



Fighting Back for 40 Years

Impact Report 2020/2021





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Our dream is...

...a world without motor neurone disease (MND).

We believe...

...no one should have to experience the devastation of MND.

We are here to...

...do everything in our power to make life easier for people living with MND right now; and build a movement to end MND.



Adrian Murphy
Chair of MND Scotland

This year has 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.

Over the past year we have had to make some very difficult decisions. At the start of the pandemic our key priority for the year ahead was to minimise the risk of people with MND, their carers, supporters, volunteers and our staff, from contracting Covid-19, as well as continuing to provide support to people living with MND in Scotland.

In March 2020, all MND Scotland face-to-face services were postponed – this included complementary therapies, physiotherapy, in-person counselling and support groups, and our holiday service was, at times, unable to operate. Regrettably, this resulted in two members of our services team being made redundant, a decision we did not take lightly. I thank Dawn and Ian for all their contributions over the years.

To help combat the loneliness and isolation of the pandemic, we launched our refocused MND Scotland Connected services, to help people living with MND stay connected, find support and feel in

control, during a time when nothing felt certain.

All face-to-face fundraising events were cancelled and community fundraising was largely restricted. However, thanks to your continued support, through donation drives, virtual events and unique fundraising initiatives, we only saw a 23% drop in income. Thank you for continuing to help us fightback against MND.

I would also like to extend my gratitude to our staff, who have shown incredible resilience this past year; balancing working from home, dealing with a global pandemic and still keeping people living with MND at the heart of everything they do.

During this time, one thing that has never changed is our commitment to make life easier for every individual and family living with MND in Scotland, and our determination to continue our search for a cure.

Thank you,

Adrian Murphy

Here for you. No matter what.

This year, people with MND were impacted more than ever before, with social-isolation measures placing huge restrictions on the care and support many rely on every single day.

To make sure that no one had to go through MND alone, while the country was on lockdown, we launched our refocused MND Scotland Connected services.

Our Connected services introduced one-to-one phone support, video support groups and emergency financial grants, to ease some of the financial and emotional stress experienced by families, as a result of Covid-19.



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After weeks of self-isolation, MND Scotland reached out and connected me with other people with MND through a video support group. It's heart-warming to be able to speak to other people who live with MND and share experiences on how to get through this terrible experience.

Robert Elliot



**In 2020/21, your support
meant we could reach
people when they needed
us most...**

Emotional support



We spoke to **272 people** to check in during the first lockdown and **30%** asked us to keep in touch.



Unfortunately due to the pandemic we had to stop face-to-face counselling which meant many people decided not to continue using the service. However, **17 people** took up the opportunity for video or telephone counselling. We will re-introduce face-to-face counselling as soon as it is safe to do so.



We launched our **first video support group** in response to Covid-19 and hosted **51 sessions** over the year. Due to its success we'll continue to run an online group to connect those who cannot attend our in-person support groups when they return.

Financial support



124 people accessed our Wills and Power of Attorney service



192 grants were awarded to those affected, worth **£168,180**



We helped **374 people** claim a total of over **£1.2 million** in benefits



Practical support



196 pieces of equipment were given to help people with MND live more independently



We helped **32 people** get their voice back by funding **Speak Unique** – a service which offers personalised synthetic voices for use in communication aids. To read more about it go to page 21.



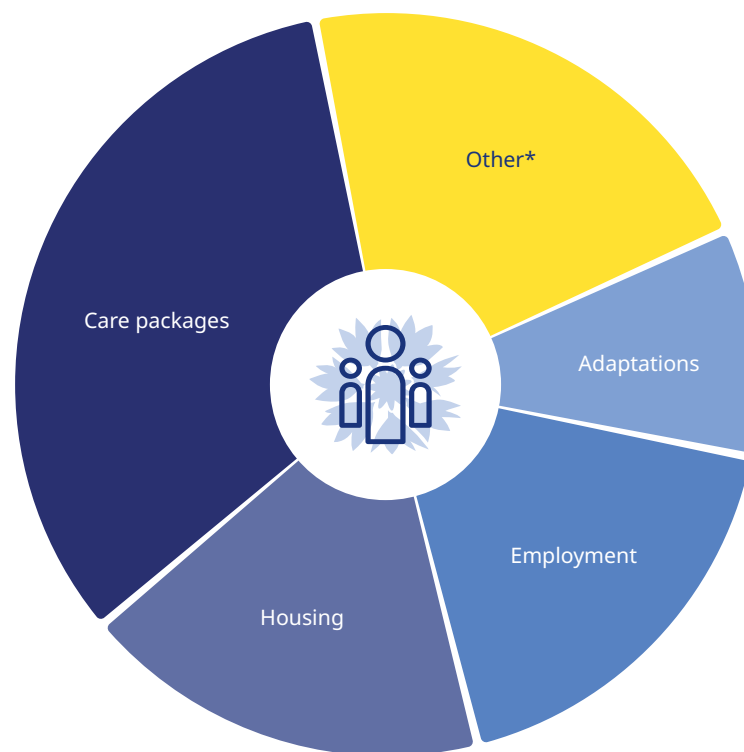
We assisted with **120 information requests, 90% of which were people with MND**, or their friends and family, seeking support and information about living with MND.



