

**MY
NAME'S
DODDIE**
foundation

Impact Report

1 Nov 2019 – 31 Oct 2020



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Introduction

It is fair to say that 2020 has been a challenging year for us all. The coronavirus outbreak has affected the way we all go about our daily lives. Ongoing restrictions have had a major impact on all charities and we are no different, with many events cancelled or postponed. But we continue to receive amazing support and remain committed to our vision of a world free of motor neuron disease.

As we celebrate our 3rd anniversary, we are delighted to have committed £3.2 million to research projects and over £1 million to people living with MND. This is only possible through the support and efforts of our fantastic fundraisers who are inspired by Doddie and his positive approach to life and who share our ambition.

In the year to 31 October 2020:

£2,204,293

was collected through
fundraising activities



£418,119

was granted to medical
research projects



£402,992

was given in grants to
help sufferers of MND



Message from our Chairman

Little did we know that the Covid-19 global pandemic would have such an impact on us all and clearly this has affected many charitable organisations. However, I am delighted to report that so many supporters thought 'out the box' and continued to find creative and imaginative ways to continue to raise funds for the Foundation. From online Zoom quiz nights and events, to cycling events and outdoor pursuits, a huge thank-you to all our wonderful fundraisers.

The Foundation is on a solid financial footing with funds available to meet all its ongoing commitments and we are excited that the funds that we have invested will see progress made in meeting our new strategic goal for a world free of MND.

As well as investing in research we have given additional grants to MND Scotland and the MND Association to help support people and their families living with MND. We have also made a number of individual gifts to help support those requiring additional needs and as always Doddie has been there to offer encouragement and positivity to the MND family.

Doddie's ongoing media profile including numerous BBC Breakfast interviews alongside Rob Burrow and Stephen Darby ensure that the Foundation is at the forefront whenever MND is mentioned. Doddie is an inspiration to all of us and a fantastic ambassador for all things MND.

I'd like to thank Fin Calder and Gary Armstrong for all that they did to get the Foundation up and running. They stepped down as trustees during the year but I was delighted to welcome our new trustees Eric Lowe and Annabel Howel during the course of the year. Jill Douglas our CEO and Sean McGrath our Medical Strategy Lead also deserve special mention as does Jim Roberston who looks after our finances and makes sure that we meet our funding and charitable obligations. I'd also like to thank Kenny Logan and his team for developing our commercial relationships and to our supporters, Thrifty, Aberdeen Standard Investments, Gen!us, Gaucho and The Digital Age as well as our merchandise partners who do such a brilliant job.

With one eye on the future the board met in September at the Renaissance Club in East Lothian to thrash out a new strategy for the Foundation. It was a fantastic couple of days and we will refine this over the next few months coupled with a new brand identity. It will take a few months for everything to be nailed down but to ensure that we are 'fit for purpose' we will be looking to recruit personnel so that we can meet the challenges ahead.

Scott Hastings
Chairman



A few words from Doddie

"My two favourite four-letter words are 'Hope' and 'Cure'. Like many people with MND, I use them a lot. The last year has been a big challenge for Hope, for the fight for a Cure, and for all of us. I know I am very lucky: I live in beautiful countryside, have a noisy family and an accessible garden. Not everyone with MND is as fortunate. That is why the extra financial support our Foundation has given to MNDA and MND Scotland to fund support grants for those with MND has been doubly important in this time of Covid-19, shielding and lockdowns.

To do that, we rely on our army of supporters. And I'm delighted to confirm that not even a global pandemic can stop their amazing fundraising work. Static bike rides from Land's End to John o' Groats; ascending Ben Nevis via the house stairs, quizzes on Zoom – you guys have got it covered! Thank you so much.

For me, the Spring lockdown was a bit of a novelty at first: I enjoyed having more quiet time at home in the family bubble. My 50th birthday in July was smaller-scale than anticipated, but such a special time to spend with the family – particularly as I never thought I would see it! I received so many lovely gifts and good wishes, it was overwhelming.

