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The newsletter of **MND Scotland**
2018 • Issue 2

MND
Scotland 
Supporting people affected by Motor Neurone Disease

Campaign victory for people with MND

New law means all people with MND in Scotland should be fast-tracked for benefits. Read more on *(page 8)*



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Fundraising Events 2018



Kiltwalk - Aberdeen

3rd June 2018

Take on the Mighty Stride, the Big Stroll or the Wee Wander and walk for MND Scotland.

Gordon's Fightback Dinner

21st June 2018

Join us for a dinner in memory of MND campaigner Gordon Aikman, at Prestonfield House, with special guests Doddie Weir and Scott Hastings.

Kiltwalk - Dundee

19th August 2018

Take on the Mighty Stride, the Big Stroll or the Wee Wander and walk for MND Scotland.

Firewalk & Glasswalk

12th October 2018

The Firewalk is back at Hampden Park and will be joined by the brand new MND Scotland Glasswalk. Are you brave enough?

Zipslide

16th-17th June 2018 and
25th-26th August 2018

Sign up for this exhilarating zipline experience across the Clyde in aid of MND Scotland.

Holyrood Fun Run

18th August 2018

Our annual Fun Run at Holyrood Park is back for another year. You can walk, jog, run or use your wheelchair for the 5k route around Arthur's Seat in Edinburgh.

Scottish Half Marathon & 10K

23rd September 2018

If you're looking for a new challenge or a new personal best, then the fast and flat Scottish Half Marathon could be for you. Get in touch for charity places.

Forth Bridge Abseil

21st October 2018

Challenge yourself with Scotland's biggest abseil from Scotland's most iconic structure.

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 or call us on **0141 332 3903**. You can also sign up for email updates by emailing communications@mndscotland.org.uk.

CEO Update

Firstly, I want to thank everyone who supported our campaign on the terminal illness definition to ensure a fairer social security system in Scotland. Your action and the work of our Campaigns team, along with Marie Curie Scotland, has meant that there will be no life expectancy qualification for people who are terminally ill, when applying for fast-tracked benefits. Instead people with a terminal illness will be fast-tracked for benefits based on clinical judgment. This will make an enormous difference to the lives of people with MND. Read more on page [page 8](#).

We had a cracking day for our annual Fun Run at Strathclyde Park on Saturday 12th May. The sun was shining and hordes of MND Scotland t-shirts flooded the park. Thanks to you we have raised an outstanding **£30,000** and counting. Thank you to everyone who made the day a success. Have a look at some of the photos on page [page 12](#).

In April I attended the Neuroprogressive Conditions Research Day in Dundee, where current research into MND and other neurological conditions was showcased. You can read more about that on [page 10](#).

Finally, we are fast approaching MND Awareness Week again. This week runs from 18th – 24th June with Global MND Awareness Day on Thursday 21st June. Over the week our team, supporters and partners will be raising awareness of the illness and how it affects families. Find out what's happening and how you can get involved on [page 5](#).



Craig Stockton, CEO



Caravan Closure

We are sad to announce that after 14 years on-site, our caravan at St Andrews will be closing in October 2018. We still have availability for bookings between now and October so make sure you book soon at mndscotland.org.uk. The closure is due to the policy of the caravan site but we are already putting plans in place to replace it with new and improved accommodation on the East Coast, which we hope will be ready for March 2019. Watch this space for more updates.

New Privacy Policy

MND Scotland has updated its Privacy Policy in line with new data protection laws which have come into place. These new laws will strengthen your privacy rights and keeping your data safe is very important to us.

To view our new Privacy Policy please visit mndscotland.org.uk/privacypolicy or request a copy in the post by calling us on **0141 332 3903** or emailing info@mndscotland.org.uk.

Legal Right for Communications Aid

It is now a legal obligation for health boards across Scotland to provide people who need it, with a communications device.

In 2015 MND Scotland launched the Let Me Speak campaign which called on the Scottish Government to introduce a legal duty for the NHS to provide communications equipment for those who need it, highlighting that people with MND should be treated as a priority. Thanks to our campaigning, the provision of communications equipment was passed into law in April 2016.

