

aware

**MND
Scotland** 
Supporting people affected by Motor Neurone Disease

The newsletter of **MND Scotland** 2021 • Issue 1

It's About Time

Election campaign begins – *pages 8-10*

What's Inside:

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Remote Physiotherapy Service

We are delighted that we can now offer remote physiotherapy sessions to people with MND via video calls.

Our refocused MND Scotland Connected services are here to make sure that families affected by MND are not facing MND alone during the Coronavirus pandemic. Physiotherapy can help people stay independent for longer and improve

quality of life. It may help manage pain and maintain existing movement of limbs for as long as possible. Physiotherapists can provide a range of tailored assisted motion exercises to help with circulation and the reduction of muscle aches and pains.

For more information call **0141 332 3903**, email info@mndscotland.org.uk or visit mndscotland.org.uk/physio.

Welcome to the Team

We'd like to give a warm welcome to Catriona Griffin who joins our Advocacy team. Thanks to a large donation from the Alan Davidson Foundation ([page 14](#)) we have been able to expand the team, which steps in to fight the corner of people with MND when the system fails.

"I have been delivering advocacy for five years and I'm excited to be joining a dedicated team which delivers much needed services to people living with MND across Scotland.

"I take real satisfaction in my role as an advocacy worker. I am passionate about promoting the rights of those affected by disability and enjoy working with individuals and families to ensure ensure they can fully participate, understand and be at the centre of in decisions which affect them."

If you need advocacy support call us on **0141 332 3903** or visit www.mndscotland.org.uk/connected.



CEO Update

For the last 20 years I have had the honour and privilege to lead MND Scotland, but now is time for me to step down and seek new challenges.

During my time as Chief Executive I have met many incredible, committed and brave people, and I have witnessed a number of improvements in the care and support available to people affected by MND in Scotland, as well as many advancements in research which have expanded our knowledge and taken us closer than ever to new treatments.

I take comfort in knowing that, although we haven't yet found a cure for this terrible disease through the work of the charity, we have been able to improve the quality of life for so many patients and carers.

Iain McWhirter, MND Scotland's Head of Fundraising, will act as Interim Chief Executive in my absence.

I am extremely proud to have been associated with the achievements and advancements made within the MND field

over the last two decades and I'm confident that there is much more to come in the near future.

A message from the Chairman

Adrian Murphy, Chair of MND Scotland's Board of Trustees, said: *"I would like to thank Craig for all that he has done to lead this organisation and how he has worked to raise awareness of this terrible disease across Scotland."*

"This is a period of great challenge, change and opportunity for MND Scotland and our priority is – as it always has been – to serve and work with those who are living with motor neurone disease."

"We are committed to fighting against motor neurone disease and finding a cure. We will continue to do this with the incredible support of our fundraisers, donors, volunteers, staff and partners."



Craig Stockton, CEO

A handwritten signature in black ink that reads "Craig Stockton".

COVID-19 Updates

The situation around Coronavirus (COVID-19) and the risks it poses is changing rapidly. We will continue to monitor and provide updates at www.mndscotland.org.uk/coronavirus-updates and we advise visiting www.nhsinform.scot for real-time updates and advice.



Charity Update

New leadership



In November we said goodbye to Lawrence Cowan, as he stepped down as Chair of MND Scotland's Board of Trustees, and we welcomed Adrian Murphy as our new Chairman.

Lawrence joined the Board, alongside his best friend and MND campaigner Gordon Aikman in 2015, after Gordon was diagnosed with MND in 2014.

Together Gordon and Lawrence founded Gordon's Fightback, a campaign to lobby for better care for people with the illness and to raise funds towards finding a cure for MND. The campaign achieved extraordinary success, including doubling the number of MND specialist nurses in Scotland and ensuring these roles are paid for by the public purse, as well as raising £640,000 for MND Scotland to invest in vital research.

