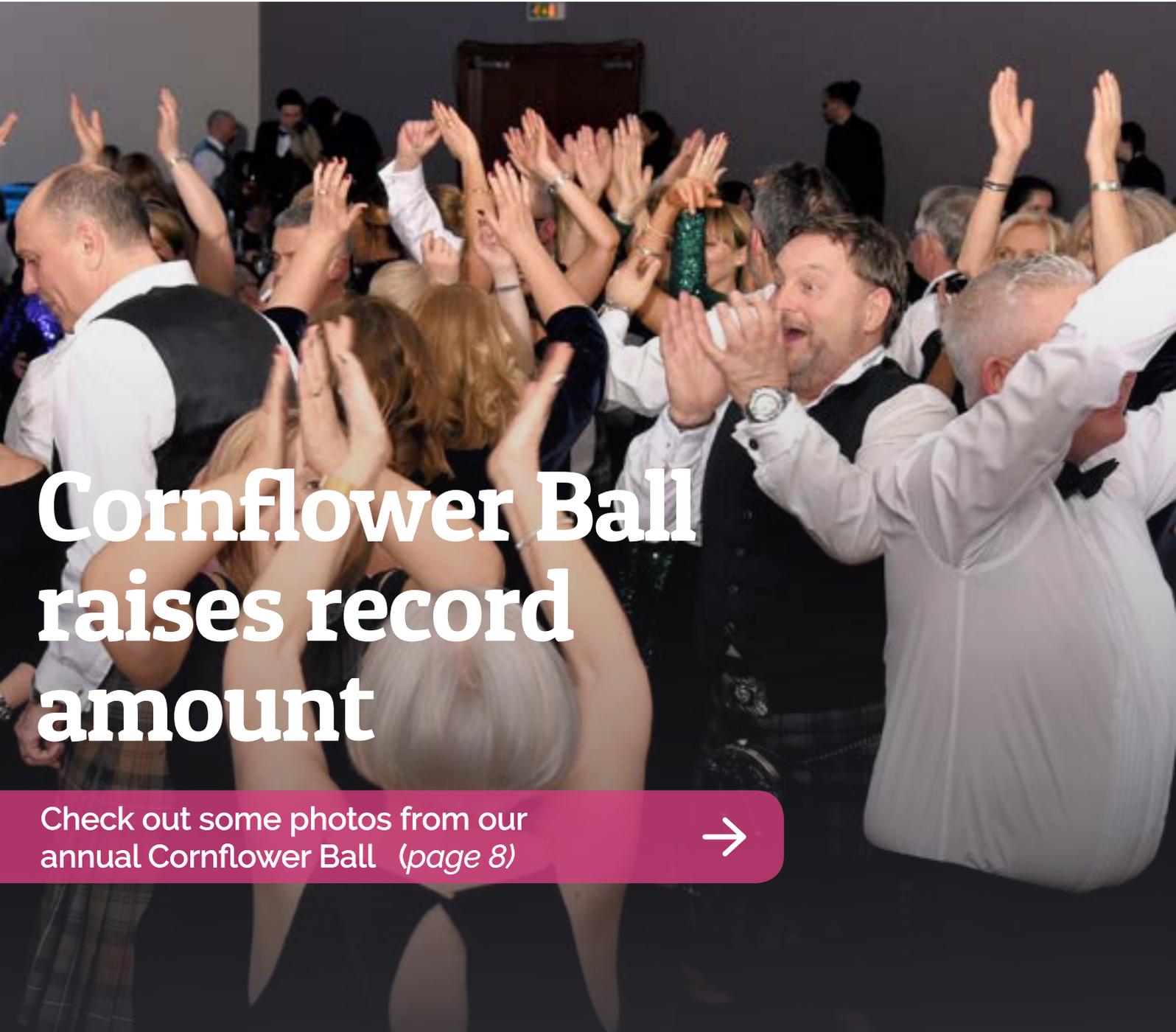


aware

The newsletter of **MND Scotland**
2019 • Issue 2

MND
Scotland 
Supporting people affected by Motor Neurone Disease



Cornflower Ball raises record amount

Check out some photos from our
annual Cornflower Ball *(page 8)*



What's inside:

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Fundraising Events 2019

Kiltwalk 2019

Throughout the year

Lace up your trainers and join us in Dundee or Edinburgh for the Kiltwalk 2019.

Cumbrae Cycle

6th October

Our annual cycle around the beautiful island of Cumbrae.

Tough Mudder

15th June

Test your all around strength, stamina, determination and camaraderie with a 12-mile obstacle course.

Forth Bridge Abseil

6th October

This unique challenge allows you to abseil, free-fall style like the SAS, from a UNESCO World Heritage Site.