On 19th March 2018 this law came into effect and now health boards across Scotland have a legal obligation to provide people who need it, with a communications device.

Lawrence Cowan, Chairman of MND Scotland said:



"This is another huge step that will transform care for people with MND, and so many other conditions.

"Many people with MND find losing their voice one of the hardest symptoms of the illness to live with. This law unlocks so much more than a piece of equipment; it will support people's independence and help them communicate with those they love.

"MND Scotland is proud to have campaigned for this law alongside so many people affected by the disease, including Gordon Aikman. The change that they have secured will be felt for generations to come."

Health Secretary Shona Robison said:

"We're committed to improving the lives of people who have lost their voice or have difficulty speaking.

"That's why I'm delighted that from today (March 19), all NHS boards in Scotland now have a duty to provide communications equipment and the support to use it, frequently referred to as Augmentative and Alternative Communication (AAC), to anyone who needs it.

"Across Scotland, specialist AAC services are already provided in response to local need. Today marks this provision becoming a legal duty.

"These forms of equipment can make a real difference in the lives of people facing profound challenges, making sure they have a voice to be heard."



MND Scotland can still provide some equipment for people who have MND, while they are waiting for their device. Find out more about our service at mndscotland.org.uk or get in touch at info@mndscotland.org.uk or **0141 332 3903**.

MND Awareness Week 2018

MND Awareness Week is the **18th - 24th June 2018**, with Global MND Awareness Day on **Thursday 21st June**.

As usual we'll be trying to spread as much awareness across the country as possible, of what MND is and how it affects people here in Scotland and across the world. This year we will be focusing on the misconceptions and stigmas faced by people with MND. We'll be sharing people's experiences in national and local press and on social media. **If you have a story about a time when you, or someone you know, experienced a stigma or misconception of MND, please get in touch.**

What else is happening?



Shine a Light on MND

We've been asking local councils and companies to **'Shine a Light on MND'** for Awareness Week by lighting landmarks and buildings up in blue. Last year we saw the likes of the Kelpies, the SSE Hydro and the Titan Crane light up, and we hope to have even more this year! If you have any contacts that might be able to help with this, please let us know, and if you see anyone Shining a Light on MND, send your photos to us or share them on social media.

ScotRail Alliance

Our charity partners the ScotRail Alliance will be helping us raise awareness during MND Awareness Week. Look out for us on **21st June** at these stations or get in touch if you'd like to volunteer to bucket collect; Glasgow Central, Glasgow Queen Street, Aberdeen, Inverness, Motherwell, Paisley, Johnstone, Ayr, Haymarket, Waverley and Dundee. Staff will be dressing down on 21st June so if you see any staff on trains or in stations please take pictures and share using **#journeytoacure**. A group of ScotRail Alliance employees will also be taking the plunge with a sponsored skydive on Sunday 24th June to round off the week.



Scottish Parliament reception

On the evening of Wednesday 20th June we will be hosting a reception in the Garden Lobby of the Scottish Parliament. Find out more on **page 9**.

Gordon's Fightback Dinner

On Thursday 21st June we will be holding a fundraising dinner in memory of MND campaigner Gordon Aikman, with special guests Doddie Weir and Scott Hastings. Get your tickets at **mndscotland.org.uk**

Support, Branches & Volunteering

Welcome to the team

Our new Advocacy service launched in April and our two new members of staff are raring to go. Our Advocacy Workers will cover the whole of Scotland and the service will help people affected by MND if they are having issues, for example accessing local support or care packages, or moving to accessible housing.



Suzie Sturrock
Central and South of Scotland

"I have over 20 years' extensive experience in the field of advocacy and have worked within various areas including complex and life-limiting health conditions; addictions; mental health; and homelessness.

"I often feel that a lot of the issues are created by a lack of understanding of the medical condition and the persons' circumstances, and I see my role as also educating other services about the difficulties that people with a diagnosis of MND experience.

