, Mark Styles, who is living with MND, and his wife, Campaigns Contact volunteer Katy, who is also Mark’s carer.

Mark and Katy spoke very movingly about the financial impact of a diagnosis like MND and emphasised the importance of financial support through benefits.

Katy said “Having MND is bad enough, living with the financial impact is even worse”.

She called on MPs to support the removal of Carer’s Allowance from the benefits cap.

The APPG agreed to write to the Minister for Employment Priti Patel MP about the impact of the Bill on benefits for people with MND.

A huge thank you to over 680 supporters who emailed their MP encouraging them to attend this meeting.

Planning for the future

We all have an important part to play in shaping the Association’s strategy and now is the time to make sure your voice is heard.

As we look ahead to 2017-2021, we have started the process by talking to our trustees, staff and the clinical community as well as looking at the results of the Improving MND Care Survey to help identify key themes.

Already some areas for discussions are starting to emerge, including whether it is right to fill any gaps left by statutory services, who are working in a very challenging funding environment, and what the best ways are to raise awareness of MND.

To ensure we collect as many views as possible, a copy of the survey, Our Future, will be included in the next edition of Thumb Print and we really want to hear as many of your views as possible. We hope you will take the opportunity to complete the survey and help us to shape our future.

Some focus groups will be held for volunteers over the coming weeks.
**Fundraising**

Colleagues unite across the Atlantic

Supporters of the MND Association took part in a 5k run in New York and London at the same time. Grant Lee, a friend and colleague of Steve Cliff, who is living with MND, organised the event at the London offices of Credit Suisse, and in New York.

Fifteen people took part in New York, while 20 joined in the run in London, raising a fantastic £6,000.

Grant said: “Steve, as always, is an inspiration to the people he has met and worked with and I think I speak for both myself and Robert Cesario, who organised the New York event, and the wider community here, when I say that it’s the least we could do. From a personal perspective it has been one of the most rewarding activities we have organised.”

It has been a busy time for Steve and his family and friends who have organised a whole host of imaginative events to show their support for both Steve and the Association.

In July, Steve took part in the Joss Naylor Challenge in the Lake District, which saw him run 48 miles over 30 summits.

Steve’s sister Becky Fawcett, raised £5,000 through a curry night and auction, while his granddaughter, Emma Barnes, tested her mettle in a Rough Runner event alongside her friends Clare, Natalie and Ben, raising £700.

An additional £800 was raised at a quiz night organised by his friends at Leicestershire Aero Club.

Steve, who since his diagnosis has chosen to volunteer for the North and West Cumbria Group, said he hoped the money raised to date, together with funds raised at events held in November, would take his Fightback Fund total to over £25,000.

**Coffee, cake and plenty of cash!**

This little girl was just one of the many fundraisers who enjoyed the treats on offer at a coffee morning organised to raise money for the Association.

The Mayor of Barry, Councillor Emma Pritchard has chosen the MND Association’s Cardiff and Vale of Glamorgan Branch as one of the charities she will support during her term in office and has pledged to host a coffee morning every five weeks to raise funds.

The first event was held in May and raised more than £300. Share your fundraising activities with us: Email Thumb Print at editor@mndassociation.org

**Melvin and his family stand up to MND**

When Melvin Jones was diagnosed with MND in 2013 he decided not to let it stand in his way.

Instead, his wife, Wendy, their children, grandchildren and friends came together to organise a number of fundraising events for the MND Association, which together have raised more than £3,000.

The family started by organising a Walk to D’Feet event and a surprise retirement party followed for Melvin, which raised £650.

Most recently, a charity football match between the Lyndon Old Boys and Lyndon Legends in Solihull, West Midlands, saw the players paying for the privilege of taking part.

Melvin’s daughter, Rachel Adcock said: “Team Jones has no intention of stopping. Watch this space!”

Are you interested in finding out more about fundraising? Contact our fundraising team on 01604 611860.

If you are a person living with MND, you could set-up a Fightback Fund to help raise money for the Association. To find out more visit fightbackfunds@mndassociation.org or call the fundraising team on 01604 611860.

