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It is often said that to understand the future you must look to the past - something which I believe is particularly poignant in this, the Association's 40th anniversary year.

Throughout the past 12 months, our founder members have played an important part in helping us to mark this important milestone, bravely sharing stories of how their own lives were affected by MND and the series of events in the late 1970s which led to the birth of the Association we know today. We are incredibly grateful to all of them for their enduring wisdom and support.

Hearing their memories and their fascinating - and often very moving - accounts of the hardship and isolation they felt, provides a timely reminder of why the work we do remains so important to people living with, and affected by, MND to this day.

Since it was formed 40 years ago, our Association has worked hard to improve the care people living with MND receive, campaigning for their needs and developing close bonds with researchers around the world to give us the best chance of developing new treatments for this cruel and devastating disease.

It’s true to say that we have come a long way, but we know there is still much more which needs to be done and many more families who need our help.

In the weeks and months ahead, we will continue to work closely with all of you, listening to you and learning from you to better understand the complex and ever-changing needs of people living with MND and the ways in which we can continue offering our help and support.

As we near the end of our anniversary year, I want to take this opportunity to thank you all for everything you do to support us, for inspiring our work and for driving us forward.

As we look ahead to the future we will always remain true to our past, building on the strong sense of community spirit, volunteering and friendship which lie at our foundation, with people living with MND at the very heart of everything we do.

Sally Light
Chief Executive
A PETITION signed by more than 55,000 people has been handed into 10 Downing Street demanding that the Government take urgent action to change the welfare benefits system.

On 7 August, Association campaigns contact, David Setters, who is living with MND, his wife Helen, Association trustee Nik Sharma and Downton Abbey star Jim Carter visited Downing Street to hand in a petition calling on the Government to change the law to ensure that people living with MND, and other terminal illnesses, can get timely access to the benefits they are entitled to.

At present, to access the Special Rules for Terminal Illness fast-track process, there needs to be a ‘reasonable expectation of death’ within six months – something which is impossible to predict in people living with MND.

In response, on 21 June last year – Global MND Awareness Day – the Association launched its Scrap 6 Months campaign and, together with our partners at Marie Curie, has been campaigning for the law to be changed, as it has been in Scotland.

Speaking on the day of the petition hand-in, David Setters, who was diagnosed with MND in 2012, said: “Let’s be clear, we are not asking for money. While that would be nice, we are simply asking for fast-track access to the benefits people with terminal illnesses need and deserve so that affected families don’t have to waste time fighting the system and instead can
spend more precious time together, making memories.

“I am fortunate to have a relatively slowly progressing form of MND and so have time to advocate on behalf of those whose progression is much quicker. Half of people die within two years of diagnosis – with that type of nuclear bomb dropping on your family, especially if you have young children, you really shouldn’t have to waste precious time fighting the system.”

“Instead of enjoying life with their loved ones, dying people have to spend time filling in forms, attending interviews with benefits advisors, or coaching sessions aimed at getting them back to work.”

Dr Nik Sharma, Consultant Neurologist and Association trustee, was also in Downing Street. He said: “The current system forces us into making impossible predictions to satisfy an arbitrary time limit. For patients with complex conditions such as motor neurone disease, dementia, frailty and organ failure, predicting when someone is going to die is often all-but impossible.

“It is enormously frustrating knowing that, because we can’t give an exact prognosis our patients could face incredible financial and emotional distress. And this is all because of a rule that was made up by politicians nearly 30 years ago. The rules need changing and they need changing now.”

Actor and Marie Curie ambassador Jim Carter, described the current situation as ‘ludicrous’. He said: “Instead of enjoying life with their loved ones, dying people have to spend time filling in forms, attending interviews with benefits advisors, or coaching sessions aimed at getting them back to work. Every day 10 people die while waiting for the benefits they need. That can’t be right – and is why I’ve signed the petition along with tens of thousands of other people across the UK who are urging the government to end the cruel benefit system for dying people.”

In July, the then Secretary of State for Work and Pensions, Amber Rudd MP, announced a review of how the benefits system works for people who are terminally ill – news that was welcomed by the Association and its members.

Since then, following an initial meeting with the Department for Work and Pensions, the Association has written to the new Secretary of State, Thérèse Coffey to ask for the review to be conducted as quickly as possible. We are currently awaiting details on the next steps and will continue to provide updates in future issues of Thumb Print.

Help with money when it matters most

The MND Association’s benefits advice service provides advice and guidance on all matters relating to benefits.

Call 0808 801 0620 if you live in England and Wales or 0808 802 0020 if you live in Northern Ireland or you can visit www.mndassociation.org/benefits-advice

In the first six months of the year, the service helped nearly 500 people identify £1.2million of benefits for which they were eligible.

Scrap6months

The story so far

**JUNE 2018**
- Scrap 6 Months campaign is launched on 21 June - Global MND Awareness Day.
- MND Association launches report on Universal Credit.
- A letter signed by more than 30 neurologists calling on the Government to scrap the Special Rules for Terminal Illness fast-track is published in the Daily Telegraph.

**JULY 2018**
- Madeleine Moon MP delivers an emotional speech about the Scrap 6 Months campaigns to MPs in the House of Commons.
- MPs meet local campaigners and 125 of them sign letter to Secretary of State

**AUG – SEP 2018**
- More than a thousand postcards are sent to MPs urging them to support our campaign.

**OCTOBER 2018**
- More than 50 MPs attend a Parliamentary drop-in to learn more about the Association and its campaign.

**NOVEMBER 2018**
- Survey and poll shows GPs and neurologists support the campaign and its proposals.

**DECEMBER 2018**
- MND Association launches Scrap 6 Months petition.

**APRIL 2019**
- New guidance published to accompany the DS1500 form, which is used by medical practitioners to support benefit applications for terminally ill people through the Special Rules for Terminal Illness SRTI fast-track process. The Association was involved in advising on the development of the new guidance, which contains some positive changes including softer language around eligibility criteria, clarification that the form is not just for cancer patients, and an acknowledgement that a firm prognosis is not required.

**JUNE 2019**
- On the first anniversary of the campaign, Scrap 6 Months receives extensive coverage in the regional press.

**JULY 2019**
- On 11 July, Works and Pensions Secretary Amber Rudd announced that a review into how the benefits system supports people nearing the end of life and those with severe conditions.
  - All-Party Parliamentary Group on MND launches its report at a Parliamentary drop-in – 60 MPs attend.
  - The Scrap 6 Months petition which was signed by more than 55,000 people is handed into 10 Downing Street, attracting coverage in local and national media.

www.mndassociation.org
AN OVATION for the founder members of the MND Association in recognition of their ‘vision, commitment and dedication’ was one of the many highlights of the Association’s annual conference and AGM.

Two of the Association’s founders, Jenny Elston and Martin Anderson attended the event on 13 July to mark the Association’s 40th anniversary and to reflect on some of the Association’s most important developments and milestones.

Jenny, whose husband, Roger was diagnosed with MND in the 70s, said that at the time there was nothing, except an overwhelming feeling of isolation.

She said: “Nobody had heard of MND. We were totally lost, so we decided to set up a self-help group.”

Martin Anderson, who was friends with Roger and Jenny and was instrumental in helping to set up the Association, said their priorities were clear from the beginning.

“Patient care and research – exactly the same as they are today,” he explained.

In a moving tribute to the founders of the Association, Director of External Affairs, Chris James, thanked them for their ‘extraordinary vision’ – a moment which was followed by warm applause from the audience.

During the day, the Association’s Chief Executive, Sally Light reflected on the progress made during 2018, including the opening of the North Midlands MND Care Network in June and work to improve the support the Association offers to children and young people.

She also paid tribute to the ‘strong sense of community spirit and desire to help others’ which forms the foundation of the Association and thanked its members, fundraisers, volunteers and campaigners for the extraordinary work they do.

During the formal AGM, the Association welcomed three new trustees to the board – Andy Cawdell, Catherine Knights and Vicky Paeschel, while Dr Heather Smith and Jan Warren were re-elected.

Out-going trustees, Sue Edwards, Steve Perry-Hern, Dr Peter Scott-Morgan and Charlotte Layton were all thanked for their hard work and dedication by the Association’s Chair, Richard Coleman.

There were also warm tributes to Association trustee Janis Parks who died in April.

In recognition of the tremendous work she did to support people living with MND, a certificate of appreciation was presented to her husband Jim. He bravely spoke about Janis, describing her as ‘a true friend to people living with MND.’

The day ended with a presentation by keynote speaker Christopher Shaw, Professor of Neurology and Neurogenetics and Co-Director of the MND Care and Research Centre at King’s College London.

During his speech, Prof Shaw outlined some of the important developments being made in gene therapy and how they could pave the way for new treatments.

To find out more, turn to page 11.

ASSOCIATION on the move to new offices

PLANS for the Association’s move to new offices in Moulton Park, Northampton are continuing with a move date now expected for mid-January.

Designs for the new office have been finalised with a focus on accessibility, flexibility and inclusivity. At the heart of the design is the desire to enable staff to work more collaboratively and efficiently to improve the service and support provided to people affected by MND.

A new telephone system – already introduced at the current offices in Northampton town centre – and an upgrade to new technology, will make it easier for staff to hold meetings and share information with each other, volunteers and supporters. The Association’s current telephone numbers will remain in use and post will be redirected to the new office.