Our two accessible holiday facilities in St Andrews and Oban were closed for much of 2020/21, however we were still able to give **7 families** living with MND a break away from their normal routine.

152 cases

our **Advocacy team supported** on a range of issues affecting families with MND:



* Other ways we have helped people includes, supporting them with accessibility issues, pensions, power of attorney, insurance issues, making complaints to companies and organisations, and much more.



“

When I first got my MND diagnosis at 29, I thought about all the things that I wanted to do, all the places that I wanted to go.

My future would be cut short and I wouldn't be able to do all those things anymore. It made me just want to drop everything and book a trip as soon as possible, while I could still walk and still breathe on my own. I hadn't been abroad for a holiday for about five years.

MND Scotland helped me to tick traveling to Reykjavík, Iceland off of my bucket list. I was able to make lasting memories with my family and had the most fantastic experience. I used the photographs from the trip to create a memory book for my family for when I'm not here. Without your help, the trip wouldn't have been possible.”

Jo Knowlton
Diagnosed with MND in 2019

Bringing hope of a cure



UK's biggest clinical drug trial


In January 2020, the biggest MND drug trial in the UK was launched, following a £1.5 million investment from MND Scotland. This means almost every person living with MND in Scotland now has access to a clinical trial.

Unlike typical clinical trials which test a single treatment at a time, MND-SMART, which is run by the Euan MacDonald Centre for MND Research at the University of Edinburgh, tests multiple drugs at a time. This innovative process aims to speed up the time it takes to find medicines that can slow, stop, or reverse the progression of MND.

Unfortunately, in March 2020, due to Covid-19 restrictions, recruitment for the trial was paused. After months of hard work to adjust processes and procedures, to ensure the safety of everyone taking part, the trial team reopened recruitment in July 2020.

Centres have now launched in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness, as well as across England.

This was only made possible by your generous donations.

The background is a blue gradient with a diagonal split. Scattered across the background are several stylized banknotes, each featuring a large circle in the center and decorative patterns. The text is centered and reads:

We are currently investing
£2.8 million
into MND Research

This year we committed
an additional **£295,000**
into **2** new MND
research projects

We want those affected by MND, both directly and indirectly, to know that we are with them and that we will continue to strive to do all we can to understand the condition, towards the common goal of finding new treatments."



Professor Rob Layfield will lead a team, at the University of Nottingham and Nottingham Trent University, to 'decode' protein signals in MND.

Professor Sharon Abrahams will lead a team at the University of Edinburgh to develop our understanding of mental capacity to make treatment decisions in people with MND.



We will look at why people with MND may have these difficulties and if there are ways we can support them through this decision-making process. We thank MND Scotland and all their supporters for funding this project."

Creating lasting change



It's About Time

As we all know too well, MND is brutally fast, and people need support put in place quickly. In Scotland, people with MND are still waiting too long for statutory services, and some never receive the support they need in time.

Madhia Chaudhry, from Glasgow, spent eight months showering her mum at the local leisure centre while waiting for an essential wet room. Tragically, it was not completed until the day her mum died.

"I had an absolutely horrific time and had to face so many challenges just to get my mother what she deserved for her dignity."

Madhia isn't alone.

That's why we launched our campaign 'It's About Time' – to ensure politicians know the system can't keep pace with MND and to call for change now.

What we did

In the run up to the Scottish Parliament elections on 6th May 2021, we developed MND Scotland's Manifesto, calling for improvements to social care, accessible housing and adaptations. We sent this to all the political parties in Scotland and to all Members of the Scottish Parliament (MSPs). In it we call for:



**A National
Care Service
for Scotland**



**A National Accessible
Housing Strategy
for Scotland**

Weeks before the election, our supporters backed this campaign by emailing their local candidates, to share their personal experiences of delays in services, and ask candidates to pledge support for our manifesto.