"When I'm not at work I enjoy spending quality time with my family, going out for dinner, the theatre and cinema, and also going for long walks with our miniature schnauzer dog Abi!"

Contact Suzie on suzie.sturrock@mndscotland.org.uk or **07889 418 397** for more information about our Advocacy Service.



Carla Belkevitz
Central and North of Scotland

"After being made redundant from my previous advocacy post due to a loss of funding, I was devastated at the thought of being unable to continue to do the job that I loved. My background is varied, from working with young parents, managing an employability project and advocating for young people and adults.

"My passion is supporting disadvantaged groups in society and ensuring they are able to gain access to the supports they require. I want to help them tear down whichever barrier they come up against.

"In my personal life I am a busy mum of two sporty boys. I have continued to study and work hard to make sure that my skills are always sharp, and I am about to start the 5th year of my honours degree with the Open University."

Contact Carla on carla.belkevitz@mndscotland.org.uk or **07889 416 504** for more information about our Advocacy Service.

Our Services

We are here to help support you and your family by offering practical, financial and emotional support.

All of our services listed below can be accessed by getting in touch with your MND Clinical Specialist, by contacting us at info@mndscotland.org.uk, or by calling us on **0141 332 3903**:

- Advocacy
- Benefits Advice
- Equipment Loan
- Grants
- Complementary Therapy
- Counselling
- Physiotherapy
- Accessible Holiday Accommodation
- Support Groups
- Education Service



Volunteer at Holyrood Fun Run

Are you free on **Saturday 18th August 2018** from 9.30am to 12.30pm to help out at our Fun Run at Holyrood Park, Edinburgh? We need around 40 volunteers to help with tasks such as route stewarding; car park management; registration duties; handing out goody bags and manning merchandise stalls within the tent.

Last year we had a record breaking **650 runners** take part with hopefully more this year, so your role is vital in ensuring that the event runs as smoothly as possible. Once you have registered your interest you will receive further information nearer the time. T-shirts and instructions will be issued on the day. Volunteers aged 14-16 may apply if there is a supervising adult to accompany them.

If you would like to volunteer for this event can you contact Dawn Hamilton on **0141 332 3903** or email her on dawn.hamilton@mndscotland.org.uk.