Our website, social media and printed information will carry the new address from January.
HERE was a very warm welcome for the Association’s new trustees at the annual conference and AGM.

Andy Cawdell, Catherine Knights and Vicky Paeschel were elected by Association members in June and formally welcomed to the Board at the AGM in July.

Andy said he was looking forward to supporting the Association in any way possible.

He said: “I was diagnosed with MND in June 2017, having started to experience the first symptoms in May 2015.

“Since then, it has been a steep learning curve, focusing on what motor neurone disease is and how it will affect me.

“Initially, I went along to the South London Branch of the Association to find out what support might be offered there. I received a very warm welcome, and after joining the committee I have been involved in helping with ICT matters and supporting various fundraising activities. I am also a Campaigns Contact. I am really looking forward to supporting the Association’s mission in any way I can.”

“Being elected as a trustee has come as a huge surprise but I am incredibly grateful for the opportunity to help drive the Association forward. I’ll be doing everything I can to raise awareness of MND and the needs of all those affected”

Catherine was the Clinical Care Co-ordinator at King’s MND Care and Research Centre for six years prior to her retirement in 2016.

Throughout her career she has been heavily involved in supporting people living with MND and their families at every stage.

She said: “I have always had the greatest admiration for the Association and the work it does to support people living with, and affected by, MND.

“Being elected as a trustee is a huge privilege and I see it as the perfect opportunity for me to give something back. It is a big responsibility, but I hope my skills and experience will make a positive contribution to the Association’s work.”

Vicky has been a supporter of the Association for many years, both as a fundraiser and volunteer.

Vicky’s mum, Annina died from MND in 2008 aged just 39 and, since then, Vicky has been determined to do everything possible to support all those affected by this devastating disease.

On 25 August, on what would have been her mum’s 50th birthday, Vicky held Big Steps of Hope, her biggest fundraiser to date, which saw 120 people walk 5k to raise money for the Association, with others taking part in the event virtually, wherever they live.

She said: “Being elected as a trustee has come as a huge surprise but I am incredibly grateful for the opportunity to help drive the Association forward. I’ll be doing everything I can to raise awareness of MND and the needs of all those affected.”

To read more about Big Steps of Hope, turn to page 25.
Improving how much we know about MND is a key priority for the Association as we look to step up our efforts in MND research with our partners around the world.

A big part of our understanding comes from the MND Register of England, Wales and Northern Ireland, a joint research project between King’s College London and the University of Oxford.

By having as many people living with MND as possible on the register, researchers hope to learn more about the disease and how it develops, identify possible trends and plan care services for people living with MND.

Preliminary data from the first 655 people who joined the register shows that weakness in the limbs is usually one of the first symptoms to appear and that the average age of diagnosis is 63. The data also shows that men are more likely to be affected.

To date, more than 1,800 people have signed up to the MND Register of England, Wales and Northern Ireland making it one of the biggest MND registers in Europe.

Veronica Lamb is living with MND and decided to join the register after reading about it in Thumb Print and on social media.

She said: “When I first heard about the MND Register I was very keen to sign up for a number of reasons. I had recently been diagnosed after a very long investigation and I wanted to be part of this initiative. I thought it was very important to know the exact number of people in the UK with MND and I wanted to help in any way possible.

“I doubt if any cause or treatment will be identified in my lifetime, but it’s imperative that this is done as soon as possible to protect future generations.

“It is very simple to do online and only takes a few minutes, but the potential benefits for our children and grandchildren are huge. If you have MND please sign up and help to make a difference.”

People living with MND can join the register either via their clinic or by registering themselves online.

We are grateful for the generous support of the Betty Messenger Charitable Foundation and a family trust that wishes to remain anonymous in funding this project.

For more information about how to get involved visit www.mndregister.ac.uk

More research news: pages 10 and 11

£5,000 to be won in our festive fundraiser

Do you fancy winning a £5,000 top prize just in time for Christmas?

You could, simply by taking part in the MND Association’s Christmas raffle.

Each ticket costs just £1 and the more that are sold, the bigger difference we can make to the lives of those living with, and affected by, MND.

Taking part couldn’t be easier – simply visit www.raffleentry.org.uk/mnda to enter online or call our ticket hotline on 0330 002 0342. The raffle closes on 16 December and the lucky winners will be drawn before Christmas on 23 December.

As well as buying tickets for yourself, you may also be able to sell some to friends, colleagues and neighbours. You can order extra books of tickets by emailing raffle@mndassociation.org.

We’d also like to thank all of our members who entered and sold tickets for our 40th Anniversary raffle - you helped raise an incredible £81,000 to help support people with MND and their families.

Congratulations to the winners who included Sylvia Coe who won the first prize of £5,000, Shena Sarjeant who won £1,000 and Joyce Roach who won £500. For the full list of winners, please visit www.mndassociation.org/raffle

Regulations mean entry is open to all UK residents excluding Northern Ireland, Jersey, Guernsey and the Isle of Man. Tickets are not for sale to or by anyone under 16 years of age.
In July, at the Association’s annual conference and AGM, I marked my first year as Chair – a quite extraordinary year which has coincided with our 40th anniversary.

During the year, I’ve had the great privilege of attending a number of events to mark this poignant milestone, meeting volunteers, fundraisers, supporters and campaigners, hearing their stories and learning more about their work.

Many of them joined the Association having been touched by MND themselves – motivated to do something – anything – to support us at a time of great personal hardship and uncertainty.

It is this extraordinary commitment to our cause which really does make a difference and I would like to thank all of you for everything you do to support us.

Following the election in June, I was delighted to formally welcome three new trustees to the Board at the AGM – each with their own personal experience of MND and a strong desire to help us move the Association forward.

Vicky Paeschel, Catherine Knights and Andy Cawdell bring with them a wealth of experience and enthusiasm and my colleagues on the Board are very much looking forward to working alongside them as we continue to make plans for 2020 and beyond.

The role of trustee is a varied one, but one which is integral to the success of the Association and work we do. We are always interested in hearing from members who might be interested in putting themselves forward for the role and an information day has been organised for anyone who wants to learn more.

You’ll find details about the event at the bottom of the page and I hope to meet you on the day.

In the meantime, do take a moment to read more about our new trustees by turning to page 7.
People with MND call the shots at video event

People living with MND have met with leading MND researchers to discuss the ways they can work more closely together.

Called MND Engage, the one-day event was held at the Francis Crick Institute in London in July and was supported by the Association’s research development and communication teams.

Researchers from several London laboratories took part, working alongside people living with MND to create short videos to raise awareness of the disease. There was also a focus on building lasting, working relationships.

Nick Cole, the Association’s Head of Research said: “MND Engage was conceived to give researchers the opportunity to do something they don’t often get the chance to do; meet and collaborate directly with people affected by MND. The event is also a unique opportunity for those living with MND to ask researchers to provide understandable answers to their questions relating to MND research. The day was a great success. It was exciting to be part of the event, to feel the buzz in the room as everyone combined their personal insights to create their videos and I am very much looking forward to the next event.”

After some initial training on how to get the best out of video, the group was split and those taking part were let loose with mobile phones, laptops, VideoScribe and Movani software. A couple of hours later 10 videos were produced. They were short, entertaining and packed with concise and easy to understand information on a variety of MND-related topics.

An ‘Oscar’ was presented by the Association’s Chief Executive, Sally Light for the best video, bringing this wonderful day to a close.

The videos produced on the day are going to be made available on our research blog, visit mndresearch.blog.

International Symposium heads to Perth

PERTH in Western Australia will be the venue for the Association’s 30th International Symposium on ALS/ MND in December.

Around 800 of the world’s leading researchers are expected to attend the three-day event to discuss the progress being made and to build relationships with colleagues who share the vision of a world free from MND.

With new therapies being developed and more people living with MND being admitted to clinical trials, it is an exciting time for MND research and once again, the Symposium will help nurture new ideas and discussions.

On 3 December, you can join a live-stream of the ALS/MND Connect Session which will feature presentations by neurologists and researchers followed by a Q&A session which you can take part in via Facebook. For more information about the session, or to follow the Symposium conversation, join us on Twitter using #alssymp #alsmndsymp or visit www.mndassociation.org/symposium-live where blog articles and video interviews with prominent researchers will appear.

To suggest a topic you wish to see on the SymposiumLIVE periodic table of MND research, or to ask any question about the Symposium, email research@mndassociation.org.
EXCITING developments being made in gene therapy were discussed at the Association’s annual conference and AGM in July.

In his keynote speech, Professor Christopher Shaw from King’s College London outlined the work currently being carried out in his laboratory which focuses on the question, ‘If we discover the defective gene, can we do something about that directly?’

He explained that proteins, which are the building blocks of the body, are created from our genetic information – our DNA – via ‘blueprints’ – RNA. If a piece of DNA is damaged, the RNA will also be damaged, and this produces a faulty protein. In MND, this causes the proteins to form ‘sticky clumps’ in the cell’s cytoplasm, which is thought to be toxic to motor neurones.

One way to address the problem is with antisense oligonucleotides (ASOs) – tiny man-made fragments of DNA that can recognise and target faulty RNA, preventing the faulty protein being made. The ASO is injected into the spinal fluid and can continue to work for between three and six months from a single injection. A multicentre trial is currently underway, including at a centre in Sheffield, which is using ASOs to target the faulty SOD1 gene.

