

The magazine of the Motor Neurone Disease Association

# Thumb Print

Summer 2018



**'How I helped  
to give my  
Mum a voice'**

Supporting the communication needs of people living with Motor Neurone Disease in the UK.

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### Thank you!

Turning the spotlight on our amazing fundraisers and supporters



Thumb Print is the quarterly magazine of the Motor Neurone Disease (MND) Association, David Niven House, 10-15 Notre Dame Mews, Northampton, NN1 2BG. Reg. charity number 294354.

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If you have comments or feedback about the magazine and its content, please do not hesitate to get in touch.

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Thumb Print is available to read online and as a downloadable pdf at [www.mndassociation.org/thumbprint](http://www.mndassociation.org/thumbprint)



# welcome...

Behind all the work the Association does is one central message – people living with MND are at the heart of everything we do.

Having people with MND and everyone who cares for them at the forefront of our minds at all times is of paramount importance to staff and volunteers alike, guiding us to make sure the work we do continues to change the lives of all those affected for the better.

Our focus in recent months has been on making sure people with MND have what they need, whether that be access to specialist care, help claiming the benefits they are entitled to or revolutionary new equipment like the Head Up Collar which the MND Association has been involved in creating.

On Global MND Awareness Day, held on 21 June, we launched a new campaign – Scrap6months – challenging decision-makers to change the rules when it comes to claiming benefits such as the new Universal Credit. Not only do we believe the rules are desperately unfair, but a report commissioned on behalf of the Association concludes that people living with MND may be financially worse off as a result.

We are also listening to people affected by MND to ensure we fully understand the issues they face when it comes to adapting their existing homes or finding accessible ones. The information we receive – through face-to-face sessions and surveys – will directly influence the work we do with councils and housing professionals to ensure people with MND and families can access the facilities they so desperately need.

While we continue to make good progress in our work, I am always very conscious of the fact that there is still much more which needs to be done, something I was reminded of when I attended the Service of Thanksgiving for our late patron, Prof Stephen Hawking, at Westminster Abbey in June.

During the service, I reflected on how he must have felt, being told at the age of 20 that he had MND and how, more than 50 years later, we still have so little to offer in the way of treatments or hope for a cure.

It's stories like his, together with those of countless others who face the devastating effects of MND with such bravery every day, which will continue to inspire our work both now, and in the months and years to come.

A handwritten signature in blue ink that reads 'Sally Light'.

**Sally Light**

Chief Executive





Members of the group, MND Patients, pictured during the protest at Westminster

## ESA demonstration is held in Westminster

**A** PROTEST against current rules surrounding the claiming of Employment and Support Allowance (ESA) which affect people living with MND has been held in Westminster.

Last year, a new severe conditions exemption was introduced for all new higher-rate claimants of ESA, following a successful campaign, but as things stand, those already claiming the benefit will need to undergo one final, paper-based reassessment to receive exempt status. The Association, and many of its members, believe this is wrong.

Organised by a group of people who are living with MND, called MND Patients, the protest on 16 May, attracted cross-party support from 18 MPs as well as Madeleine Moon MP, who is chair of the All Party Parliamentary Group on MND. She expressed her ongoing commitment to raise awareness of MND among her fellow parliamentarians, and support all those affected by the disease so they can access benefits in the most timely and stress-free way.

It was the second time MND Patients had organised a protest at Westminster.

The first demonstration, held in February, had seen members of the group brave freezing temperatures in their determination to make their voices heard by MPs.

**“We want to work with everyone affected by the reassessments to make sure they receive the support they need.”**

David Setters, who is living with MND and was among those who attended both events, said: “Many charities do a great job campaigning for the people they represent, including, notably, our Association. In our case the effect on policymakers is much enhanced when they are able to hear the passionately, but politely expressed, views of people living with MND, their carers, families and supporters.

“Patients, carers and Association staff continue to show that by working together, injustices in the health and social care system can be changed. As is well known, time for those living with MND is at a premium, so we need to address short-term issues at the same time as planning

to create change in the longer term.”

During the event, MND Patients were joined by volunteers as well as the Association’s Chief Executive, Sally Light, Director of External Affairs, Chris James and trustee Katy Styles.

Sally said: “The situation surrounding reassessments is unacceptable and the anxiety it causes to people, who are already dealing with the devastating effects of MND, is completely wrong.

“We want to work with everyone affected by the reassessments to make sure they receive the support they need and I would urge anyone who hasn’t already done so, to make contact with us as soon as possible.”

Anyone who thinks they may be in the reassessment group should contact MND Connect on 0808 802 6262, so the Association can keep in touch and offer support if needed. If you are sent an ESA50 form for reassessment, you can contact our Benefits Advice Service on 0808 801 0620 (England and Wales) or 0808 802 0020 (Northern Ireland) for help and support completing the form.

*More campaigns news: Pages 7 and 23*



# Tributes paid to Olga who 'spent a lifetime caring for others'

*Olga Bannister, pictured after receiving her medal*

**O**LGA Bannister, who received the British Empire Medal in June in recognition of her work supporting people living with MND, has died aged 84.

Olga started volunteering for the Association after her husband Neville sadly died from motor neurone disease in 2001 and was honoured for her work in the Queen's Birthday Honours.

**"I am so proud and delighted that Mum was given this honour, which recognises a lifetime devoted to caring for others."**

The medal was presented during a moving ceremony at St Luke's Hospice in Sheffield on 9 June where she was being cared for having been diagnosed with terminal cancer. She sadly died just days later.



Olga's eldest son, broadcaster Matthew Bannister, said: "She spent 17 years as a volunteer offering support to hundreds of MND patients and their families across South Yorkshire.

She drew strength from the fact that the families she had buoyed up with her cheery compassion and steely determination to cut through bureaucracy usually wanted her there at the end. Many became lifelong friends.

"I am so proud and delighted that Mum was given this honour, which recognises a lifetime devoted to caring for others.

"Her amazing kindness and compassion made a huge impact on so many people – not least on my Dad who she looked after through every second of his struggle with motor neurone disease. For me and my brothers she will always simply be our wonderful and beloved Mum."

# Group's new bilingual website

**A** NEW bilingual website for speakers of English and Welsh has been created by a family whose lives have been turned upside down by MND.

Jen Roberts, whose husband Mike sadly died from MND in 2017, has created the website for the North West Wales Support Group alongside her daughter Ceri.

The site carries articles in both languages, making it easier for those who have Welsh as their first language to access the information they need.

Jen explained: "When you are unwell and need help and support, it is comforting to be able to use your first language.

"My husband Mike started a web design company, called Delwedd, in 1998. Very early on, he decided to design one free website a year for a local good cause and agreed to keep supporting the websites for as long as they were

needed. They were varied and included organisations such as Gafael Llaw, a charity which supports children with cancer, and Ysgol Pendalar – a special needs school in Caernarfon.

"In late 2017, it was decided that the next free website should be for the North West Wales Support Group and my daughter Ceri and I started working on the design and the content.

"It was apparent to us that the website should be bilingual as it would be beneficial for people using the site to have the option of using either language.

"People who have used the site have already been very complimentary."

Kevin Thomas, Regional Care Development Adviser, said "It looks fantastic. Well done and thank you to the team at Delwedd. The site is friendly and welcoming to users.

The site is available at [www.mndnorthwestwales.org](http://www.mndnorthwestwales.org)

## Teulu'n creu gwefan ddwyieithog newydd i'r Grŵp

**M**AE gwefan NEWYDD ddwyieithog wedi cael ei chreu ar gyfer siaradwyr Cymraeg a Saesneg gan deulu sydd wedi cael eu heffeithio'n galed gan Glefyd Motor Niwron.

Mae Jen Roberts, a gollodd ei gŵr Mike i GMN yn 2017, wedi creu'r wefan gyda'i merch Ceri ar gyfer Grŵp Cefnogi Gogledd Orllewin Cymru.

Mae cynnwys y safle ar gael yn y ddwy iaith ac yn ei gwneud hi'n haws i Gymry Cymraeg i ddod o hyd i'r wybodaeth maent eu hangen.

Esboniodd Jen: "Pan yr ydych yn glaf ac angen cymorth a chefnogaeth, mae'n braf gallu defnyddio eich iaith gyntaf.

"Yn 1998 dechreuodd fy ngŵr Mike gwmni Delwedd, sef cwmni dylunio gwefannau.

"Yn fuan iawn penderfynodd ddylunio un gwefan yn rhad ac am ddim yn flynyddol at achos da yn lleol, gan gytuno i gefnogi'r gwefannau am faint bynnag yr oedd eu hangen. Mae'r gwefannau

yma'n rai amrywiol iawn ac yn cynnwys mudiadau fel Gafael Llaw, elusen sy'n cefnogi plant gyda chanser, ac Ysgol Pendalar - ysgol ar gyfer plant gydag anghenion dysgu ychwanegol.

"Ar ddiwedd 2017 penderfynwyd y byddai'r wefan rad ac am ddim nesaf ar gyfer Grŵp Cefnogi Gogledd Orllewin Cymru a dechreuodd fy merch Ceri a minnau weithio ar y dyluniad a'r cynnwys.

"Yr oedd yn amlwg i ni y dylai'r wefan fod yn ddwyieithog, gan y byddai'n fuddiol i bobl fyddai'n defnyddio'r safle gael yr opsiwn o ddefnyddio naill ai'r Gymraeg neu'r Saesneg.

"Mae pobl sydd eisoes wedi defnyddio'r safle wedi ei ganmol yn fawr."

Dywedodd Kevin Thomas, Ymgynghorydd Datblygiad Gofal Rhanbarthol, "Mae'n edrych yn ffantastig. Da iawn a diolch yn fawr i'r tim yn Delwedd. Mae'r safle yn gyfeillgar ac yn groesawgar i ddefnyddiwy'r."

Mae'r safle ar gael ar [www.mndnorthwestwales.org](http://www.mndnorthwestwales.org)



Main image: Jen Roberts with her daughter Ceri and son Aled

# is a family affair



Left inset: Michael Roberts who sadly died in 2017. Right inset: The North West Wales Group launches their website

## Learning more about housing adaptations



**I**N 2017, the Association's MND Costs report showed that housing adaptations are the biggest one-off cost people living with MND face.

Over the last few months, the Association has been carrying out a consultation programme to gain a better understanding of the problems associated with adapting existing homes and finding accessible homes for people with MND.

The programme consisted of face to face engagement sessions at regional events and online surveys. We consulted with people living with MND, their carers and families. We also consulted with volunteers and staff working to support people with MND, councillors and professionals working in accessible housing and housing adaptations provision or commissioning.

The surveys close on 13 July and the findings will be used to inform our policy and campaigning work to push for improvements so people with MND and their families can access the homes or adaptations they need, when they need them.

If you are not already a member, please join our MND Campaign Network to get up to date information on all our latest campaigning work. For more information please visit [www.mndassociation.org/campaignnetwork](http://www.mndassociation.org/campaignnetwork)

A photograph of a woman with short dark hair, wearing a blue and white striped shirt, sitting at a table with two children. She is smiling and looking down at an open book. The child on the left is a young girl with blonde hair, wearing a dark blue dress with a white collar, resting her head on her hand. The child on the right is a young boy with blonde hair, wearing a white shirt with a colorful pattern, pointing at the book. The background is a bright, indoor setting with a window.

*Jane was determined her mum was still able to read with her grandchildren Jessica, six and Daniel who is two*

**‘When mum could no longer speak I gave her my voice’**

**W**HEN Jane Stearne's mum Carol was diagnosed with MND Jane decided she wanted to give her back the greatest gift she could – a voice.