Another highlight has been meeting up with Rob Burrow and Stephen Darby. We are all in the same boat and have developed a special bond which has helped keep us going through this last difficult year. And the support of Sally Nugent and BBC Breakfast has really lifted the profile of MND to another level.

My biggest frustration is the impact of Covid-19 and the lockdowns on research trial progress. But I'm looking forward to 2021 when things will hopefully return to some kind of normality and, with the unflinching drive of the Foundation's trustees encouraging the research community forward, we will see those trials take off at last.

We have the Hope, let's get to the Cure."

A handwritten signature in blue ink that reads "Doddie Weir".

Doddie Weir, OBE



Raising funds

It's been another busy year for all our fundraisers and organisations who have set new challenges and goals to fundraise for the Foundation. We have continued to increase the sums raised through generous donations and through our JustGiving and Virgin Money Giving pages.

Our fundraisers have gone the extra mile to raise money for the Foundation and we would love to say thank you to all the individuals, businesses, rugby clubs, schools and families who have donated to the cause.

Major events included the Rugby Captain's Dinner, which saw us partner with the Matt Hampson Foundation for a dinner at Battersea Evolution. The New Year started with a Burns Night Supper hosted by Microsoft, Doddie's painting by Gerard M Burns was unveiled for a limited time at The National Galleries of Scotland, the first Doddie Dog Walk was established to coincide with MND Awareness Day and of course Doddie turned the big 5-0 in July!

To celebrate Doddie's big day we ran a virtual birthday fundraiser across our social media. This was a great way for our supporters to say cheers to the big man for everything he has done with the Foundation. Thanks to all our amazing supporters this event raised over £100,000.

We were still able to squeeze in the annual Auld Enemy Dinner on the eve of the Calcutta Cup and Rob Wainwright continued his heroic efforts for the Foundation with his 'Wounded Lions 500' cycling fundraiser. Rob and a group of fellow cycling dafties journeyed from Twickenham to Murrayfield in 48hrs with the match ball for the Calcutta Cup to support his Lions teammates, Doddie and Tom Smith.

Many of our annual events, such as "The Doddie Weir Cup", the annual golf days and Doddie's Ride were disrupted due to Covid-19 restrictions. However, our amazing fundraiser and supporter, Peter Winterbottom, showed his resilience and made Doddie's Ride happen virtually instead.

Two amazing supporters have put in herculean efforts with their fundraising. John Davidson rowed solo across the Atlantic in his boat, "The Mad Giraffe", in the Talisker Whisky Atlantic Challenge. Davy Zyw hit £116,000 raised for the Foundation and received the Points of Light Award by the Prime Minister's office.

FUNDRAISING

Since inception, we have raised a total of
£8,094,704
 with thanks to all our supporters



Our relationship and support from all our partners over the last year has been incredible. We have continued to build this with our friends at Scottish Rugby and also with Thrifty, who renewed its partnership with the Foundation to support our ongoing fundraising efforts. We launched our new podcast series, "The Dodcast", which is supported by Aberdeen Standard Investments, our friends at RugbyPass and produced by fellow Scotland and lock forward Jim Hamilton and Tim Groves.

The last year has also been full of awards with Doddie being honoured with the Helen Rollason Award at Sports Personality of the Year and was inducted into the Scottish Rugby Hall of Fame. The Foundation itself also picked up The People's Choice Award at the Scottish Charity Awards.



Clockwise from top left: Thrifty, our Official Partner. The Burns Night Supper hosted by Microsoft. The Foundation won The People's Choice Award at the Scottish Charity Awards.

Thank you to our commercial partners

Our commercial partnerships have continued to support the Foundation over the last year. We have been working with businesses and licenced partners on various activations and sales of merchandise to raise funds and awareness of the Foundation.

BE PART OF THE CURE

Official Partner:



Official Supporter:



Fundraising Partners:



Official Charity Partner of:



We're proud to have worked with:



Suppliers:





We'd like to say a huge

THANK YOU!

to all of our amazing fundraisers!