Talking about the results to date, Prof Shaw said: “The people taking the active drug didn’t progress or progressed by only one point on the ALS Functioning Rate Scale, which is the standard measure for the progression of MND. Some people got better, that’s never happened before.”

ASOs are already licensed in the UK to treat spinal muscular atrophy (SMA) – a motor neurone disorder that affects infants, and are being trialled to treat Huntington’s disease and Alzheimer’s disease. Trials targeting the C9ORF72 gene, the most frequent genetic cause of MND, began on 16 September.

Professor Christopher Shaw is testing the use of part of the common cold virus to deliver the granulin gene in a model of frontotemporal dementia (FTD), which has close links to MND. Mutations in the granulin gene lead to low levels of the granulin protein in the brain of people with FTD. The virus will be used to try and bring the level of granulin back to normal. He is also looking at ways to ‘knock down’ the C9ORF72 gene, making it inoperative. This has worked in C9ORF72 cell models and Professor Shaw is now testing this in mice models of MND. But these therapies will only work for people who have those particular gene defects, so the team is looking at developing gene therapies that will benefit everyone with MND. One of these is investigating the Ataxin-2 pathway. We know that some people with MND have an expansion mutation (where a short sequence of DNA is repeated many more times than normal) in the Ataxin-2 gene. Experiments using mouse models have shown that when Ataxin-2 is knocked-out completely it seems to provide protection against TDP-43 accumulation – seen in the majority of people with MND.

Is this all realistic? Results from two very successful trials for therapies – one using ASOs and one using a viral delivery system – to treat SMA would suggest it is. The results from these trials showed improved neurological and muscle function and increased survival. Knowing these treatments work in other motor neurone disorders offers hope they will prove to be equally successful in the treatment of MND.
Sonja Castle-Mott’s husband, Steve, died from MND in April, aged just 57. Here, she speaks honestly about her experiences as his carer and how she is now trying to rebuild her life after MND.

“It has been just over six months now since my husband Steve lost his battle with MND. ‘It has been a strange time with many mixed emotions.

“I am filled with positive thoughts for the future, but still experience extreme sadness at the loss of such a vibrant, strong man who used to be my world. Sometimes it’s still hard to believe that it’s actually real and it has happened. Steve was only 57, he was a loving family man and grandad, and had fought for his country when he was a young man serving with the Royal Green Jackets. He did tours in Northern Ireland and Cyprus and fought in the Falklands war.

“I am very grateful for all the help and support I received, but people living with MND genuinely don’t have the time to wait. It has been an experience and a hard lesson in life.”

“I find myself talking to him sometimes and I tell him how sorry I am that this happened. I mention his name a lot in my everyday life - I find it helps to keep things normal. Six months is a very short time, however in other ways it feels like a lifetime. I think one of the hardest things for me is to realise that when any person is diagnosed with MND the outcome is already known. The only missing pieces of the puzzle are what exactly will happen and when? “My thoughts on life have always been, ‘live for today, but pay your bills in case you’re here tomorrow;’ and that hasn’t changed, but I think it has really brought home to me how precious a good quality of life is. Steve was lucky in that sense, as he was able to stay at home, where he wanted to be, in familiar surroundings and be with who he wanted to be with. I was able to ensure he was as comfortable as he could be and he felt safe and loved. This was only made possible by the services we were able to access and we were so very lucky that staff at our local GP surgery were fantastic with their support. They were also very honest that they knew nothing about MND. Steve was the first MND patient our GP had ever come across. She said she would help in every way she could, and she did.

“If I could give constructive feedback to some of the services we accessed, I would say that while everyone was very amenable and tried to be so helpful, systems and waiting lists rule. "When supporting people living with MND with equipment such as a motorised wheelchair, moving and handling equipment and a Grid Pad computer, the time factor is the most frustrating thing. By the time the equipment arrives, the person’s condition has moved on and you need something different which then needs to be ordered and the process starts again.

“I was pleased to be able to send £276.40 from the collection at Steve’s funeral service to support the Association. I am very grateful for all the help and support I received, but people living with MND genuinely don’t have the time to wait. It has been an experience and a hard lesson in life.”

Bereavement Guide wins national award – page 27
Sonja and her husband Steve who was a fan of Wolverhampton Wanderers Football Club, featured on this truck.

 leven a hard lesson in life’

Life After MND

I’m really not angry
Just so incredibly sad
Got so used to being loved by you
In that wonderful life we had

The house is now full of emptiness
the quiet - so loud and clear
I try not to let you fill my thoughts
although I feel you near

I go through the motions every day
I tell myself to smile
I feel relief, still sad inside
I know it takes a while

The sadness sometimes catches my breath
Of what was still to come
More memories for the two of us
Yes, the two of us - not one

My darling man you fought the fight
so well, so brave and true
What you endured, was too much to say
Still - your love so bright, shone through

I have your love and arms around me
Etched into my heart
That warmth will never leave me
Although we’re now apart

To find the balance of life again
takes time and space and more
the need for friends, the need for me
I don’t know quite what I’m looking for

But I’ll keep strong and I’ll still look,
and some days I will cry
But I’ll never regret one moment
with you
and I know my tears will dry.

Sonja Castle-Mott
A NEW report, highlighting the challenges people with MND face when it comes to living independently and safely in their own homes, has been published by the MND Association.

Called *Act to Adapt*, the report is the result of an extensive research project carried out in 2018, which saw the Association consult with 850 people, including those living with MND.

The report shows that many people with MND who want to adapt their homes to meet their ever-changing needs face enormous challenges to do so – from the time it takes to go through the adaptations process to the high costs involved.

At present, housing adaptations are offered by local authorities in England and Wales, and the Northern Ireland Housing Executive. Schemes like Disabled Facilities Grants (DFG) can provide vital support to people who need to adapt their home.

A person will qualify for a DFG if they can demonstrate that the work is ‘necessary and appropriate’ to meet their needs. This includes moving around and getting in and out of their property, and that the work is ‘reasonable and practicable’.

Under these circumstances, a local authority has a legal duty to offer a DFG, providing financial eligibility criteria are met.

While some services provide adaptations in a timely and supportive way, there are significant local variations in availability, effectiveness and affordability. Serious problems in policy and delivery can also make the DFG scheme difficult to access.

*Act to Adapt* sets out recommendations for local and national governments to overhaul the home adaptations process and the Association is also calling on the national governments in England, Wales and Northern Ireland to improve funding and eligibility criteria for DFGs. At a local level, the Association wants councils to make the process of applying for adaptations easier - fast-tracking support for people with a terminal illness, removing the means test for low-cost and high-impact adaptations, and maintaining a register of accessible homes.

To find out about our campaigning work and how you can get involved, join our Campaign Network at www.mndassociation.org/campaignnetwork.

If you are living with MND, or know someone with MND who needs help or advice to adapt their home, please contact MND Connect on 0808 802 6262 or email us at mndconnect@mndassociation.org

It’s time for us all to Act to Adapt
Come and meet our MND buddies!

A
d

 activity hub to help children learn about MND through stories and games has now been launched by the MND Association.

Called MND Buddies, the hub features five new colourful characters – Carly the Cat, Eric the Elephant, Max the Monkey, Ali the Alligator and Rini the Rabbit - who provide a gentle overview of MND in a way that is easy for young children to understand.

"Knowing there are other young people in a similar situation to yourself can be important to a child. Sharing funny jokes, poems or drawings on MND Buddies helps children feel reassured they are not alone."

Since they were launched in the summer, the hub and the accompanying storybook called Why are things changing?, are already proving popular with families whose lives have been affected by MND.

One family told us: "My grandson has some ‘flash cards’, that I can’t use now, to practice his own writing. You have to put a steel, sprung ring through the cards to hold them together. He’d been looking at MND Buddies to learn about my MND and when he took his pack, he showed great understanding in asking someone else, ‘Can you do this for me because Grandad has motor neurone disease and can’t do it anymore.’"

The hub has also earned praise from health and social care professionals who have worked alongside the Association to help develop content.

Dr Audrey Daisley and Dr Rachel Tams, were expert mentors. They are both consultant clinical neuropsychologists from the Oxford Centre for Enablement, part of Oxford University Hospitals NHS Foundation Trust. They said: "We feel the hub and storybook will be invaluable in providing parents and other family members with appropriate ways of beginning conversations about MND and supporting young children."

Samantha Holden-Smith, MND Care Centre Co-ordinator for Manchester was also an expert mentor. She said: "Knowing there are other young people in a similar situation to yourself can be important to a child. Sharing funny jokes, poems or drawings on MND Buddies helps children feel reassured they are not alone."

You can access the hub through our website at www.mndassociation.org/cyp. Once online, young visitors will find plenty to do – they can ask the characters questions through a contact page – with help from a trusted adult, play a range of simple games and send in stories and pictures to include in the art and writing galleries.

A beautiful picture of a pig, pictured, has already been sent in by seven-year-old Lily whose grandad is living with MND. She drew it because, 'Piggies are grandad’s favourite animal!'

If your child would like to send in a picture, poem or story to feature on MND Buddies please send a photo, Word file or PDF using the contact form in the hub galleries. Selected entries may also appear in Thumb Print. If you would like a different way to send in artwork or need guidance about all our resources for children and young people contact MND Connect on 0808 802 6262 or email mndconnect@mndassociation.org.
Kiera’s unique talents raise awareness of MND

A MAKE-UP artist from Hampshire has been using her talents to help raise awareness of MND.

