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



The newsletter of **MND Scotland** 2020 • Issue 4

## **MND Christmas Appeal**

Give a gift that will change the future - *page 12*

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# 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](http://www.mndscotland.org.uk/coronavirus-updates) and we advise visiting [www.nhsinform.scot](http://www.nhsinform.scot) for real-time updates and advice.

Don't forget we are still here if you need support, information or advice, or if you just want to talk. Simply call us on **0141 332 3903** or email [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk).



## Services

The Coronavirus pandemic has placed restrictions on many of our services. We understand how worrying the current situation is and the challenges it presents for people living with MND and Carers alike.

We have launched our refocused **MND Scotland Connected** services to make sure no one goes through MND alone. To find out how we can help, please visit [www.mndscotland.org.uk/connected](http://www.mndscotland.org.uk/connected).

## Fundraising

There has been severe disruption to all mass-participation events throughout the year, which has impacted many of our planned fundraising activities.

Many of our supporters are now organising their own sponsorship activities to raise money and our fundraising team would love to hear from you too. Speak to us on **0141 332 3903** or email [fundraising@mndscotland.org.uk](mailto:fundraising@mndscotland.org.uk).

# CEO Update

**There is hope in every story – good within almost every bad – sometimes we just have to work a little harder to find it. People who face MND every day know this well.**

I won't sugar coat it; this has been a very challenging year. While many charities have faced a financial cliff-edge, we have been fortunate to have such passionate supporters like you donating and fundraising to allow us to keep being here for people affected by MND. However, we have not been immune to the effects of the pandemic, and we've had difficult decisions to make.

Last month we announced that we had reached the difficult decision to make two members of our services team redundant due to the effect of the pandemic. We have also reached the decision to close MND Scotland's office in Glasgow, after our lease came to an end. **(More on page 4)**

We have launched our MND Christmas Appeal to help generate funds and secure the future of MND research and practical, financial, and emotional support to people affected by MND. If you are able to support the charity, either through a one-time donation, signing up to give regularly, or upping your regular donation, I am asking you for your support this Christmas. **(More on page 12)**

Funding MND research is an important part of what we do and I am pleased to confirm that we are joining together with the MND Association of England, Wales and Northern Ireland and with Doddie Weir's 'My Name's Doddie Foundation' to call on the UK

Government to increase its investment in MND research. **(More on page 8)**

I know this year hasn't been what we would have hoped for, but I think it's important to remember the big achievements we have made this year, including the launch of the UK's biggest clinical trial in a generation. After pausing recruitment during the height of the initial lockdown, MND-SMART is back up and running and now has four centres open across the UK, three of which are in Scotland. **(More on page 10)**

We were able to invest £1.5m, over half of our annual income, in this cutting-edge clinical trial because of people like you. With your continued support, we can make sure that we continue to innovate in the year ahead.

Finally, as the year draws to a close, I'd like to make you aware of a new fundraising initiative we have launched; Go Free For MND. That's right, you can help MND Scotland by giving something up for the first month in 2021. Whether you're going dry for January, giving up your comforting cup of tea or coffee, sacrificing your wine or chocolate, or even going without your mobile phone, we're asking you to help raise sponsorship to make sure cutting-edge MND research doesn't stop. **(More on page 11)**

On behalf of all the team at MND Scotland I would like to wish you all a very Merry Christmas and a Happy New Year when they come. Thank you.



**Craig Stockton, CEO**

## How are we doing?

We're looking for your feedback to help us improve Aware. Starting next year, we will be sprucing up your newsletter with a fresh design and we'd love to hear your thoughts on how we could improve the content we offer too.

Tell us at:  
[www.surveymonkey.co.uk/r/AwareMND](http://www.surveymonkey.co.uk/r/AwareMND)

or email your thoughts to:  
[communications@mndscotland.org.uk](mailto:communications@mndscotland.org.uk)

# Charity Update

## Difficult Decisions

**The past eight months have been incredibly difficult for the whole country, and for people with MND the worries and challenges have been amplified many times over due to the pandemic.**

Social-isolation measures, while essential, are placing huge restrictions on the care and support many rely on every single day. Unfortunately, this has meant all face-to-face support provided by MND Scotland has been suspended indefinitely. As a result, we can no longer host local support groups or offer complementary therapy, physiotherapy, and face-to-face counselling.