Great Scottish Run Half Marathon and 10K

29th September

Join Team MND Scotland at the Great Scottish Run!

Loch Ness Marathon

6th October

Run alongside Loch Ness and its breath-taking scenery at the Baxters Loch Ness Marathon 2019.

Organise your own event

Throughout the year

From coffee mornings to race nights, concerts to quizzes, bag packs to ceilidhs...there are so many ways you can make a big difference. Whatever you want to do, we'll help you make it as successful – and as much fun – as possible!

Treks and Challenges

Throughout the year

We offer a number of treks and challenges throughout the year. From Mount Kilimanjaro, to Machu Picchu and Mount Everest Base Camp, we've got you covered! Find out more by getting in touch.

Please contact the Fundraising Department on fundraising@mndscotland.org.uk or **0141 332 3903**. You can also visit www.mndscotland.org.uk for more information.

Picking up Aware for the first time?

If you would like to receive Aware through the post, please visit www.mndscotland.org.uk/awarepost. To receive Aware by email, get in touch at communications@mndscotland.org.uk, or call us on **0141 332 3903**.

CEO Update

In March, we were thrilled to announce the biggest ever total raised at our annual Cornflower Ball. Thank you so much to everyone who made it a huge success including guests, those who donated prizes, our host and entertainment, and our hard-working fundraising team for pulling it all together.

This July we'll be having the official opening of our brand new accessible lodge in Fife. [See below](#) for details and I hope to see some of you there.

Global MND Awareness Day (21st June) is just around the corner and every year our team at MND Scotland use the week around this date to raise awareness of MND and how it affects families. This year we'll be doing something a little different – have a look on page 4 for more details.

For the past two years, in partnership with the Scottish Government, we have awarded a **£50,000** scholarship to health professionals in Scotland. The Gordon Aikman Scholarship was set up in memory of the late MND campaigner to improve MND care across Scotland. To find out more about our two most recent recipients of the scholarship and their projects, [go to page 7](#).

By the time you read this we'll have just had our annual MND Fun Run at Strathclyde Park (let's hope the weather was good to us!), so make sure you check back in the next issue for photos and the total amount raised.



Craig Stockton, CEO

Craig Stockton

Save the Date

We would like to invite people affected by MND to the opening of our new custom-built accessible lodge on Thursday 4th July. Clayton Lodge is set on the scenic Clayton Caravan Park, in North East Fife. The state-of-the-art disabled-friendly lodge has been specially designed with MND in mind. The new lodge aims to provide families affected by MND, and other disabilities, with a chance to take a break from their normal routine and to enjoy a break together.

The opening of the lodge will be hosted by HRH Princess Royal, and guests will have the opportunity to meet HRH, have a tour of the lodge and are invited to join us for tea and coffee afterwards. Places will be given on a first-come-first-served basis, so please get in touch if you would be interested in attending. You can call Mairi Hughes on **0141 332 3903** or email mairi.hughes@mndscotland.org.uk.



MND Action Week

That's right! We're revamping our annual MND Awareness Week this year. Now known as MND Action Week, we'll be calling on you to take action and pull together to help us end MND.

Between 17th and 23rd June we'll be raising awareness with the general public of how MND affects families and what we can all do together to make a difference and fund a cure.



Throwback! Staff at the ScotRail Alliance supporting MND Awareness Week 2018

What's happening?

- We'll be launching an exciting new campaign to increase awareness and raise funds to take us closer to a cure for MND. We don't want to tell you too much about it yet but keep an eye on our social media accounts for more updates. We can't wait to hear what you think!
- Our corporate partners, the ScotRail Alliance, are donating advertising space across stations and on trains to help us raise awareness of our new campaign. If you see any posters, take a selfie and share it on Twitter and Instagram and tag [@MNDScotland](#). We'll also be doing something new and exciting in key stations across the country. If you see us, come and say hi.
- To help raise awareness of what MND is and how it affects families in Scotland, we are asking people affected by MND to share their personal stories and experiences of the disease. We'll share these in the media and online to boost awareness and understanding. If you want to tell your story, please get us in touch with our Communications Team on **0141 332 3903** or email communications@mndscotland.org.uk.

Over the week we'll be shouting out about what's happening and how you can take action. Keep your eyes peeled on social media, your emails and in the post to find out more about how you can get involved.

Policy and Campaigns



Consultation round up

Over the last few months, the policy team has been responding to various consultations, where we have been asked to give our views on the impact of government policies on people affected by MND. These include consultations on disability assistance, the provision of fully accessible toilets in new buildings and carers assessments for people caring for someone with a terminal illness. In our responses, we were able to incorporate views you have shared in the surveys we have conducted over the last 12 months. Your views are an integral part of our policy work so thank you again to everyone who has contributed to our surveys. If you would like to contribute to our surveys on a regular basis, please email colette.mcdiarmid@mndscotland.org.uk to join our MND Voices group.