Kiera O’Brien, who is 20, is currently studying for a degree in make-up and hair at Southampton Solent University and decided to create this stunning orange and blue look to show her support for the Association.

“The MND Association is so important to me and my family and I wanted to do something to raise awareness of the charity.”

Kiera’s grandfather James, was diagnosed with MND 18 years ago and she posted pictures of her Association-themed design on Instagram to encourage people to raise money on the charity’s behalf.

She said: “The MND Association is so important to me and my family and I wanted to do something to raise awareness of the charity and encourage people to donate at the same time. I thought this was a different way of raising awareness which might catch people’s eye.

“I have always been interested in make-up and hair and I have been a dancer so it has always been part of me.

I’ve already done some shoots for our student magazine as well as clothing labels such as Never Fully Dressed... and Boden.

“In the future I would really like to work in television and I am already on the ITV talent pool which is very exciting.”

If you would like learn more about Kiera’s work, visit her Instagram page at www.instagram.com/kierobmakeup or her website at kieraobmakeup.wixsite.com/portfolio

TandemWow make their way through India

MORE than 100 days after leaving Oxford, two women have made it to India as they attempt to become the fastest women to cycle around the world on a tandem.

In June, Rachael Marsden and Catherine Dixon set off from the Beeline bike shop on Cowley Road as they set off on the epic challenge called TandemWow, which will see them travel through 25 countries and five continents.

As well as attempting to make it into the record books, Rachael, an MND nurse consultant and Catherine, who is married to the MND Association’s Chief Executive, Sally Light, are hoping to raise £18,000 for the MND Association and Oxfam, causes which are close to both their hearts.

As Thumb Print went to press, Rachael and Catherine were in good spirits having made it past the southernmost point in India. They are currently heading north on their way to Kolkata before they fly to Myanmar for the next stage of their journey. They are expected to return to Oxford in the spring.

You can follow Rachael and Catherine’s journey on Twitter, Facebook and Instagram or by visiting their website www.tandemwow.com. You can donate by visiting uk.virginmoneygiving.com/tandemwow
Barney the therapy dog is everyone’s best friend

BARNEY really is a dog like no other. Not only is he a much-loved member of the family for his owners, Paul and Rachael Johnson, but he is also a very special four-legged friend for people who are living with MND.

That’s because Barney, pictured is a Pets as Therapy (PAT) dog who works with patients who are living with MND.

Barney’s owner Paul explained: “Barney was a rescue dog who came to us when he was ten weeks old. He is a whippet crossed with a Staffordshire Bull Terrier.

‘Despite their poor reputation, Staffies are ideally suited to being a PAT dog having been known as ‘nanny dogs’

by the Victorians. The laid-back nature of the whippet makes him an ideal candidate.

“One of the key skills Barney has learnt is to nudge his head into patients’ hands so they can still enjoy stroking him even once they start to lose mobility.”

“I became involved with the Association when my gran died from the disease and my mum Ruth and I are both on the committee of the Leicestershire and Rutland Branch.”

Paul said that Barney has become something of a celebrity across Leicestershire having appeared on BBC Radio Leicester and attended Crufts.

Paul also writes a regular column for the Leicestershire and Rutland Branch newsletter which includes details of all Barney’s adventures.

Barney can also be seen attending events in his bright yellow jacket, raising awareness of MND and the work of the Association at the same time.

But most importantly of all, he is helping to improve the lives of people living with MND, offering friendship and enjoyment.

Paul said: “One of the key skills Barney has learnt is to nudge his head into patients’ hands so they can still enjoy stroking him even once they start to lose mobility. He is also trained to stand at the side of wheelchairs so patients can reach him.”

Do you have a special bond with your pet? Tell us your story – Email clarebrennan@mndassociation.org
“I am sharing my experience so that people within policing have confidence in coming forward if they have a disability. It is okay not to be okay.”
‘I’m fighting MND, but I’ll keep on fighting crime’

F

OR Assistant Chief Constable Chris Johnson serving the community across the West Midlands has always been much more than just a job. It’s a way of life.

Having started as a beat bobby on the streets of Acocks Green 29 years ago, Chris has risen through the ranks, helping to fight crime, protect the community and work alongside some of the region’s most vulnerable people.

It’s a job he loves and, despite having been diagnosed with MND in November last year, it’s a job he’s determined to keep on doing, thanks to the support and goodwill of colleagues from right across the force.

He said: “I was diagnosed with MND in November having started to realise something wasn’t quite right during a holiday to Disney World with my family to celebrate being promoted to Assistant Chief Constable.

“It just didn’t feel very well. I was a bit breathless and, at first, I did wonder if I might have an embolism brought on by the long flight. I had lots of tests – x-rays and scans – and was admitted to hospital after a test showed that the levels of carbon dioxide in my blood were extremely high. I was diagnosed shortly afterwards.”

It was a devastating time for both Chris and his family, who struggled to come to terms with the diagnosis and what the future may hold.

In March, Chris bravely decided to share his story on Twitter, helping to raise awareness of the disease and the Association’s work. Since then he has appeared in countless newspaper articles and on ITV’s Good Morning Britain where he was interviewed by Association patron, Charlotte Hawkins, alongside his wife, Sharon.

Since announcing that he has been diagnosed with MND, Chris said that he had been ‘overwhelmed’ by the support and generosity of many of his colleagues who have been inspired to raise money for the Association on his behalf.

He said: “It has been really touching, very humbling and I am incredibly grateful to everyone for their support. I want to say thank you as often as I can because it really has been fabulous.”

PC Will Salt, who once worked for Chris has released an updated version of the single Midnight Girl which Chris recorded in 1988 with his band Highway, while a group of colleagues recently took on a walk along the length of Hadrian’s Wall, raising more than £15,000. In May next year, West Midlands Police Federation representative Trudy Gittins will run Liverpool’s Rock and Roll Marathon alongside a team of more than 100 colleagues and on 31 October, a big event is being planned to raise money and awareness in Birmingham.

But being able to continue working, is among the things he is most grateful for.

He said: “I am lucky to have a considerate employer. The changes that we have had to make are not costly, but they make all the difference.

“With the decline in my breathing I’m not able to give lengthy presentations like I used to, so I just ask that people are patient. I have also been given the opportunity to work flexibly from home at times. West Midlands Police have been very understanding and I am very fortunate. Thanks to them, the concerns I had about my ability and my credibility as a professional have disappeared. While I am clearly not able to beat the disease, I am determined to remain positive for my own wellbeing and for my young family. I am sharing my experience so that people within policing have confidence in coming forward if they have a disability. It is okay not to be okay.”

In July, his professionalism and dedication to the community and his hometown force were rewarded when he was presented with the Queen’s Police Medal in recognition of his remarkable service.

He said: “Receiving the Queen’s Police Medal really was the pinnacle of my career, it’s a huge honour. I am very proud to receive an award for policing as it brings together everything from the past 30 years. To be able to share that moment with my friends and family was remarkable. It’s a fantastic memory for us all.”

A fundraising force to be reckoned with!

A

CHANCE to meet some real-life 999 heroes, take part in a spooky fancy dress competition and face-painting will be just some of the many activities at a family fundraising day being held in Birmingham on 31 October.

Organised by Chris Johnson’s colleagues at West Midlands Police, the event will be held at Birmingham’s New Street Station to help raise money for the MND Association.

You’ll be able to meet officers from the force, who will be there collecting money, and there will also be some surprises! The fun starts from 10am. All activities are free but donations will be very welcome.
A GARDEN party was held in June to mark the Association’s 40th anniversary and to thank 250 invited volunteers for all they do to support people living with MND and the work we do. During the event, which was held in the beautiful surroundings of Boughton House in Northamptonshire, guests were treated to a tour of the house and gardens by the estate’s owner, The Duke
They also had the chance to meet some of the Association’s founders, learn more about MND research and listen to a speech by Jane Hawking, the former wife of the Association’s patron Professor Stephen Hawking, who died from MND last year. The event was held on Global MND Awareness Day, 21 June.

Turn the page for more about the Association’s 40th anniversary
SHARPEN those colouring pencils and grab your glitter for the launch of the MND Association’s annual Christmas card competition!

With a little over eight weeks to go until Christmas 2019, our search for a Christmas card for 2020 has begun and we are calling on all young artists up to the age of 16 to get involved.

Among the artists taking part in the exhibition were photographer Simon Adams and one of the world’s leading eyegaze artist, Sarah Ezekiel. There was also work from photographer, Miles Pilling, Lucy Pittaway, whose father, Middlesbrough Football Club legend Willie Madran, died from MND and Dr Peter Scott-Morgan who uses technology to push boundaries.

Other artists taking part, included the late David Shaw, who died from MND in 2014, Ron Wheeler, whose style includes fantasy and seascapes, former Daily Mail cartoonist Stanley McMurtry MBE, who lost his wife to MND and Wayne O’Leary who died from MND in May.

The Guardian newspaper previewed Art Beyond Limits in the days leading up to the event, describing all those taking part as ‘heroes’.

You can read more about Art Beyond Limits in the winter edition of Thumb Print.

Could you design our next Christmas card?

SHARPEN those colouring pencils and grab your glitter for the launch of the MND Association’s annual Christmas card competition!

With a little over eight weeks to go until Christmas 2019, our search for a Christmas card for 2020 has begun and we are calling on all young artists up to the age of 16 to get involved.