In 2017, having experienced the weakening of her left hand and problems with her speech, Carol was diagnosed with MND and for both her and her whole family, life would never be the same again.

Jane explained: "My Mum was an incredible woman, a wonderful Mum, she doted on my brother and I. She was an amazing Nanny to her grandchildren Sidney, who is eleven, Jessica, who is six and Daniel who is two.

"She had always been very fit. She was always outside and loved gardening and power-walking and simple things like spending time with her family and friends and a glass of wine with her meal.

"She noticed something wasn't quite right when she started experiencing a weakening of the grip in her left hand and a slight slur in her speech. We talked it through and I urged her to go and see her GP."

After being diagnosed, Carol gradually lost the ability to walk and eat, but it was not being able to read aloud to her grandchildren as her voice deteriorated which she found particularly hard.

Jane said: "It was a great loss. It was so cruel. MND just took away all of the things in her life which she enjoyed."

Jane decided to record her own voice to use with Carol's communication aids and when she looked back at old videos she realised just how similar her own voice was to her mum's.

She said: "When Mum first started losing her speech she used an app called Predictable on an iPad and we used the best voice we could find – an Australian voice which we named Raquel. Mum used it, but she didn't embrace it.

"I first read about voice-banking in *Thumb Print*. I started attending our local branch coffee mornings and found out more. I was lent a headset by Association visitor, Kim Archer, and with her support, accessed some online software along with the instructions.

"I used a website called [www.modeltalker.org](http://www.modeltalker.org), which is based in America, and they were tremendous with their support."

Using the software, Jane was able to build up a library of 1,600 pre-determined sentences over a number of weeks. Once recorded, the sentences were used to create a phonetic structure which could then be used to build a voice.

Jane said: "There had to be complete quiet when I was recording and when you have two young children, that can be quite difficult.

"I also couldn't do it when I was too tired as the software would pick up changes in my voice. It was important to make the recordings as high quality as I could."

After completing the recordings, Jane and her mum then went through a calibration process to enable the voice to be tweaked to suit Carol's preferences. Once the voice was released, it was clear that Carol felt more comfortable using the Predictable app.

Jane said: "Mum remained immensely grateful for the voice. I was determined to find a way to help her continue to enjoy special time with her grandchildren, so I typed my children's books into Predictable. It built so many bridges and it was wonderful to be able to give

Mum that precious time with my children.

"I believe Mum felt that using my voice gave her some identity back. She was always immensely grateful for the work I did on it.

"I would encourage anyone in the same position to consider voice-banking as there is nothing to lose."

Sadly, Carol died in February, just 11 months after being diagnosed and her family has continued to fundraise on behalf of the Association in her memory. Jane said: "Giving Mum back her voice was very reflective of our relationship and my love for her. "We spoke or texted each other every day and I still can't believe that we find ourselves without her. She was magic and remains an inspiration to us all."



*Carol Conyers pictured with her grandson*

**T**HE Association is piloting a new Voice Banking Volunteer (VBV) role in seven areas of the country. Up to two volunteers per area have been recruited and are either ready to accept referrals or will undergo training shortly.

We are keen to ensure that people with MND have the opportunity to create their own personalised synthetic voice as early as possible, and so a VBV can act as a support to the person to ensure the correct equipment is provided, help to get them registered and start the voice-banking process, and offer support throughout the recording process. They should also be able to advise about the funding options and would also have some

basic knowledge about message banking.

The seven pilot areas are Cornwall and Devon, Portsmouth and Hampshire, Oxfordshire and Berkshire, North West London, Buckinghamshire and Bedfordshire, North Wales and West Yorkshire.

Anyone can refer in for volunteer support and this can either be done online or via a paper form, both of which are available at [www.mndassociation.org/communicationaids](http://www.mndassociation.org/communicationaids) within the *How can you help me with voice banking* section.

For more information about voice banking please contact MND Connect on 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

# Richard prepares to take over as Association Chair

*Out-going chair, Alun Owen, left, pictured with the Association's new chair, Richard Coleman*



There will be challenges ahead, but we have an excellent team of directors and trustees. Our trustees have very personal knowledge of MND.

A new Chair will take over at the helm of the Board of Trustees at the Association's AGM later this month.

Richard Coleman, who has been a trustee since 2011, will take over from Alun Owen, who has been involved with the Association both as a volunteer and a trustee since 2002, at the AGM on 14 July. Alun became the chair in 2014 but through our strong governance processes that ensure we have the most effective Board of Trustees at all times, his tenure will end at the AGM.

Both men have personal experience of MND, Richard sadly lost his wife to the disease in 2006, while Alun lost his partner in 2001.

Richard said: "My wife was diagnosed with MND in 2004 and shortly afterwards our Association visitor invited her to attend the South Bucks Branch meetings.

"My involvement at that stage was limited to dropping her off and picking her up for committee meetings, but I was then invited to join the committee and subsequently, in 2007, to take over as committee chair.

"I became a trustee in 2011 and stood again in 2014 and I am very much looking forward to becoming the Association's Chair.

"There will be challenges ahead, but we have an excellent team of directors and

trustees. Our trustees have very personal knowledge of MND.

I get a lot of satisfaction knowing that everyone at the Association is doing everything they can to help people living with a disease which is truly devastating."

Although Alun is standing down as a trustee he will be continuing his voluntary work with the MND Association within the Merseyside Branch as an Association visitor as well as a volunteer on the rota of the Association's helpline, MND Connect.

He said: "It has been a great privilege to be the Association's chair and there have been many special moments that I will never forget.

"I became Chair just after the Ice Bucket Challenge happened in 2014 and I felt a great sense of responsibility in making sure we used the money wisely. The range of different activities in which I have been involved has also been memorable; from rattling tins in supermarkets to attending a dinner at Buckingham Palace with our Royal Patron HRH The Princess Royal. Having to give a speech in front of people such as our Patron Benedict Cumberbatch was quite unexpected!

"One of the main things that has really stood out though, is the uniqueness of the Association – the sense of the family that exists among everyone involved and that collective sense of belonging. I believe that over the last four years, the Association has become far more accessible, inclusive and a much stronger and connected organisation. I think that is one of its greatest strengths and something we must work hard to retain."

The AGM and annual conference will be held at the Radisson Blu at East Midlands Airport. For more information or to register to attend please visit [www.mndassociation.org/agm](http://www.mndassociation.org/agm)

## SnapAction – a big thank you!

A BIG thank you to everyone who shared and promoted our SnapAction Thunderclap on Micro-Volunteering Day, 15 April.

A total of 226 people supported our Thunderclap and shared our *What is motor neurone disease?* animation with more than 127,000 people on social media.

Thank you for helping us to raise awareness of MND.

## Volunteering for all

VOLUNTEERS' Week was held from 1-7 June and this year's theme was volunteering for all.

The week recognised that people of all ages and abilities can volunteer for a cause they care about in a variety of ways.

Throughout the week, we celebrated the contribution of our diverse community of volunteers, who volunteer their time to fundraise, campaign, and support people with MND in their local areas.

We're very grateful for the invaluable contribution that our volunteers give to support people affected by MND.

## Innovation with corporate volunteering

STAFF based at global accounting firm EY volunteered a day of their time to work with the Association on ideas for volunteer recruitment.

During the day, EY staff learnt more about the Association and met Zeb Naggarr who is living with MND.

Liz Tosolini, Marketing Manager at EY said: "We were delighted to participate in the MND Association volunteering, communications and strategy day. It was a highly rewarding experience that allowed us to use our skills and knowledge for a great cause."



Jim and Helena pictured on holiday

## Helena Schofield lost her beloved husband, Jim to MND in July last year. Here, she tells their story.

**“**AM so angry with MND. It left my husband, Jim, with no movement, no speech. All that remained was his brilliant brain and his wonderful eyes. He could communicate all of his feelings and thoughts through his eyes.

“When he was well he never wasted a minute of his life, fitting another job in if there was a moment to spare. Our motto was always, ‘make every day count.’



Jim enjoying time in Yorkshire before he was diagnosed with MND

“He loved outdoor pursuits, including walking, cycling, climbing, pot-holing and sailing to name a few. We used to travel extensively, exploring each country, and having adventures every day on our holidays.

“When he was diagnosed with MND, it made it even harder to bear, knowing we could not do any of these activities again.

“He attended a day hospice and particularly enjoyed arts and crafts. He hadn’t painted before, but the watercolours he produced there are beautiful.

“I spoke to someone last week who told me they had all loved Jim at the hospice – they were always laughing. Jim had always loved playing bowls and she told me how, when he became unable to throw the ball, she went home and asked her husband what she could use to make it easier for him. The following Monday, she turned up with a guttering pipe to put between his legs in his wheelchair in order for him to roll the ball down onto the mat!

“The support staff said they had never



The watercolours painted by Jim

met anyone who bore this terrible disease with such dignity, he was so brave until the very end. I’m sure he engineered his final days in order to be in respite care while I visited my daughter, Becky, in Hove. Becky organised a sponsored silence as soon as Jim was diagnosed and, together with her friends, raised quite a large amount for the Association.

“My friend, Elaine Marsden, also organised a coffee morning and I donated all Jim’s watercolours together with my paintings, which I started when I became his full-time carer. Elaine has decided to do another coffee morning in aid of the Association this summer, so I am now busy painting. “Learning painting techniques has been very therapeutic.”

**“T**WO years ago, my father was diagnosed with MND. “The past two years have been a rollercoaster to say the least – the speed at which Dad’s strength and mobility has deteriorated, the fear of seeing him fall as his muscles weakened until he lost the ability to walk completely. And of course, on a rollercoaster, you never know what’s around the corner.

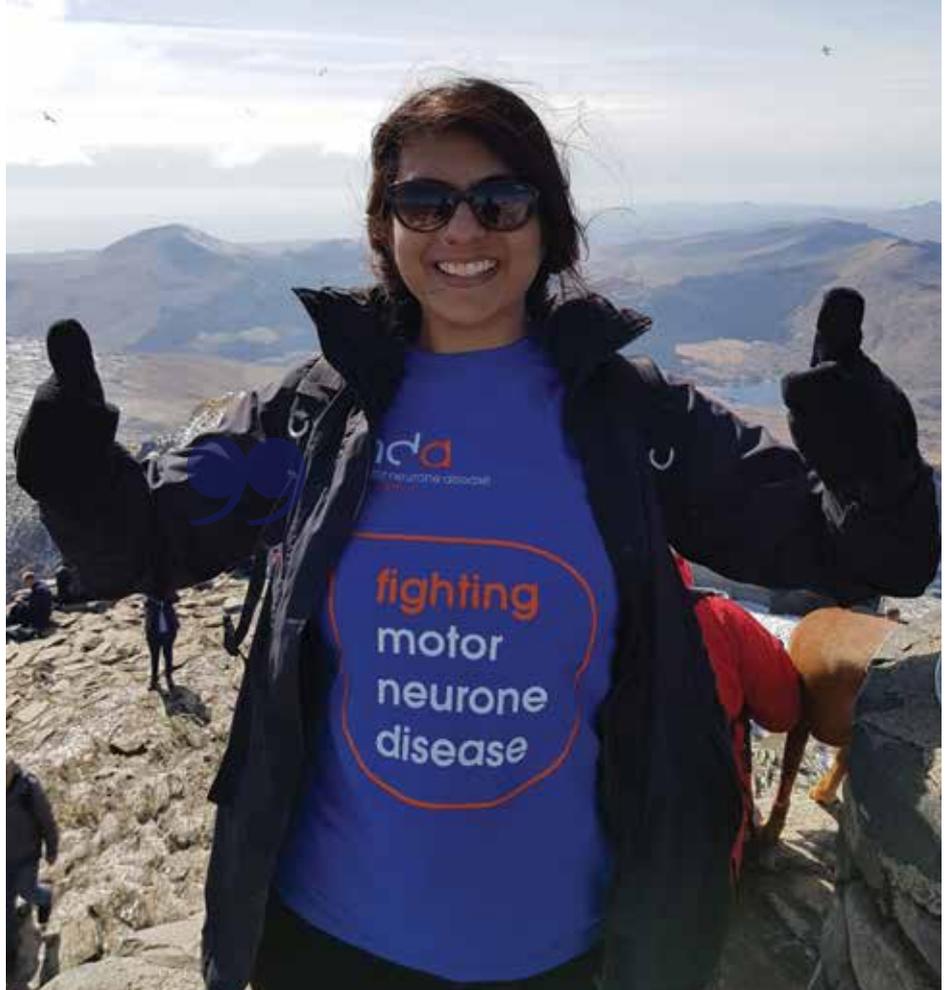
“Seeing Dad this way made me realise how much we take the simple act of walking for granted. Always an avid walker, I decided to invest more time into my hobby and took up more adventurous hiking pursuits, and, after reading more about the wonderful work of the MND Association, I wanted to combine my charitable and outdoor endeavours and tackle the great Mount Snowdon in Wales, the highest point in the British Isles. My husband joined me.