Supporting medical research

The Foundation's quest to find meaningful treatments for MND as quickly and efficiently as possible has been at the heart of all its MND research activities.

The Scientific Advisory Board continues to be a critical element of this, meeting twice a year to discuss the MND research landscape, updates on Foundation-funded research programmes, and new findings. Regular contact with these trusted individuals also enables the Foundation to obtain advice on clinical trial drugs, sense-check scientific claims and funding requests, and collaborate on projects.

The Foundation's Medical Strategy Lead, Sean McGrath, manages these relationships, as well as those with others in the scientific community, MND charities, and organisations involved with MND research. This includes the Medicine Discovery Catapult with whom the Foundation is partnering on a project to develop a roadmap from pre-clinical to clinical MND research.

Working collaboratively like this has enabled the Foundation to continue to gain insight and influence, as has been seen with the current campaign to Government for increased MND research funding, #United2EndMND.

The Foundation continues to award grants where desired research can be accelerated or new projects funded.

Areas we particularly focus on include:

- Biomarkers – improving the understanding of MND, its causes and its progression, so as to help with the development of new treatments
- Gene Therapy – research into using gene therapy to change the cellular environment of MND
- TDP-43 – research around this protein, which is over expressed in the cells of MND patients
- Repurposing – where existing drugs being used for other diseases could make a meaningful difference in MND
- Platform Trials – larger-scale clinical trials testing new treatments, which include significant numbers of patients, aimed at making a meaningful impact on MND
- Personnel – where the presence of an individual can start, or speed up, any of the research that meets our criteria

Medical research projects we've supported include:

- Clinical trial of a drug repurposed for MND: Edinburgh and Oxford Universities
- Postdoctorate research fellow for a biomarker discovery project: University of Sussex
- Neurosurgical trainee for developing a new technique for delivering AAV gene therapies to the spinal cord: King's College London
- Staff to run gene therapy trials: King's College London
- MND SMART – platform, adaptive clinical trial for MND: Edinburgh University and various trial sites throughout the UK
- TRICALS – Europe wide platform, adaptive clinical trial for MND: multi-centre throughout the UK
- Medicines Discovery Catapult – development of a roadmap for the discovery and development of novel therapeutics for MND

Since inception, we have committed

£3,207,406

to MND medical research projects

**WE FUND,
GUIDE & ENABLE
THE SMARTEST, MOST
EFFICIENT RESEARCH TO
EXPEDITE NEW TREATMENTS
FOR MND**



Supporting medical research continued



"Doddie's reputation has enabled fundraising to be very successful, and has promoted all the big MND research centres to work collaboratively together. This has driven some really important developments, including new clinical trial designs that allow more patients to be involved in experimental medicine trials."

Professor Dame Pamela Shaw, University of Sheffield

"Working with someone like Doddie who has spent his professional life in a team has been very refreshing for us as scientists - we are in teams but we are often competing for the same resources, so bringing us together allows us to share openly what we are doing so we can work in a complementary way."



"For those who are actively fundraising, who want to make a difference, your money is being used in a very real way to change the world of MND. Without it we aren't going to be able to take that knowledge and resources to work in partnership with our patients to really make a difference."

Professor Kevin Talbot, University of Oxford



"The My Name's Doddie Foundation has been spectacular and has made a difference in three ways: by raising awareness of MND through the personality of Doddie; by raising funds for MND research; and by bringing a sense of controlled urgency and the idea of adopting new ways of getting the job done, and also promoting collaboration."

Professor Siddharthan Chandran, Edinburgh University

FUNDING THE MOST PROMISING MND RESEARCH

"Funding from the My Name's Doddie Foundation is critical for us because it helps to support staff to run clinical trials. Without them it becomes extremely difficult to do the trials in a timely way. Ultimately the Foundation helps us accelerate finding new treatments for MND."



Professor Ammar Al-Chalabi, King's College London



"Through the generosity of the public who have helped fundraise for the My Name's Doddie Foundation, I have been able to continue doing my research to help identify biomarkers for the disease to not only help diagnose it, but provide new ways to predict prognosis and to measure disease progression, all of which are critical for clinical trials to be successful."