It’s time to really let your creativity run wild – the brighter and bolder your design the better!

You might like to feature some of our MND Buddies characters or perhaps you could draw a festive picture of your pet. You might want to use the MND Association’s colours – orange and blue – or you could choose traditional red and green instead. The possibilities are endless.

Taking part is easy too. The competition opens on 4 November. You can find details about submitting your design, our terms and conditions, and the rules of the competition on our website at www.mndassociation.org/christmascard

The entries will be judged in two categories: nine and under and 10-16 and the winner in each category will see their design made into a card for Christmas 2020. The closing date is 15 December at midnight.

In the meantime, if you’re looking to buy cards for this Christmas, why not choose the designs created by last year’s winners Mya and Ella-Jane? You can buy them now from our online shop: www.mndassociation.org/shop

Street party marks Association’s 40 years

A n indoor street party was held in Surrey in July to mark the Association’s 40th anniversary.

More than 30 members and supporters of the East Surrey branch of the Association attended the event in Great Tattenham to mark the occasion.

During the party, branch chairman Simon Edmands, presented long service awards to five members – Beryl Daniel, Christine Cottrell, Margaret Metcalfe, John Edwards and Roger Wakeford - who between them have given almost 100 years of service to the branch and the Association.

For more stories from the Association’s branches and groups turn to pages 34 and 35.
TEAM spirit was at an all-time high at the Great North Run in September with three inspiring women living with MND completing the course in their wheelchairs.

Rachel Cropper, Cath Muir and Dawn Johnson were supported by teams of family, friends and MND Association staff who pushed them round the 13.1 mile course before crossing the iconic finish line in South Shields.

52-year-old Rachel, who was diagnosed with MND in 2004 just after giving birth to her second child, also completed the race 10 years ago.

She said: “I consider myself truly lucky and fortunate to be still here watching my lovely family grow up, surrounded by amazing family and fantastic friends – very lucky indeed.”

Cath was pushed around the course last year by her two sons and was this year supported by friends and MND Association staff members.

Grandmother Dawn, who took on the race for the first time, said: “I want people to understand what living with a terminal illness is like; MND slowly takes parts of you away, destroying your identity, but worse still is watching the people you love the most trying to deal with such a cruel illness. I am determined to fight each day at a time. It is so important to remain mentally strong and positive and this can only be achieved with a strong will and a loving and supportive family and friends.”

Another of the Association’s runners, 28-year-old Adam Stephenson, took a novel approach to fundraising by using an MND Association collection bucket as his ‘something blue’ on his wedding day.

Adam and his wife Jessica got married one week before the race and guests donated in memory of his grandad on their special day.

Adam said: “I’ve always loved running and being able to do it for a charity so close to my heart is very rewarding. My Grandad would have loved it. The majority of guests at the wedding knew my Grandad so we thought it would be a nice way to celebrate his memory on our big day.”

Andrew New was one of a team of 20 who ran in memory of his dad Ken.

Andrew said: “My dad Ken was a keen runner, and the Great North Run was by far his favourite event of the year. On 1 September it would have been Ken’s 70th birthday – so to honour his memory, 20 of us completed this iconic event – one for every year he managed, plus one extra, for the race he never got to compete in Twenty For Ken.”

The Association’s 242-strong team have set us on track to raise an amazing £135,000. Could you follow in their footsteps next year?

We have a limited number of places available for the Great North Run 2020 now. Sign up at www.mndassociation.org/gnr.

The MND Register of England, Wales and Northern Ireland will be the first comprehensive source of information collected by experts about people living with MND and you can play a vital role in its development.

Pioneered by MND specialists Professor Ammar Al-Chalabi of King’s College London and Professor Kevin Talbot of University of Oxford, the MND Register aims to:

- Collect information about people with MND, to understand more about why certain people are vulnerable to the disease
- Find out precisely how many people currently have the disease and how this is changing over time
- Establish where people with MND live, to help improve care in those areas
- Collect detailed information about the disease to detect patterns of change in incidence and outcomes.

How to join the MND Register
You can apply online at www.mndregister.ac.uk or ask about joining when attending your next clinic appointment. If you have any questions please visit the website www.mndregister.ac.uk alternatively you can email mndregister@kcl.ac.uk or call Oxford 01865 227 714 or KCL 0207 848 5258.
Sale of family heirloom raises money for research

A FAMILY whose life has been touched by MND has agreed to sell a family heirloom to help raise money for MND research.

In January 2012, David Tordoff, who had travelled the world as a sound engineer for the rock band Radiohead was diagnosed with MND.

David died in 2014 leaving his wife, Penny and two daughters, but his parents Brian and Valerie continued to support the Association in many different ways, both as fundraisers and supporters of the Chiltern Branch.

But it was growing interest in an unusual family painting which led to the couple, together with Valerie’s brother, Michael, agreeing to make a very special donation to the Association in David’s memory.

Brian explained: “Valerie and Michael’s mother was Yorkshire-born author Malachi Whitaker who wrote books of short stories in the 1930s. They were so popular that she was described by several literary critics as the ‘Bradford Chekhov’.

“Her portrait was painted by a Leeds-based artist Jacob Kramer, who’d originally fled to Britain from the Ukraine as a child, and it hung in Michael’s house after she died. All of this might have been forgotten were it not for a moment to remember some of those who have died from MND. People who have lost loved ones are being invited to send in photographs to include in a special montage.”

Neil explained: “My father’s journey with MND was incredibly traumatic. It was devastating for the whole family. Having gone through that experience we decided that we wanted to give something back, to support the Association and to raise money for MND Research to help find a cure.”

For the latest news on MND Research turn to pages 10 and 11.
More than 1,170,000 steps were taken to d’feet MND at a special event held in Sheffield in August.

*Big Steps of Hope* – a 5k walk to raise money for the MND Association - was organised by Association trustee, Vicky Paeschel in memory of her mum Annina, who died from MND at the age of 39. The event was held on August 25 on what would have been her 50th birthday.

“We calculated that more than 1,170,000 steps have been taken which is such a huge number. The response has been really positive, so we are now looking at making it an annual event.”

Vicky said: “We had a wonderful day, it was a really special and memorable event. The glorious Yorkshire sunshine was also shining on us which made it even better! We had 120 supporters taking part on the day - there were blue and orange shirts everywhere.

“It was a very emotional day for me personally, but a wonderful way to remember Mum. It was so inspiring to see so many people coming together to fight MND, in memory of loved ones and alongside those who are living with MND.”

Anyone who couldn’t make the Sheffield walk in person is being encouraged to take part in the 5k walk virtually. So far, people have been joining in from across England, Wales and Northern Ireland and as far afield as The Netherlands.

Vicky said: "We calculated that more than 1,170,000 steps have been taken which is such a huge number. The response has been really positive, so we are now looking at making it an annual event. We have also raised around £3,500 for the Association which is wonderful."

You can add your own steps by taking part in *Big Steps of Hope* virtually. For more information about how to join in, or to register, visit www.bigstepsofhope.co.uk

If you’ve been inspired by Vicky’s story and would like to Walk to d’feet MND, visit mndassociation.org/walk. You can register to organise your own walk in a location that suits you and we’ll also send you a fundraising pack with everything you need to get started. If you’d like to join an organised walk, our online walk finder will also help you find details of Walk to d’feet MND events taking place in your local area.

Introducing our new trustees: turn to page 7
Making sure people living with MND have the support they need to make important decisions about ventilation is the aim of the Association’s newly-revised information sheets.

After listening to feedback from people living with MND, the Association has redeveloped its information sheet 8B: Ventilation for motor neurone disease to focus on both non-invasive ventilation (NIV) and tracheostomy ventilation (trache ventilation), including the possible benefits, things to consider and the aftercare that may be needed with each type.

In the past, our ventilation information has focused mainly on NIV, in line with clinical guidelines and evidence from the UK. However, when making informed decisions, people need to be aware of all available options. We were also responding to feedback from people living with MND who were using, or wanting to use; trache ventilation and felt our information could be better balanced.

Nick Goldup, the Association’s Director of Care Improvement said: “I am delighted we have worked closely with people affected by MND and health care professionals to update our information on assisted ventilation, which is a subject full of complexity and consideration. The Association can play a role providing information to people with MND and their families, supporting them in understanding their respiratory options to, in turn, allow informed decisions with their clinical teams.”

Assisted ventilation can help support breathing if MND has caused the breathing muscles to weaken. There are two types, NIV and trache ventilation.

NIV is where a machine supports your breathing by blowing air through a mask, which usually covers your nose, or your nose and mouth. It is commonly used to support breathing with MND and is recommended in the NICE guideline on the assessment and management of MND.

Trache ventilation is where a machine supports your breathing by blowing air through a tube inserted into your windpipe. This is done by making an opening in the neck during a surgical procedure called a tracheostomy. As surgery is needed for this type of ventilation, you may hear some people call this invasive ventilation.

After reading the information, we recommend discussing it with your respiratory team. Our information is designed to be a bridge between families affected by MND and the health and social care professionals who support them.

The respiratory team can assess symptoms, explain the benefits and risks of both types of ventilation and discuss local practice, including ongoing care support.

Following their launch in May, sheets 8A and 8B on breathing and ventilation have been endorsed by the Association of Chartered Physiotherapists in Respiratory Care (ACPRC).