“Collecting online donations before the climb, I was truly overwhelmed by people’s generosity. Some of my colleagues approached me with sympathy and concern, but the most common remarks I got were, ‘I had no idea he was suffering’ or, ‘What exactly is MND?’ This just demonstrates the vital need to raise awareness of the condition.

“The hike to the summit was treacherous, yet exhilarating. Knowing I was doing it for a deeply personal cause, yet one to which 50 people had donated more than £1,800, was what kept us going through the snow and ice that covered the ground from a low 500 metres.

“We were lucky though, if we had embarked on that hike any earlier in the week, as we had planned, we wouldn’t have been able to reach the summit as

# Zainab takes the ultimate challenge to raise money



Zainab, pictured at the top of Mount Snowdon

the terrain was too dangerous. The owner of the bed and breakfast warned us of the dangers he’d heard about and even told us to save the number for the Snowdon Mountain Rescue Team on our phones in case of an emergency!

**“Together we can fight this devastating disease.”**

“We went to bed feeling apprehensive about what tomorrow would bring. The morning greeted us with glorious sunshine and bright blue sky and we filled ourselves up on a satisfying breakfast ready to make our way to the top. There wasn’t a single cloud in the sky and we captured some real postcard-worthy photos on our phones, so we had a double incentive, charity and the awesome view. The treacherous snow actually made the mountain look breathtakingly beautiful. It

was the first day that week that Snowdon’s summit was free of any cloud cover. But of course, after a three-and-a-half hour ascent, we then had the descent to negotiate too – as if the trek up wasn’t bad enough, the way down was muddy and slippery. Despite my love of nature, it was a relief to walk on the pavement again.

“The Association was fantastic at supporting our efforts and sent us lots of fundraising material, including T-shirts, so if you are considering doing some fundraising yourself, they can guide you and the best thing is, you can raise money and awareness doing something you enjoy! Action can only come from awareness.

**“Together we can fight this devastating disease.”**

Naeem Khalid lost his battle with MND on 15 June 2018. He passed away peacefully surrounded by his family



Zainab’s father Naeem Khalid, who is living with MND

# New collar for people with MND is launched

After years of research and development, a collar made specifically to help people with MND who are experiencing weakness in their neck has been launched. Here, we explain more about the collar and the research behind it.

**F**OR Philip Brindle, using the Head Up Collar has been life-changing. Diagnosed with MND in 2015, Philip soon started experiencing weakness in his neck meaning that everyday tasks such as eating, reading a newspaper or using a computer became almost impossible.

He explained: "My head dropped forward which just meant that life became really difficult. I couldn't even have a face-to-face conversation. It also affected my self-confidence, I just didn't want to go anywhere."

Philip first started using the collar during the trial phase and the effect it has had on his quality of life has been remarkable.

He said: "Using the collar meant that I could keep driving for a while, as before all I could see were the pedals. I don't drive any more because my arms are now too weak, but it gave me my independence which was wonderful. It also meant we could go on holiday and that I didn't feel self-conscious. The collar is very comfortable, I would say that it feels like a scarf and it is also discreet. It can hardly be seen under clothing such as a shirt. The level of support is also variable, you can use different strength struts which come with the collar because the support needed varies depending on what you are doing at the time."

The creation of the Head Up Collar has been made possible



*Philip Brindle, wearing the Head Up Collar*

thanks to the efforts of clinicians based at the University of Sheffield, whose work has been supported by the National Institute for Health Research, the Association and TalarMade, the company which produces it.

Professor Christopher McDermott, from the University of Sheffield, was one of the clinicians behind the collar's development.

He explained: "We started from scratch by working collaboratively with people living with MND to identify what the problems were with current neck collars and what features the ideal collar would have.

"The design team listened to everything the user group suggested and went away to make prototypes. There were at least six or seven different types of design solutions being developed and it was the expert

users who influenced which ones had merit and went forward into more advanced prototyping."

The final design, which became known as the Head Up collar, was produced and tested by 150 people living with MND. After wearing it for a month, they were asked to provide feedback and were given the opportunity to keep the collar if they wanted to.

Prof McDermott said: "Eighty percent of participants in the study continued to use the Head Up Collar after the end of the study, judging it to be better for them in terms of support and

We started from scratch by working collaboratively with people living with MND to identify what the problems were with current neck collars and what features the ideal collar would have



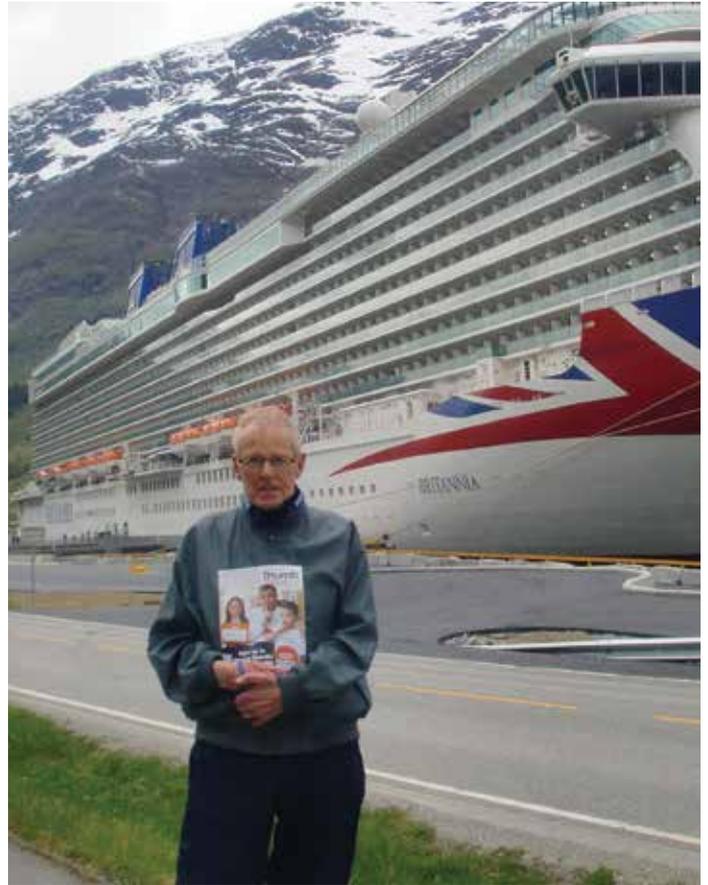
*Professor Christopher McDermott, one of the leading clinicians on the project*

comfort compared to other collars they had tried.

“Our hope is that the Head Up Collar will be something that, rather than being abandoned under the stairs or in the cupboard, people will actually use and we hope they can experience an improved quality of life.”

**The collar was launched in April and is now available on the NHS – you can request it via your MND Care Centre or GP. Alternatively, the collar is available direct from TalarMade. For more information, visit [www.talarmade.co.uk](http://www.talarmade.co.uk)**

**Have you used the Head Up Collar? Send your views to [clare.brennan@mndassociation.org](mailto:clare.brennan@mndassociation.org)**



*Philip Brindle pictured wearing the collar on holiday*

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# Finding hope th

For some people who are living with MND continuing with a hobby – or taking up a new one – can offer a way to cope. Here *Thumb Print* tells the stories of two people who are living with MND who found that their hobby gave them hope in the darkest of times.



Steve Newton with some of the wooden products he has produced with help from his wife, Heather

**S**TEVE Newton from Cheshire, was diagnosed with MND in May 2016 after experiencing problems with his hands.

He had always had an interest in working with wood and with help from his wife, Heather, they started making bird feeders, bird boxes and other items which they hoped might raise money for the Association.

**“The diagnosis came as a shock and it took some time to adjust, but making the wooden goods has been great therapy.”**

To their surprise they have sold 100 bird boxes, 55 bird feeders and more than 60 pens turned from exotic wood. Most of the wood is donated, so the cost is minimal and they have found their hobby very cathartic.

Heather said: “The diagnosis came as a shock and it took some time to adjust, but making the wooden goods has been great therapy. It means Steve is using his hands and raising money at the same time. It is something very positive for both of us.

“He is doing really well and although he is getting weaker he remains very positive and we continue our fundraising efforts

“It has been a surprise to us how much help and support we have received, it has been incredible. It has been something very positive for us to focus on throughout the winter months.”

So far, the couple has raised an amazing amount and they are generating more funds all the time. They also plan to hold a fundraising event on 22 September.

**D**EAN Halkes was just 35 when he was diagnosed with MND – a shocking diagnosis for someone who had always been so active both at home and in his work as a structural engineer.

At the time, he was happily married with two young children, but as he struggled to

# rough a hobby

come to terms with his diagnosis his world fell apart.

He explained: "I worked as a contractor so if I didn't work, I didn't get paid. I had to give up work a year after I was diagnosed and my marriage ended. It was the worst time of my life. I found myself in a hole, everything was going wrong."

Soon afterwards his father, Richard, had the idea of making craft items out of copper pipe to sell online. He approached Dean to see if he would be interested in getting involved.



Dean in his workshop

Dean said: "The business we have started has helped me keep my head above water. I am now in a wheelchair, but it is something I can still do which I love."

"The whole family is involved. My dad and I design and manufacture the items, mum helps with the orders and my sister does the social media and advertising."

"The website Etsy is really big for us, we also sell on Ebay and we have taken part in the Bristol Christmas Market. People contact us through Facebook and bespoke orders also come through. 10% of the money we make goes to the MND Association."

It has been a big year for Dean, who fulfilled one of his ambitions by taking part in the Brighton Marathon in April.

Dean was pushed around the course by five friends, a group he is now proud to call his 'band of brothers.'

He said: "It is the best thing I have ever done. I felt like a rock star, it was amazing."

"Four of the lads I have known since childhood, but the fifth Rob, knew one of my friends. He is now a friend for life."

"They all pushed me round wearing green pants, which raised a



Dean Halkes pictured at the Brighton Marathon

lot of attention. It was one hell of an achievement!"