For more fundraising stories turn to Down Your Way on pages 34, 35 and 36.
JOHN Head’s life was full of love, music and classic cars.

He played the banjo and was part of a four-piece band, working in clubs, pubs and during holiday camp summer seasons. He was a full-time musician during part of his working life and also appeared on television and in the theatre.

He loved cars and during his life owned two classics – a 1938 Morgan Three Wheeler, which he and his wife Angela sold in 2012 and a 1961 MGA, which was left to him by his friend Douglas.

When John died from MND in 2013, Angela reluctantly decided to sell the car and donated £10,000 from its sale to The John Leslie Head Tribute Fund.

She explained: “We had great times driving it and now it is with a new owner who seems equally passionate about our motoring heritage. The car will be driven and enjoyed, rather than languishing in a garage."

“The car was built in 1961 and John’s friend, Douglas, acquired it in early 1962. In the 1980s, Douglas became unwilling to drive it, but determined not to sell it, so John looked after it and we drove it to local car club meetings and rallies. Jersey was a week of adventure in the company of like-minded enthusiasts driving around narrow lanes – not for the fainthearted!”

Angela and John met in 1965 when the couple, from Essex, worked at a local public library. They married in 1971 while John was working as a musician. In the 1980s, he qualified as a Chartered Surveyor and then pursued a career in the Civil Service, until his retirement in 2008.

“We were both so appreciative of the support from the Association during his illness and it gives some satisfaction to know that this donation will help others in the same way.”

John was diagnosed with MND in 2012, but Angela believes he started experiencing symptoms in early 2008. She said: “John was having difficulty playing his beloved banjos and tinkering with and driving classic cars was becoming very hard and dispiriting.

“We were both so appreciative of the support from the Association during his illness and it gives some satisfaction to know that the donation from the sale of the car will help others in the same way.

“John’s MND Association Tribute Fund was a way of recording all the kind donations made at the time of John’s death and for future contributions. It was also a cathartic process at a time when I needed to be positive.

“I feel it keeps his life and achievements visible to others and ensures he is not forgotten.”

If you would like more information about setting up a Tribute Fund in memory of someone special, please visit www.mndassociation.org/tributefunds. Alternatively, please call us on 01604 611864.
Brothers unite in memory of their mum

WHEN their beloved mum Pat was diagnosed with MND in April 2012, brothers Richard and Daniel Callear decided the only thing they could do was fight back. As the family united to make her final years as happy and comfortable as possible, Rich and Dan also embarked on a fundraising journey which took them to the very top of Mount Kilimanjaro, helping to raise almost £40,000 for the Pat Callear Fightback Fund.

Dan explained: “Mum was born on the Isle of Man. She left to attend Manchester University where she graduated as an Optometrist and met David, our Dad, her best friend and husband.

“She loved gardening and watching the trees she planted grow, she also loved to talk, as I am sure many of her patients over the last 30 years could vouch for!”

Pat lost her battle with MND in January 2015, but just two months later, surrounded by a team of devoted family and friends, Rich and Dan climbed Mount Kilimanjaro.

The family also decided to convert Pat’s Fightback Fund to a Tribute Fund so they could continue fundraising.

Dan said: “The adventure was a challenging, emotional and rewarding experience but we all made it to the top and raised over £15,000 in Mum’s name. It was a very proud moment for us both.

“Mum was described by her friends as being wonderful and witty, vibrant, funny and clever. For those whose lives she touched, her passing is a true loss and she is deeply missed. Mum is an inspiration to us both, and everyone who witnessed her brave approach to her battle with MND. She was the best role model we could have asked for throughout our lives.”

Together, the brothers, their family and friends have been able to raise an incredible £57,500 for the Pat Callear Tribute Fund.

To find out more about Fightback Funds and Tribute Funds please contact the Association’s fundraising team on 01604 611860.
Beating MND – one step at a time

LITTLE by little, one step at a time, our fundraisers are fighting MND.

By coming together at Walk to D’Feet events across the country, fundraisers of all ages have been making a real difference and have raised an incredible £175,000 in 2015.

But it isn’t just about the money – our army of walkers have also done a huge amount to raise awareness of MND and the work of the Association.