12,304

**emails sent by
470 supporters**

85

**candidates pledged
their support**

20

**pledged candidates
were elected to the
parliament as MSPs**



Making change happen

During the election, introducing a National Care Service became a key topic of debate and the Scottish Government has committed to developing this. We will work hard to ensure it meets the needs of those with MND and lobby for the implementation of positive change as soon as possible. We will also strive to ensure government accessible housing commitments are met, while continuing to lobby national and local government, particularly as we gear up for the local council elections in 2022.

United to End MND

We joined forces with the MND Association, the My Name's Doddie Foundation, neurologists and people living with MND, to call for the UK Government to fund our search for a cure.

The United to End MND campaign urged the UK Government to invest £50 million over five years into targeted MND research. Currently, the UK Government's funding for targeted MND research stands at less than £5 million a year. **This is not enough.**

£50 million over five years would fund a virtual institute for MND Research, providing the infrastructure needed for accelerating treatments for MND, bringing together advances in both clinical and core science research. The institute would make a real difference to MND research by:



Focussing on **world-leading drug discovery** and development



Developing a **sustainable MND trials platform**



Implementing a **rigorous clinical research programme**



£50m victory

At the time of publishing this report, we received the incredible news that the UK Government has pledged £50 million for targeted MND research, which will accelerate the development of meaningful treatments.

Thank you from the bottom of our hearts to everyone who has united with us and contributed to this incredible success. We will continue funding pioneering MND research across the UK to bring us closer to finding a cure.



Former Leeds rugby league captain, **Rob Burrow**, and Bradford footballer, **Stephen Darby**, joined a delegation of people calling for the funds at Downing Street.

To find out more visit
mndscotland.org.uk/united2endmnd

Raising awareness

How Game Show Appearance Helped Give Mum Her Voice Back

Helen Whitelaw, who sadly passed away in May 2021, was just one incredible example of all the brave people who spoke out publicly about their experience of living with MND. Helen, a retired secretary from Glasgow, appeared as a contestant on the ITV programme Tipping Point a few years before she was diagnosed with MND.

As a result of MND, Helen lost her voice, but thanks to the recordings from the game show, a voice banking company 'SpeakUnique' was able to use the audio clippings from the show to create a synthetic voice, which sounded like her own. Helen was then able to use her own voice through a communication aid, giving her back the power of speech.

MND Scotland provides funding to everyone in Scotland with MND who wishes to use the SpeakUnique voice banking service.





Helen's story **reached millions of people across the UK**, appearing on Good Morning Britain, ITV News, STV news, and global, national and local online and print press.



Thanks to everyone who shared their story this year, MND Scotland featured in **over 1,000 online and print articles**, which were seen **830,340,821** times.

Thank you to everyone who spoke out to raise awareness of our cause and how it affects people across Scotland.

Every year awareness with the Scottish public continues to increase.

% who have heard of MND Scotland

2016	30%
2018	39%
2020	47%
2021	53%

Charity Awareness Survey. Based on 1,000 adults each year.

You're doing something incredible



You raised an incredible
£2,154,708
in 2020/21

Thank you so much!

When the country went into lockdown in March 2020, all MND Scotland face-to-face fundraising events were cancelled or postponed.

That didn't stop supporters like you from continuing to fightback against MND in different ways! We know how hard it has been, so we have been overwhelmed by the continued support we have received.

People across the country took part in our virtual Fun Run relay, stepped out on their local streets for the virtual Kiltwalk, held online quizzes and whisky tastings, and continued to donate to help people living with MND today and fund our search for a cure.

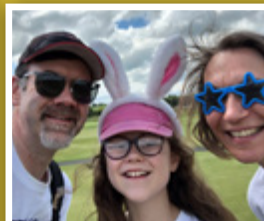
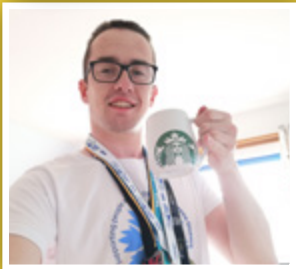
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MND Scotland is a beacon of light for families devastated by a diagnosis of MND. I support the charity because as a family we are eternally grateful for the assistance we received over the years that our mum Christine had MND.