To purchase Dean's designs visit [www.etsy.com](http://www.etsy.com) and search for Hawkescopperwork

**Do you have a hobby which enables you to cope with the effects of MND? Send your stories to Clare Brennan at [clare.brennan@mndassociation.org](mailto:clare.brennan@mndassociation.org)**



## RESEARCH INFORMATION SHEETS

The Research Development Team produces a number of information sheets for people living with MND, clinicians, and health and social care professionals:

- A:** Introduction to MND research
  - B1:** Introduction to inherited MND
  - B2:** Inherited MND: Genetic testing
  - B3:** Inherited MND: Options when starting a family
  - C:** Unproven treatments
  - D:** Clinical trials
  - DA:** MIROCALS clinical trial
  - E:** Research we fund 2018
  - F:** Stem cells
  - G:** Biomarkers
  - H:** Accessing unapproved drugs\*
  - I:** Tissue donation
  - J:** What happened to my DNA Bank sample?
  - K:** Statins\*
  - L:** Research involving animals
- \*New information sheets

All information sheets can be downloaded from [www.mndassociation.org/researchsheets](http://www.mndassociation.org/researchsheets) or you can request a print copy from the MND Connect helpline on 0808 802 6262

In this edition of *Thumb Print*, we meet Emma Smith, one of the Association's PhD researchers. Based at the Sheffield Institute for Translational Neuroscience (SiTraN), Emma's work involves looking closely at mitochondria and their role in MND.

# 'I hope to keep making a difference for people living with MND'

**"M**UTATIONS in a gene called C9orf72 are the most common cause of MND.

"It is thought people with C9orf72-related MND may have reduced levels of the C9orf72 protein in their cells. Our lab is interested in identifying the function of the C9orf72 protein in the cell, as this may help us to understand what is happening in C9orf72 MND.

"My first involvement with MND was investigating the function of the C9orf72 protein in the cell's self-eating process called autophagy. Autophagy is essential to the survival of cells as it helps maintain a healthy pool of proteins and organelles, through removal (or eating and recycling) of the damaged ones. Evidence suggests that autophagy is impaired in C9orf72 MND and our research showed that the C9orf72 protein plays a crucial role in the autophagy pathway.

**"Lots of evidence shows that mitochondria do not function properly in MND and this could contribute to motor neurons not being able to survive."**

"In my PhD project, I have been investigating the role of mitochondria in C9orf72 MND. Mitochondria are important cellular organelles which are responsible for many different aspects of cell biology. Crucially, mitochondria are responsible for the generation of energy that cells need to survive, which is why they are often referred to as the 'powerhouse' of the cell. Lots of evidence shows that mitochondria do not function properly in MND and this could contribute to motor neurons not being able to survive. We have found that the C9orf72 protein interacts with mitochondria and plays a role in maintaining their health through a mitochondria-specific autophagy pathway, called mitophagy.

"As a part of my PhD I have been able to attend the International Symposium on ALS/MND held in Dublin in 2016 and this year's ENCALS meeting in Oxford. The chance to participate in these meetings has offered me opportunities to expand my knowledge on MND research and gain helpful insight through discussion with other MND researchers.

"I am hoping to keep working in the world of science after my PhD to make a difference for people living with MND and other neurodegenerative diseases."

*More research news: Pages 14, 15, 24 and 25*





Prof Stephen Hawking's family pictured inside Westminster Abbey

## Remembering Stephen Hawking

THE Association's patron Professor Stephen Hawking, who sadly died from MND in March, was laid to rest at Westminster Abbey during a Service of Thanksgiving in June.

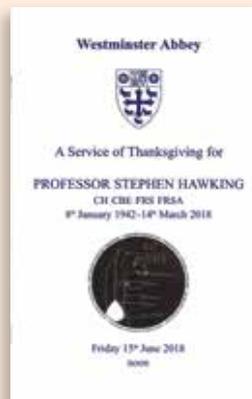
Members of the MND family, including Association Chief Executive Sally Light and Chair of the Board of Trustees Alun Owen, who represented our Royal Patron, HRH The Princess Royal, attended the service which saw Prof Hawking's ashes interred within the Abbey. Association patrons Benedict Cumberbatch and Charlotte Hawkins also attended.

Prof Hawking was diagnosed with MND at the age of 21 and lived for 55 years with the disease, using his experiences to raise awareness of MND around the world, while supporting the Association's work.

In the months since his passing, members of the MND community have come together to remember his work.

For Lesley Ogden, a founding member of the Association, news of his death brought back memories of the early days of the Association, which celebrates its 40th anniversary next year.

She said: "When the charity was being set-up, the founder member of the London group, John Prince, wrote to Prof Hawking asking if he would be



Patron of the Association. He replied that he was honoured to be asked and accepted.

"He became the Patients' Patron for a number of years and gave one of the first donations from a talk he gave. He and his wife, Jane, were very supportive of the Association in those early years.

She also described how her own daughter Kate, who is now 47, had met Prof Hawking at an early AGM.

She said: "Aged eight, Kate was fascinated by the way his wheelchair was moving 'on its own' and he gave her a ride around the room."

In Cambridge, the city which became synonymous with Prof Hawking's work, a special screening of the film *The Theory of Everything*, which tells the story of his life and relationship with his first wife, Jane Wilde, was held to raise money for the Cambridgeshire Branch of the Association.

Chair and branch contact, Cynthia George said: "Throughout Prof Hawking's inspirational life, he played a vital role in raising awareness of MND locally and around the world. We were delighted to be chosen by The Light Cinema in Cambridge as a local charity to receive all the funding from this screening."

A total of £688 was raised during the event.  
*Your letters – pages 38 and 39*



Louise Jeffery



Jean Waters



Glenn Bourne



Nikki Birmingham

# Runners take on the c

**R**UNNERS from across the country have taken part in a month of marathons to raise money for the MND Association.

During April and May a host of events were held including marathons in Manchester, Paris, Brighton, London and Milton Keynes as well as the Marathon Des Sables.

**Jean Waters**, who is living with MND, took part in the Brighton Marathon on 15 April, ably assisted by Becky Amor and Vicky Paeschel, who agreed to push her around the 26.2 mile course.

She said: "One thing I never thought I would do with MND was participate in a marathon, but that is precisely what I did. This year my bluff was called when the lovely Becky offered to push me around.

"After such a long, hard winter with snow in April, I knew that keeping warm would be my major challenge and that by the time I piled on enough layers I'd resemble Michelin woman! I wanted to sport the #TeamMND running vest too and after careful consideration and online research I decided fancy dress onesies would be the answer. #DuckforMND was born.

Jean completed the course in just over five hours.

41-year-old **Alex Wilson** took part in the London Marathon after signing up for her first 10k in 2016.

The mum-of-two who used to 'hate running with a passion' has completed a number of half marathons, marathons and even ultra marathons, raising more than £4,000.

She was inspired to raise money on behalf of the Association after supporting a lady living with MND in a care home.

**Chris Evans MP**, who represents the Islwyn constituency in South Wales became the first ever MP to run a marathon for the Association when he took part in the London Marathon in April.

Chris is a member of the All-Party Parliamentary Group on MND and is great supporter of the Association's work, meeting in Parliament to raise awareness and understanding of MND among parliamentarians.

Chris completed the marathon in four hours and 51 minutes, raising more than £1,300.

46-year-old **Glenn Bourne**, who is living with MND, took part in his first ever London Marathon with the support of his wife Amanda, who is a personal trainer.



Alex Wilson



Chris Evans MP



Oliver Griffiths



Michelle Frost

# challenge of a lifetime

He said: "I thought what better way to challenge myself and raise awareness. I wanted to prove that MND doesn't have to be the end. It felt great to run this event for #TeamMND."

**Louise Jeffery** took part in her sixth London Marathon dressed in a dog costume, in memory of her friend Andrew Gaskell who was diagnosed with MND in 2011.

She explained: "The support the Association gave to Andrew and his family was unbelievable. If I can support the Association to help others, I will do anything I can to raise funds and awareness. I know Andrew is somewhere looking down and laughing at my efforts!"

The Association's Events Fundraising Co-ordinator **Michelle Frost** set a new Guinness World Record when she took part in the London Marathon on stilts.

She originally set the record in 2008 when she finished the race in eight hours and 25 minutes and wanted to reclaim her crown by beating the current record which stood at six hours and 50 minutes. She completed the course in an incredible six hours and 37 minutes, setting a new world record.

**Nikki Birmingham** took part in her second London Marathon in memory of her dad Richard who sadly died from MND on the same day as the race, five years ago.

She said: "He would have thought I was crazy, but I like to think he would have been proud too, raising awareness and a little more money for the Association."

**Oliver Griffiths** took part in the Marathon Des Sables – a six day event which sees competitors run more than 156 miles over dunes and white-hot salt plains, while carrying their back pack.

He took part in the gruelling event in memory of his closest friend's father who died from MND, raising over £12,000.

He said: "It was an amazing experience. I surprised myself and finished 39th in the end, way above my expectations. I'm so pleased with the amount I raised, I know it will go to great use."

**Inspired to support our work by taking part in a fundraising event in 2019?**

**Contact our fundraising team on 01604 611860 or email [fundraising@mndassociation.org](mailto:fundraising@mndassociation.org)**

# Friendship inspires Firas to raise £3,600

**A**RABIC teacher Firas Alhawat has raised more than £3,600 for the Association after taking part in the Kingston Half Marathon in honour of his friend Helen Carmichael who is living with MND.

Firas met Helen, a Classics teacher from North London, when she approached him about learning Arabic. Since then, they have become good friends and her story inspired Firas to want to support the Association's work.

**"I'm really touched that Firas has chosen to dedicate his time and energy to raising money for the Association."**

He explained: "Helen and I have been friends for a few years. I came to the UK from Syria as a student. When the war broke out in my home country, I wasn't able to return. Instead, I stayed in London as a refugee and started working as an Arabic language teacher. We first met when she wanted to take some Arabic lessons. I was always impressed by her sharp understanding and wide knowledge of Arabic literature. In lessons where I was supposed to be the tutor, I found myself learning more than teaching."

Helen, who was diagnosed with MND in May last year said: "It's the extent of his efforts for charity that amazes me. He volunteers as an interpreter for the Red Cross and always seems to be heading off across London to help with an interview



Firas and his friend Helen Carmichael, who is living with MND

for a refugee. He has also spent two Christmases working at refugee camps. It's in view of this that I'm really touched that Firas has chosen to dedicate his time and energy to raising money for the Association."

Helen writes a blog about life with MND, which describes her experiences of living with MND in a frank, honest and often hilarious manner.

She said: "I'm living with an illness that most people probably regard as the ultimate in misery. I thought there might be some value in talking a bit about what it's like and how life isn't necessarily unbearable."

You can visit Helen's blog at [www.followingafullmoon.wordpress.com](http://www.followingafullmoon.wordpress.com)  
*Please note the site uses strong language.*



Steve Marshall-Taylor and Graham Kennedy pictured presenting a cheque to Association visitor Julia Peckham from the East Sussex Branch

## Making waves to raise funds

**T**WO members of staff from Brighton College swam the English Channel to raise money for the MND Association.

Steve Marshall-Taylor who is the deputy head and housemaster Graham Kennedy, took part in the challenge in support of a friend and former teacher who is living with MND.

The event was the culmination of almost a year of training for Graham and Steve and part of a wider school initiative to support people living with MND locally and nationally. Pupils at the school have already raised almost £4,000 while undertaking a Three Peaks Challenge, organised by Nathan Wrigglesworth, taking the total raised to more than £17,000.

Regional fundraiser Pamela Fry said: "We are delighted to be working with so many people at Brighton College and thank everyone very much for all their hard work and support."

# MPs hear powerful statement on PIP experience

THE All-Party Parliamentary Group (APPG) on MND met in March to discuss access to the benefit Personal Independence Payment (PIP) for people with MND.

More than 650 supporters invited their MPs to attend this important meeting, and we were pleased to see such a good turnout.