To download, select Information sheets at: www.mndassociation.org/careinfo or order in hard copy from MND Connect: Telephone: 0808 802 6262, Email: mndconnect@mndassociation.org
Care information updates

Living with motor neurone disease (MND) Our main guide about MND has been fully updated, providing a detailed overview on how to manage daily life with the disease.

Information sheet 1A – About the NICE guideline on motor neurone disease: this sheet has been revised and explains how the guideline can help you get appropriate treatment and care with MND.

Information sheet 10A – Benefits and entitlements: this sheet has been revised and can help you think about financial support if you are living with MND or a carer.

Information sheet 11E – Environmental controls: this new sheet explores how to use remote technology around the home to prolong independence.

MND Buddies: Our new activity hub for young children has launched! Find the hub at: www.mndbuddies.org to help children learn about MND through stories, activities and games.

Why are things changing? Three family stories on the MND Buddies hub are also available in this colourful printed storybook, to help children adjust to the changes MND will bring.

Care information vlog: our latest vlog looks at how we support carers through our information resources. See the video on our website at www.mndassociation.org/careinfo

Bereavement guide wins at national award ceremony

The Association’s new guide Finding your way with bereavement won first prize in the Ethics category at the British Medical Association’s (BMA) Patient Information Awards in September.

The booklet, which has been put together with the generous support of people whose lives have been affected by MND, supports people who have been recently bereaved. It was highlighted in the BMA Awards review as a, ‘phenomenal achievement and will undoubtedly positively impact on the illness journey of those alongside patients with MND.’

The Association’s guide for care workers, Caring for a person with motor neurone disease was also highly commended with reviewers describing it as, ‘a very proactive and useful resource for workers in this field.’

The Association’s Education and Information Team, would like to thank all those with or affected by MND, and our expert panel, for their help and support.

You can find out more about our publications for people living with, and affected by, MND or Kennedy’s disease, at: www.mndassociation.org/careinfo and our publications for health and social care professionals at: www.mndassociation.org/pro/publications

See our resources at:
www.mndassociation.org/publications or order printed copies from our MND Connect helpline: 0808 802 6262, mndconnect@mndassociation.org

Would you like to help with our information?

We’re looking for people with MND or Kennedy’s disease, and their carers, to help with our information. We have opportunities to get involved with content on a range of resources and different formats, including animations.

You can pick and choose which tasks you want to work on and make a difference from the comfort of your own home. To find out how to join our User Review Group, contact: volunteering@mndassociation.org

www.mndassociation.org 27
Providing the right care

In June 2018, the MND Association opened its 22nd care centre network based at The Royal Stoke Hospital, Stoke-on-Trent. One year on, Thumb Print went along to find out more about what goes on behind the scenes and how the people that work there are making a difference to people living with MND.

Way back in 1993 the MND Association launched its very first care centre at King’s College Hospital in London.

The idea was simple, but in many ways revolutionary - ensure that people living with MND can access timely and co-ordinated support from a team of MND specialists on the same day, under one roof.

It was an important step forward for people living with MND, reducing the need for repeat hospital visits and providing support much closer to home. This type of care has also now been shown to improve quality of life and life expectancy.

Over the years, the Association’s care centre network has continued to grow, thanks in no small part to the generosity of our supporters and our partnership with the NHS. By the end of 2018, the Association had 22 care centres and care networks across England, Wales and Northern Ireland helping to provide care to more than 3,800 people living with MND.

In June 2018, the Association’s most recent care network opened to patients before being officially opened by the Association Royal Patron, HRH The Princess Royal, a year later.

The network is now co-ordinated by Louise Wilsdon, who is responsible for ensuring the network runs smoothly and for developing the service it provides. Her post is supported through funding from the MND Association.

“It has been a very busy, but very exciting year,” she explained.

“There is a monthly clinic at County Hospital in Stafford and we now have people coming along to the new clinic at Royal Stoke Hospital as well. People can have their breathing tests done and see consultants and nurse specialists from neurology, respiratory and palliative medicine all on the same afternoon, depending on what they need. They may also speak to our research practitioner, and our local Regional Care Development Adviser (RCDA) Jackie Dornford-May is also available if people want to chat with her.

“It’s really important for us to make sure that people attending the clinics are seen as quickly as possible, and we’re working hard to improve the service we provide. We’re just taking it step by step.

“We are also starting to take on new referrals for people living in South Staffordshire who would previously have had to travel to the Birmingham Care Centre, so they can be seen much closer to home.”
Margaret Cross, who is living with MND, attends the care centre regularly. She said: “We always have someone to contact if there is a problem and there is no longer a need for separate clinics which means we can be seen by everyone at the same appointment. “The staff are all MND specialists who provide the best medical care with understanding, compassion and gentle humour, and if one doesn’t know the answer, they will search for someone who does. “The access to research also gives us a way to contribute to the fight to defeat MND.”

Joanne Cole, who is also living with MND, said the opening of the clinic in Stafford had made a huge difference to her and her young family. She said: “We don’t have to travel so far which helps us enormously.”

Looking ahead to the future, Louise says she is determined to keep listening to patients to ensure the network continues to offer the support they need. She said: “There’s a lot of work which still needs to be done and we always appreciate the feedback from patients so we can improve and learn. We will also be taking part in the Improving MND Care Audit, which will show us the areas we need to develop.

“We are developing an education programme for health and social care professionals to learn more about MND. We are also working with communication services to highlight inequitable service provision in different areas and working on speedier access to neurologists for people where an MND diagnosis is looking possible. “We are currently involved in promoting the MND Register, as well as two research projects and we are also looking for opportunities to run clinical treatments trials in the future.”

If you would like more information about the Association’s care centres and networks you can download information sheet 3a MND Care Centres and Networks from our website at www.mndassociation.org/information-resources or visit www.mndassociation.org/carecentres

Are you a professional supporting people living with MND? We can support you. www.mndassociation.org/professionals
‘We’re determined to keep on living and giving’

A COUPLE whose lives have been touched by MND renewed their wedding vows in a ‘celebration of love’ surrounded by their family and friends.

Ian and June Campbell, pictured, got married 13 years ago and decided to renew their wedding vows in May after Ian was diagnosed with MND in 2016.

As well as giving the couple a chance to celebrate their lives together – as well as the love they have for their family and friends – they also used the party to raise money for the MND Association, a cause very close to their hearts.

Ian said: “We have been very well supported by the Chiltern Branch of the MND Association and we wanted to do something to help. People were able to donate online or in the collection tins we had. It was absolutely wonderful. We’re determined to keep on living and giving.”

June explained that opera singer, Davide Sorrentino, who appeared on Michael McIntyre’s Big Show last November, was on hand to entertain their guests.

She said: “He helped us out big time and donated to the Association too which was fantastic.”

Ian and June are determined to live life to the full and, just weeks after renewing their vows, the couple took part in a fundraising skydive.

It proved to be a particularly big challenge for June who was forced to confront her fear of heights.

Ian explained: “The day before, we stayed at a hotel and we were sitting in the garden enjoying a glass of wine when a plane came over and we saw all these parachutes dropping out of it. We looked at each and said, ‘that will be us tomorrow morning!’

“We were very well looked after, the company running it all was amazing. I went first. I was lying down near the door and then it opened and it just happened! The instructor turned me over onto my back so I could see the plane as we were falling, which was quite amazing.”

June said: “I did feel very safe but the freefall was the hardest bit. We fell 5,000ft in about 30 seconds and even though I was told not to open my mouth I couldn’t help it! I was very glad to get back on the ground again!”

Thanks to their extraordinary efforts, the couple has raised more than £4,000 for MND research and the Association’s Chiltern Branch. If you would like to donate please visit www.justgiving.com/fundraising/ian-campbell43
Daredevil Dawn flies again!

DAREDEVIL Dawn Goodson conquered Europe’s longest zipwire when she took part in her latest fundraising challenge in June.

Dawn, who is 88, reached speeds of 100mph as she sped through the skies above Penrhyn Quarry in Snowdonia alongside her friends Neil Allen, whose wife Annie is living with MND, and their son, Samuel; Annie’s friend Gail Mills and Brian Kendrick, whose brother died from MND last year. Together, the team raised more than £3,000.

“Wing-walking was exceptional, but this was pretty exhilarating too!”

Dawn’s husband Brigadier John H Goodson died from MND in 2015 and since then has dedicated her life to raising money for the Association, in particular, the East Dorset and New Forest Branch where the money is being spent to improve access to voice-banking.

She said: “Wing-walking was exceptional, but this was pretty exhilarating too!”

The night before it started raining, but when we arrived, there was no wind, so after many security checks we set off to the top of the quarry in a truck.

“We lay down head first and the rain was like hail, but we all would have happily done it again.”

Fearless Dawn is no stranger to taking part in daring fundraising feats.

In 2016, at the age of 85, Dawn raised more than £5,000 for the Association when she flew on top of a Boeing Spearman Bi-Plane as part of the Bournemouth Air Show. A year later, she abseiled down Portsmouth’s iconic Spinnaker Tower, raising £3,000.

A talented artist, Dawn also supported the Association by organising an open art exhibition which was held in December last year.

She said: “We had entries from all over Dorset. It was full of colour with more than 208 paintings, 124 portfolio works, 23 sculptures and 393 cards.

“I auctioned two of my paintings including one of Poldark which had been signed by the actor Aiden Turner. Through the Fine Arts Society, I went along to the National Trust house where Poldark is filmed and left the painting for him and he very kindly signed it and sent it back to me.