Lawrence said: *"It has been a privilege to lead MND Scotland in achieving historic milestones in the fightback against the disease. People with MND in Scotland now have world-leading levels of access to MND nurses and almost everyone with the disease now has access to a drug trial in Scotland. Six years ago, progress like this was a dream. Now, because of our determination to fight back, it is a reality.*

"If there's one thing that witnessing the devastation of MND has taught me is that life is fragile, unpredictable and every moment matters. I need to take some time out to make the most of the moments with my young family.



"I wish Adrian well as new Chair and look forward to playing a role in the future of this great charity and community – albeit in a different capacity."

We want to thank Lawrence for his hard work, inspirational leadership and commitment to the fight back against MND over the years. As we say goodbye to one member of the Board, we also welcome Adrian Murphy as our new Chair.

One of our newest Trustees, Adrian brings invaluable knowledge and skills to the role, with expertise in cash flow analysis, due diligence, investment research, risk management, and long-term planning.

The CEO of Murphy Wealth, a multi award-winning financial planning business based in the centre of Glasgow, Adrian is also bringing his own personal experience of MND as his brother, Brian, was diagnosed with the disease in 2018.

Adrian said: *"It's an honour and a privilege to follow Lawrence as Chair of MND Scotland. I plan to build on the fantastic work that has been done over the last few years and work with the Board and the rest of the team to make a difference in peoples' lives today, while we continue the search for a cure for this terrible disease.*

"I am lucky to have the full support of my family and my senior team at Murphy Wealth, to devote time and energy to the mission of MND Scotland, and plan on speaking to all of our key stakeholders to progress our key objectives of care and a cure."



Doddie's Donation

The My Name's Doddie Foundation, founded by rugby legend Doddie Weir, has donated an additional £100,000 to MND Scotland to support people living with MND across the country.

Doddie, who first shared his MND diagnosis in June 2017, has pledged to help others living with the rapidly progressing terminal illness, as well as funding for vital research into finding a cure.

To support families currently affected, the Foundation has committed annual funding to MND Scotland since 2018. The Foundation also made a one-off donation to the charity in response to the COVID-19 pandemic, taking its total contributions to MND Scotland to £380,000.

These new funds will be used to help families cover some of the financial burden that comes with a diagnosis of MND, through essential grants.

MND Scotland's grants, backed-up by the My Name's Doddie Foundation, can be used in various ways, for instance; to help with

costs towards home adaptations, such as ramps and stairlifts, for specialist equipment to live life more independently, and for respite activities for carers and families.

The Foundation has also provided a donation of £200,000 to the MND Association of England, Wales and Northern Ireland.

Adrian Murphy, Chair of MND Scotland, said: *"I'd like to thank the Foundation for its ongoing support of our grants programme which allows us to provide essential support to the families affected by this devastating disease."*

"Since his own diagnosis, Doddie has raised an incredible amount of awareness by sharing his personal journey with MND, and through his Foundation has raised vital funds to support the cause. By continuing to work together we can help make life a little easier for people living with MND right now."

You can learn more about our grants and apply online at www.mndscotland.org.uk/connected.

Research

New Axons Discovery

Scientists are a step closer to being able to reverse the damage caused by MND following a new discovery by researchers in Edinburgh.

The team has proven for the first time that axons – the long nerve fibres which connect and send electrical impulses from the nerve cells to the muscles – are shorter in cells affected by MND than in healthy cells.

They also discovered that the movement of the mitochondria, the tiny energy cells which move up and down the axons, is impaired.

However, researchers have found that the damage to the nerve cells - or motor neurons - caused by MND can be repaired by boosting the energy levels in these mitochondria.

Once this was done the axon reverted to normal length in laboratory experiments.

The effect was achieved using motor neurons grown from stem cells collected from people with a genetic mutation known to cause MND.

These lab-grown motor neurons were then exposed to a virus which supercharged a key molecule vital to the healthy

functioning of mitochondria.

The team, based at the Euan MacDonald Centre for MND Research at Edinburgh University, believe they will be able to produce the same result in patients - not with a virus, but by re-purposing an existing drug instead.