James Douglas, who was diagnosed with MND aged just 29, gave a powerful account of the difficulties he faced claiming PIP, at an already extremely difficult time in his life.



James Douglas who is living with MND, speaking at the APPG meeting

James described the problems he had completing a lengthy form and attending a physically and mentally demanding assessment. He then also had to go through the reconsideration process after initially being awarded zero points and being denied PIP.

James said the PIP process was a, 'lengthy, stressful, time-consuming, pointless exercise' that he felt could be made much simpler for people with terminal illnesses such as MND.

James has subsequently claimed PIP under the Special Rules for Terminal Illness and was awarded the benefit very quickly. The Association is campaigning to ensure more people with MND can access benefits via this fast-track route.

The APPG also heard from representatives from assessment providers Capita and Independent Assessment Services, formerly

Atos, who described the steps they were taking to educate their assessors about MND. MPs discussed the findings from last year's APPG inquiry and agreed urgent action was needed to improve the process for people with MND, including removing the need for people with MND on the highest rates of PIP to be reassessed.

The meeting has already led to further discussions with the Department for Work and Pensions (DWP) and assessment providers about changes to the PIP process.

If you would like more information on the APPG on MND, please visit [www.mndassociation.org/APPG](http://www.mndassociation.org/APPG) or email [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org).

If you need any support or information regarding benefits, you can contact our Benefits Advice Service on 0808 801 0620 (England and Wales) or 0808 802 0020 (Northern Ireland)

In a further development, the Government has announced new guidance which would scrap reassessments for people living with MND who are awarded the enhanced rates of both the daily living and mobility components of PIP.

They will receive an ongoing award with a 'light touch' review after ten years. We will be working with the Department of Work and Pensions to ensure this is fully implemented and we expect the new guidance to be published this summer.

## Share your views on Universal Credit

THE Association is growing increasingly concerned about Universal Credit, and the financial impact it could have on people living with MND.

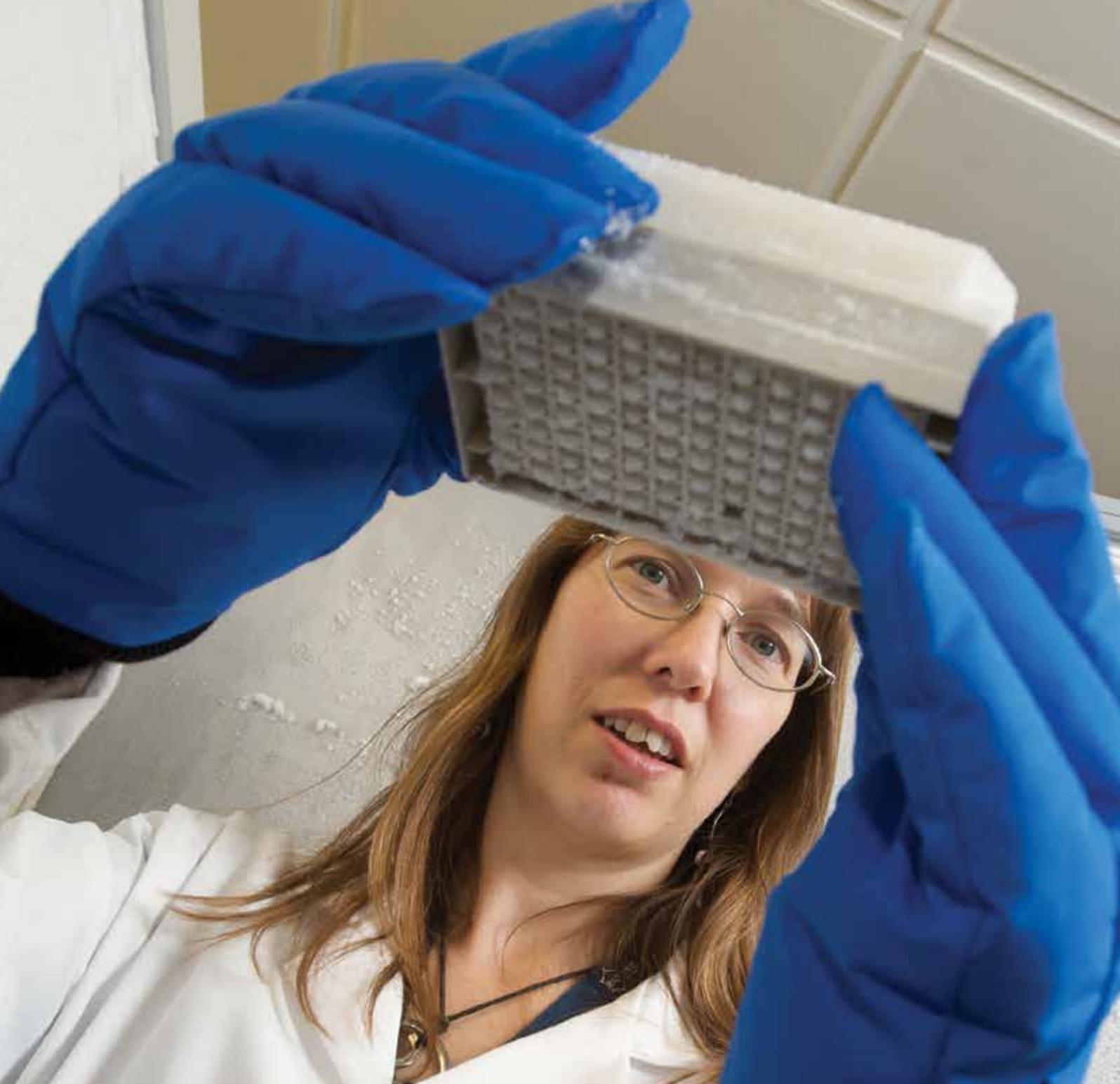
If you or a relative or friend have experience of applying for Universal Credit and would be willing to discuss this further with us, please get in touch with us at [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org)

## Cardiff and Vale Branch achieve 71st Charter adoption

CARDIFF City Council and the Cardiff and Vale University Health Board have agreed to adopt the MND Charter.

This MND Charter adoption was achieved thanks to the hard work of the Cardiff and Vale of Glamorgan Branch, including Campaigns Contact Kate Bryon. The adoption was supported by councillors Huw Thomas, Susan Elsmore and Graham Hinchey, and has helped the Association reach a total of 71 MND Charter council adoptions to date.





In this issue of *Thumb Print*, we meet Dr Janine Kirby who has dedicated much of her career to the pursuit of MND research

# 'The support of those living with MND is essential to our work'

**A** LEADING MND researcher has thanked people living with MND for contributing to the research projects which it is hoped will lead to new treatments and ultimately, a cure.

Dr Janine Kirby, from the Sheffield Institute for Translational Neuroscience (SITraN), described the involvement of people living with MND as 'essential' and would continue to be so in the future.

She said: "Whether they are donating samples such as blood, cerebrospinal fluid (CSF), a skin biopsy, urine or responding to a questionnaire, their involvement is essential and most appreciated."

She explained that the strategy for collecting samples had now moved towards taking a number of samples over a period of time rather than at one single point – a development which was leading to a greater understanding of how the disease progresses.

She said: "This personalised medicine approach is likely to evolve further in the future, particularly with the early development of approaches to gene therapy which targets genetic variations of SOD1 and C9ORF72-related MND."

Dr Kirby began her career in MND research after choosing to study Genetics at university, in the days before the Human Genome was sequenced.

**"We hope this treatment will be another therapeutic option for all MND patients, through the collection of and analysis of the additional samples."**

She said: "Having graduated, I wanted to specialise in Human Genetics and so went on to a PhD at University College London (UCL) where I was trying to find a gene.

"I then decided I wanted to go into medical research and a one-year post-doctoral position came up in Newcastle, working



*Dr Janine Kirby*

on the genetics of MND within the MND Research Group.

"Many years and a further 25 ALS genes later, I'm still working on MND, focussing on understanding the disease process, so that therapeutic targets can be identified. One highlight of my work was finding that a protein, which switches genes on and off, was not working properly in a cell model of MND which means we have a potential therapeutic target to investigate further."

Dr Kirby explained that she is working on a project called MIROCALS, which has collaborators across the UK and Europe. MIROCALS is a clinical trial which is looking at a low dose of Interleukin-2 (IL2). IL2 is already used to treat some rare forms of cancer, but at much higher doses than is being used in MIROCALS. She said her current role was to look at the changes in how the genes are working in the blood samples over the course of the clinical trial and to see if IL2 has an effect on these changes. She explained that the information from this, and other tests, would be combined to give a complete

picture of how the treatment is working.

She said: "I am also co-lead of NECTAR, a project funded by the MND Association, alongside Dr Pietro Fratta, to genetically characterise the samples being collected as part of the AMBRoSIA study, a joint initiative between Sheffield, Oxford and Queen Mary University of London (QMUL).

Outside of work, Dr Kirby explained that research was never very far away from her mind.

She said: "I am a trustee of Sheffield Hackspace, a communal workshop which provides its members with facilities for making things and sharing skills, including electronics, woodworking and craft and I have combined this interest with work by making a giant motor neurone with LEDs running down the axon to demonstrate how signals are sent down the muscles."

*More research news: Pages 14, 15 and 18*

Ashley Morgan was diagnosed with MND 15 years ago and has had her fair share of problems when it comes to travelling abroad. She spoke to *Thumb Print* about her story and explains how she found her perfect holiday on the island of Jersey.

**W**HEN it comes to travel nightmares, Ashley Morgan has perhaps experienced more than most.

Diagnosed with MND 15 years ago, Ashley was still determined to get out and about, particularly as she was keen to visit her native America.

She said: "My prognosis when I was diagnosed was between five and 10 years. I have a slowly progressing type of MND which perhaps makes me more fortunate than many.

"I manage quite well most of the time and live alone, apart from when my son or my friend comes to visit. With the adaptations I have made to my house, together with all the gadgets and gizmos I have I manage well, but when you go away things change.

"There are certain pieces of equipment you can take with you, but not everything and in a lot of hotels the facilities are not right at all.

"Flying when you are a wheelchair user can be a complete nightmare, particularly in these times of heightened security.

"On one trip I took my mobility scooter on a flight, only to find that the baggage handlers broke it.

"I haven't flown again since that experience seven years ago. Before that I went on a couple of cruises because they are so accessible, but now that my condition has worsened, I think it



*Ashley enjoys a visit to the beach in Jersey*

## 'How I found paradise on the island of Jersey'

would be much more of a struggle."

In May this year, Ashley decided to visit Jersey after spotting an advertisement on social media.

She said: "My friend and I went as foot passengers on the ferry. It was so easy because I could just ride on and off in my electric wheelchair, and the hotel picked us up from the ferry in their adapted mini-van."

"I stayed at Maison des Landes Hotel in St Oeun, which has a lovely atmosphere and very kind and caring staff. I couldn't recommend them highly enough.

"They have a full supply of equipment, for example zimmer frames, profiling beds and wheelchairs which are available free of charge, and the whole hotel was very accessible, including a swimming pool with hoist. I visited St Helier and a World War II museum. I was even able to use a beach wheelchair to go up to the water's edge and enjoy the sea.

"Each year, my condition gets a little bit worse but it was a wonderful holiday and I will be going to Jersey again."

Maison des Landes Hotel is a charitable trust offering holidays for people living with a disability. For more

information visit [www.maisondeslandes.co.uk](http://www.maisondeslandes.co.uk)

For more advice about getting out and about for people living with MND you can download information sheets *12C Travel and Transport* and *12D Planning a holiday*. Visit [www.mndassociation.org](http://www.mndassociation.org) and click on the Information Resources tab at the top of the page.