Regrettably, the impact of the current circumstances has resulted in us taking the extremely tough decision to make two members of the MND Scotland team redundant. This is, of course, not something we wanted to do or a decision we have taken lightly. However, as we do not know when we will be able to resume our face-to-face services, this has affected two key roles within our charity, meaning Dawn Hamilton, our Client Services Coordinator, and Ian Stuart, our Inclusive Technology Coordinator, have been made redundant.

Dawn and Ian worked at MND Scotland for 12 and 5 years respectively and have provided invaluable support to families affected by MND over the years. Dawn hosted MND Scotland's support groups across the country, bringing local families affected by MND together, as well co-ordinating our complementary therapy, physiotherapy and counselling services. Ian provided specialised equipment and advice to people whose voice has been affected by MND, to give them a way of communicating, while waiting for their NHS equipment to arrive.

We are very sad to see Dawn and Ian go, and we thank them for their huge contribution and unstinting dedication to the charity, and for the difference they have made to so many families. We appreciate all their hard work and compassion and wish them the very best for the future.

## Office Closure

As staff continue to work from home for the foreseeable, we have also decided we will not be renewing the lease for our Head Office in Glasgow, which is due in February.

We are currently developing plans and requirements for a new office space, so that when it is safe to return to office working, we are ready to move these plans forward. In the meantime, we'll be moving our equipment into storage and our post will be redirected to our unit at 76 Firhill Road, Glasgow, G20 7BA.

## Your Support

While we are still unsure what the future holds for face-to-face support and fundraising events, we are all in this together. We have been overwhelmed by the support we have received during this time and we would like to take this opportunity to extend our sincere thanks to all of our supporters.

From one-off and monthly donations, to joining our virtual fundraising events and getting creative in your own ways at home, your motivation and determination to continue fighting back against MND has been a true inspiration to us and we could not continue supporting families during these trying times without you.

# AGM Awards

Every year we want to recognise members of the Scottish MND community, who have gone above and beyond personally and professionally, in the fightback against MND.

We're delighted to award our 2020 John MacLeod Award to Jennifer Bell, a young mum of two who was diagnosed with MND in March 2019, and our Carole Ferguson Award to Janice Hatrick, MND Clinical Nurse Specialist for NHS Greater Glasgow and Clyde.

## Janice Hatrick



The Carole Ferguson Award recognises Health and Social Care professionals who demonstrate exceptional care and support for someone with MND, and who go above and beyond what is expected of them as a part of their job. MND Clinical Nurse Specialist Janice Hatrick (pictured at 2018 fundraising event) was nominated by a number of people she cares for with MND, as well people she works with to support those affected by MND.

One person said, "*Janice is a very compassionate, caring, kind, thoughtful and lovely person. Nothing is too much for her. She goes out of her way to help and support not only my husband who has MND, but me too. She is like a ray of sunshine and deserves to be honoured for going above and beyond the call of duty on many occasions.*"

## Jennifer Bell



The John MacLeod award honours someone who has made an exceptional contribution to the MND community, and since her diagnosis Jennifer Bell (29) has spent her time not only creating precious memories with her family, but raising awareness of MND and funds for MND Scotland.

Jennifer has bravely shared her MND journey in the national press, reaching people across the country with her story, including a poignant open letter urging people not to take life for granted. She started sharing her experience of living with MND on social media, opening up about her decision to move to hospice. In her words she wanted to give people "an insight into my life as a single mum, living with a terminal illness called motor neurone disease. The good, the bad, the ugly."

Through her own fundraising, and the generous donations of the many people touched by her story, an incredible £80,000 has been raised for MND Scotland. She has inspired so many people, even receiving messages from First Minister Nicola Sturgeon, pop sensation Lewis Capaldi and Her Royal Highness, the Princess Royal, because of her outstanding contributions.



# Care and Support



**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.**

If you are affected by MND, we're here for you – no matter what.

