

Impact Report

1 Nov 2020 – 31 Dec 2021



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Message from our Chairman

I am extremely proud of what My Name's Doddie Foundation was able to achieve when we were all affected by the impact of the Covid-19 pandemic.

Much of our fundraising activity boiled down to the amazing energy from our supporters, fundraisers and stakeholders who showed such passion and innovation, helping ensure that our fundraising efforts continued to grow despite social restrictions.

As we headed into the New Year, Doddie Aid gave us a tremendous launch pad with fundraisers helping to raise over £1m, logging their steps, miles and kilometres across a dizzying array of activities including, running, swimming (ice swims!), cycling, skating and walking to name but a few activities. During the month we announced that we had donated £300K to MNDA and MNDS to assist them with awarding of grants to those that suffer from MND. The letters of thanks that we receive are heart-warming and hugely appreciated from the recipients and their families.

The 6 Nations rolled into town and despite the tournament being played behind closed doors the widespread support across the rugby community and with Scottish Rugby connects us to the game. Wales won the Doddie Weir Cup, but being appointed as one of the charity partners of the British & Irish Lions Tour to South Africa kept Doddie's name at the forefront of the summer tour.

A number of new partnerships were launched including Maximuscle, Oddballs, Smart Outdoor, Slingsby and Sporting Wine Club with Doddie's Red Blend. Thrifty Car and Van Rental, Aberdeen Standard Investments, Genius Brewing, Scotland Shop, The Cycle Jersey and Halbros continue to be valued as key partners, official supporters, and merchandise partners.

During the year we launched the Foundation's Strategic plan; with a clear vision of a world free of MND and 5 key strategic pillars to take the Foundation forward: Research, Support, Awareness, Sustainability and Fun, Love & Support. This led to an update of the Foundation's website and visual identity which clearly demonstrates the Foundation's plan and vision of the future.

Our operations team headed by our CEO, Jill Douglas, are to be congratulated for helping to ensure that our charity remains at the forefront of the MND community. During the year the board recruited two new trustees Sheela Upadhyaya and Matt Cooper. Sheela is a rare disease strategic advisor and Matt has been involved in clinical research for over 20 years.

The board held numerous online 'zoom meetings' and held an away day in October at the Renaissance Club in East Lothian which hosts one of our annual 'Doddie Golf' days. During this two day retreat we started planning the 'legacy' phase of our charitable efforts (for life without Doddie who at the time of this publication sadly passed in November 2022) that included the appointment of a new CFO in November, Head of Fundraising (appointed Feb 2022), Director of Research (appointed September 2022) and ongoing support of operations and administration.

The Foundation is in excellent financial health, and we continue to build on the Foundation's successful events programme to coincide with the launch of our new research strategy.



Scott Hastings
Chairman

A tribute to our founder

Instantly recognised as an outstanding rugby player, Doddie was diagnosed with MND just two days before Christmas in 2016, eventually going public with the news the following summer on what was Motor Neuron Disease Awareness Day.

Since making his condition known, Doddie has championed the campaign for more to be done for sufferers of the disease, both in terms of finding a possible cure, and with the treatment and welfare of patients and their carers.

Doddie's work over the past five years saw him recognised with several honours and accolades, including an OBE, presented by Queen Elizabeth II for his services to rugby, MND research and the Borders community. He also collected Honorary Doctorates from both Glasgow Caledonian and Abertay Universities, as well as becoming a recipient of the prestigious Edinburgh Award. Within sport, a trophy named after him is now contested between Scotland and Wales, and he became recipient of the Helen Rollason Award at the BBC Sports Personality of the Year ceremony in 2019.

He also became a best-selling and nominated author, oversaw the design of his own distinctive tartan, and was captured on canvas by artist Gerard Burns, the painting now hung in the National Portrait Gallery in Edinburgh.

Born in 1970, Doddie won the first of his 61 caps for Scotland against Argentina in November 1990, but came to prominence as a member of the Scotland side which reached the semi-final of the World Cup the following year. He would go on to appear in the 1995 and 1999 tournaments, the latter coming months after he helped Scotland claim the Five Nations Championship.

At club level, Doddie was part of the outstanding Melrose side which dominated the domestic club game in the early 90s, before becoming one of Scotland's first professional players when he moved to Newcastle Falcons where he scored championship and cup success, his performances there earning him arguably his biggest accolade, namely, a call up for the British and Irish Lions in 1997 for their tour to South Africa.

With several appearances for the Barbarians to his name, Doddie saw out his career with Borders, retiring in 2004 to concentrate on business as a director of a drainage and wastewater company.

Doddie would also become an accomplished speaker on the after-dinner circuit, and as a commentator, columnist and host.

However, his life, and that of his family, was changed forever when diagnosed with MND in 2016.

Doddie had always lived a life full of fun and love and it was this approach which shone through in his determination to make a difference and help others following his diagnosis.