**Are you going on holiday this year? Send your travel hints and tips to [clare.brennan@mndassociation.org](mailto:clare.brennan@mndassociation.org)**

**For more stories from our readers turn to pages 12 and 13**

# One million members join fight against MND

**M**ORE than one million members of the Caravan and Motorhome Club are joining forces to help the Association fight MND.

The club has chosen the Association as its Charity of the Year thanks to Mark Falzon, a site owner and member of the club who put the Association forward as a potential partner.

Founded in 1907 as the Caravan Club, the organisation, which has recently become known as the Caravan and Motorhome Club, helps caravanners, motorhomers and campers access more than 3,000 stunning locations in the UK and Europe.

The Association's chief executive Sally Light said: "We are incredibly grateful to the Caravan and Motorhome club for choosing us as their Charity of The Year and we look forward to working alongside

them in the months ahead."

Over the May Bank Holiday, thousands of visitors came together at the Caravan and Motorhome Club's National event which was held at Sledmere House in Yorkshire.

On the Sunday, guests were invited to a Royal Garden Party to celebrate the

Duke and Duchess of Sussex's wedding with stalls, tombolas, raffles and treats with the money raised going to the MND Association and each region's own supported charity.

During the event, the MND Association had a stall within the club marquee which gave visitors the chance to learn more about the Association's work.

The club is committed to providing excellent facilities which make a stay on a club site as easy as possible for those with mobility difficulties. Access statements provide a clear and accurate description of a site's facilities and services, and are designed to help members make an informed decision when choosing a site to visit.

For more information about the Caravan and Motorhome Club please visit: [www.caravanclub.co.uk](http://www.caravanclub.co.uk)



*Staff and volunteers from the MND Association attended the event*



# New care centre opens

**T**HE 22nd care centre to be funded by the Association in partnership with the NHS has opened in Stoke-on-Trent.

The new North Midlands MND Care Network is based at the Royal Stoke University Hospital and will provide services to people living with MND across most of Staffordshire. 82 people will receive care initially, although that number is expected to increase as the network expands.

**“The opening of the care centre in Stoke will be a huge benefit to people living across Staffordshire and we are incredibly grateful to all our partners for making it possible.”**

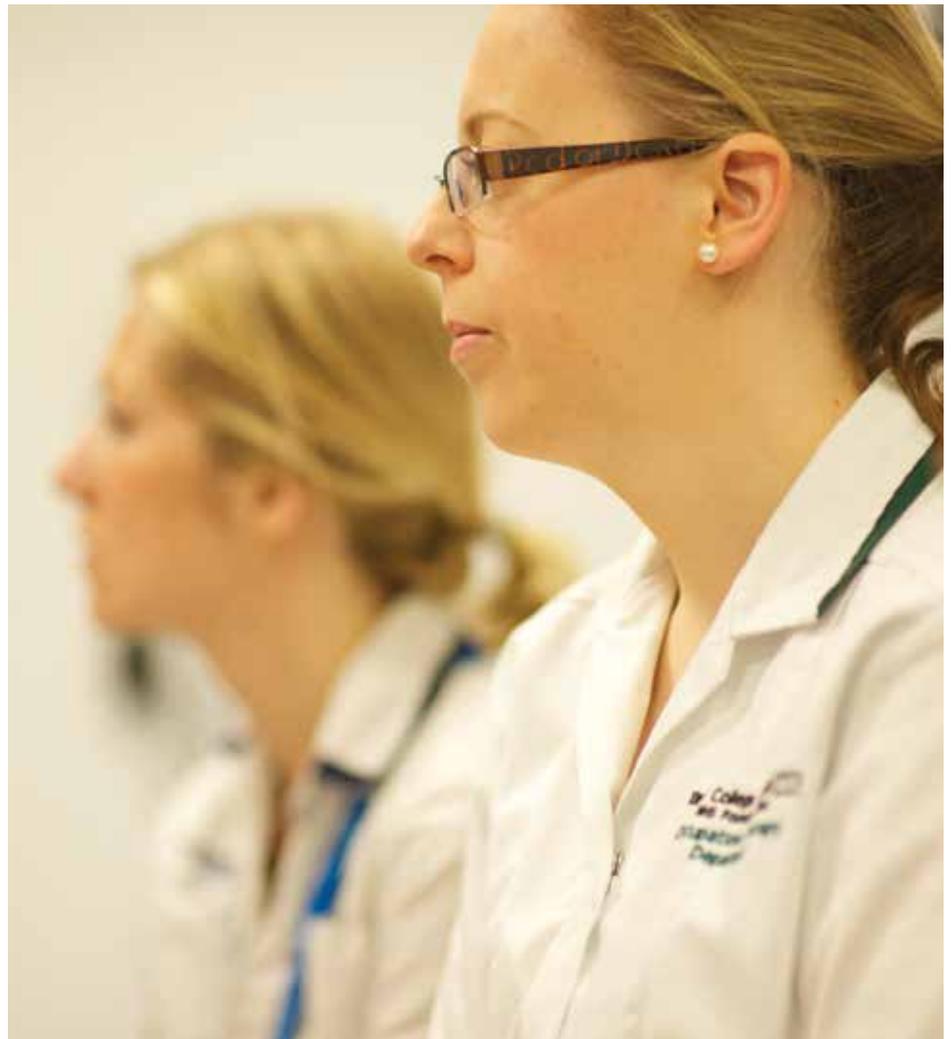
Association Chief Executive Sally Light said she was delighted to see the care centre open.

She said: “The Association is committed to making sure people living with MND have access to the care they need, when they need it and without the need for unnecessary journeys which cause additional stress at an already difficult time.

“The opening of the care centre in Stoke will be a huge benefit to people living across Staffordshire and we are incredibly grateful to all our partners for making it possible.”

A new full-time MND Care Co-ordinator, Louise Wilsdon, has been recruited with grant funding from the MND Association and will supplement the care provided by MND specialist nurses and lead the development of the network over the next four years.

Immediate plans are already underway



to open a new multi-disciplinary clinic at County Hospital in Stafford and to develop a business case to expand the current clinics in Stoke and Crewe to include other therapy disciplines. It is envisaged that all clinics will provide access to neurology, palliative medicine

and a respiratory physician.

In a further development, lead consultants in both neurology and palliative medicine in Shropshire and Telford have already been approached to extend the new network to include services for people with MND from these areas.

## New information vlog is launched



Emily Richardson and Kaye Stevens from the Association's Care Information Team

**A** NEW series of vlogs, aimed at updating people on the work of the Care Information Team, have been launched.

While much of the Association's information is available to download from a list on our website and from specific web pages, it was felt a central resource for news about our information would be useful.

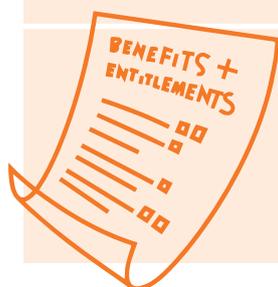
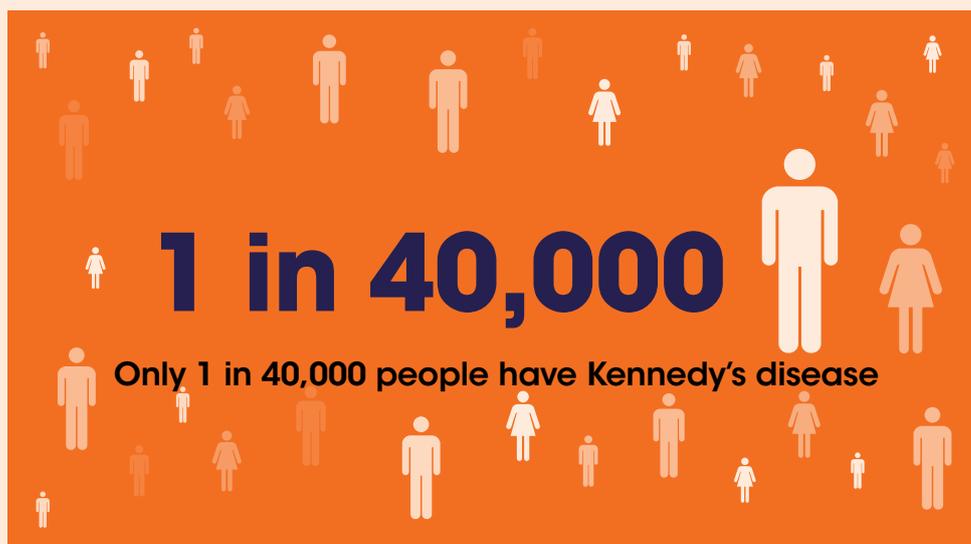
The vlog, can be viewed at [www.mndassociation.org/careinfo](http://www.mndassociation.org/careinfo), using a tablet, smartphone or computer and subtitles are available.

The first vlog in the series introduces the information team and information we supply and features Chris, who is living with MND, and Hina, a carer. In the vlog, they both discuss their experiences with MND Association information, including some of the titles they have found helpful in their journeys.

We are producing vlogs throughout the year to give regular updates on our information.

### What is Kennedy's disease?

**W**E have developed a new animation to provide an audio-visual overview of Kennedy's disease. This video is aimed at people living with, or affected by Kennedy's disease, following diagnosis. Find the animation at: [www.mndassociation.org/kennedys](http://www.mndassociation.org/kennedys)



### Revised information sheet

#### Information sheet 10A – *Benefits and entitlements*

This sheet gives an overview of the relevant benefits and entitlements you may be able to claim when living with or supporting someone with MND or Kennedy's disease. It also highlights where you can get guidance and support with benefits, such as our Benefits Advice Service.

## 'An easy way to manage PEG feeds'

In recent issues of *Thumb Print* we have asked readers to send in hints and tips which could make life easier for people living with MND.

Astrid Hartland, whose Dad is living with MND, got in touch to explain how they have managed PEG feeds.

She said: "My Dad has bulbar onset MND and very quickly became reliant on PEG feeding as he cannot eat, drink or speak.

"He is mobile and has good strength in his hands and we researched how we could make managing the syringe, the liquids and the clamp easier. We found a very inexpensive flexible mobile phone holder that did the job perfectly. This means that Dad can administer his food and medication intake himself and is still a real help even if two people are doing it.

"I was so surprised that a stand wasn't supplied with the PEG equipment and this has been invaluable for us, so hope it might be for others."

**If you have a hint or tip you would like to share – or if you have tried one detailed in a previous edition – please email [clare.brennan@mndassociation.org](mailto:clare.brennan@mndassociation.org)**



# Shining a light on MN

CONIC buildings across England were lit up in the colours of the MND Association to mark Global MND Awareness Day on 21 June.

As darkness fell in towns such as Berwick and Norwich, buildings and bridges were swathed in orange and blue light, a poignant reminder of those who are living with MND and of the Association's work.

Thanks to the hard work of many of our volunteers, a number of buildings were lit up to raise awareness including The Royal Border Bridge in Berwick, Cliffords Tower in York, the Steve Prescott Bridge in St Helens and Norwich City Hall.

The Blackpool Tower was also illuminated to celebrate the launch of the new Fylde and Wyre Support Group which aims to help people living with MND and their families.

**"We hope all parties in Westminster will support a change to make access to benefits simpler and faster for people with MND across the rest of the UK."**

The day also saw the launch of the Association's new campaign *Scrap 6 months* which calls for all people living with MND to be able to access benefits via the Special Rules for Terminal Illness (SRTI). This enables claimants to be fast-tracked to the highest rates of support.

A report commissioned by the Association to mark Global MND Awareness Day looked closely at the implications the new Universal Credit has on people living with MND.

It showed that the claims process can be difficult and concluded that some people living with MND may also be financially worse off.