"With the challenging conditions in research funding as a result of Covid-19 that nearly stopped this work, this timely funding from the Foundation has allowed us to keep pushing forward to what looks like very promising data."

Dr Greig Joilin, My Name's Doddie Research Fellow, School of Life Sciences, University of Sussex

Helping people affected by MND

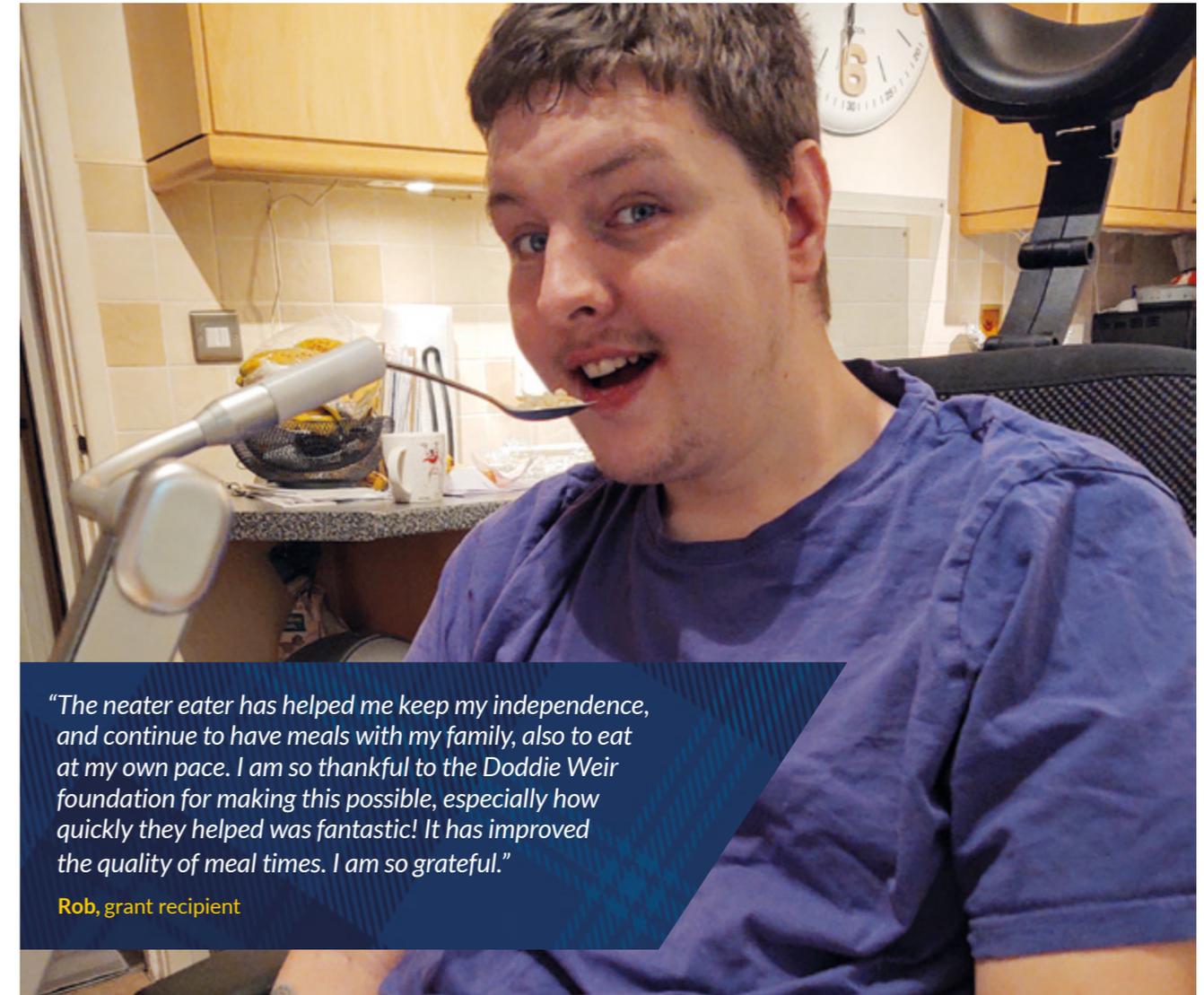
We are committed to supporting people living with motor neuron disease and continue to work with existing care and information providers to ensure people can make informed decisions about their treatment and care. We have provided significant funding to relevant care charities and organisations to deliver grant aid to people with MND and their families, to help them live as fulfilled a life as possible.

