



**MY
NAME'S
DODDIE**
foundation

Tackling MND.
Be part of the cure.

Impact Report

1 Nov 2018 – 31 Oct 2019

Our mission

My Name's Doddie Foundation was established by Doddie Weir OBE and the trustees following Doddie's diagnosis with Motor Neuron Disease (MND) in 2017. The charity was founded in response to his frustration at the lack of options given to people affected by MND – no effective treatment, no access to meaningful clinical trials, and no hope.

The aims of the Foundation are simple:

- To raise funds to aid research into the causes of MND and investigate potential cures.
- To make grants to individuals suffering from MND, to enable them to live as fulfilled a life as possible.

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Introduction

As the Foundation celebrates its second anniversary, we continue to receive incredible support and thanks to your generosity, we have committed over £4 million to research projects and to provide practical support to those affected by MND.

Doddie's energy and enthusiasm knows no bounds and his positive attitude is an inspiration to our team – we are determined to tackle MND and be part of the cure.

In the year to 31 October 2019:

£3,217,532

was collected through fundraising activities



£2,049,287

was granted to medical research projects



£508,433

was given in grants to help sufferers of MND



Message from our Chairman

As a former teammate and great friend of Doddie, I am proud to serve as Chairman of the trustees. It gives me great pleasure to announce that in our second year of operation we have pledged over £4 million to support others who suffer from MND and contributed to some amazing research projects following the establishment of our Scientific Advisory Board lead by Sean McGrath.

I attended our 3rd meeting of the Scientific Advisory Board back in March 2019 held at Boughton House which was very kindly hosted by the Duke of Buccleuch. The collaboration shown by those in attendance was utterly amazing and the board categorically was in favour of fast tracking a number of platform trials.

Doddie has been an absolute inspiration in raising the profile of MND, with recognition at the World Rugby Awards and in the Queen's New Year Honours list, where he was awarded an OBE for his services to rugby and MND. He was also presented with the Edinburgh Award by the Lord Provost of the City of Edinburgh, and he appeared on Lorraine and The One Show in the lead up to the inaugural Doddie Cup match between Wales and Scotland in Cardiff in November 2018.

The Foundation has benefited greatly from an amazing range of fundraising activities in support of Doddie, and you can read about these later in this Impact Report.

Our commercial partners and our relationships with major organisations and events are also important to our fundraising activities and we greatly appreciate their involvement and commitment to the Foundation.

The purpose of all of these activities is to raise money to invest in research and support patients. The Foundation has given £450,000 to the Motor Neurone Disease Association (MNDA) and MND Scotland to provide grants for people affected by MND; for example to fund house adaptations to allow people to continue to live at home and to provide respite care.

The feedback that we receive from those that receive these grants reminds us all of how Doddie has made a difference in his quest to support others who suffer from MND. He continues to inspire us all and as we head into our 3rd year of operation, plans are well established for the launch of a multi-armed, multicentre drugs platform trial which will revolutionise how research is conducted.

May I take this opportunity to thank our CEO, Jill Douglas, our CFO, Jim Robertson, our Medical Strategy Lead, Sean McGrath, Joe Davies of Gilson Gray and my fellow trustees of the Foundation. Doddie is a great friend, a wonderful inspiration and together, I hope that one day with your support we will find effective treatments and a cure for MND.

Scott Hastings, Chairman



Scott and Doddie share the commentary booth at Melrose Sevens

Scott takes to the stage in Hong Kong at The Greatest Rugby Dinner Ever

A few words from Doddie

"2019. What a great year it's been for the Foundation, and what a busy one! Thousands of fundraising events run by our great and growing family of supporters have taken place. From headline sporting events to dinners, auctions, shows, sponsored walks, cycles, climbs, swims, bakes, lemonade stalls! You name it - our supporters and partners are an ingenious bunch when it comes to raising funds to fight MND.

And I sincerely thank you all for your hard work. Our investment of your funds in some of the world's best MND research teams here in the UK is now coming to fruition, with drug trials due to start throughout the UK in 2020.

But there's no cure or treatment yet, and that's what keeps me going, keeps me fighting this disease. Personally, I'm feeling the effects of MND a wee bit more now. But I'm lucky. I have a great family, great support network and I'm still here: still walking, talking, still enjoying life and causing trouble. I'm inspired every day by the stories of others with MND. Their strength, bravery and determination gives me the energy and focus to keep pushing for that cure.