“Our fundraisers have been imaginative and come up with some wonderful ways to raise money and awareness.”

The Hull and East Yorkshire Branch who walk across the Humber Bridge each year went one step further thanks to a balloon release at their walk which saw a whole bunch of balloons travel a little further than expected – raising awareness of MND all the way to Germany!

Mike Findley MBE, who is living with MND has organised 10 Walk to D’Feet events between 2005 and 2015, raising £55,000.

He explained: “On 17 June, 2015, I celebrated living with MND for ten years and in September we held a wonderful concert in our local church where 200 people attended to celebrate our 10th anniversary of fundraising.

“The one annual event which caught the imagination and support of many people was our sponsored walk. In 2008 we won the Association’s award for the most walkers in a team, then in 2010, we won the award again, as well as an award for the most money raised.”

Mike was presented with an MBE in 2010 by The Queen, a hugely proud moment which gave him the opportunity to speak to her about motor neurone disease and the need to raise much-needed funds.

Sue Povey arranged for over 50 family members and friends to walk the Test Way in June, in memory of her mum, Rene Clark. With so much support she took the opportunity to hold a party the next day and raised £25,000 for her mum’s Tribute Fund.

When it comes to beautiful places to explore while walking, it doesn’t get much better than the iconic Badminton Estate which for the first time was the venue for the Gloucestershire Branch’s Walk to D’Feet, MND.

More than 60 walkers took part and over £1,100 was raised.

Newly-crowned World Snooker Champion Stuart Bingham led the way at the South Essex Branch’s Walk to D’Feet in May and walked the whole ten mile route holding his trophy.

Stuart’s wife Michelle lost her father to MND and the couple have been supporters of the branch ever since. The walk raises huge funds to support people living with MND.

The East Surrey Branch held their Walk to D’Feet, MND event around Box Hill – one of the county’s premier beauty spots.

Around 12 people took part and over £500 was raised.

The Association’s Community and Events Fundraiser, Anita Solan said: “We are extremely grateful to everyone who has taken part in our Walk to D’Feet, MND events in 2015. We are hoping even more people will join in the fun and take part in a Walk to D’Feet event in 2016.”

To find out more about Walk to D’Feet and to get hold of a fundraising pack call 01604 611860 or email fundraising@mndassociation.org

From top: Mike Findley MBE held walks from 2005 to 2015. Pictured are the walks in 2005 and 2015, Teresa Hardy and the Hull and East Yorkshire Branch cross the Humber Bridge, Sue Povey and her team walking The Test Way, Snooker World Champion Stuart Bingham walked with Sue Nash and the South Essex Branch.

*Walk to D’Feet is a Trademark of The ALS Association and is used with permission. All rights reserved.
Every step makes a difference

Thanks to the efforts of our amazing runners the Association raised more than £200,000 at the Great North Run and the Royal Parks Half Marathon. Here are the inspiring stories of some of those who took part.

Great North Run

TEAM MND raised more than £100,000 for the Association at the Great North Run.

The event which was held in September, proved to be an emotional day as many of our runners had very personal reasons for taking part and showing their support.

Christine Baker was taking part in her tenth run, having completed every one since her mother was diagnosed with MND in December 2005. She sadly died in October 2006.

She said: “I wanted to do something for her, to challenge myself and to raise money for the Association and the Great North Run seemed the ideal thing to do. Training for it the first year helped me cope though a difficult time.

“I want to help make a difference to those who are suffering with MND and I really want to do something positive towards helping find treatment and ultimately a cure for the disease.”

Christine didn’t stop there – throughout 2015 she took part in 15 challenges, including a 10k, 15k, 10 half marathons, one marathon, a Tough Mudder and a 24 hour relay.

Rachael Smith was taking part in her second run in memory of her uncle.

She was joined by her brother Ben and cousin Ryan Kirton and they pulled together to take the Stephen Kirton Tribute Fund to over £10,000.

She said: “I like to do something to raise money for the MND Association every year and I had so much fun doing the Great North Run last year that I wanted to do it again and bring more family members with me this time.

“Sadly I lost my uncle Stephen, seven years ago to MND so my family has felt the devastating effects it has on sufferers and their relatives.