He launched the My Name's Doddie Foundation with his close friends in November 2017, and has inspired everything we do.

The Foundation has raised significant funds through the amazing efforts of incredible supporters and has committed £8 million to MND research over this time. We have also given considerable funds to people living with MND and their families to help them live as fulfilled a life as possible.

With Doddie's enthusiasm and drive, we have collaborated with other stakeholders within the MND community and firmly established the Foundation as a trusted, influential and well supported charity.

And our vision of a world free of MND remains at the heart of our strategy. As we look to the future, we will honour Doddie's name and deliver on his legacy. There is much still to do and with your support, we will continue our work, remaining true to the values and ambition of our founder.



Raising funds

It's been a challenging and difficult year for many of us and we're so grateful for all our partners, supporters and fundraisers who have stuck by the Foundation. Despite all of this it has been one of our most successful years of fundraising, and that's all down to you.

Just when we thought we'd seen it all, more and more wonderful fundraising challenges and ideas come together. This year we've had hit songs, art pieces, Atlantic rowers, whisky auctions, kayakers, cyclists, golfers and many more!

Our fundraising in 2021 was kicked off in style with the launch of the revamped Doddie Aid. Despite it taking place during lockdown, our fundraisers went above and beyond to raise £1m over the month-long inter-district challenge. We were also excited to announce that we would be one of the charity partners for the British & Irish Lions Trust. With this partnership we launched three fundraisers over the summer – Lions Trek for Doddie, Doddie's Lions Big Draw and Auction and Doddie's Super Saturdays.

We once again had a team of mad rowers called 'On Shoulders with Giants' taking part in the Talisker Whisky Atlantic Challenge. The Motoron Cymru appeal also launched which was set up by an amazing fundraiser called Lowri Davies to raise more awareness of MND in Wales. We now have a chart-topping charity single to add to our repertoire! The talented Bruce MacGregor brought together a star-studded group of musicians, including the classical violinist, Nicola Benedetti. Doddie's Dream is an inspirational, positive, and uplifting single which matches the amazing collective spirit of the Foundation and its supporters.

A team from the borders, led by Jamie Murray, completed their Coast to Coast in 24 hours challenge in June and the fantastic Munros 4 MND team completed their dad's challenge of climb the last 15 Munros left on his list, both raising over £30,000. One of our youngest supporters, 4-year-old Charlie Mackenzie, pulled on his running shoes for the Foundation, running half a mile everyday as part of Ross Sutherland Rugby Club's March into May fundraiser.

Normal service resumed with Doddie's Ride, although this was moved from July to August in line with Covid restrictions. Despite the weather it was, as usual, a roaring success, and we look forward to this again in 2022. From the rolling hills of Melrose to the greens and bunkers of North Berwick, the Doddie Scotland golf day returned to the Renaissance Club. It was a glorious day filling with friends, beer, pipers and of course golf. We were also treated to one of the hottest days Scotland has seen!

Our friends at Dual Asset hosted a magnificent charity dinner to raise money for the Foundation and the Logan Invitational also supported us through their annual golf day, which took place at Stoke Park at the end of September.

We also launched a number of new partnerships this year including Maximuscle, Oddballs, Smart Outdoors and of course Sporting Wine Club with Doddie's Red Blend! Of course, thank you to all our current commercial partners we have been working with over the last 12 months to help us raise awareness of the Foundation and MND.

As well as our fundraising we have launched our new strategic plan, which gives our supporters a clear idea of our vision and plan of the future and how their fundraising efforts will help us find a cure to MND and help families and individuals in need.



This year we raised

£4,270,221

with thanks to all our supporters

We have now raised a total of

£12,364,925

to put towards research into MND and to support patients and their families



↑
Your efforts continue to take us closer towards a world free of MND.



We'd like to say a huge
THANK YOU!
to all of our amazing
fundraisers!



United2EndMND

The Foundation continues to play a pivotal role in the #UnitedToEndMND campaign to secure government funding for MND research. In November 2021, the Government announced its commitment to give £50 million for MND research over five years, following intense campaigning by our coalition of MND patients, neurologists and charities. This included a petition in Doddie's name that secured over 100,000 signatures and a debate in Parliament, the delivery of a campaign letter directly to 10 Downing Street, and many meetings with Ministers, MPs and civil servants.

The challenge now is to ensure this money is released quickly and efficiently so that our incredible UK researchers can make further progress towards finding meaningful treatments for MND and ultimately a cure. Government processes are proving slow and bureaucratic, and we are determined to keep the pressure up for those living with MND who do not have time on their side. Further meetings with Ministers and Government departments have been taking place and will continue until the funds are secured.



Research update

We have continued to invest in research across the UK, and although the impact of the pandemic was felt in laboratories and clinical facilities, the last year has seen activity recover and we are pleased to report that all research is now back underway. We are very grateful to the researchers who have worked tirelessly to ensure minimal disruption to their projects during this time.