I hope you'll keep pushing with me."

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

Doddie Weir, OBE

Raising funds

Hundreds of individual fundraisers and organisations continue to challenge themselves to fundraise for the Foundation and this is reflected through the sums gathered by platforms such as JustGiving and Virgin Money Giving.

Schools, rugby clubs, families, businesses and individuals have ran, walked, climbed, cycled, driven and baked to support the Foundation.

Major events included another Hong Kong Sevens dinner, activities around the rugby matches between Wales and Scotland “The Doddie Weir Cup”, a ceilidh in Banchory, the annual Auld Enemy Dinner on the eve of the Calcutta Cup rugby match, continued support from the Stonehaven community through “Strive” activities, a dinner in Elgin and a dinner arranged by Stewart’s Melville school in Edinburgh.

Doddie’s Ride (a cycling event) has allowed local people in the Scottish Borders to show their support and, despite atrocious weather during the inaugural event in 2018 and the second ride in 2019, there is another one planned! Stuart

Thom’s Great Rugby Cycle continues to attract huge interest and support and Rob Wainwright, a former teammate of Doddie’s, has raised significant funds through the sale of headbands and by embarking on challenging cycle rides which gather enormous support and publicity.

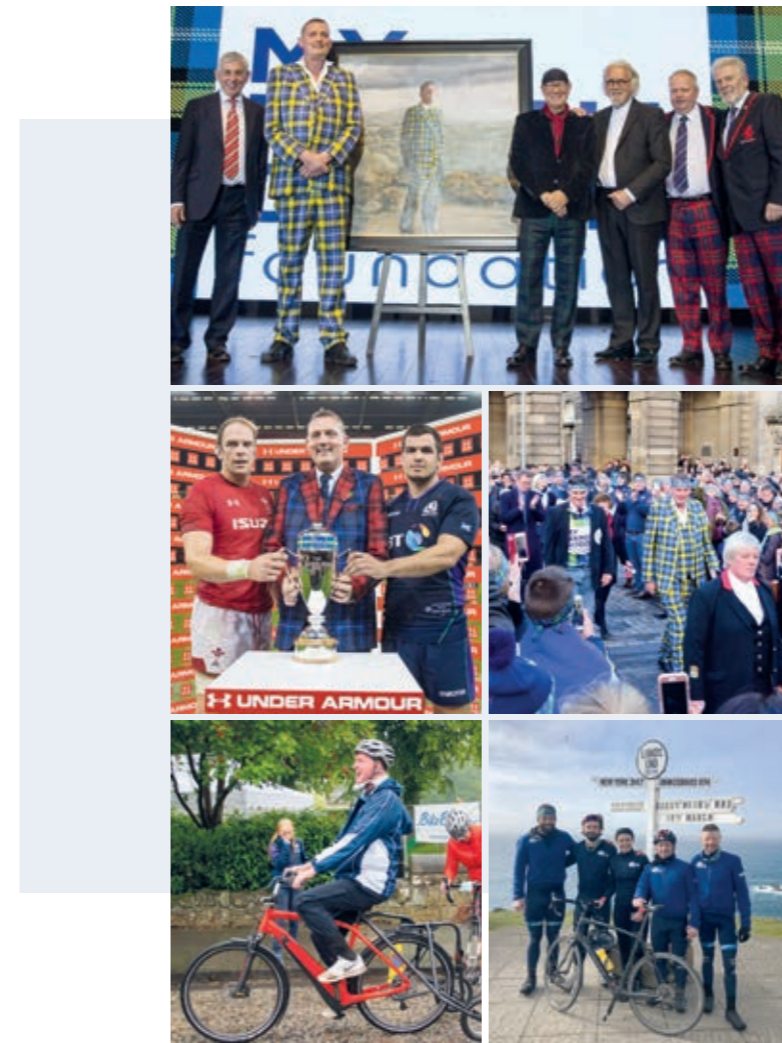
The Foundation runs its own golf days and they have grown in popularity. Golf has proved popular as a means of fundraising with several independent events being organised with the Foundation as beneficiary, most notably The Archerfield Golf Day and the Paul Lawrie Foundation event.

The Foundation has again benefitted from partnering major events such as The European Rugby Finals at Newcastle’s St James Park and a second year of improved activity around the Aberdeen Standard Investments Scottish Open Golf.

The relationship with Scottish Rugby, as an official charity partner, has also been of huge value. The sale of Doddie “headbands” continues to engage supporters and raise funds for the charity.