“It was another amazing day and I’m so proud of my brother and cousin too. We’ve raised a lot of money. We are so very happy.”

Supporter Ken Durose stepped out from behind the camera to run the race for the Association.

Ken has kindly supported the Association by taking photos of our runners on the course for the past seven years, but this time decided to lace up his trainers to tackle the route himself.

It was a memorable one for Ken as it was the first race he had taken part in since being involved in a life-threatening accident on a road run 20 years ago.

Ken said: “Afterwards, back at the charity tent, there is a real sense of community and comradeship – more of a buzz than at the other charity tents. The MND Association means you are never alone.”

Meg the bearded collie was Pamela Brewis’ training buddy ahead of the big day.

Pamela took part in the event in memory of her father, Bob Nicholson, who died from MND in 1995.

She said: “It is 20 years since my Dad died and we still don’t have a cure for this cruel disease. He was a bit of a character; he loved animals and he was always fit, healthy and full of fun until he got MND.”

Alan Dignam completed the race in just over two hours. He said: “I had some bad sunburn and sore legs. I proudly came 15,648 places behind Mo Farah and with 41,352 runners behind me. Thank you to everyone who donated to the Association.”

The MND Association has guaranteed charity places available for the Great North Run 2016. We ask for an early-bird registration fee of £20 and a minimum sponsorship pledge of £425 for each place.

To register your interest for a place email stephanie.steward@mndassociation.org or call direct on 01604 611 761.
Maria Smith was joined by her nephews, Tom Bridle and Lee and Jamie Pearce and raised more than £3,000.

Her sister-in-law, Carol March, who is also Lee and Jamie’s mum and Tom’s aunt, was diagnosed with MND in 2014.

She said: “She started experiencing symptoms two years ago, but when she was diagnosed it was completely devastating. I immediately felt that I wanted to do something – I desperately wanted to help.

“To hit back, we wanted to fundraise and I know that Carol has felt a lot of comfort from that.

“The day was amazing, it was so emotional. Every step was for Carol – I was determined to finish, even if I had to drag myself over the line!”

Maria said that the personal support she had received from the Association had been fantastic and that she had now been inspired to become a volunteer.

Two former soldiers carrying 45lb backpacks were among those taking part in the Royal Parks Half Marathon last October.

Joe Duhan and Ian Shaw ran the 13 mile course which featured four of the eight Royal Parks, after being inspired by a mutual friend whose mother died from MND in 2014.

Joe explained: “It’s one of those times when you just want to do something – anything – to be able to help. She was one of the nicest, kindest people I’ve ever met, so we thought we would do this in her memory and try and raise some money for the Association in the process.”

Joe and Ian’s backpacks – weighed roughly the same as Joe’s six-year-old daughter Eliza - were filled with sand to ensure they moulded to the shape of their backs.

Cathy Haynes, her husband, Duncan, and her colleague, Tim Linehan were joined by family, friends and colleagues at the event, raising a whopping £62,874.47.

Cathy has been inspired to raise money for the Association after losing her father Michael Burns to MND in 2010.

She set up the Michael Burns Tribute Fund in his memory and has since taken part in a number of endurance events as a way of thanking the Association for supporting her family during her father’s illness.

She said: “It is still a charity which few people know much about and I want to do everything I can to help find a cure.”

She explained that her colleague Tim had been behind the team’s involvement with the run after a mutual friend was also diagnosed with MND.

Carol added: “Tim decided that he wanted to improve his fitness and had never taken part in anything like this before. He completed the course in just over one hour 46 minutes, which was incredible.”

If you are interested in running the Royal Parks Half Marathon in 2016 for #TeamMND, register your interest in a place now by calling Stephanie Steward on 01604 611 761 or emailing stephanie.steward@mndassociation.org

For one of our places we ask for a £30 registration fee and a minimum sponsorship pledge of £395.
Thank you to all those who raise vital funds and awareness to support our work. Here is a small selection of recent events – share your pictures at www.facebook.com/mndassociation

**A step in the right direction:** The West London and Middlesex Branch’s annual Bushy Park walk raised over £13,000. The walkers also enjoyed funfair attractions and a great buffet lunch. Jai Krishnan, who recently lost his wife Lekshmi to MND, walked with a group of family and friends and won one of the raffle prizes. Jai’s nieces Deepa and Rekha climbed Kilimanjaro in October to raise more funds for the branch.