The Association's director of external affairs, Chris James said: "The standard process for applying for Universal Credit is completely unacceptable for those living with a terminal illness such as MND.

"It is extremely promising to see that the Scottish Government recently voted to change the definition of a terminal illness for claiming benefits. We hope all parties in Westminster will support a change to make access to benefits simpler and faster for



people with MND across the rest of the UK."

A new video, detailing the Association's impact in 2017 has also been launched.

The video reflects the often complex needs of people living with MND and focuses on the four key areas of the Association's work. It details the difference the Association has been able to make in these areas over the past year and explains how we all need to work together to achieve our vision of a world free from MND.

The video, which can be seen at [www.mndassociation.org](http://www.mndassociation.org), also featured as part of a dedicated blog published by the International ALS Alliance. Visit [www.alsmndalliance.org](http://www.alsmndalliance.org) for more details.

**What did you do to mark Global MND Awareness Day? Contact the editor at [clare.brennan@mndassociation.org](mailto:clare.brennan@mndassociation.org)**

**For more news from our branches and groups turn to pages 34 and 35.**



# D awareness



## Start shopping for your festive treats

It may be the middle of summer, but there has never been a better time to start planning your Christmas shopping!

You will find a copy of the Association's Christmas catalogue in this edition of *Thumb Print* including a wide range of cards, wrapping paper and gifts for the whole family.

Shopping for your special festive treats couldn't be easier, simply browse now and then order, either using the catalogue form or from our online shop from 1 August.

Every order you make will also help support our work on behalf of people living with MND as every penny of profit, together with additional donations will go straight into Association funds.

A gift of £10 can help to provide an information pack for someone who is newly-diagnosed, while £25 will run the MND Connect helpline for an hour.

Our online shop is available at [shop.mndassociation.org](http://shop.mndassociation.org)

## Roch Maher



Roch and Deirdre Maher

**T**RIBUTES have been paid to Roch Maher who spent many years campaigning to raise awareness of, and improve care and support, for people affected by MND.

Diagnosed in 2009, Roch retired early from Hammersmith and Fulham council after a career dedicated to helping vulnerable people access housing services.

Chris James, the Association's Director of External Affairs said: "I met Roch fairly soon after joining the Association and was immediately struck by his commitment to both raise awareness of MND but also never to be defined by the disease. Together with his wife Deirdre, they played a huge part in our campaigning at Westminster, speaking there several times and also sharing their experience with our All Party Parliamentary Group. They were always open and candid about the challenges of MND, taking part in NHS Choices filming about planning care and also passionately supported the Dignity in Dying charity. Roch also played a key role in establishing our NICE

guideline on MND as part of the original Guideline Development Group.

"He will be missed by all those who met him at the Association and learned from his approach; which was always tenacious but fair and with good humour – a pre-requisite for a long-term Brentford FC fan!"

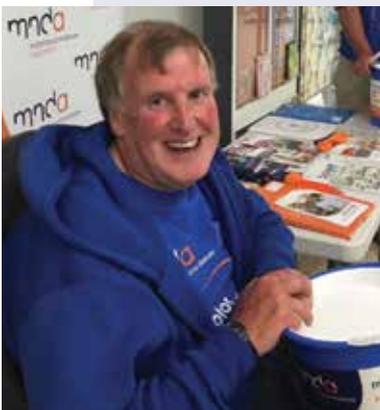
The Association's Care Information Manager, Kaye Stephens, said: "As a member of the User Review Group for our information resources at the Association, Roch gently challenged, informed and applauded our work as appropriate. His sense of balance, even where he held a strong view, was outstanding, and this measured intelligence shone through. He was a remarkable man and it was a privilege to work with him."

Roch, his family and friends took part in filming for a Channel 4 series looking at rites of passage around the world from birth to death. It is presented by the artist Grayson Perry who met the family on several occasions and is scheduled for transmission this autumn.

Dublin-born Roch died at Princess Alice Hospice in April aged 56, surrounded by his family. He is survived by Deirdre, Tom and Kate.

Deirdre has written a powerful and poignant blog about her experience of caring for someone living with MND. Called *The Diary of an MND Wife* you can find the blog at <http://deirdre-amonkeyonhisback.blogspot.com>

## Arthur Newell



Arthur Newell

**A**RTHUR Newell, a member of the Northern Ireland Branch and the group's website co-ordinator died suddenly on 19 December 2017.

Arthur was well known to many in the MND community due to his enthusiasm for life and his never-ending quest for better conditions for those with MND.

He was a vital part of the Northern Ireland Branch, looking after all IT issues, designing and sourcing publicity materials, managing

the Just Giving sites and anything else that crossed his path.

Branch chairman Stephen Thompson said: "He was almost always cheery and positive, the few times he wasn't it was usually because someone had not delivered the service he expected for people with MND and he would work away until he got what he wanted.

"His great love was travelling to America. He visited at least twice a year often on his own with his wheelchair – Florida, Washington, Boston and Texas were high on the list.

"Arthur will never be replaced, but the Branch will continue to work hard for those with MND and hopefully bring to fruition the plans we have for 2018, plans which Arthur was fully involved with. The Northern Ireland Branch extends its deepest sympathy to his son, David, and Arthur's family and friends."



Ingrid Turner Photography

Madeleine Parkinson is presented with an award at the event

## Saying thank you to volunteers and fundraisers

**T**HE work and achievements of volunteers and fundraisers from Greater Manchester and Lancashire has been celebrated at a special awards ceremony.

The Association's chief executive Sally Light and two care centre co-ordinators, Sam Holden Smith and Pauline Callagher, spoke about the impact those present had on the Association's work and the difference they make to those living with MND.

Kathryn Sheldon, regional fundraiser for Northern England said the event had been a huge success and that guests had commented on how inspiring it had been.



Fundraisers take part in the quiz night

## Quiz night raises £575

**M**ORE than £500 was raised at a charity quiz night to raise money for the Association in May.

Bishop Norton Village Hall in Lincolnshire was the venue for the event which was hosted by Brian Shears and Imelda McDonnell to raise awareness and funds.

A total of 68 people divided into 13 teams to pit their wits against each other. A raffle was also held in the interval to boost funds.

Brian and Imelda would like to thank everyone who made the event such a success, either by taking part or making donations.

## Joe and Stephen take on Island challenge



**I**NSPIRED by Susan Dickerson who is living with PLS, a form of MND, Joe Turner and Stephen Barnes took part in the Isle of Sheppey Island 10k in May to raise money for the MND Association.

Susan Dickerson was diagnosed with PLS in 2003 and both Joe, who is Susan's nephew and Stephen, who is her niece's boyfriend, decided to raise money for the Association as the cause is close to their hearts.

Joe's mum Sandra, who is also Susan's sister, also came up with the idea of collecting donations on the day. The North West Kent branch loaned buckets and collection boxes which raised an additional £93.91.

The whole family, pictured above, turned out to cheer on Joe and Stephen as they made their way around the course, including Stephen's girlfriend Jessie, Susan's husband John and the rest of Stephen's family.

## Hospice receives stunning gift from royal couple

**F**LOWERS from the Duke and Duchess of Sussex's wedding were donated to St Joseph's Hospice in Hackney which supports many people living with MND.

The hospice was the venue for the filming of the Association's training video *Understanding MND* and staff there said they were 'delighted' to receive the stunning flowers.

Chief executive Nigel Harding said: "We are so excited and honoured to receive this wonderful gift, it really feels like we're part of the royal wedding. The flowers are simply stunning and our patients were both surprised and delighted to receive them."

# Special event remembers loved ones lost to MND



Those who lost loved ones to MND attended a reunion event organised by the East Surrey Branch

**A** REUNION of people who have lost loved ones to MND was held by the East Surrey Branch in April.

The Denbies Wine Estate in Dorking was the venue for the event hosted by branch chairman, Simon Edmands.

At the end of the evening, which included wine and canapés, Simon thanked the branch's Patient Care Co-ordinators, Beryl Daniel and Mary Williams, for organising the event, adding that this was now the 11th such reunion for former carers that the branch had organised.

Everyone present also enjoyed a quiz, and a raffle raised over £250 for the branch.

On 15 April around 30 members of

the branch attended its AGM at St Mark's Church Hall, Great Tattenham.

Almost £50,000 had been raised by the branch throughout the year. Simon presented a long service award to David Willmott, in recognition of his support over the past five years and a special presentation was also made to Ted Ballam, who was stepping down from the committee after almost 20 years of invaluable service.

After the AGM, everyone enjoyed an afternoon of barbershop singing from The Downsmen North Surrey Barbershop Harmony Club, together with a sandwich tea. A raffle raised more than £150.



Ted Ballam and David Willmott who were recognised at the branch's AGM in April



Len and Fran Gurd

## Remembering Len

**L**EON 'Len' Gurd was passionate about caring for people affected by MND, having lost his first wife, Shirley to the disease. He received valuable support from the Milton Keynes Branch drop-in meetings and, as a hugely energetic, inspirational director of both a fishing and a video company, he was driven to channel his talents into making a huge difference.

While attending a branch meeting, Len met Fran, who had also lost her husband Alan to MND, and a few years later, the couple were married.

Together, Len and Fran were motivated to use his contacts and expertise in the carp fishing world to host the most successful fishing event the MND

Association has ever known, Fish With The Stars! Over five years they worked tirelessly to raise an incredible £150,000 for MND care and research.

His final contribution, despite being in the latter stages of a terminal disease, was to write a book, which was illustrated by his grandson, Luke, called *Me: The Fluff Monster*, with donations at the Christmas drop-in going to the Milton Keynes Branch.

Sadly, Len passed away in March and will be sadly missed by so many of his family, friends and colleagues. He will always be remembered for his wonderful cartoons and his constant cheeky smile.

*Me: The Fluff Monster* is available to buy from Amazon.

## Branch says a big thank you



### A year of fundraising pays off

**T**HE hard work paid off for members of the Birmingham and Solihull Group when they received a cheque for £12,263 from the Knowle and Dorridge Lions Club.

The group had applied to the Lions to be one of their nominated charities during 2017 and attended meetings to explain more about the MND Association's work.

They also helped to support a number of the Lions' major fundraising events including a Christmas Pudding Walk, an Easter Raffle and the Knowle Fun Run.

Representatives from the Birmingham and Solihull group are pictured collecting the cheque from the Lions Club.



**A**N event to thank all those who had supported the South Hertfordshire Branch over the past year has been held in St Albans.

More than 40 people attended including health and social care professionals and all of the companies, golf clubs, rotary clubs and supporters who had made donations.

The city's mayor, Councillor Mohammed Iqbal Zia gave a speech and The Rickmansworth Players sang songs from the musicals.

Cheques for £3,200 were also donated on the day from two recent fundraising events.