“The event was a huge success and we raised more than £1,000 in entries and £2,359 in sales.”

After such a busy time you would be forgiven for thinking that she might want a break – but Dawn is already planning her next adventure.

“I’m planning something for my 90th,” she said.

“I’m just not sure what it will be!”

Pictured from left to right are Neil Allen, Dawn Goodson, Annie Allen, Samuel Allen, Brian Kendrick, Gail and her son Alex.
Brothers take part in coast-to-coast adventure in memory of their dad

A family has united to raise money for the MND Association after their father, David, was diagnosed with MND.

Friends of the Sargent family held their first fundraising event in June 2018, raising more than £28,000 at a cabaret performance and charity auction which was held in Wootton, Norfolk.

Soon afterwards, David’s daughters-in-law, Alice and Emma, decided to lend their support by taking part in the Royal Parks Half Marathon raising an additional £1,500.

“We know that Dad would have been incredibly proud of what we have achieved and hopefully our contribution can help to find a cure for this awful disease.”

David died in November last year, but his sons Tim, George and Will were keen to take part in a challenge of their own, canoeing from Fort William to Inverness, alongside their cousin, Tom and friends Will, Chris and Dave.

Tim explained: “We booked the trip last September and Dad was really impressed and pleased that so many people were on board. He passed away at the start of November and suddenly, the challenge took on greater significance for us all.

“We set off on 3 June with the wind behind us and a little bit of sunshine, but soon the conditions changed. By Tuesday, the Force 3 wind was in our faces and the rain was coming down in droves.

“Wednesday and Thursday were the toughest days and it was touch and go whether we would be able to finish the challenge. If the wind had got any stronger it wouldn’t have been safe to continue.

“On the Friday, after canoeing 100kms, we were met in Inverness by our step-mum Mary, George’s wife Emma, my wife Nicola and our son Alexander. We were stiff, sore and smelly and we had been through some really tough days but we all felt very proud and pleased to have completed the challenge.

“While we were away, instead of reading our son a bedtime story, Nicola explained to Alexander that Daddy, his uncles and friends were taking part in the challenge so that more little boys in the future can spend more time with their grandfathers. We know that Dad would have been incredibly proud of what we have achieved and hopefully our contribution can help to find a cure for this awful disease.”

Are you inspired to organise your own fundraising event? You can find more information online at www.mndassociation.org/fundraising

Friends, fun and fundraising – a recipe for success!

Calling all star bakers!

If you have been inspired by the latest series of Channel 4’s Great British Bake Off then why not put your skills to good use by raising money for the MND Association.

Hosting one of our bakeit! events has never been easier thanks to our new packs which include all the information you need to organise a truly showstopping event.

You could host a bakeit! breakfast, a coffee morning, an afternoon tea complete with your best china or even cake and fizz for something even more indulgent!

Baking is great fun and can be enjoyed by the whole family, so with half term approaching, why not get your little ones to help you organise a special event? Invite your family, welcome your friends and colleagues and enjoy some tasty treats and quality time together.

For more information about how to get started visit www.mndassociation.org/bakeit or contact our fundraising team on 01604 611860 for your free pack.
Celebrating a successful partnership

A certificate of partnership has been presented by the MND Association to a health board in North Wales in recognition of its work in developing services for people affected by MND.

The award was presented to Betsi Cadwaladr University Health Board (BCUHB) in September to formally recognise the constructive and successful partnership it has developed with the MND Association over many years and the work it has done to improve standards of care for people who are affected by MND.

Regional care development adviser Kevin Thomas said: “The Certificate of Partnership formalises an already close working relationship with in North Wales between BCUHB and the MND Association, which has achieved so much. Formalising the partnership takes the relationship a step further ensuring that the MND Care Coordination service has access to the national expertise and training opportunities of the MND Association and its care centres and networks.”

Annette Morris, Director of Neurosciences at BCUHB said that she looked forward to working closely with the MND Association to improve standards of care for people affected by MND.

Time to get your winter flu jab

With flu season just around the corner it’s the perfect time to book an appointment with your GP.

The Department of Health is advising that people with certain health conditions, including MND, have a free flu jab each winter. Carers, or people who live with someone who has MND, are advised to get a flu jab at the same time.

For more information please contact your GP or visit your local pharmacy.

Remembering Ron – a ‘tenacious’ campaigner for those with MND

RON Stevenson, a tireless and much-loved campaigner for people living with MND, who played a key role in ensuring those with MND have timely access to communications aids, has died.

Ron, a former special needs teacher, was diagnosed with MND in 2009 and died on 19 August, just days after celebrating his 70th birthday surrounded by family and friends.

In May, Ron appeared in The Mirror newspaper to highlight the problems people living with terminal illnesses face when it comes to claiming benefits, explaining he was ‘devastated’ when told by the Department for Pensions (DWP) that he would need to reassessed.

His bravery in speaking out helped lead to the then Secretary of State for Work and Pensions, Amber Rudd, to say the process would be reviewed, something which is yet to be confirmed by the new Secretary of State, Thérèse Coffey.

In an article which appeared in the last edition of Thumb Print, Ron explained how the work had begun in 2013 after he was contacted by Liam Dwyer, who is living with MND, who asked him to be part of an advocacy team.

In the article, Ron paid tribute to the ‘help, hard work and perseverance of the NHS’ in helping to create a network of specialist centres which continue to make a huge difference to people living with MND.

The Association’s Director of External Affairs, Chris James said: “Ron was a tenacious campaigner who did so much to support people living with MND and the Association. He made people sit up and take notice and we will be forever grateful to him for everything that he did. The thoughts of everyone at the Association, and the wider MND community, are with Ron’s family and friends.”

Ron leaves behind his beloved wife Gill, daughters Hannah and Polly and his granddaughter, Amelie.
Caterpillar employees are hungry for success

Under the blue skies and sunshine of Bournemouth, 23 employees from Caterpillar Marine Power UK in Wimborne, along with their partners and friends, took on Bournemouth’s 5k to raise money for the MND Association in June. Caterpillar Marine Power UK is organising and taking part in several events over the next two years to help raise money for the MND Association’s East Dorset and New Forest Branch.

Jude Castell, Customer Services Representative and Charity Co-ordinator at the company, said: “Motor neurone disease took the life of a colleague’s father so we understand first-hand what this rapidly-progressing, terrible disease is capable of and the effect it has on family and friends.

“Knowing that we were raising money for such a wonderful cause pushed the team, who became known as the ‘Inflatapillars,’ right to the finish line.”

For more information, or to donate, visit: www.justgiving.com/fundraising/inflatapillars

Friends come together for school fundraiser

Noah Lambert and his friends Sean Jacobs, Mathilda and Hermione Johnson and Molly Chittock raised £313.58 at the Combs Village Fete in memory of Noah’s grandfather Gordon Paton who died from MND in 2010. The funds have been donated to the Suffolk Group.

Branch enjoys visit to botanical gardens

The botanical gardens in Sheffield were the venue for a visit by members of the South Yorkshire Branch during the summer. After a guided tour of the gardens and during some refreshments, Professor Dame Pamela Shaw, Professor of Neurology at the University of Sheffield, gave a talk explaining more about the work of the Sheffield Institute for Translational Neuroscience (SITraN) and the progress being made in MND research.

Branch Chair, Mel White said: “We had a wonderful evening and Dame Pamela Shaw’s talk was both fascinating and encouraging.”

Generous shoppers support Association

Generous shoppers helped to raise more than £282 for the MND Association.

Members of the East Surrey Branch of the MND Association collected donations outside Sainsbury’s in Dorking on 29 June, which will now be used to help support people living with MND in the region.

Branch Chair, Simon Edmands, said he was very grateful to everyone who had supported the collection, adding: “I would especially like to thank all the branch members and supporters who gave up their time throughout the day to help collect.”
Queen’s Award is group’s crowning glory

Volunteers from the North Wiltshire Group of the MND Association were presented with the Queen’s Award for Voluntary Service at a special event in July.

The crystal award and scroll signed by the Queen were presented at a special meeting of the group by the Lord Lieutenant of Wiltshire, Sarah Troughton, who made a speech highlighting the achievements of the group and the value of the support provided by the group’s volunteers over the past 30 years.

The event was also attended by the Association’s Director of Engagement Chris Wade. A celebration cake was cut by members of the support group followed by a glass of bubbly and light refreshments.

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

www.mndassociation.org/wills
Inspiring a new generation: While reading her school book *The Fun Run*, five-year-old Isobel Charnock asked her Mummy, Rosie, if she could take part in a fun run to help people in wheelchairs like her Uncle Chris, who is living with MND. Along with her sister Phoebe, who is three, they took on the Lacock 1K family run raising £393. The event was also a special tribute to the girls’ Grandad Tim, who also had MND and died when Rosie was just 15. Isobel is hoping they can do it all over again next year!

An incredible journey: Hand cyclist Joanna Martin travelled more than 400 miles from Helensburgh to Cheltenham in just over seven days to raise money for the Association in honour of her friend Marjory Daldry. Joanna’s life changed completely in 2005 when an accident left her with a spinal injury and paralysed from the lower chest down. She became friends with Marjory and her family and over the years they enjoyed many special moments. During her journey, Joanna, who had only hand cycled 13 miles previously, met many interesting people who had connections to MND and was delighted to receive a warm reception of support from the communities she visited. Halfway through Joanna’s challenge, Marjory passed away, but Joanna bravely continued and raised more than £9,000 for MND Research.