**Going the distance:** Hamish Sabey-Corkindale took part in the Iron Distance Triathlon at Hever Castle in Kent in July and raised more than £4,200. He was inspired to take part by his 26-year-old sister, Charlotte who is living with MND.

**A night to remember:** A Midsummer Ball was held in Exmouth by the Exeter and East Devon Branch. There was an auction and raffle, great music and great company and the event raised £6,500.

**A team effort:** Staff at Dynamic Futures organised a charity 5k run and raised nearly £1,900 in memory of Krishna Rawley who died from MND in 2012. Prior to being diagnosed with MND, Krishna brought up three small children while continuing her professional career as a community pharmacist. Friends said Krishna will be remembered as a kind-hearted and strong woman.

**Curtain call:** A wonderful evening of songs from the shows was attended by the Mayor of Barnstaple recently. Performed by local group Encore to a packed audience, the event raised £634.21 for local people living with MND.
Pitch perfect: Among the North Lancashire and South Cumbria Branch’s most successful fundraisers are the friends of the late Nicky Dent, an enthusiastic member of the football team and a valued coach for the junior players. Recently, some committee members were invited to join some of the lads for a photo shoot with the Staveley United Football Club Team. Out of their own pockets they have funded special football shirts sporting the MND logo – our thanks to them all.

In memory of Ruth: Glynwen Lewis and Lyn Bellis climbed the three Welsh peaks in 16 hours on July 2 in memory of their friend Ruth Williams who had MND. They climbed Snowdon first, followed by Cader Idris and Pen y Fan and raised over £1,000 for the MND Association. Lyn said: “At the end we enjoyed a glass of champagne to celebrate our victory and to say ‘cheers’ to our friend Ruth. Thank you for all your sponsorship.”

Reach for the sky: Rhianna Wood raised over £1,600 by jumping out of an aeroplane. Rihanna cares for Cynthia Hodson, who is living with MND and was inspired to raise money for the Association. She said: “Cynthia faces each day with such determination and positivity and always gets up in the morning with that fabulous smile of hers. She never allows the disease to get her down. She faces each day with such bravery and she has inspired me to raise money for the Association.”

Never give up: 12-year-old Jess Howe took part in the Hever Castle Triathlon and raised £465 in memory of her grandfather, who died from MND seven years ago. She said: “It was tough in places but it felt really good to cross the finish line with one of my friends. We love you lots Grandad and I hope you’re proud of me.”

‘I’m doing it for Dad’: Olivia Howatson-Kerr and her friend India Abbott took part in the Great Scottish Swim raising over £2,300 to be split between the MND Association and St Michael’s Hospice. Olivia said: “I did the Ice Bucket Challenge last year and donated, without really giving a thought to the cause I was donating to, but my Dad was unfortunately diagnosed with MND in November 2014 so I’m doing it for him - he inspires me every single day.”

Turn the page for more of your fundraising stories
Showing their true colours: Archie and Ted Heard joined in a 5k colour run in memory of their Grandad Trev, who they lost to MND in December 2014, raising £185. Their mum Louise also took part in the Leeds 10k earlier this year, in memory of her Dad and raised nearly £300. All of the money raised from the family has been donated to the Trevor Sampson Tribute Fund.

‘For my Grandma’: Six-year-old Aidan Robinson bravely took on the Skyride 11k cycle challenge despite only being able to ride a bike for a short time. He completed the challenge in about an hour, including a few drink and recovery stops at the top of some of the hills.

When the going gets tough: Rhys Lockett, his best friend Gemma Filliter and his cousin Ella-Mae John braved a mini Tough Mudder event in memory of his grandad, Steve Lockett, and raised £937. Rhys’ mum, Hannah John said: “There were a few tears on the day when they were asked who they were raising money for, but we know Rhys’ Grandad Steve would have been so proud of them! They want to do it again next year.”