Dr. Arpan Mehta, one of the lead scientists on the project, said: *“Our data provides hope that by restoring the cell's energy source we can protect the axons and their connection to muscle from degeneration.”*

“Work is already underway to identify existing licensed drugs that can boost the mitochondria and repair the motor neurons. This will then pave the way to test them in clinical trials.”

Researchers will begin testing thousands of drugs they believe could have the desired effect of super-charging the mitochondria. If a promising drug is identified, this treatment could then be a target for future clinical trials in humans.

The study was funded by the Medical Research Council, MND Association, Euan MacDonald Centre for MND Research, My Name's Doddie Foundation, UK Dementia Research Institute and the Anne Rowling Regenerative Neurology Clinic.

Photo credit: Euan MacDonald Centre for MND Research





MND-SMART update

The pioneering MND clinical drugs trial, MND-SMART, has now opened in Aberdeen, following sites in Edinburgh, Dundee, Glasgow and Salford.

People diagnosed with MND will now be able to join the clinical trial from across the NHS Grampian region, at Aberdeen Royal Infirmary.

MND-SMART, into which MND Scotland has invested £1.5 million, is a pioneering clinical drugs trial in its reach and design that launched in January 2020. The trial is recruiting hundreds of people living with MND across the UK to take part in tests of potential treatments.

Unlike typical clinical drugs trials which test a single treatment at a time, MND-SMART is testing multiple drugs and so aims to speed up the time it takes to find medicines that can slow, stop, or reverse the progression of MND.

Whilst working to open new sites as quickly as possible, ensuring the safety of people taking part in MND-SMART is the trial teams' highest priority. The trial sponsor and local research and development teams have

carefully reviewed the impact of COVID-19 and have provided clear guidance that recruitment to MND-SMART can continue in line with the ongoing delivery of essential healthcare.

People with MND who have already registered interest in the trial online, and who live in the NHS Grampian region, will be contacted by the trial team over the coming months to discuss taking part. Please be aware that COVID-19 rules will have an impact on the pace of recruitment.

Dr Callum Duncan, the Consultant Neurologist leading the study at Aberdeen Royal Infirmary, said: *"We are looking forward to welcoming people into the MND-SMART trial. This is the first wide-scale MND clinical trial in years and so is a very exciting step forward amongst hugely challenging times in healthcare."*

To read more about the trial, and how to register your interest, please visit [MND-SMART.org](https://www.mnd-smart.org).

MND-SMART is funded by the Euan MacDonald Centre, substantial private donations, MND Scotland and the My Name's Doddie Foundation.

The system can't keep pace with MND

Now is the time for change

The countdown is on to the Scottish Parliament elections in May 2021 and we need your help.

MND is brutally fast. People with MND can quickly lose their ability to walk, talk, eat and breathe unaided. They need services, such as social care and home adaptations, to help them live their lives safely.

Services need put in place quickly yet many people wait too long. Tragically, some never receive what they need in time. We need a system that can keep pace with MND.



What we're up against

MND Scotland is here to guide people through a labyrinth of confusing processes; and to be here when the system fails. Every year we see the same problems again and again.



Social care

People with MND can wait months for essential care to be fully put in place.



Home adaptations

Delays in adaptations can leave people with MND trapped in their homes.



Accessible housing

Some people with MND never get the accessible home they need in time.

We are calling for change

The Scottish Parliament elections take place on Thursday 6th May. In January, we sent our own manifesto for these elections to all the political parties and MSPs.

In it, we call for the next Scottish Government to introduce:

1. **A National Care Service for Scotland**
2. **A National Accessible Housing Strategy**

Download your copy of MND Scotland's election manifesto at www.mndscotland.org.uk/time.