The 2019 My Name’s Doddie Foundation Golf Day at The Renaissance Club, East Lothian



Thank you to our commercial partners

Commercial partnerships have been developed between the Foundation and businesses and there are also a number of licensed partners who produce and sell branded merchandise with the Foundation benefitting from each sale.



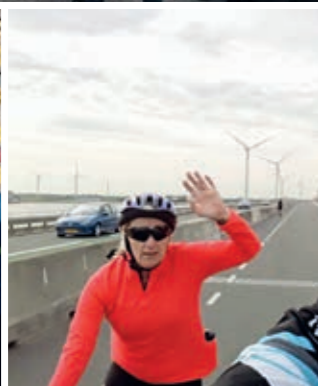
Since inception, the Foundation has raised a total of **£5,879,601** with thanks to all our supporters.

From top:

‘The Greatest Rugby Dinner Ever’ in Hong Kong; Scotland play Wales for the Doddie Weir Cup; a gathering of supporters wearing Doddie headbands at Mercat Cross; the big man on his electric bike during Doddie’s Ride in Melrose; participants of the Great Rugby Cycle at Land’s End; Doddie with Rory McIlroy at the Scottish Open



We'd like to say a huge
thank you
 to all of our amazing
 fundraisers!



Supporting medical research

The role of the Foundation's Scientific Advisory Board has continued to grow and this is now a cornerstone of how the trustees steer their investment into MND research.

It meets twice a year and provides updates, discusses new findings and shares the most up to date research into MND and the potential for meaningful clinical trials.

The Foundation's medical strategy lead, Sean McGrath, acts as the conduit to help further the Foundation's ambitions and foster better relationships between the charity and the medical research community. This, and the activities of the Foundation, has led to it being recognised as a well-respected element of the MND community.

The Foundation has also established links with existing foundations and trusts to look at working together and maximising the Scientific Advisory Board's guidance.



The My Name's Doddie Foundation Scientific Advisory Board and the trustees

Since inception, the Foundation has committed a total of **£2,789,287** to MND medical research projects.

"The My Name's Doddie Foundation in such a short space of time has become one of the leading MND charities. It is having a major positive influence on the fight against MND in Scotland, the wider UK and Europe. They have dramatically raised awareness of MND and thereby achieved significant fundraising. The achievements have been impressive and will continue to make a real difference."

Professor Christopher McDermott, Professor of Transitional Neurology at the University of Sheffield



Doddie visits the team at King's College, London and is shown round by Professor Chris Shaw



Professor Christopher McDermott from the University of Sheffield

Medical research projects that we've supported

- Using stem cells and other models to explore repurposing of old drugs for MND purposes: *Edinburgh and Oxford Universities*
- Gene therapy technologies to prevent build up, and to clear, cellular TDP-43: *King's College, London*
- MIROCALS – support for completing clinical trial of IL-2 in three centres: *Milan, King's and Sheffield*
- The Physiotherapy Trust – grant to support patients with essential physio services, and to measure the results: *Borders, Scotland*
- Post-doctoral neuroimaging scientist for biomarker research: *Oxford University*
- Clinical trial manager and staff to initiate and complete key work: *King's College, London*
- Research staff, PhD student and hardware for clinical trial analysis and completion: *SITRAN, Sheffield University*
- Convection enhanced delivery (CED) project: *Funding Neuro and Prof Steven Gill, Bristol*



Supporting medical research continued

"I'm very grateful for the support I've received from the My Name's5 Doddie Foundation. It has been a humbling and inspirational experience to work alongside people living with MND through my involvement in the clinical trials at Sheffield."

I feel very strongly about protecting our MND community and continuing my involvement in MND research. I would not have had these opportunities without the support from the My Name's5 Doddie Foundation. Thank you again for this life changing experience."

Alexis Collins, 'Doddie Fellow', Sheffield Institute for Translational Neuroscience



"We are immensely grateful to the My Name's5 Doddie Foundation for their grant allowing us to employ Mahrufa Choudhury. This funding is vital help in our search for a cure."