### Gifts in Wills

A gift in your Will could give  
**hope**  
 of a world free  
 from MND

Please help us create a world free from MND for future generations with a gift in your Will

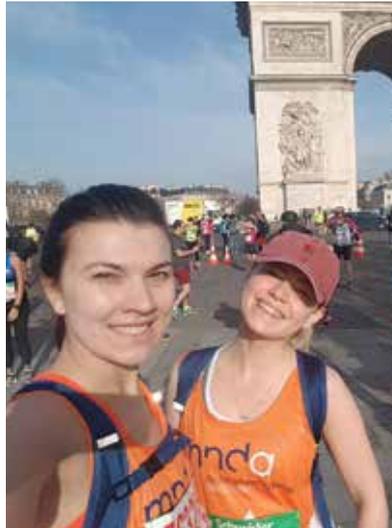
To request an information pack please contact Emma Fellows, Legacy Manager  
 on 01604 611898 or email [emma.fellows@mndassociation.org](mailto:emma.fellows@mndassociation.org)

[www.mndassociation.org/wills](http://www.mndassociation.org/wills)

Share your pictures at [www.facebook.com/mndassociation](http://www.facebook.com/mndassociation)



**'For mum':** Rebecca, her family and friends, were inspired to take part in the Great Welsh Half Marathon in memory of her mum, Alison who sadly died from MND. The event was held on what would have been Alison's 55th birthday. Rebecca said: "She was always such a selfless and giving person so we knew that's how she would wish for us to spend her birthday, raising money in her name to help others still going through their own journey with MND." The team raised £6,544



**French connection:** When Imogen Comrie's mother, Rosemary, was diagnosed with MND in March 2017, just as she was about to retire from her long teaching career, Imogen decided to take on the Paris Marathon along with her friend Liz Carter. After the event, Imogen said: "We did it. Feeling sore but happy! We've had a lovely few days in Paris to recover." Along with matched giving from Imogen's employer, they raised a 'fantastique' £25,000.

**Slime time:** Eleven-year-old Arianna has been busy selling slime as part of a fundraising challenge at Pennthorpe School in Horsham. She sold the homemade slime at school, her local hockey club and to friends and family and raised over £800. She even sold one pot for £100! Arianna's dad sadly died from MND and he and the whole family were proud of her fundraising efforts.



**A marathon effort:** Personal trainer Ben Moorhouse wanted to set himself a gruelling challenge to raise money in honour of his dad, Dale, who is living with MND. He decided to take on the task of rowing the distance of a marathon; 26.2 miles. He raised an amazing £650 and completed the challenge in just three hours and eight minutes.



**Toddy's titans:** When Cheryl Todd was diagnosed with MND in August 2017, her response was to reach out to family and friends and form Team Todd. Since then, the group has organised a darts marathon, a big night out and taken on Yorkshire's three peaks. Team Todd is continually inspired by Cheryl whose attitude is, 'MND will have to live with me rather than me live with it!' They have raised more than £22,000. Pictured are the Siddal Under 14s Rugby Team during the Three Peaks Challenge.



**Over the moon!**

A conversation between Jay Lucas and his children about the solar system provided the inspiration for his latest fundraiser. The MND Move the World challenge. The challenge saw 43 fundraisers virtually circumnavigate the globe, by running, swimming, rowing, cycling, jogging and walking 24,881 miles over the course of a year. The challenge ended on 7 May and so far the team has raised more than £3,000.



**Gaming for good!**

**Rob Barrie**, from Cheshire, was diagnosed with MND last year aged just 24. He is a keen gamer and wanted to use his skills to raise money for the MND Association so set himself a challenge to play for more than 24 hours using his specially adapted controller, and livestream his efforts. He said: "I can't jump out of a plane, or run a marathon, so I'm doing a marathon in a different way." He raised over £500 and received lots of encouragement when his story was shared on Facebook.

**Rising to the challenge:**

Physiotherapist and pilates instructor **Priya Rajavrothayam** was inspired to sign up for the Reading Half Marathon by one of her patients who is living with MND. They had both shared a love of running and he recommended the race for her first half marathon. However, when Priya had to pull out of the race due to injury, she didn't let it stop her fundraising efforts. Instead, she turned to her other skills, and organised a charity pilates class which raised £164.



**A family affair:** **Paul Green**, who sadly lost his wife Joy to MND last year, was surrounded by his family when they all took part in a 79-mile trek along the Yorkshire Wolds Way. While some were able to do the whole walk, others joined in on various stages and the last leg was planned to coincide with what would have been, Joy's birthday. Together, they raised more than £700.



**Remembering Rifat:** **Haaris**, who is eleven, decided to take on the Mercy4Mankind Charity Challenge in memory of his grandmother, Rifat Bashir who died from MND in November last year. Haaris smashed his target of £750 and ended up raising a fantastic £1,330.

If you have something you would like to share with other members of our MND family, we would love to hear from you. Letters, which must include your full address, can be sent to **Your letters, Thumb Print, PO Box 246, Northampton, NN1 2PR** or via email to **editor@mndassociation.org**. Please note that letters may be edited. If your letter is printed we will send you an MND Association coin keyring.

# 'Genius, a massive inspiration – slightly annoying to the average MND patient'

In the days following Stephen Hawking's death, Andrew Knowlman, who is living with MND, wrote this account of his own journey and explained what Prof Hawking meant to him.

**W**IN our family, we called him 'Our Stevie'. Well, you need some laughs when you get a motor neurone disease diagnosis. "You might live as long as Stephen Hawking,' well-meaning people have said to me. Genius, massive inspiration, innovator in non-verbal communication, yes. Slightly annoying to the average MND patient, yes. One third die within twelve months from diagnosis, the average is two to three years. Then, there are the statistical

outliers. In the three years since diagnosis, I've lost the use of my legs, arms, hands, voice, tongue and swallow. I am a 50-year-old father of two children, aged 11 and 15. "I am generally positive, I write children's books and a blog with my eyegaze computer. I do what I can with my kids. I try to support my wife, now a single parent. I campaign where I see injustice. I have my daily routine in the care home where I live. Four feeds through the stomach tube, twice daily ventilation, hoisting, personal care, outside time.



Andrew Knowlman

**"Daily life has to go on, all with the knowledge that I will die at some time in the not too distant future."**

"MND teaches you a lot about people. Some step up, others disappear. One couple has changed their life to help us, one friend helps with medical matters and another has built my website. Another person visits every week, has illustrated my books and takes me out; I didn't know her two years ago.

"But it's not ok. I miss being an active dad and husband. I can't have a decent conversation with my kids, I can't help my wife, I can't support my parents. The impact on the family is huge. The kids are very frustrated, because I can do so little. There is worry about financial security, 'Why can't we have a normal family? Will you get better, Daddy? Why don't we go away like

other families?' Our kids have watched the physical decline of their dad, they've seen falls, dribbling, loss of speech and, well, dad just being dad. Still they are positive and enthusiastic young people.

"The untold story in any illness is that of the partner who is well. In our case, Jane cared for me in the first 18 months, and has held the family together. Daily life has to go on, all with the knowledge that I will die at some time in the not too distant future.

"I encourage you to read *Travelling To Infinity – The True Story Behind The Theory of Everything*, written by Jane Hawking, to whom Stephen was married for 30 years. It's a story of immense personal sacrifice. She didn't get many plaudits, while her husband was being rightly praised.

"So, our Stevie, thank you for your life, rest in peace. I hope you get to know your Creator, who was not part of your earthly existence. I try and imagine how it is for Jane and the three children. God bless you."



## diarydates

• Annual Conference and AGM: 14 July 2018 • Prudential RideLondon: 29 July 2018

- Great North Run: 9 September 2018 • Regional Conference: 15 September, Dunsilly Hotel, Antrim, Northern Ireland
- The London City Swim: 21 September 2018 • Walk to d'feet MND: All year round

## 'Please take my hand'

I have begun a peculiar journey  
Which I didn't expect to take  
A very difficult one I have to say  
And one I would rather not make.

For life has thrown a terrible fate  
By casting MND on me  
But the key to getting through all this  
Is to take all the opportunities that be.

My husband is there all the time  
My protector to the end  
My family are all there for me  
No matter where they live, me they will fend.

My in laws also have a say  
To support us when we ask  
I know they do care very much  
Their concern they try to mask.

Our friends want to help as much as they can  
To ease the burden on us  
We can call on them at any time  
They will be here without a fuss.

The great people I work with past and present  
All share the same concern  
Anything they can do to help  
About my journey they want to learn.

The wonderful team at Amersham Hospital  
So very patient and very kind  
Trying all sorts of ways  
To give us peace of mind.

The volunteers from MNDA  
Were quick to offer support  
Will be nice to meet with them again  
And go through any thoughts.

I have met the priest at my local church  
Long time overdue  
A very endearing and gentle man  
It was something I had to do.

I honestly feel quite brave so far  
One day at a time I must take  
I have so much support to see me through  
All the difference it does make.

Don't be frightened, don't be scared  
I am carrying on as norm  
I am focusing on the positive  
And on the calm before the storm.

I do not know what lies ahead  
It is different for each and every one  
It may not be that bad for me  
Whilst I can, I will still have fun.

So please take my hand, I'd like you to  
We can do and share so much  
Life continues in a different form  
But we can still remain in touch.

*Patricia Billett, Via email*

## 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.

## 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](http://www.facebook.com/mndassociation)

 **Twitter** @mndassoc

## MND Connect

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

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

**mndconnect**  
**0808 802 6262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

## Membership

To receive a regular copy of Thumb Print, call 01604 611855 or email [membership@mndassociation.org](mailto:membership@mndassociation.org)

## Get involved

Telephone: 01604 250505

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

[www.mndassociation.org](http://www.mndassociation.org)

In the last edition of *Thumb Print*, we featured the story of Stephen Bluff and his experiences of hospice care. Many of you agreed with his comments and a selection of your letters are featured here. If you have anything to add, please email Clare Brennan at [clare.brennan@mndassociation.org](mailto:clare.brennan@mndassociation.org)

## 'They care for me so well'

**A**S I write this, I have just come home from the hospice at Weston Super Mare.

Like Stephen, I get so much fun and laughter from my hospice, they care for me so well.

I go twice a week, to the day centre on a Wednesday where I enjoy a sherry on arrival, a three-course lunch with wine and activities in the afternoon and on Thursdays I go to expressive movement which I enjoy, but it isn't for everyone. We make memory boxes, where you can put anything in you want including photographs. We also do gardening, make pot pourri and many other things. We have a lovely garden there.

I was diagnosed with MND in 2010, so I have done well, the secret is to stay positive. We went on a cruise in April to celebrate our 40th wedding anniversary, something I did not expect to see.

*Martyn Brummell, via email*

## 'Hospice care is excellent'

**T**HE hospice in Exeter is excellent.

When my late husband was diagnosed in 2010, we were referred to them for emotional and practical support.

A visitor came to our house each fortnight and I went to a carers' group at their office in Exmouth. In time this became a Bereavement Group. Neither could be faulted.

Eventually, Mike went to day care each week and they were tremendous. He got to talk about every aspect of MND, his end of life care – a subject which is hard to talk about with loved ones. He decided that he wanted to pass away there, rather than at home and this eventually happened. He had a 'good death' which was still very sad, of course. The support we had was, I think, the only thing which helped us to cope with what was a very dark time. I also cannot speak highly enough of our Association visitor Cynthia Hopkins. It was a great help in coming to terms with what was a bleak diagnosis.

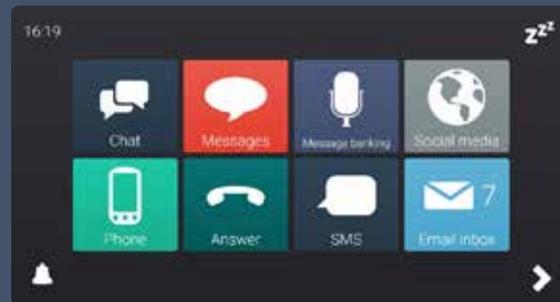
*Pat Quick, via email*

Now with  
Message  
banking



## Quickly generate messages in the moment

**Grid 3** is our complete solution for communicating, controlling your home, and connecting with the world - packed with innovative features for natural and efficient conversation.



Get in touch to arrange a free home visit with a member of our team

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- Use accessible apps to keep in touch with friends and family, or connect on social media
- Control devices around your home using radio and infrared technology
- Works with touch, switch, pointer or eye gaze access

thinkSmartbox.com