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Eric Rivers

ERIC Rivers, one of the Association’s most prolific campaigners lost his fight with MND in November 2015, aged 49.

In November 2011, Eric was chosen to appear on the BBC show *DIY SOS* alongside his wife, Davina and their three daughters. Their story touched the hearts of everyone who saw the episode and, when it was repeated a couple of years later, hundreds of messages of support were left on the Association’s Facebook and Twitter pages.

The show’s presenter, Nick Knowles, became a family friend and, thanks to his help and generosity, the family appeared in the Association’s first ever advertisement, which was broadcast across ITV3, Gold and the Good Food channels as well as selected UK cinemas.

Sally Light, Chief Executive of the MND Association said: “It’s hard to put into words exactly what Eric has meant to the Association.

“From the success of *DIY SOS* to being the focus of our first TV and cinema advertisement and so many things in between, he has been part of our family and so supportive of the work that we do for many years.

“Together with wife Davina and their girls, or the Five Rivers Gang, as Eric referred to them, they also featured in a hugely successful Christmas appeal for us.

“In June, Eric attended our Charter event at Westminster and it had obviously been a huge effort to come. His speech that day which he had painstakingly pre-recorded on his communication aid inspired the whole audience – both those who knew him and those who didn’t, and reminded us all why we do what we do to fight MND together.

“I know his passing will have left a huge hole for his family and friends and also in the wider MND community, where he was so much respected, loved and admired.

“All our thoughts are with Davina and the girls.”

Lena Marsh

ASSOCIATION Trustee, Lena Marsh, sadly died in November. Lena had been diagnosed with MND in October 2011 and was elected as a Trustee in September 2013, where she was a very valuable member of both the Engagement and Finance & Audit Committees.

Away from the Board of Trustees, she was an active committee member of her local Gloucestershire Branch, helping to raise funds and awareness while also being involved in campaigns such as *Don’t let me die without a voice*.

Jean Waters, Chair of the Gloucestershire Branch of the Association said: “Right from first contact, Lena was determined to support the fight against MND both locally and nationally.

“Both Lena and her husband Alan, who gave her such magnificent support with all her activities, brought positivity, enthusiasm and practical help to our branch. Whether it was running the Tewkesbury Abbey coffee shop and volunteering Alan to lead the catering for a choir and orchestra, taking part in the monthly support group, or chivvying us at committee meetings to go that little bit further, Lena was there.

“Despite torrential rain, she joined the branch’s first *Walk to D’Feet*, steering her powerchair over some rough paths with her chin. She was a strong, determined lady who never gave in despite the rapidity of her progression.

“Her wonderful smile, charm and good humour left an indelible mark on us all and her memory will always be supremely inspirational for those of us who had the privilege of getting to know her.”
Raising funds in memory of Catherine

My wife, Catherine, sadly passed away from MND in September 2015 after a brave, four year battle.

She was only 50 and we had been together since she was 17. When she died a huge chunk of my life was cut from me.

We had struggled for four years financially – we both had to give up work, we had to sell our home, and we had to move to another area.

I spent four years giving 24/7 care to my wife and it is thanks to our occupational therapist that we eventually got some help and equipment to make life easier.

The information which the Association supplied to me was invaluable.

We tried to enjoy life to the full; we went to London to see a show and to enjoy the sights, although getting accommodation to suit our needs was very difficult.

Before her death, we accessed support from the Marie Curie Hospice in Newcastle and we were welcomed and made to feel really at home. This led to my wife staying for a few weeks to give us both a break while still being able to see each other.

In September, my wife lost her battle with MND with me by her side. I was devastated because it was so sudden.

We made her funeral special. Her favourite colour was purple so we got her a purple coffin, everyone attended wearing something purple, and we celebrated her life in style with many family and friends.

She received messages from all over the world, which I placed in her coffin together with a wedding photo.

We had planned a fundraising raffle to take place on Hallowe’en in aid of the Association at which Cath was to pull out the winning tickets, unfortunately this was not to be, but we still went ahead and had a successful raffle with some good prizes and raised £400.