- Our **Video Support Groups** take place each Thursday
- We can help you into **counselling** via telephone and video calling
- We are still delivering essential **equipment and communication aids**
- Our **Benefits Advisors** continue to make sure you are maximising financial support
- We continue to award thousands of pounds via **grants** to people in need
- We can help you access **Wills, Power of Attorney, and Advance Directive** services for free

Our **Advocacy Service** is also on hand to help anyone with MND who is dealing with issues, such as care provision, employment disputes, and priority for accessible housing or home adaptations.

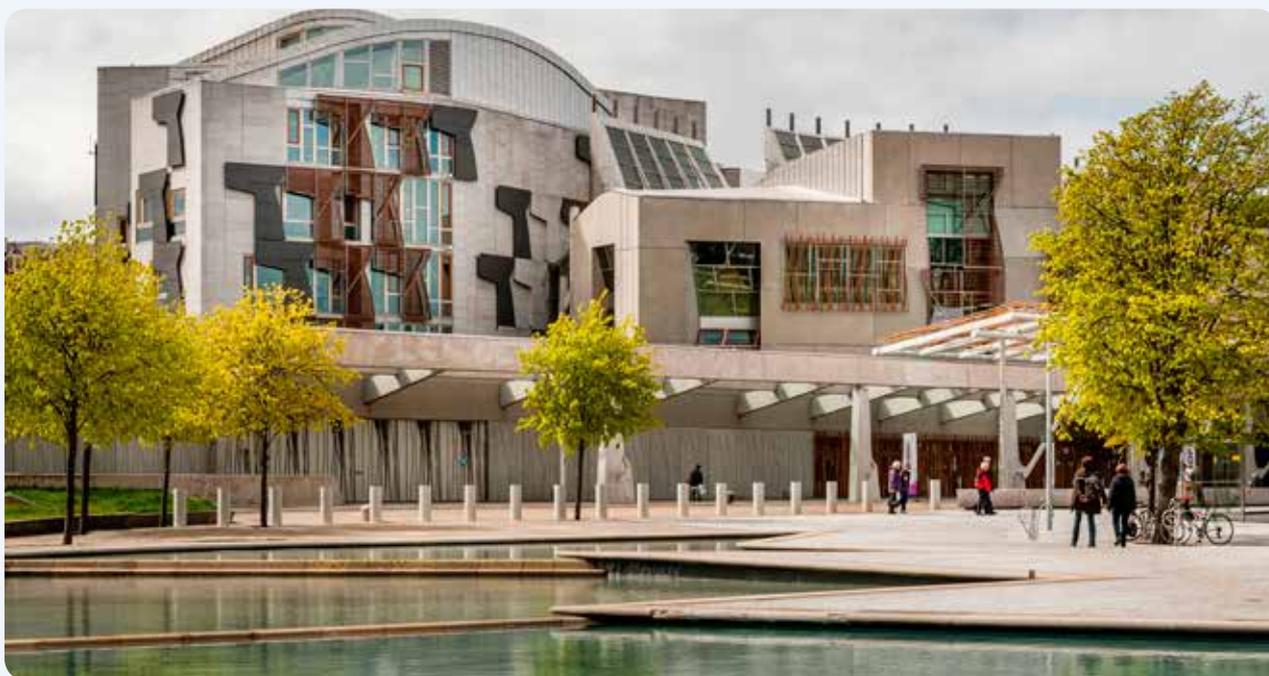
Over the course of this year we have developed new ways of bringing our community together over large distances and we have also provided thousands of pounds in financial relief to those most in need.

To find out more about any of our services, or to let us know if we can help in any other ways, please get in touch by calling us on **0141 332 3903** or emailing **info@mndscotland.org.uk**.

You can also read more at **[www.mndscotland.org.uk/connected](http://www.mndscotland.org.uk/connected)**.



# Policy and Campaigns



## Policy and Campaigns Update

**Over the last few months, the policy team have been busy working on key consultations relating to social security and social care.**

The Scottish Parliament's Social Security Committee launched a consultation to look at what the Scottish Government can do through its powers over social security to protect people during the Coronavirus pandemic. In response to the consultation, we have called for the continuation of fast-tracking benefits for people with MND to ensure there are no unnecessary delays. We have also called for a focus on recruiting the right workforce to deliver the social security benefits, as well as no further delay in the roll out on disability benefits, in Scotland.