Professor Ammar Al-Chalabi, Kings College London

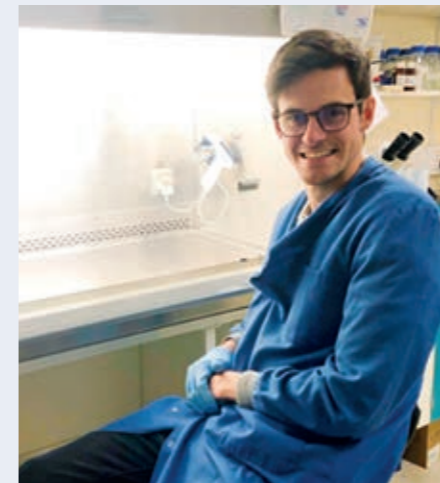
"I'm very grateful to be given this opportunity to work on clinical trials in MND and look forward to settling into the role."

Mahrufa Choudhury, Clinical Trials Manager leading on co-ordinating the Lighthouse 2 study of Triumeq in MND with TRICALS and Macquarie University



"Many thanks to the My Name's5 Doddie Foundation for funding our research technician, Alex. This wouldn't have been possible without all the fundraisers, so a huge thanks to them too! Alex is busy processing samples from all of the MIROCALS clinical trial sites across the UK and France. This will give us a better understanding of how the treatment works in each patient during the course of the disease."

Professor Janine Kirby, Sheffield Institute for Translational Neuroscience



"It has been a tremendous privilege to be supported by the My Name's5 Doddie Foundation during my time in Sheffield."

Over the past few months, I have been investigating novel genetic causes of MND, which may in future lead to personalised medicine and a greater understanding of how the disease develops.

I feel there is no greater unmet need in modern healthcare than the lack of effective treatments for patients with neurodegenerative diseases such as MND: it is therefore my aim to pursue research in this field in my future career."

John Franklin, 'Doddie Fellow', Sheffield Institute for Translational Neuroscience

Helping people affected by MND

The Foundation continues to help families affected by MND and its small grants, administered by MND Scotland and MND Association, have reached over 1,000 people. The Foundation donated £150,000 to these two established charities in 2019, to be used in direct grants to MND patients and their families.

"From the start, I wanted to do something to help people who were going through the same as me. When you are diagnosed with MND, the future for you and your family is so terribly bleak. We are committed to helping find a cure for this devastating disease while also helping people affected by MND."

Doddie Weir

Since inception, the Foundation has donated a total of **£683,562** in grants to MND patients and their families.



"The My Name's Doddie Foundation were there for us in our hour of need. After renovating our home to suit Mike's needs, we came up short when completing the wet room. The grant enabled us to finish the wet room and give Mike the dignity he deserves."

Becky and Mike Crisp



"I have used grants to contribute towards the cost of the ramp built outside my home. Without it I would be house-bound."

Jim Grant

Helping people affected by MND continued



An example of a bathroom conversion facilitated by one of our grants

“The grant has been used to buy my wife a Riser Recliner chair. The MND has caused her to develop a sore back and the chair is designed to alleviate this by allowing better posture, thank you Doddie.”

As a Scot I followed you on the rugby pitch and now you have improved my wife’s wellbeing tremendously, I won’t forget it now or in the future.”

Stuart

“Thank you very much for the support from the My Name’s Doddie Foundation. Making adaptations to my bathroom into a wetroom and installing a washer dryer toilet will make my daily routine much safer and a great help for my personal dignity both for me and my carers.”

Yvonne

Our grants have also paid for...



Family visits

“Time with my family in Pakistan who I had not seen since my diagnosis with MND helped so much. It was helpful to get away from the daily routine at home.”



Short breaks

“Thank you for such a kind gesture without which we would not have been able to take this break for our honeymoon.”



Dream trips

“We used the grant for a long weekend in Egypt, staying in Cairo with my husband and my two daughters. We were able to experience the pyramids and all have some amazing memories that we still laugh about. We were so lucky to receive the grant that made this dream come true.”



Dog walkers

“It has made such a difference to me and my dogs.”



Josie and Mark Wilshaw’s grant allowed them to have an external ramp fitted and their bathroom converted



Our trustees

Kathy Weir

(appointed from 30 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 30 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 30 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 30 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

(appointed from 29 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.