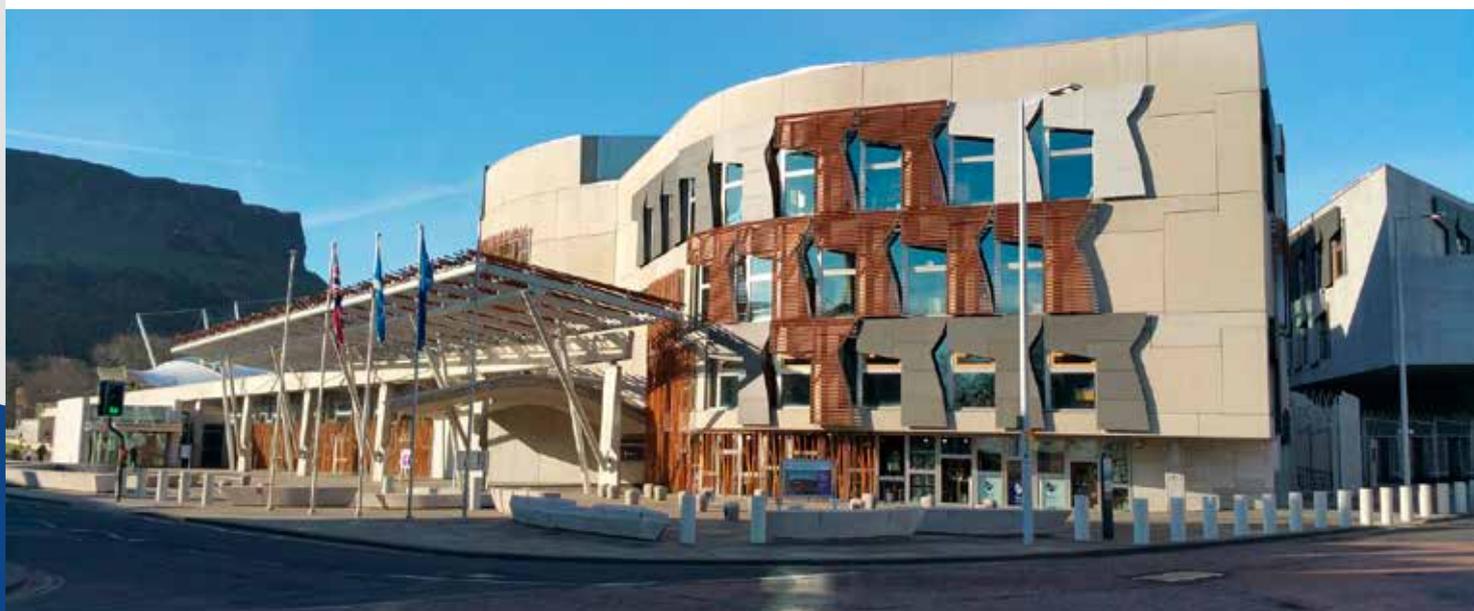


Campaigns and Policy

New law for fast-tracked benefits

On 25th April, the Scottish Parliament took a historic vote to pass the Social Security (Scotland) Bill. This includes a much fairer system for people with MND who need to access those benefits which have been devolved to the Scottish Government, such as Personal Independence Payment (PIP). The Act comes into force in 2021.

The current UK-wide system only fast-tracks terminally ill people, including those with MND, for benefits if their doctor or nurse completes a form to state they have just 6 months or less to live. This means that many people with MND have to wait months for their benefits and undergo face-to-face assessments.



We have been working with Marie Curie to ensure a fairer system for all those with a terminal illness in Scotland. Together, we lobbied the Scottish Government, MSPs, and civil servants over a period of many months. We launched a campaign for supporters to engage with their own MSPs explaining why a fairer system is essential. Our dedicated MND Scotland supporters sent an incredible 3700 emails to their MSPs. We also secured press coverage in the Times and BBC in which people with MND told their personal story about living with the illness and the problems they faced with the benefits system. The Times article included a 'letter to editor' signed by **57 medical specialists** supporting our call for a fairer system.

We were delighted when finally the Scottish Government and all MSPs agreed to a Scottish social security system which will have no reference to life expectancy. Instead, it will be down to the clinical judgment of a person's own doctor or nurse meaning all people with MND should be fast-tracked for benefits, receive them at the higher rate and without face-to-face assessment. In addition, a proposal for reassessing terminally people for benefits like PIP was dismissed by MSPs earlier in the legislative process, meaning people with MND should be awarded these benefits for life.

We would like to thank our partners Marie Curie, many MSPs who worked tirelessly to support our cause, and finally our amazing MND Scotland supporters who helped us achieve this landmark result for all those affected by the illness.

Carers Act update

Last month, a new Carers (Scotland) Act was launched by the Scottish Government. Under this Act, anyone providing unpaid care for friends, family, and neighbours will now have the right to a personalised plan. The plan aims to identify a carers needs and help them access information, advice and support. The new Act also places duties on local authorities to consider short breaks for carers and to involve them in the process of hospital discharge planning of the cared-for person. If you are a carer of someone with MND and you need support, why not get in touch with our new Advocacy Workers who can offer you support and advice. Find out more about our Advocacy Service on [page 6](#).

Parliamentary Reception

On Wednesday 20th June we will be hosting our annual reception in the Garden Lobby of the Scottish Parliament, with longstanding supporter, Christina McKelvie MSP. The Minister for Public Health and Sport, Aileen Campbell, will also be a guest speaker at the event. Our aim is to raise awareness of MND and our work, during Awareness Week, in the Parliament to ensure MSPs and Scottish Government Ministers know how they can support people affected by the illness. We have posted invites to people affected by MND across Scotland and we hope you can join us. At the event, you will have an opportunity to meet the staff from MND Scotland and MSPs on the night to raise issues that are important to you. If you have any questions about the reception, please get in touch with our Policy Officer, Colette McDiarmid - colette.mcdiarmid@mndscotland.org.uk or **0141 332 3903**.