In September, the Scottish Government announced an Independent review into Adult Social Care. The review will look at a wide range of issues including the needs, rights and preferences of people using social care and the experience of staff working in the sector.

As part of the review, our policy team have been attending meetings with the Chair of the Adult Social Care review, Dr Derek Feeley, to highlight the experiences of people with MND.

We have also submitted a written report to the Adult Social Care Review panel to highlight the key changes we would like to see with social care to improve the experiences of people with MND. These changes include a fast-tracking system to ensure that people with MND get access to social care quickly, and crucially, a sustainable social care sector which sees improvements in the pay and conditions of the workforce who look after the most vulnerable people in society.

The review will report back to the Scottish Government at the end of January. The Scottish Government will consider the reviews findings and announce the next steps for social care in Scotland.

# Research



**MND**  
Scotland 

**mnda**  
motor neurone disease  
association

**MY  
NAME'S  
DODDIE**  
foundation

## United to End MND

**We are proud to stand with the MND Association of England, Wales and NI and the My Name's Doddie Foundation to ask the UK Government for an investment of £50m into Motor Neurone Disease research.**

Currently the UK government's funding for targeted MND research has plateaued at around £3 million a year. That's not enough.

Launching very soon, United To End MND brings together people with MND, researchers, clinicians and charities in a call to Government to fund a virtual centre of excellence for MND research leading us towards treatments and cures.

In late November, Doddie Weir OBE, joined MND Scotland-funded researcher Ammar

Al-Chalabi on BBC Breakfast, to explain why government investment in fighting MND is needed.

Our shared initiative United To End MND brings together lived experience of MND and top researchers and clinicians in a call to the UK Government to fund the important infrastructure needed to accelerate the discovery and development of new treatments for MND.

**With an adequate investment of £50m over 5 years from the UK Government we can:**

- Focus on world-leading drug discovery and development
- Develop a sustainable MND trials platform
- Implement a rigorous clinical research programme

There has never been a better time for the UK Government to invest in MND research. Scientists across the UK are establishing world-leading drug discovery processes and current clinical trials offer a real promise of licensed treatment for some forms of MND in just 2-3 years.

Earlier this year MND Scotland invested £1.5m (over half of our annual income) into the MND-SMART clinical trial – the UK's biggest clinical trial in a generation.

We know that world-class research costs money and funding from MND charities currently outstrips that from the UK Government. Without government support this vital progress is in danger of halting.

To find out more about our initiative, please visit [www.mndscotland.org.uk/united2endMND](http://www.mndscotland.org.uk/united2endMND).



"If you asked me 25 years ago if there would ever be a cure for MND, I would have said no. But now, in the next few years, I can honestly say that we will probably be able to stop MND in some forms of the disease."

**Ammar Al-Chalabi**  
Professor of Neurology and Complex Disease  
Genetics, Kings College, London



# Research

## MND-SMART

**After a brief pause during the height of the initial lockdown, recruitment for the MND-SMART clinical drug trial has resumed.**

MND-SMART is the UK's biggest MND clinical trial in a generation and was made possible by a £1.5m investment from MND Scotland and all the charity fundraisers, volunteers and donors who helped make it happen.

The clinical trial is now operating out of three

Scottish centres, Edinburgh, Dundee, and Glasgow, and one English centre in Salford. Further centres are expected to come online across the UK in the coming months.