Neurological Standards published

Healthcare Improvement Scotland recently published the Standards for Neurological Care and Support in

Scotland. The new standards are applicable to anyone living with a neurological condition in Scotland. Organisations across health, social care and the third sector who support people living with neurological conditions will use the standards to make sure they are delivering high quality services. There are 7 key standards which include guidance for professionals on diagnosis, treatment & management, & staff training and development.



Parliamentary reception

During MND Action Week, we will be hosting our annual parliamentary reception at the Scottish Parliament on 18 June 2019. In our last issue, we announced that Bob Doris MSP for Maryhill and Springburn will be hosting the event. Bob will be joined by his colleague, and long-term supporter of MND Scotland, Christina McKelvie, Minister for Older People and Equalities. The reception is an opportunity for people with MND and their carers to meet with MSPs and ask them to take action on their behalf. If you are unable to attend the parliamentary reception but would like your MSP to take action to improve the lives of people with MND, why not email your local MSP with your concerns. Visit the Scottish Parliament website at www.parliament.scot and enter your postcode on the homepage to locate your MSPs.

Research

How common is MND?

Dr. Danielle Leighton was funded by MND Scotland for a three-year MND Clinical Research Fellowship, at the University of Edinburgh. One of the questions she sought to answer was, how common is MND in Scotland? She recently published the findings in the Journal of Neurology in April 2019 and her findings can be found below.

This study investigated the number of people newly diagnosed with MND each year (the incidence) and the number of people living with MND in Scotland at any one time (the prevalence). The research investigated the time period of 2015-2017, and used data from the Scottish MND Register/ CARE-MND platform.

The CARE-MND platform is set up to collect and store information about people with MND. This information helps researchers to build a broad picture of why MND happens to some people and not others, and can be used to audit care standards across different health boards and local authorities.

The team discovered the following:

- About 200 people are diagnosed in Scotland annually. This represents an incidence of about 4 per 100,000 of the population per year.
- The number of people living with MND at any one time ranges between 400 and 430. This represents a prevalence of about 8 per 100,000 of the population.
- The incidence of MND in Scotland is not associated with social deprivation.
- The incidence of MND in Scotland has increased (compared with 20 years ago) and is higher than that of other European countries. It is thought the main reason for this is that we have an exceptionally good infrastructure for MND care in Scotland, with a recent doubling of the number of MND Clinical Specialists. Researchers have therefore been able to identify and record people with MND better. Researchers are also now more aware of the different types of MND, and include these different types in our numbers.
- Work is ongoing to explore other reasons which might explain the increased incidence, such as environmental and genetic factors. Theories include i) improved treatment of other diseases such as heart disease, ii) genetic variations which may be more common in Scotland.



It was a privilege to take the lead on this study as part of my PhD Fellowship. Being aware of how common MND is in Scotland is essential for planning regional and national health services. Hopefully we have also been able to answer some important questions that people with MND and our supporters might have.

This work is a result of the collaborative efforts of all MND healthcare teams in Scotland. We'll be reporting back on more research findings soon and hope to continue our work to find out as much as possible about MND in Scotland.

Gordon Aikman Scholarship

The Gordon Aikman Scholarship was set up in 2017 to support healthcare professionals to develop new ideas which could improve MND care.

In June 2017, we announced that we would be match-funding the Scottish Government's annual **£25,000** investment into the Scholarship, bringing its total value up to **£50,000** per year. We have now selected the two recipients of our 2018 funding.

Andy Bethell, MND Clinical Specialist Mental Health Support Plans for People Affected by MND

This project aims to improve the wellbeing of people who care (unpaid) for someone with MND by creating and implementing a mental health support plan. This plan will provide a tool to enable the person caring for someone with MND to recognise and prevent developing mental health issues in themselves.



"Approximately 10% of people with MND suffer from a mental health issue during the course of their disease, however over 30% of carers experience significant mental health issues when caring for someone with MND.

"This has a detrimental effect on both the wellbeing (mental and physical) of the carer and also the level of care they can provide for the person with MND, as well as its effects on the wider family group.

"My hope is that this project will reduce worry, stress and distress for carers which will then allow them to provide a better level of care for the person with MND, and improve the lives of those living with the disease."

Dr Jenny Preston, MBE Optimising the Health and Social Care Professionals Team for MND

People with MND are cared for by a number of different healthcare professionals with differing expertise. This group of professionals is known as a multidisciplinary team (MDT). This project aims to review the role of the MDT in the management of MND, and to develop consensus on best clinical practice in the configuration and format of MDT in the UK.