MND Scotland Parliamentary Reception 2017

Research

Neuroprogressive Conditions Research Day

The inaugural Neuroprogressive Conditions Research Day was held in Dundee on 19th April. The meeting, which was sponsored by The Chief Scientist Office (CSO) of the Scottish Government, in partnership with the NHS Research Scotland and Neuroprogressive and Dementia Network, was attended by health professionals, and patients with various neurological conditions such as Multiple Sclerosis, Parkinson's Disease, Huntington's disease and MND.

The theme of the day was the current landscape and future direction for patient-centred research in Scotland. Speakers included members of the public, third sector and research staff. Representing MND, Dr. Danielle Leighton, Dr. George Gorrie and Dr. Suvankar Pal discussed their research in MND.

Dianne Fraser and Alison Clark, the first recipients of the Gordon Aikman scholarship also spoke: Dianne focussed on the hurdles she overcame when applying for funding for her project and Alison gave a brief outline of her study into the provision of Non-Invasive Ventilation. Strict time keeping meant no-one was allowed to overrun their time slot and ensured that everyone's opinions were heard. At the poster exhibition, Dianne displayed a poster about her work on Breath Stacking. Dr. Menai McDonald and Dr. Gorrie, displayed the results of their study on Mortality and Artificial Nutrition on the Scottish MND population diagnosed between 2015 and 2016.

If you'd like to find out more about the Research Day or any of the talks, please email info@mndscotland.org.uk or call us on **0141 332 3903**.

CARE-MND

CARE-MND stands for Clinical Audit Research Evaluation - Motor Neurone Disease. CARE-MND is the clinical and research platform for MND in Scotland.

The platform allows the clinical team and researchers to accurately map the number of people living with MND across all 14 health boards, your clinical features and ensure your management is delivered to the highest standards. It also allows researchers to study every aspect of the condition from the number of newly diagnosed people each year, to genetic causes of MND, better diagnostic tests, the effects of supportive treatments and ultimately deliver treatment trials. **84%** of you have already signed up to be contacted about ongoing and future research projects.

For further information on signing up or taking part in research go to www.care-mnd.org.uk or contact your MND Clinical Specialist.



International Symposium on ALS/MND 2018

MND Scotland is proud to host the 29th International Symposium on ALS / MND

This event is organised by the Motor Neurone Disease Association (MNDA) of England, Wales and Northern Ireland, in cooperation with the International Alliance of ALS/MND Associations.

Each year, the Symposium attracts over 1,000 delegates from around the world, representing a unique opportunity for the world's top MND/ALS professionals to come together to share the work they are doing in research, genetics, care and clinical management.

The Symposium is the largest medical and scientific conference specific to MND/ALS and helps demonstrate the enthusiasm and commitment of the global MND community to develop new ways of tackling MND.

We are delighted to have the next Symposium in Glasgow from 7th-9th December 2018. To keep up to date with all the latest updates from the Symposium, visit www.mndassociation.org/symposium.



Call for Research Projects

One of MND Scotland's key priorities is funding and supporting research into all aspects of MND and we have recently put out a 'call' across the country for new research applications.

All our research grants aim to stimulate and increase high quality research projects into MND. Grants will be awarded for up to a maximum of three years. Prospective researchers, associated with UK Institutions, should submit an application by **30th June 2018**.

For further details please visit www.mndscotland.org.uk/researchawards or contact our Education and Research Officer, Steven Karlsson-Brown on **0141 332 3903** or email steven@mndscotland.org.uk.

We'll update you when new projects have been selected for funding.