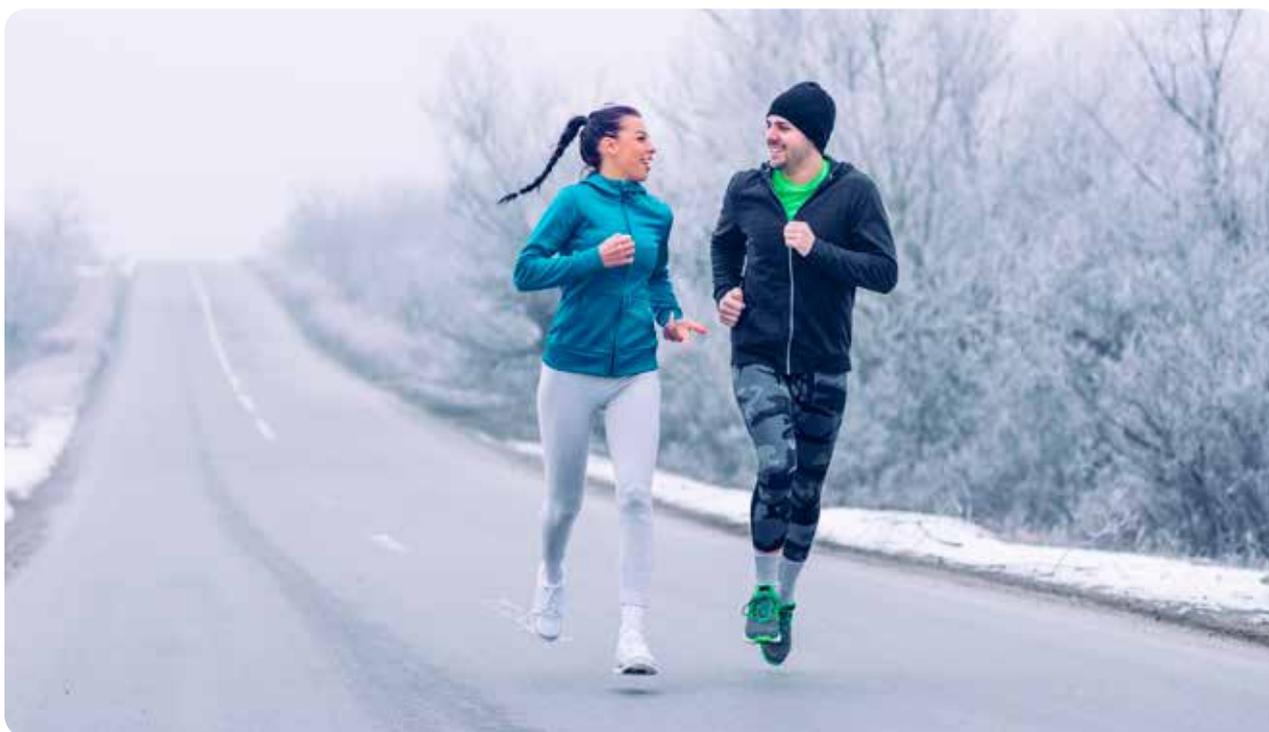
Hundreds of people with MND across the UK have already registered their interest at [www.mnd-smart.org](http://www.mnd-smart.org) to take part in the landmark trial.



## Researcher Q&A

In the New Year we will be launching a series of virtual Q&A session with some of the leading clinicians and researchers in the MND community. It is our hope to connect leaders in MND research to families affected by MND, and everyone who supports our mission, so you can find out more about the vital progress being made and why your continued support to fund research is so important.

We will announce details on our website and social media when details have been confirmed.



## New Year, New You?

This January, we're asking you to **Go Free for MND!** Choose to give up something you love for the month and raise some vital funds to support people with MND.

Whether you cut out cake, ban the booze or turn off the technology, get your friends and family to sponsor you and make a real difference to people with MND.

The tougher the challenge, the more you could raise, as you prove just how determined you are.



## What do I do?

Taking part is super easy. Sign up at [www.mndscotland.org.uk/gofree](http://www.mndscotland.org.uk/gofree) where you will find 21 ideas for what you can choose give up in January 2021.

Once you've signed up simply set up your online JustGiving page where you can collect donations by sharing on social media or even by text or email.

**Every penny takes us a step closer to a cure for MND.**



For many of us this will be a Christmas like no other. But for every family who has lost someone special to Motor Neurone Disease their dinner table may never feel complete again.

MND needs to be stopped and this Christmas thousands are wishing for a cure. With your help we can get there faster. This year we took our biggest ever leap forward, with the launch of the UK's biggest MND clinical trial in a generation. But now, because of the pandemic, future research could be at risk.