The trustees agreed extra grant awards to MND Association and MND Scotland to support people living with MND as well as a number of individual care grants. The Foundation gave a total of £270,000 to MND Association and £130,000 to MND Scotland. These sums included an extra payment to help these frontline care charities respond to patients' needs and reduced income during the Covid-19 crisis.

**WE
INFORM &
SUPPORT
PATIENTS &
THEIR
FAMILIES**



Since inception, we have donated a total of
£1,086,554
in grants to MND patients and their families



"The neater eater has helped me keep my independence, and continue to have meals with my family, also to eat at my own pace. I am so thankful to the Doddie Weir foundation for making this possible, especially how quickly they helped was fantastic! It has improved the quality of meal times. I am so grateful."

Rob, grant recipient

"I'd like to thank the Foundation for its ongoing support of our grants programme, which allows us to provide essential support to the families affected by this devastating disease."

"The grants can be used in various ways to help reduce some of the extra costs that come with living with MND. Our grants can help with costs towards home adaptations, such as ramps and stairlifts, for specialist equipment to live life more independently, for respite activities for carers and families, and much more."

"Over the past year we have awarded 192 grants to families in Scotland, worth almost £170,000. The Foundation's donation of £100,000 has been vital to this service and by continuing to work together we can help make life easier for people living with MND right now."

Iain McWhirter, MND Scotland's Interim Chief Executive



Denis received a riser recliner chair with thanks to a grant, greatly improving his quality of life.



"I have always lived within my means and I've never gone on holidays if I couldn't afford it, so I hadn't been abroad in about five years. Now I have a bucket list and with the help of MND Scotland I completed my first bucket list trip to Iceland in December 2019. I look forward to planning my next trip once it's safe to travel again – a Caribbean or Mediterranean cruise is first on the list!"

Jo, grant recipient

Helping people affected by MND continued

"I would like to say a big thank you for the two grants that I have received in relation to the two ceiling hoists recently fitted in my home. These hoists mean that I can now get in and out of bed and chairs safely after having been on the floor a few times and had to call for help. My wife can continue to care for me at home without the help of carers."

MND Association grant beneficiary



"This grant contributed hugely in giving me my freedom to go outdoors albeit in a wheelchair but a million times better than being housebound looking at four walls."

MND Scotland grant beneficiary



"I am writing to say a huge thank you for my riser recliner chair. It's going to make life so much easier. I can see that it's made a massive difference already. As a result of my condition we have, only this week, moved into an adapted bungalow. This has meant that our cash reserves are very low and I would not have been able to get a specialist chair without your support. I'm so grateful to the Doddie Foundation."

MND Association grant beneficiary



"We are so grateful for the help we received over the festive period. My wife did not want to celebrate Christmas this time with all that was going on with me and the worry over money."

MND Scotland grant beneficiary



Our trustees

Kathy Weir

(appointed from October 2017 to date)

Kathy and Doddie married in 1997. They have three sons and live in the Borders on their farm.

Scott Hastings

(appointed from October 2017 to date)

Scott is Scotland's most capped rugby centre three quarter with 65 caps. He played in 51 Internationals with his brother Gavin and is now a respected rugby commentator.

John Jeffrey

(appointed from October 2017 to date)

John Jeffrey played 40 times for Scotland in an international career that spanned from 1984 until 1991. Since retiring from playing, JJ has remained involved in the administration and governance of the global game.