Whether it was advice on benefit entitlement, loan equipment, grants for holidays, family breaks at the MND lodge, counselling for the whole family, a superb advocacy service...there really is too much to list.

"At each stage of our journey, there was friendly advice, and thoughtful and sensitive support. If our small contribution can allow this wonderful charity to continue to flourish, then it is very worthwhile."

David Sweeney
MND Scotland fundraiser



Corporate Support

Thank you to all our corporate partners who continued to support our work throughout 2020/21.



Chivas Brothers donated its pitch-side advertising space at Old Trafford. The pitch perimeter digiboards - that would usually promote the world-famous whisky - instead featured MND Scotland's logo for the the match, helping us reach a massive new audience.



Around **230 Tesco** stores across Scotland and England raised almost £40,000 for MND Scotland, in support of 29-year-old mum Jennifer Bell, who sadly passed away from MND in December 2020.



To date our partner, the **ScotRail Alliance**, has donated an incredible £276,418, through staff fundraising, customer donations and gifts-in-kind.



Staff at **Nucleus**, an Edinburgh-based financial services company, raised a total of £67,902 over a two-year partnership with MND Scotland. The company started supporting MND Scotland after staff member, the late Mike Wallis, was diagnosed with the disease.

Trusts and Foundations

Thank you to all the trusts and foundations who supported us in 2020/21.

Alan Davidson Foundation

Alexander Moncur Trust

Bank of Scotland Foundation

Broughton Charitable Trust

Crerar Trust

Darroch Charitable Trust

Dr Spalding Trust

Duncly Trust

DWT Cargill Fund

Hugh Fraser Foundation

IBB Trust

J&JR Wilson Trust

James Wood Bequest Fund

JTH Charitable Trust

Meikel Foundation

Mrs M A Black Charitable Trust

Murdoch Forrest Charitable Trust

MV Hillhouse Trust

My Name's Doddie Foundation

Netherdale Trust

Northwood Charitable Trust

Peter Brough Bequest Fund

Postcode Community Trust

RBS Community Cashback

Ronald Miller Foundation

RS Macdonald Charitable Trust

Sir Iain Stewart Foundation

St Katherine's Fund

Talteg Ltd

Templeton Goodwill Trust

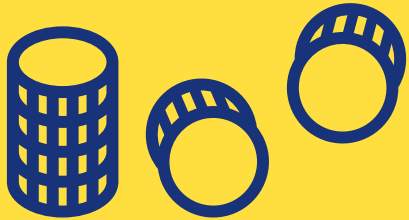
The Hunter Foundation

The Princess Anne's Charities Trust

Summary of accounts

Summary of the financial statements for the year ended 31st March 2021.

	2021 (£)	2020 (£)
INCOME		
Donations & legacies	1,545,600	1,688,197
Income from other trading activities	604,348	1,093,376
Investment income	4,760	26,670
	2,154,708	2,808,243
EXPENDITURE		
Raising funds	360,536	410,470
Care	739,596	898,669
Research	855,372	888,762
Information	387,348	397,064
	2,342,852	2,594,965
Gain / (losses) on investments	136,585	(56,273)
	(51,559)	157,005



This year **for every £1 we spent on raising funds, we raised £5.96**, so we can continue making life easier for people affected by MND, and powering our search to find a cure.

£739k+

making life easier for people living with MND

£855k+

taking us closer to a cure for MND

£387k+

providing valuable information

£360k+

raising more funds

Fighting back for 40 years

At the time of publishing this document we'll have entered MND Scotland's 40th anniversary year. Throughout 2021/22, we'll be looking back at all the incredible achievements thanks to supporters like you.



Peggie and John MacLeod counting donations



Kirkintilloch Fun Run 1988

AN ENTERTAINING OPENING

On the evening of 14 December our new Office at 50 Parnie Street was officially opened. The actual "opening" was performed by the very popular Glasgow comedian, Mr. Jack Milroy and his wife Mary Lee. They surprised and delighted everyone present by "doing a turn", and treated us all to a delightful comedy routine and one or two of the old favourite Scottish Songs. After which, they presented Mr. Dave Roberts B.E.M. and Mr. Grant Findlay with a decanter and tankard, respectively, as a small token of our thanks for all the help they gave S.M.N.D.A. at the Garden Festival.

The evening was very well attended and it was very encouraging for the National Executive Committee to see so many members and friends present and interested in the new office.