It’s showtime! Nicola Little and her team raised more than £600 at the Penrith Show. They successfully nominated the Association’s North and West Cumbria Group to be the show’s chosen charity for 2019. Visitors came from far and wide to visit the well-known agricultural show and were delighted to take part in a Play Your Cards Right game and fun cow sweepstake, as well as donating generously to the bucket collection.

Friends united: Friends Matt Crawford and Michael Hutchings took on the Southport half marathon in honour of Matt’s mother-in-law, Christine, who is living with MND. There was a strong headwind for much of the second half of the run, which made it very hard going, but they kept going and between them raised £3,450.

Thank you

Share your pictures at www.facebook.com/mndassociation

If you are sending in photographs to feature on these pages please ensure you have full permission to use the images before sending.
Making every step count:
Six-year-old Alarna and Nate, who is four, took part in the Walk to d’feet MND in Cannock Chase, Staffordshire. They completed the 1.25 mile walk for their Nanny, who is living with MND, walking alongside their Grandad Michael and other family members. Together, the family raised more than £650 and they have since held a fun day which raised more than £1,600 for the Staffordshire Group.

Fundraising inspired by friendship:
Neil Davis and Joe Alderslade ran 60 miles along the Ridgeway from Oxfordshire to Avebury, raising £1,055 in support of Win Patterson, a former deputy headteacher who is living with MND. Joe said: “When Neil and I learned that our friend and colleague who had a profound effect on our lives and careers had been diagnosed with MND, the decision to raise some money was an easy one. It was an amazing experience and having such a worthy, personal cause definitely helped us get through.”

Pushing for a world free from MND:
Mark, Daz, Helen and Carl took part in the Ackworth Pram Race to raise money for the MND Association. Their customised pram was in the shape of a Next delivery lorry with the Association’s logo on the side. The team raised more than £700 for the Association in honour of their friend, Paul Banton. Picture: Tom Bootyman Photography.

A family affair: Darren Ridgard and his family organised their second 5k Walk to d’feet MND in Tamworth, in honour of Darren’s dad Alan, who is living with MND. The Mayor of Tamworth opened the event and walkers were led by Alan on his mobility scooter to his home in Wilnecote where his wife Rita had organised a wonderful spread for the hungry walkers. Darren’s brother Andy continued the family’s fundraising efforts by hosting a quiz night in September.

Catch of the day: Darren Holt and his family took part in their annual family fishing event in memory of their dad, Alfie Holt. This year they had a record 57 people taking part and raised more than £1,700 which brings the total raised for Alfie’s tribute fund £8,500. Lisa said: “I’m sure my dad would have been so proud!” Pictured is Lisa’s mum, Christine, with her first ever catch.
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 you are including photographs please ensure you have full permission before sending.

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**‘What a privilege it was to know her’**

“T’S that brutal. She’s gone. And on Mothering Sunday too, of all the days to go.

“All those years ago when we were throwing buckets of iced water over our heads and proudly posting it to our social media declaring we would donate money and nominating new people to take part, this disease was lying dormant in her fit, agile body waiting to strike. I’m not a scientist so far be it from me to speculate how it started, why it started or even when it started - but start it did.

“I remember vividly her walking into my house, the exact spot in the hall where she stood and even what she was wearing and she said, ‘my hand has gone a little bit weak,’ and with that she squeezed my hand to demonstrate the weakness. As we did, we said it was, ‘probably motor neurone disease,’ in the same way that whenever I got an ache or pain I assumed I had cancer. But the awful, terrible irony was that she actually did have it. Again, I remember taking the phone call at work from her when she was diagnosed. Her sob as she told me, ‘I’m going to die, I have motor neurone disease,’ my utter bewilderment because I just didn’t know what it was! I was so obsessed with dying of cancer that motor neurone disease had bypassed me completely.

“That was in October 2016. She died on 31 March 2019.

“Initially we focussed on the practical. I helped her find out about what benefits and help she could get while around her everyone crumbled, shocked and stunned by her news.

“There was talk of drugs trials as she was only in her late 40s and not in the typical demographic to suffer with such a disease. We had always joked that she would never end up in an old people’s home because she wanted to stay young and sexy forever. Sex was so important to her, she was such a vital human and to lose that from her life was one of the worst things imaginable.

“She had such a lot to live for and she was the bravest woman I have ever known. The odd thing is that with such a slow and progressive illness I think I have grieved as I’ve gone along. Many times I would leave her home after visiting her and feel so sad, so very sorry that she was going through this terrible, terrible disease. You can’t just chop a bit off, or blast it with chemicals, there really is nothing to be done for MND. There were times when I thought it had halted, and she seemed stable, but she was just good at hiding it from me. She hid a lot and I didn’t ask. I now feel guilty for that. My rationale was that I didn’t want to open a wound that I would then leave gaping while I carried on living my normal life while she had only her thoughts to ping around in her head. I will never know if I did enough or if she felt that I was any use with my constant wittering about house moves, divorce, exciting gossip and trivial nonsense, but I can only hope it distracted her for a time and made her smile.

“The end came suddenly and without warning. I had seen her five days before.

“It hit me hard for about two hours and then, rather bizarrely, I felt such a relief and have done ever since. I have never seen such a cruel and awful way to die.

“Admittedly I haven’t watched many people lose battles with diseases, but to be locked into your own body, only able to move your eyes and all the while your brain continues to be as razor sharp as ever, must have been the very worst thing any human being could endure.

“Selfishly, I am sad she is not with me or her family anymore, but I am so glad that the end has finally come and that she isn’t in any pain. What a wonderful privilege it has been to know Tracey Brown.”

*Suzi Cross, via email*

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**diary dates**

- **Walk to d’feet MND:** Walks throughout the year – [www.mndassociation.org/walk](http://www.mndassociation.org/walk)
- **West Regional Conference, Wales, 29 February 2020** – [www.mndassociation.org/conferences](http://www.mndassociation.org/conferences)
- **The Vitality Big Half Marathon, 1 March 2020** – [www.mndassociation.org/big-half-marathon](http://www.mndassociation.org/big-half-marathon)
- **Brighton Marathon, 19 April 2020** – [www.mndassociation.org/brighton-marathon](http://www.mndassociation.org/brighton-marathon)
‘My observations on living with MND’

“My name is Bob Alderman, Robert when I misbehave. I am married with a grown-up son and daughter. I have had two careers. I was a design engineer at Westland Helicopters, but when that ended abruptly my hobby developed into becoming a professional model-maker building locomotive kits and creating scenery.

“I had my confirmed diagnosis in August 2017 though investigation preceded it by three years. There was the initial shock, but then knowing that there was little I could do but accept it I tried to be cheerful, it’s too easy to be miserable.”

“I think I’ve adopted the same view as the first Medici Pope Pious X, ‘Now we have the Papacy let us enjoy it.’

“In developing a rapport with my specialists and carers I have joked with them and had the inevitable thoughts on my condition. Some of these follow; forgive the schoolboy humour, I think I’m entitled.

‘Why does it only itch where you can no longer reach?’
‘Why does it only itch when the carer is out of reach?’
‘It’s not everyone who begins and ends the day with a fairground ride – swinging from the ceiling hoist. When being hoisted I used to help by flapping my hands.

“The day always starts with personal hygiene and a reading from Shakespeare, ‘Once more into the breach…’ from Henry V.

“As a teenager I used to daydream about handmaidens anointing me with exotic oriental oils. Now it’s carers applying NHS creams.

“One of my carers insists on drawing crop circles in my hairy legs after creaming.

‘Then there are the jokes… Don’t squeeze the end of my catheter bag, it makes my eyes water,

‘And when drying my feet, ‘You’re doing it wrong. This little piggy.’

‘Accepting apologies for my handling when being dressed by a new carer, ‘I’m putty in your hands’.

“During my shower showing appreciation for a vigorous back wash and dry by purring.

Bob Alderman, via email

For more stories from readers of Thumb Print turn to pages 12 and 13.

A handy way to hold a cup’

“My wife was getting cramp holding a cup for me to drink from. I’m still able to suck through a straw but putting a cup to my lips will result in a puddle.

“I thought about what I needed and described it to the members of my model railway club; they are a handy lot. Essentially a shelf with a hole that could hang around my neck.

“One member took on the challenge and found one on the internet that could be 3D printed. This was the first model with two curved edges. It proved unstable so I asked for a second version with a flat side.

“This has been a success. A further modification to the second version is desirable, to make a slot from the curved edge to one hole. The cord can then be slid in with a toggle on the end to. This will save a lot of fiddling to tie the cord to the correct length each time it’s worn.

“I am using an eco-friendly bamboo cup; the alternative to the non-recyclable from coffee shops. The hole is sized for this; if another cup is used, make sure it has a taper body that will wedge in the hole. The straw I’m using is the tube from an overnight catheter bag. We sacrificed a NEW one!”

Do you have any hints and tips you would like to share with readers of Thumb Print? Email clare.brennan@mndassociation.org.
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.

- Increase your rate of communication with powerful prediction tools and Chat History
- Quickly speak pre-stored phrases for common situations
- Prepare for conversations in advance
- Switch between conversations with ease and save messages for later
- Capture and recall personal phrases in your own voice with our new message banking tools
- 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

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