Share your story

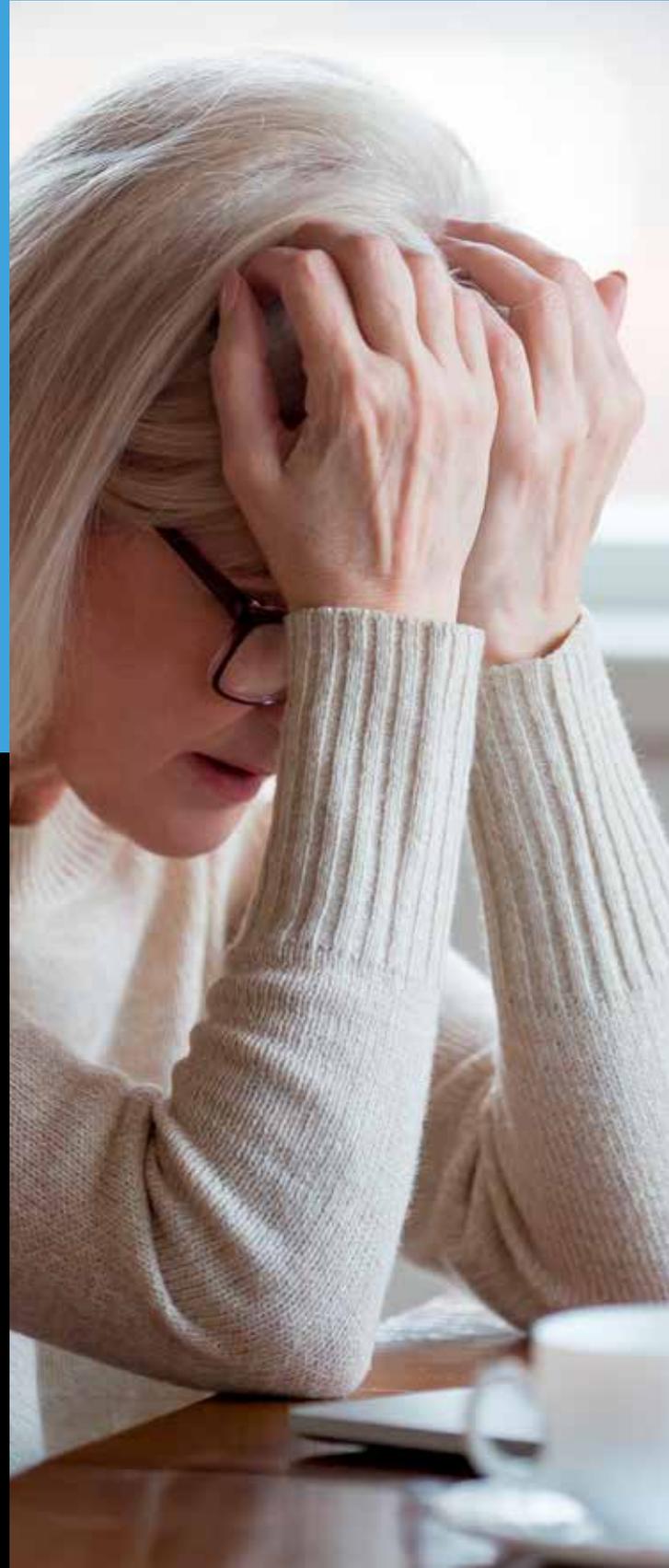
Have you been affected by delays?

Politicians value hearing directly from people affected, and you can make a big difference by adding your voice.

By sharing your story, you can help to:

- **Raise awareness of system failures**
- **Help keep MND on the political agenda**
- **Increase the chance of effecting change**

Share your story at
www.mndscotland.org.uk/time.



Help us be there for people when the system fails

No one should have to experience the stress of delays alone. With your support they won't have to.

To make a donation please visit www.mndscotland.org.uk/time or call us on **0141 332 3903**.

You can also use the form on the back page of this newsletter to donate via cheque.

Fundraising

The Virtual Kiltwalk is back for 2021!

Sign up for MND Scotland and help take us a step closer to a cure for Motor Neurone Disease.

Taking part in the Virtual Kiltwalk is super easy. Simply don a bit of tartan and complete any socially distanced challenge you wish, from walking, running, cycling, hopping, skipping or

jumping on a trampoline, all to raise money to fight back against MND.

If you decide to walk or run, you can decide how far to push yourself. Just remember to stick to the COVID-19 restrictions in your local area. The event takes place 23rd - 25th April 2021.