Stewart Weir

(appointed from October 2017 to date)

Stewart Weir is a media and PR consultant. A former chief sportswriter with the Scottish Mirror, and formerly head of sport for the Herald & Times group, Stewart co-wrote Doddie's best-selling autobiography 'My Name's Doddie'.

Eric Low OBE

(appointed from April 2020 to date)

Eric has worked in the fields of medical research, market access and patient organisations for over 25 years. He currently runs a consultancy business specialising primarily in strategic market access, life sciences and healthcare policy, and patient organisation development. He was awarded an OBE for services to charity in the Queen's Birthday Honours 2012.

Dr Annabel Howell

(appointed from September 2020 to date)

Annabel trained at the Royal Free Hospital and has enjoyed a variety of medical roles including director level appointments in primary and secondary care as well as clinical governance. As a palliative care specialist and previously as a GP, she has looked after many people with MND, ensuring they receive high quality person-centred care and was involved in the successful fundraising for the purpose-built palliative care unit in the Borders. She lives in the Scottish Borders with her husband Julian and family.

BUILDING A GREAT & SUSTAINABLE BUSINESS SO IT CAN CONTINUE TO DELIVER FOR THE MND COMMUNITY

Past trustees:

Gary Armstrong

(appointed from 30 October 2017 to 31 December 2019)

Finlay Calder

(appointed from 30 October 2017 to 29 April 2020)

Jill Douglas

(appointed from 30 October 2017 to 31 December 2017)

Our team



Jill Douglas Chief Executive Officer

Jill Douglas is CEO of My Name's Doddie Foundation and manages the day to day activity of the charity, working closely with trustees. Jill is also a respected sports broadcaster.



Jim Robertson Chief Financial Officer

Jim Robertson is the Foundation's CFO. He is a chartered accountant with considerable experience both in the UK and overseas and is responsible for all matters financial relating to the Foundation as well as liaising with Auditors, Bankers, Investment Managers and HMRC.



Sean McGrath Medical Strategy Lead

Sean McGrath is the Foundation's Medical Strategy Lead. He is a management consultant with a background in healthcare and general management. Sean has a wealth of knowledge and experience in the cancer and rare diseases environment, built over almost thirty years.

Our founder

Doddie Weir OBE is one of rugby's most recognisable personalities. He earned 61 caps for Scotland during a successful playing career, represented the British and Irish Lions on their successful tour to South Africa in 1997, and won championships with his two club sides, Melrose and Newcastle Falcons.

A talented, committed and athletic lock forward, Doddie is now facing his biggest challenge. In June 2017 the Scot revealed he was suffering from MND. From the outset, Doddie has been driven to help fellow sufferers and seek ways to further research into this, as yet, incurable disease.

“MY ATTITUDE IS THAT YOU SHOULD DO WHAT YOU CAN TODAY AND WORRY ABOUT TOMORROW WHEN IT COMES. THIS IS THE CARD I'VE BEEN DEALT SO I'VE JUST GOT TO CRACK ON”



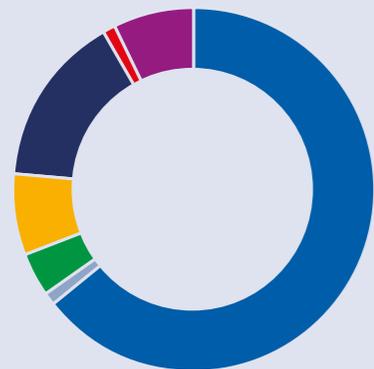
Financial summary

We know 2020 has been a challenging year with so many of us facing uncertainty and hardship. The global pandemic has had an effect on our finances but we have benefitted from some imaginative and wonderful fundraising efforts. Every donation makes a difference.

Covid-19 has had an impact on many of the MND research projects we support, with some being suspended for several months. It has also restricted our ability to engage with MND centres. In the months ahead we will be launching our new research strategy and the Foundation is well placed to invest in further MND projects to accelerate the development of new treatments.