"UK guidelines suggest that each MDT should provide co-ordinated care for people with MND. The team should include health and social care professionals with expertise in MND who see people in their own homes as well as in the clinic. There is evidence that an MDT approach in clinic can lead to improved survival rates, higher standards of care and cost effective interventions.

"However, evidence is lacking in the optimal configuration and format of the MDT clinic. Consequently, clinics vary in how they are formed and delivered. Optimising the professional configuration and format of the MDT is likely to maximise the benefit of these clinics for people with MND."

Fundraising

Cornflower Ball 2019

Thank you to everyone who helped raise nearly **£75,000** - our **biggest total ever** - at this year's MND Scotland Cornflower Ball.

Guests had a fantastic evening of fun and fundraising, with our host Tam Cowan, magician Billy Reid and music from Big Vern 'n' the Shootahs. We're already busy organising next year's event so keep your eyes peeled for updates!



Glasgow Kiltwalk 2019

Huge thanks to the 125 Glasgow Kiltwalkers who took on the 23 mile, 15 mile and 6 mile routes for MND Scotland. With money still coming in and the additional 40% contribution from The Hunter Foundation, **we hope to reach an amazing £70,000!** If you want to sign up for the Dundee or Edinburgh Kiltwalks visit www.mndscotland.org.uk/kiltwalk.



Edinburgh Branch Ceilidh

The MND Scotland Edinburgh Branch raised an incredible **£12,000** last year by undertaking a series of fundraising ventures. The team are continuing their activities in 2019 with can collections in the Edinburgh area and their two annual fundraisers – a Cheese & Wine night in the Virgin Money Lounge and a very successful Ceilidh which took place in March.



Photo: Margaret McGrath, Molly Robertson, Dave Nicklas, Ann Callaghan and Fiona Hutchison from the Edinburgh Branch at their annual Ceilidh.



Fundraising Acknowledgements

Here are just a few of our amazing fundraisers from the past few months. Thank you everyone, including those not pictured below.



Andrew, David, Kenny, Martin and Ross took part in the Inverness Half Marathon in March as part of Team Thurso raising an incredible £3,672.49.



Becky Choat raised £1,252 for running the Stirling Marathon for MND Scotland.



Fiona Greaney and Charles Stable took on the London Marathon for MND Scotland. Fiona raised over £5,000 and Charles raised £205.



Morag Barr supported MND Scotland at her recent Birthday party, raising £1,560.



Claire Peebles completed the Alloa Half Marathon and raised a massive £696.



Sarah Gibson, and friends Fran and Amy, completed the West Highland Way in memory of Sarah's dad, John. They raised a fantastic £1,891.



Clair Howison raised an amazing £1,784 at the London Marathon.



Sam Kain took on the London Marathon and raised £1,175.

How We Can Help

If you or someone you know has been diagnosed with MND, we are here to help.

Advocacy

Our advocacy service supports people affected by MND to resolve any issues, for example, delays with local authorities, and take some of the stress away from dealing with these.

Benefits Advice

A diagnosis of MND can bring additional expenses and we can help you apply for the benefits you are entitled to.

Equipment Loan

We have an equipment loan service which can lend equipment, to help people live more comfortably with the effects of MND.

Grants

We have three different kinds of grant available to people affected by MND, to help with costs associated with MND.

Complementary Therapy

We provide complementary therapy sessions to people with MND and/or their family carers. You may not consider yourself a 'carer' but if you are helping look after someone with MND you can use this service.

Communication Aids

If you have MND and need an aid to help you communicate, whether that's speech or writing, we may be able to help.

Education Service

We provide a free education service, for families and health care professionals, to those who wish to learn more about MND and the services we offer.

Counselling

Receiving a diagnosis of MND, or having a loved one receive a diagnosis, can be extremely overwhelming. We offer a counselling service to people affected by MND to help you cope with these emotions.

Physiotherapy

Our physiotherapy programme for people with MND can help you stay independent for longer and improve your quality of life. It may help you manage pain and maintain existing movement of your limbs for as long as possible.

Accessible Holiday Accommodation

If you are looking for a break from your daily routine our accessible accommodation, in Oban and St Andrews, could be perfect for you. The accommodation can be booked by anyone but people affected by MND will receive a discount.

Support Groups

Whether you have MND, or are a current carer or family member, you are welcome to join us in a social setting to exchange information and provide support to one another. We have groups available across the country.

Information

We provide information on a variety of topics to people affected MND; including carers, family members and health professionals.

To find out more about any of our services please get in touch by calling **0141 332 3903**, email us at info@mndscotland.org.uk, or ask your MND Clinical Specialist.

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 _____

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

Name _____

Address _____

_____ Post Code _____

Email _____

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

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every £10 donated, MND Scotland
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your donation you must tick the box
below and sign the declaration.

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the past 4 years. I am a UK taxpayer
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responsibility to pay any difference.**

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