Past trustees:

Gary Armstrong

(appointed from 30 October 2017 to 31 December 2019)

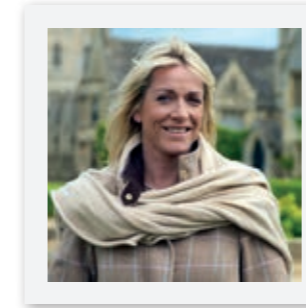
Finlay Calder

(appointed from 30 October 2017 to 29 April 2020)

Jill Douglas

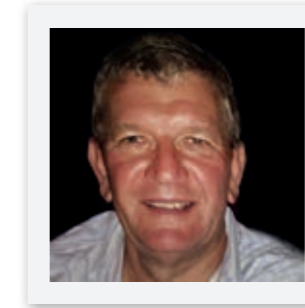
(appointed from 30 October 2017 to 31 December 2017)

Our team



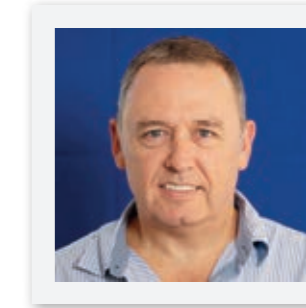
Jill Douglas Chief Executive Officer

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.



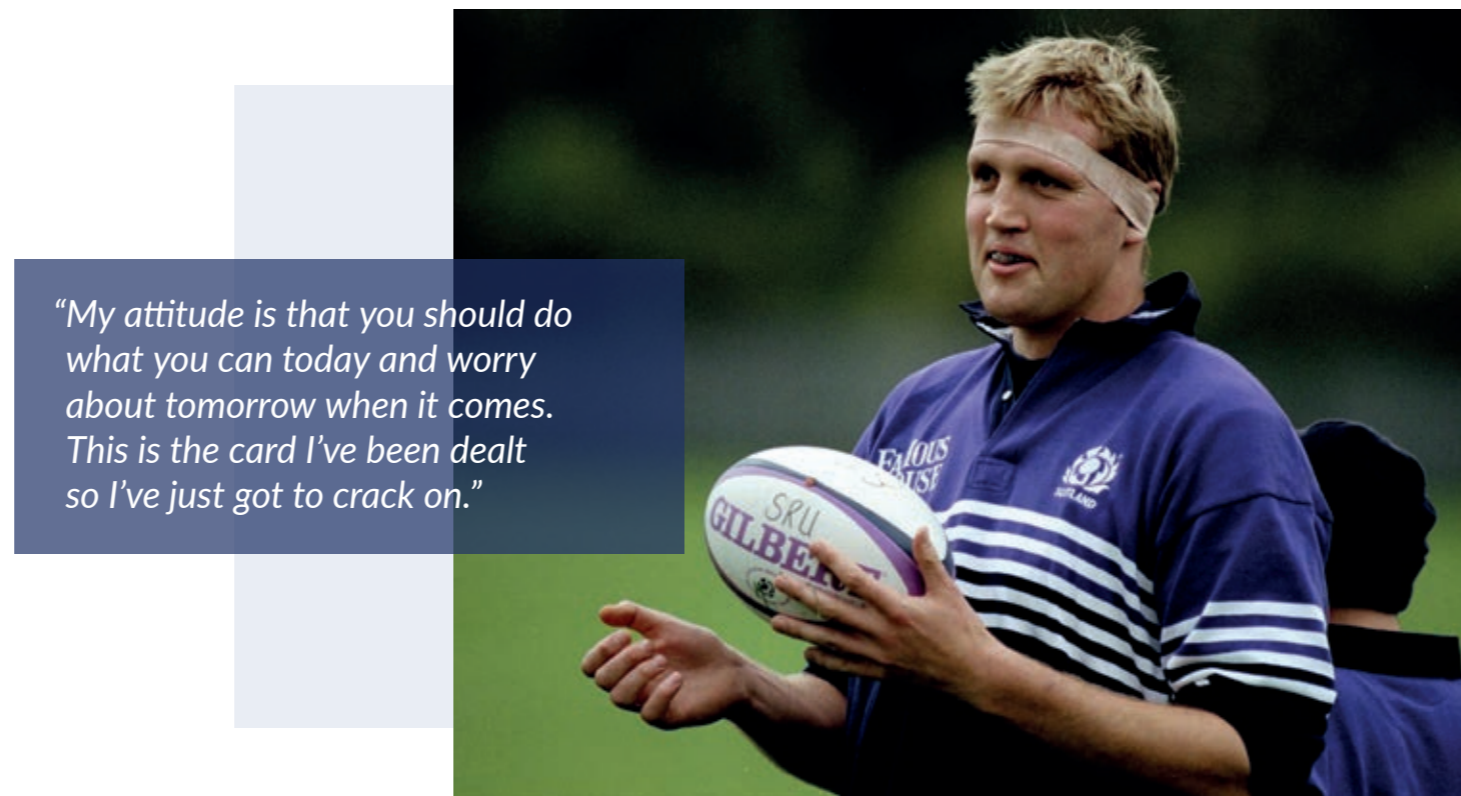
Jim Robertson Chief Financial Officer

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.