Boost your fundraising by 50%

All funds raised for MND Scotland will be topped-up by a massive *50% from the Hunter Foundation. That's right, for every £10 you raise, MND Scotland will receive £15!

Once signed up you will be sent your personal online fundraising page link on JustGiving. Click on the link and post out the link on your social media to start fundraising.

**The 50% fundraising top up will be granted up to a limit of £5,000 per walker or donor. Subject to deadline and trustee approval.*

Sign up

You can sign up to take on the Virtual Kiltwalk at www.thekiltwalk.co.uk.

Don't forget to choose MND Scotland as your chosen charity during sign up and start raising money. Kiltwalk registration is just £12.80 for adults and £6.50 for children aged 15 and below. Under 5's can take part free of charge.

Fundraising

MND Christmas Appeal

We are delighted to announce that our MND Christmas Appeal raised a total of £46,196 to help fight back against motor neurone disease.

We would like to thank each and every person who chipped in to help fund MND research.

Don't forget, you can make a donation any time to support our work. Simply call us on **0141 332 3903** or visit www.mndscotland.org.uk.



Virgin Money London Marathon

Sunday 3 October 2021

MND Scotland has secured one free charity place in this year's London Marathon and we'd love for you to declare your interest.

We hope to use this place to raise as much money and awareness as possible for MND

You can apply to run for MND Scotland on our website. Simply let us know why you want to run for the charity and also what you think you could pledge to fundraise by taking part in the coveted event.

The closing date for applications is Friday 19th March 2021. One applicant will be chosen to ensure plenty of time for training and fundraising.

We'll support our runner every step of the way, providing fundraising materials to help maximise your efforts to reach your target, an MND Scotland running vest and a T-shirt.

For more information, visit www.mndscotland.org.uk/london.



Fundraising

Nucleus staff celebrate huge fundraising total

Staff at Nucleus, an Edinburgh-based financial services company, are celebrating after raising a total of £67,902 over two years to help fight back against MND.

The company started supporting MND Scotland in January 2019 after staff member, the late Mike Wallis, was diagnosed with the progressive terminal illness. Mike sadly died in May 2020.

Over the past two years the team at Nucleus have raised money for the charity by holding a series of events to raise the total, including bake sales, bucket collections at ScotRail stations during MND Action Week, and buying a Bronze sponsorship table for their staff at MND Scotland's Cornflower Ball.

In November 2019, the team held a 'Lunch and Learn' event where staff had the opportunity to hear from the charity's staff members about the work they do to support people across Scotland living with MND. This was followed by a Great British Bake Off style event, where the company's staff members presented their best cakes and bakes to raise money.

Nucleus was also the first company to trial contactless donations in their offices to encourage on-the-spot donations from staff members at fundraising events.

Despite the challenges surrounding COVID-19 the team at Nucleus has continued to fundraise during the pandemic by staging virtual fundraising events including virtual bingo and table quizzes. One very brave member of the team even shaved his head to raise money!

Morag McGown, Corporate Partnerships Manager for MND Scotland, said: "I'd like to thank all of the team at Nucleus for raising such a fantastic total to support people living with MND across Scotland."

"Mike's diagnosis of MND really showed the people at Nucleus what this cruel disease can do to people and it was so wonderful to see the staff put their hearts and souls into fundraising for Mike."

"The creativity of staff to raise money while working from home has been incredible and every penny is already being used to improve the quality of life for people affected by MND and provide hope for a future without MND."

"We have also just celebrated one year since the launch of the UK's biggest MND clinical drug trial in a generation, to test new MND treatments. We couldn't have made that happen without incredible supporters across Scotland, including corporate supporters like Nucleus Financial."

If you're interested in selecting MND Scotland as your charity partner, or if you're just interested in fundraising at work, please contact Morag at morag.mcgown@mndscotland.org.uk or call us on **0141 332 3903**.

Mike Wallis (left) with CEO David Ferguson (right).