I think I can safely say that a good time was had by all!



The opening of new offices at Parnie Street



Superintendent Short receiving the first John MacLeod Award from Peggie MacLeod



Clockwise from top: Carole Fergusson, Elizabeth Friend, Shona Henderson, Rhona Curie

Humble beginnings

40 years ago police officer, John Macleod, set up the Scottish MND Association from his living room, two years after he was diagnosed with MND. At the time there was no support, care or treatments for people diagnosed with MND in Scotland.

Supported by his loving wife Peggy, their family, friends and John's police colleagues, a new charity was born which aimed to provide support for others going through this frightening disease.

Today, MND Scotland provides life-changing support to hundreds of families living with MND. We invest millions of pounds in cutting-edge MND research, and awareness of the disease has never been higher.

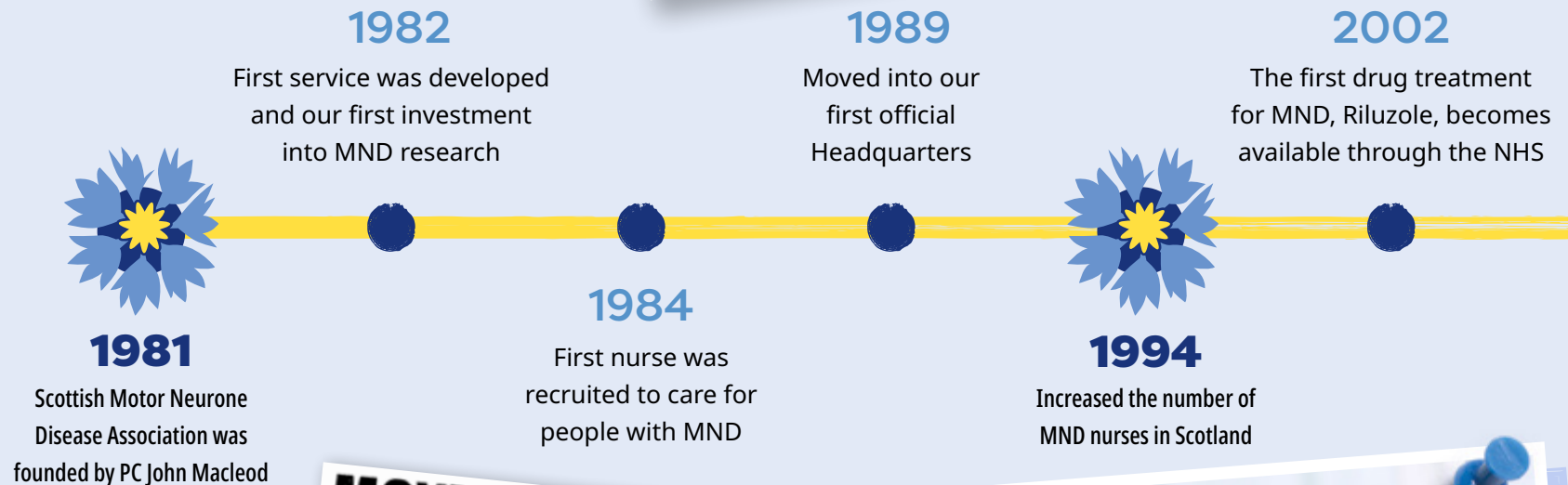
Forty years of progress has meant that almost every person living with MND in Scotland can now take part in pioneering clinical trials to find new medical treatments.

We have come a long way in forty years and none of this would have been possible without you. Thank you for always fighting with us.

More at

mndscotland.org.uk/40

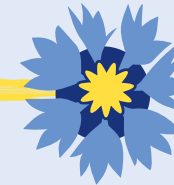
Our journey so far...





2020

Launch of UK's biggest MND drug trial in a generation

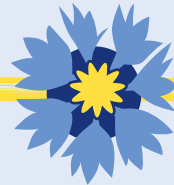


2018

First MND drug trial in 20 years and fairer fast-tracking rules for Scottish social security benefits become law

2016

The right to communication aids, free of charge from the NHS, becomes law



2015

Gordon Aikman, MND campaigner, launched Gordon's Fightback, successfully campaigns to double number of MND nurses, funded from the public purse

2014

Ice Bucket Challenge phenomenon



2009

Became MND Scotland and adopted current logo





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Founder: John Macleod
Royal Patron: HRH Princess Royal