"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."

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.

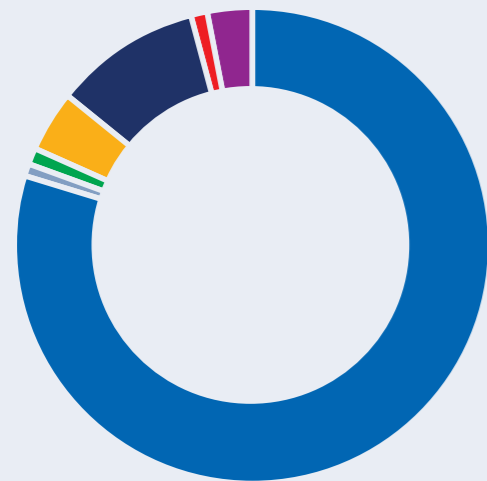
A talented, committed and athletic lock forward, Doddie is now facing his biggest challenge. In June 2017 the Scot revealed he was suffering from MND. From the outset, Doddie has been driven to help fellow sufferers and seek ways to further research into this, as yet, incurable disease.

Financial summary

Every donation makes a difference – either funding vital research to help find effective treatments and a cure for MND or supporting patients and their families affected by the disease.

How we've spent the funds raised:

	Year to 31 October 2018		Year to 31 October 2019	
	£	%	£	%
Donations to medical research and individuals	£915,129	75%	£2,557,720	79%
Administration costs	£3,915	0%	£22,525	1%
Legal professional	£32,680	3%	£39,689	1%
Analysis report	£76,343	6%	£143,076	4%
Marketing costs – consultancy	£112,330	9%	£337,602	10%
Marketing costs – goods	£32,118	3%	£31,543	1%
Salaries	£32,000	3%	£82,084	3%
Trustees travel	£8,290	1%	£2,595	0%
Bank charges	£534	0%	£697	0%
	£1,213,338		£3,217,532	



Visual representation of expenditure in the year up to 31 October 2019

- Donations to medical research and individuals (79%)
- Administration costs (1%)
- Legal professional (1%)
- Analysis report (4%)
- Marketing costs – consultancy (10%)
- Marketing costs – goods (1%)
- Salaries (3%)

78p out of every £1

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

£1.050 million

has been raised by direct marketing activities over the last two years (£2.04 for every £1 spent)

Over £705,000

was received from two successful dinners in Hong Kong

20% of donations

came from charitable websites such as JustGiving and Virgin Money

What's next?

We are committed to helping find effective treatments and a cure for MND and to continue to support families living with MND.

The COVID-19 crisis has meant many research projects have been halted, but the Scientific Advisory Board will continue to meet and maintain its momentum.

Many of our fundraising events and activities have been affected but we are ready to resume when restrictions are eased. A proposed football match in association with The Celtic Foundation, The Great Rugby Cycle in Ireland, our annual Golf Days and a Trek into the Atlas Mountains are all planned as well as another of our fantastic Hong Kong rugby dinners.

Doddie's 50th birthday in July is a cause for celebration and a chance to shine a light on MND – we have some activity planned so watch this space! We look forward to marking our third anniversary in November and embarking on the next chapter together.

Thank you for your continued support.



Doddie at the 2019 My Name's Doddie Foundation Golf Day at The Renaissance Club, East Lothian

How can you help?

Make a regular monthly donation of £5

Set up a regular donation at myname5doddie.co.uk/donate

Make a one-off donation

Donate online at myname5doddie.co.uk/donate or text 'DODDIE' to 70970 to donate £5 or text 'DODDIE' to 70191 to donate £10

Organise a fundraising event

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

Sign up to our mailing list

Sign up at myname5doddie.co.uk to receive our regular updates

Follow us and spread the word

 @MNDoddie5

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Charity number: SC047871

Fundraising, payments and donations will be processed and administered by the National Funding Scheme (Charity No: 1149800), operating as DONATE. Texts will be charged at your standard network rate. For Terms & Conditions, see www.easydonate.org

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Be part of the cure.

myname5doddie.co.uk