Fundraising

Alan's lasting legacy



The Alan Davidson Foundation has donated a massive £104,423 to MND Scotland which is already being used to expand the charity's Advocacy Service.

The foundation was founded by Aberdeen-born architect, Alan Davidson, who died of MND in 2018.

Alan, who was diagnosed with MND in 2012, was committed to helping people living with MND and other neurological conditions. Through his foundation he wanted to help initiatives that improved peoples' lives through better care and support, and fund research to find a cure.

The donated funds are being used to grow MND Scotland's Advocacy Service, which

has already led to the recruitment of a third Advocacy Worker (meet Catriona on page 2) whose role will be to help meet the demand for our advocacy service across Scotland.

The service helps people affected by MND resolve issues they are experiencing, with the aim to take away some of the stress and strain families are under, when already dealing with a devastating diagnosis. The team can help with getting a care package in place, delays in home adaptations, moving to an accessible home, employment or pension issues and much more.

Roslyn Scholarios, Head of Direct Services for MND Scotland, said: *"Our advocacy team is here to help people living with MND if they are facing delays, disputes or roadblocks of any kind, so that families do not have to fight for what they are entitled to, alone."*

"The demand for this service, since it launched in 2018, has continued to grow and the COVID-19 pandemic has meant that people with MND are coming up against even more delays when accessing statutory services."

"We are incredibly grateful to the Alan Davidson Foundation for their donation, which will ensure we are able to continue providing the highest level of support possible to families when they need us most."

Colin Reid, from the Alan Davidson Foundation, said: *"We feel privileged to be able to help MND Scotland with this critical, yet often neglected feature which comforts those living with MND and is a vital service to help reduce the stress and confusion around households, for families learning to adjust to this life changing condition."*

If you require advocacy support, please get in touch on **0141 332 3903** or visit www.mndscotland.org.uk/advocacy.

Fundraising Acknowledgements



Team Himalayas

In this edition of *Aware* we'd like to dedicate our fundraising acknowledgements section to our amazing Team Himalayas.

In September our team of 37 fundraisers will be trekking in Nepal amongst some of the world's highest mountains to raise money for charity.

Despite the challenges of Coronavirus and repeated lockdowns the team has already raised more than £53,000 to fight back against MND.

Here is just a taste of what they've been doing to raise funds.



Kirsty Hendrie has been making and selling delicious goodies for Christmas and Valentine's Day and also completed a Christmas jammies fun run!



In June, Colin Duff ran a 5K pushing his daughter Flora down the cycle path in Kilmarnock. He was worried it might be a little uncomfortable for her, but she slept for most of it!



David Sweeney raised an amazing £4388 by selling neck scarfs with a #curemnd design. David says he was "absolutely staggered" by its success and has been so proud to see people wearing the scarfs!

A gift in your Will can fund the research that takes us closer to a cure

For more information about how
you can leave a gift in your Will to
MND Scotland, please contact
Iain McWhirter on:

0141 332 3903

info@mndscotland.org.uk

We can, we must and will find a cure

I enclose a donation of £10 £50 £100

Other amount _____

Name _____

Address _____

_____ Post Code _____

Email _____

**Post to: MND Scotland, 2nd Floor, City View,
6 Eagle Street, Glasgow g4 9XA**

**Tick this box if you no longer wish to receive
Aware (please tell us your name and
postcode above so we can remove you
from our list)**

To make a regular monthly donation, or donate by
credit/debit card, please telephone 0141 332 3903.

Gift Aid

If you are a UK taxpayer you can
make your gifts worth 25% more,
at no extra cost to you by signing
the Gift Aid Declaration below. For
every £10 donated, MND Scotland
will claim an extra £2.50 from the
Inland Revenue. In order to Gift Aid
your donation you must tick the box
below and sign the declaration.

**I want to Gift Aid this donation to
MND Scotland and any donations
I make in the future or have made in
the past 4 years. I am a UK taxpayer
and understand that if I pay less Income
Tax and/or Capital Gains Tax than the
amount of Gift Aid claimed on all my
donations in that tax year it is my
responsibility to pay any difference.**

Signature

Date