I urge people who are experiencing any difficulties whatsoever to use the support of the Association and the other organisations out there to help them to cope both financially and mentally. I just wish I had known this earlier as it would have made life much easier.

We now plan to leave a legacy for my wife and to make this fundraiser for the Association an annual event in her memory; we are starting to plan now. I am getting support during these dark days which does not get rid of the pain or grief, but helps me come to terms with the loss.

I aim to raise funds and awareness in order to help others who are in a similar situation.

Brian White, via email

Talking Twitter

How Twitter is keeping our MND family connected – follow us @mndassoc

Richard Maxted @RichardMaxted – 7 October

Just had a family member diagnosed with #motorneuronedisease can anyone let me know of their experience with the disease

MND Association @mndassoc – 11 October

Hi Richard, sorry to hear about the diagnosis in your family. We do have a forum for people affected forum.mndassociation.org

Laura Jane @Lauraaa_Jane – 11 October

@RichardMaxted From the experience I had with my auntie take each day as it comes and make the good days count. Memories last forever x

Ian Wingfield @wingfield_ian – 11 October

@Lauraaa_Jane @RichardMaxted Absoluate spot on advice Laura. Use all the resources that available Richard as there is help out there

Hello myname is Char @LaytonCharlotte – 11 October

@RichardMaxted the MNDA forums are really helpful for support and guidance
Sally cruises into an adventure

Spring 2014

They told me all serious and terribly quick, that I had MND in fact you’re quite sick. Well I knew I couldn’t talk right that I was getting quite slow, But that surely is no reason to drop off or go?! The doctors said, “I’m sorry you’re terminally ill,” Well I thought I would show ‘em and swallow the pill.

My first trip up the Amazon gave me a fright, When they handed me a ‘croc’ and said, “Smile that’s right.” The photo was taken and I didn’t half look amazed, It’s either that or I just looked half crazed.

Then came the Carrib’ all sunny and spice. I wanted to snorkel and swim and look nice. Al gave me a beautiful silk dress the right colour blue. This certainly helped matters, I’d say it was true!

After the Carribean the Azores were found, About mid-Atlantic they were hanging around. With volcanoes, smelly steam and all that ash. No gimmicks or slot machines, none of that trash.

Finally home again tanned, sated and fed, I faced my future with far less dread. What I’d got left I would darn well swallow hook, line and sinker – What’s happening tomorrow?

Sally Henderson, Devon

In loving memory of Martin

This poem was written by Sylvia Wiseman, who lost her husband Martin to MND, just 18 months after he was diagnosed. She said: “We had 42 years of the most wonderful marriage. He was diagnosed six months from his retirement and was lost to me after 18 months. I have read this poem to many gatherings when I have been asked to speak and I have always found it to have the most profound effect on those listening.”

My body is twisted it will not obey
The orders I give it each frustrating day
My legs will not hold me and both arms hang limp
My head lolls forlornly, I feel like a wimp.

My mouth has gone droopy, it seems miles away
When I try to direct my food from the tray
The spoon to the dish is quite an ordeal
I’ve now come to dread each tiresome meal

As I push with my spoon, the food scurries away
It won’t let me catch it, it will take me all day
My wife holds a cup, a drink to my lips
She tells me to sup, to take a few sips
I dribble the lot down the front of my vest
I’ve exhausted myself, I must have a rest

I need to be fed and mopped up like a child
And then put to bed, it drives me just wild
I long to explain but my eyes only talk
The expression of pain that I can’t hold a fork
I’m longing to touch my dear wife’s soft hand
But my hand’s held fast in an imaginary band.

For my body is heavy and stiff like a board
I can’t go much longer – I’ve prayed to the Lord
To take me above to His heavenly place
Where I shall at last see his welcoming face
For in life there is nothing whatever you gain
When your body won’t listen to that of your brain.

Sylvia Wiseman, via email

about us:

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 directing to other services and agencies. Open Monday to Friday 9am to 5pm and 7pm to 10.30pm.

0808 8026262
mndconnect@mndassociation.org

Membership

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

get involved:

telephone: 01604 250505

website: www.mndassociation.org

email: enquiries@mndassociation.org
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