How we've spent the funds raised:

	Year to 31 October 2020		Year to 31 October 2019	
Donations to medical research and individuals	£821,111	63%	£2,557,720	79%
Administration cost	£17,866	1%	£22,525	1%
Legal professional	£57,827	4%	£39,689	1%
Medical research consultant	£89,109	7%	£143,076	4%
Marketing cost – consultancy	£192,079	15%	£337,602	10%
Marketing cost – goods	£15,904	1%	£31,543	1%
Salaries	£96,085	7%	£82,084	3%
Trustees travel	£5,946	0%	£2,595	0%
Bank charges	£716	0%	£698	0%
	£1,296,643		£3,217,532	



Visual representation of expenditure in the year up to 31 October 2020

- Donations to medical research and individuals (63%)
- Administration cost (1%)
- Legal professional (4%)
- Medical research consultant (7%)
- Marketing costs – consultancy (15%)
- Marketing costs – goods (1%)
- Salaries (7%)

62p out of every £1*

raised since the Foundation was incorporated three years ago has been spent on funding our work in research and care of MND sufferers

£1.440 million

has been raised by direct marketing activities over the last two years (£2.01 for every £1 spent)

50% of donations

came from charitable websites such as JustGiving and Virgin Money

* Reduction from last year is due to lack of expenditure on MND research projects as a result of the Covid-19 pandemic.

What's next?

We remain committed to helping find effective treatments and a cure for MND and to continue to support people living with motor neuron disease.

With this in mind, in September 2020 the trustees met to discuss and develop a ten year strategy for the future. The direction of the Foundation and its vision of a world free of MND has been refined into a Strategy Plan which we will share in the early summer of 2021.

We are strengthening our team and have appointed a Digital Marketing Lead and Community Fundraising Manager, further appointments will follow in 2021 to support our ambition and strategy.

The Covid-19 crisis has been a challenge for all charities but our amazing supporters continue to come up with imaginative and creative ways of fundraising – even amid a global pandemic – and while we were forced to cancel or postpone a great many events, we are already looking forward to 2021 and many exciting opportunities.

Doddie AID, a mass participation exercise challenge, looks set to be a major annual fundraiser for the Foundation, The Lions rugby tour to South Africa is another opportunity to raise awareness and funds, we are developing new partnerships and further branded products will come online. We look forward to building on our excellent relationship with the Hong Kong community and an agreement is in place to host an annual dinner during the week of the Hong Kong Sevens over the next four years with HKRFU, Cathay Pacific, HSBC and Laureus.

As part of our commitment to help people living with MND, we will continue with the popular Dodcast series and produce a patient booklet as a guide to supportive activities and therapies.

We are working with other stakeholders in the MND community including our good friends at MND Scotland and MND Association to lobby for more funding to establish a UK MND Research Institute.

Look out for a new, updated Foundation website in 2021 and our improved donation platform.

Thank you for your continued support.



How can you help?

Make a donation

Make a one-off or regular donation to improve the lives of those affected by MND and to further research. This can be done through our donation platform on our website: myname5doddie.enthuse.com/donate

There are lots of other ways to donate too, including bank transfers, posting a cheque, JustGiving, Virgin Money Giving, Easyfundraising and AmazonSmile. To discover more about the various ways that you can help support My Name'5 Doddie Foundation visit: myname5doddie.co.uk/how-to-donate/other-ways-to-donate

Organise a fundraising event

For inspiration and tips for organising an event as well as helpful fundraising resources visit: myname5doddie.co.uk/fundraising-support

Sign up to our newsletter

Want to keep up to date with the latest My Name'5 Doddie Foundation news, events and research? Sign up to our newsletter through myname5doddie.co.uk!

Follow us and spread the word

🐦 @MNDoddie5
📘 @MNDoddie5
📷 @myname5doddie

If you have any questions get in touch with our team and we'll be happy to help!
info@myname5doddie.co.uk

Charity number: SC047871

**MY
NAME'S
DODDIE**
foundation

**Tackling MND.
Be part of the cure.**

myname5doddie.co.uk