Fundraising



Strathclyde Park Fun Run 2018

Our annual Fun Run at Strathclyde Park on **Saturday 12th May** was again a huge success; and the sun was shining which made it even better! Almost **800 people** took part in the **4 or 6 mile** course and were cheered on by friends, family and the team at MND Scotland.

This event has already raised an incredible **£30,000** and counting. Thank you to all our runners, walkers, wheelchair users, supporters, volunteers and staff for making this possible. You are helping us continue to support people affected by MND across the country and fund research which is taking us a step closer to a cure.



If you missed out you can sign up for our Edinburgh Fun Run at Holyrood Park on Saturday 18th August by visiting www.mndscotland.org.uk/funrun.

Zip Slide Across the Clyde

Thanks to everyone who joined us in April and zoomed across the River Clyde on a zip wire to raise **£14,876** for MND Scotland. If you missed out, we have more dates available:

- Saturday 16th June
- Sunday 17th June
- Saturday 25th August
- Sunday 26th August

You'll be attached to a mobile crane, with great views of the Finneston Crane, Squinty Bridge, SECC, Armadillo and Hydro.

Registration is **£20**, with a minimum sponsorship of **£100**. MND Scotland will provide: sponsorship forms; help with setting up an online sponsorship page; a t-shirt to wear on the day; and, a great deal of encouragement!



Fundraising Acknowledgments

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



Alan Arnott completed the Maritona di Roma raising over £5,000.



Hazel Kirkland chose to support MND Scotland during her time as captain of the Ladies Section at Old Course Ranfurly Golf Club in Bridge of Weir. They raised a total of £4,012.



A group of ScotRail Alliance employees completed the West Highland Way. Led by Kenny Currie and his team "The Magnificent Seven" they have raised an incredible £2,700.



Kirkcaldy Gymnastics Club recently raised £707.83 for MND Scotland with their annual sponsored obstacle course.



£7,000 was raised by our corporate partners, Leonardo UK, through zip slides, running events, quiz nights and calendar sales.



Thanks to Bernie Robertson, Co-op stores in the Inverness/North of Scotland region held bucket collections and displayed collection cans to help raise funds for MND Scotland.



Pamela Semple, along with friends and family, held their annual Bingo Night which raised £2,415.



Claire Quinn took part in the Stranraer Colourful 5K on Saturday and raised £117.



Victoria Stewart raised a fantastic £2,380 by taking part in the London Marathon.



A team from the Provincial Grand Lodge of Edinburgh tackled Beinn Ghlas and Ben Lawers to help raise cash for MND Scotland.

Accessible Holiday Facilities

If you are looking for a break from daily routine, our accessible holiday accommodation could be perfect for you. We offer two specially adapted holiday facilities for use by people affected by Motor Neurone Disease (MND) and others with physical disabilities.

Our accommodation can be booked by anyone, however, if you are affected by MND, you will receive a discount, and may also be able to apply for our 'Time Out Grant' to put towards the cost.

Booking

You can book online at www.mndscotland.org.uk/holiday-facilities.

To find out more about the accommodation or about the discounts available to people affected by MND, please contact Mairi Hughes on **0141 332 3903** or email mairi.hughes@mndscotland.org.uk.

Tralee Bay Chalet

Our holiday chalet is situated on a breathtaking part of the west coast of Scotland, just north of Oban, at Tralee Bay Holiday Park.



Lang Break Caravan

Our accessible caravan is located at Craigtoun Meadows Holiday Park near St. Andrews. This is the perfect getaway location if you want a break from your usual routine. You can book until the caravan closes in **October 2018**.



What do you think of our Aware newsletter?

If you have any feedback on Aware or have any ideas about what you'd like to read more about, please get in touch by emailing communications@mndscotland.org.uk or call **0141 332 3903**.

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 _____

Signature _____ Date _____

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

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Using Gift Aid means
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pence from the Inland
Revenue, helping your
donation go further.

If you are a UK taxpayer
and want to take advantage
of Gift Aid, please tick the
box provided. You must pay
income or capital gains tax
at least equal to the amount
we will claim in the tax year.

**Please treat this as a
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