That's why we're asking you to give a gift this Christmas that will help transform the future. Whether it's making a one-off donation, pledging a regular monthly gift, or upping your existing regular donation amount, every penny is essential in helping us secure more cutting-edge MND research.

You can make a donation using the back page of this newsletter, by calling **0141 332 3903** during weekdays 9am-5pm, or by donating directly at [www.mndscotland.org.uk/wish](http://www.mndscotland.org.uk/wish).



# Fundraising

## Alan's Story

**"When I was diagnosed with Motor Neurone Disease in 2017 - just before Christmas - it was devastating.**

"Each stage of the disease brings new challenges. I'm at the stage where my legs are now so weak, I use a wheelchair 100% of the time. I try to just deal with one challenge at a time and not dwell too much on the future. I'm determined to be positive about where I am now and enjoy life to the full.

"Knowing there isn't currently a cure for MND is so frustrating, but I believe that if we continue to fund research and drug trials we will find one much sooner.

"That's why I'm taking part in the MND-SMART trial. This is a landmark drug trial designed to speed up the time it takes to find medicines that can slow, stop, or reverse the progression of MND.

"My Christmas Wish? For someone living with MND this is an easy question. I wish we had

a treatment that could stop and then reverse the effects of MND. We can do this by funding more research and more drug trials like the MND-SMART trial.

"Christmas is such a special time for me and my family, but it's clear that Christmas 2020 is going to be very different. It's also very challenging for charities. MND Scotland has had a significant drop in income because of the pandemic, so your support is needed now more than ever.

"This Christmas, if you can, please can you help this wish come true by making a donation to MND Scotland so that we can fund more research and clinical trials.

"I want to find a cure so I can spend even more wonderful Christmases with my family. Your donation can make that a reality for me and everyone else living with MND."

**Alan Gray**

My family celebrating Christmas



My wife and I



# Fundraising

## In Memory

**Pat Quinn, the co-creator of the Ice Bucket Challenge, has sadly passed away at the age of 37, seven years after he was diagnosed with ALS.**

In March 2013, Pat Quinn was diagnosed with amyotrophic lateral sclerosis (ALS), the most common form of MND. After his diagnosis, Pat became an inspiration to millions of people around the world, when he turned his efforts towards raising vital awareness and funds for the fight against ALS/MND.

When Pat, who lived in Yonkers, New York, saw the Ice Bucket Challenge on the social media feed of the friends and family of the late Anthony Senerchia, he knew it was the key to raising much needed awareness.

Pat established a team of supporters - Quinn for the Win - to help in his mission to raise awareness and fund the search for a cure. Pat and his 'Quinn for the Win' supporters, along with the late Pete Frates, a former college baseball star who also had ALS, turned the

challenge into the biggest social media phenomenon in history.

The Ice Bucket Challenge went viral on social media in the summer of 2014, when people around the world posted videos and photos of themselves dumping buckets of ice water on their heads and challenging others to do the same, while urging donations to local ALS/MND charities.

The challenge went on to raise over \$220 million around the world for ALS/MND research and in Scotland alone, an incredible £500,000 was raised for MND Scotland.

The momentum of the Ice Bucket Challenge has dramatically increased awareness of ALS/MND on a global scale and the funds raised have accelerated the search for a cure - leading to new research discoveries and improving care for people living with the illness.

Photo credit: ALS Association



# Fundraising Acknowledgements



8-year-old Scarlett Gaze has raised over £2,000 for MND Scotland by running 20k over 10 days in memory of her friend Dick Holgate.



Well done to all of the team at BNI who have raised a fantastic £5,000 for MND Scotland over the Kiltwalk Virtual Weekend. Thank you so much!



Lisa Mckay raised an incredible £3,055 for by climbing Ben Nevis and taking part in a Skydive. Thank you so much Lisa!



Fans raised an incredible £2,012 for the late ex-Hearts captain Marius Žaliūkas with a donated match-worn shirt. Thank you!



Well done to the stars of the Allandale youth football team who ran 5k around Falkirk's Helix Park raising over £1,000 to support the club and MND Scotland.



Well done to Emma Cunningham who climbed Ben Nevis with a group of friends, raising an incredible £2,530 for the charity.

# 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

\_\_\_\_\_