Here are some of our research highlights:

- We have continued to support MND-SMART, the UK's largest platform trial in MND, which has now recruited over 300 participants from 17 sites across the UK. This is one of several projects investigating repurposed drugs for MND; using drugs that are already approved for other diseases may reduce some of the lengthy approval processes associated with new drugs
- A Foundation-funded neurosurgical trainee has been learning a novel injection technique to deliver gene therapies to people with MND
- Researchers have extracted genetic material from an entire set of samples from participants in a clinical trial. The samples are being investigated to understand how the drug works
- We have joined a collaborative partnership aimed at accelerating the development of meaningful treatments for MND; the fund now stands at over £4 million. The call for applications opened in December 2021 and a decision is expected in the spring of 2022. Find out more at www.lifearc.org/funding/rare-disease-research-funding/mnd-collaborative-partnership

We are grateful to the members of our Scientific Advisory Board who have continued to share their time and knowledge with us, to ensure that we invest in research that will make the most difference to the MND community, as efficiently as possible. Our trusted advisors are a critical element that enable us to deliver on our promises. In 2021, we welcomed two new members; Professor Rickie Patani and Professor Carolyn Young; and we look forward to working with them closely in the coming years. We have continued to develop relationships with key stakeholders in other charitable organisations,

industry, government and patient groups; through these relationships we have entered several collaborative partnerships that have seen large investments into targeted MND research.

In addition to new members of our Scientific Advisory Board, we welcomed a new Research and Grants Officer, Olivia Bird, who is leading the management of the research projects and ensuring the research we fund is communicated with our supporters.

Plans for the next year

As well as continuing to deliver on our promise of investing in research, the coming year will see the launch of a comprehensive research strategy. This will outline our journey towards a cure for MND, and will take into account the opinions of members of the MND community, including people with MND and their families.

This year we committed

£2,317,517

to MND medical research projects

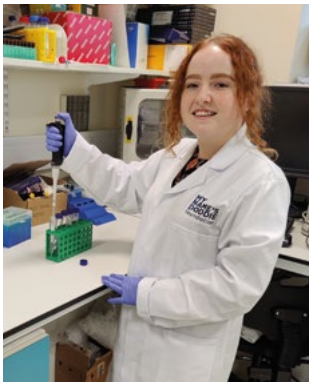
We have now committed a total of

£5,524,923

to help medical researchers find effective treatments and ultimately a cure for MND



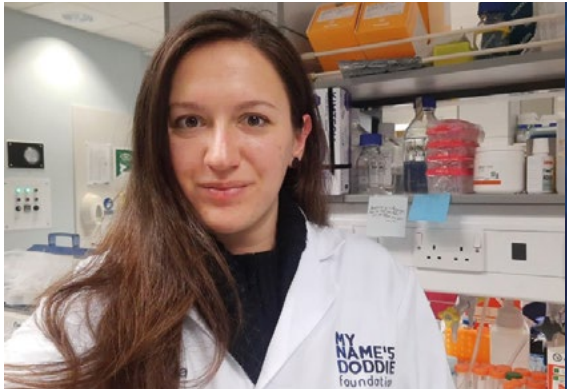
← In November, we met with our Scientific Advisory Board at Drumlanrig Castle, hosted by the Duke of Buccleuch.



← Alex Daniel, My Name's 5 Doddie-funded Research Technician at SITraN, The University of Sheffield. Alex is working on genetic profiling of samples from the MIROCALS clinical trial to understand how the drug, IL-2, works in people with MND.

"We've managed to build expertise in running MND clinical trials in areas where there wasn't any before."

Dr Suvankar Pal, Euan MacDonald Centre for MND research, University of Edinburgh and Co-lead investigator of MND-SMART




"I chose to study MND because I want my work to have a real impact on people's lives. I feel like I am really contributing to create a better future for people living with MND"

Alessandra Cardinali, My Name's 5 Doddie Foundation-funded PhD student, University of Edinburgh

"When you are on a slippery slope, a brake or a change of direction is desperately needed. Being in MND-SMART is a small glimmer of hope in the abyss that is MND. Hope is essential in all adverse situations and more hope would be great."

Alison, MND-SMART participant, Angus



Supporting patients

While My Name’s Doddie Foundation primarily funds motor neuron disease research, we are also committed to supporting people living with MND and continue to work with existing care and information providers to ensure people can make informed decisions about their treatment and care.

We continue to provide 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.

In 2021-22, the trustees agreed to 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 £200,000 to MND Association and £100,000 to MND Scotland. These sums bring our total committed contributions towards supporting people living with MND to £1,252,184.

This year we donated

£300,000

to help MND Association and MND Scotland support patients and their families

We have now contributed a total of

£1,252,184

towards supporting people living with MND



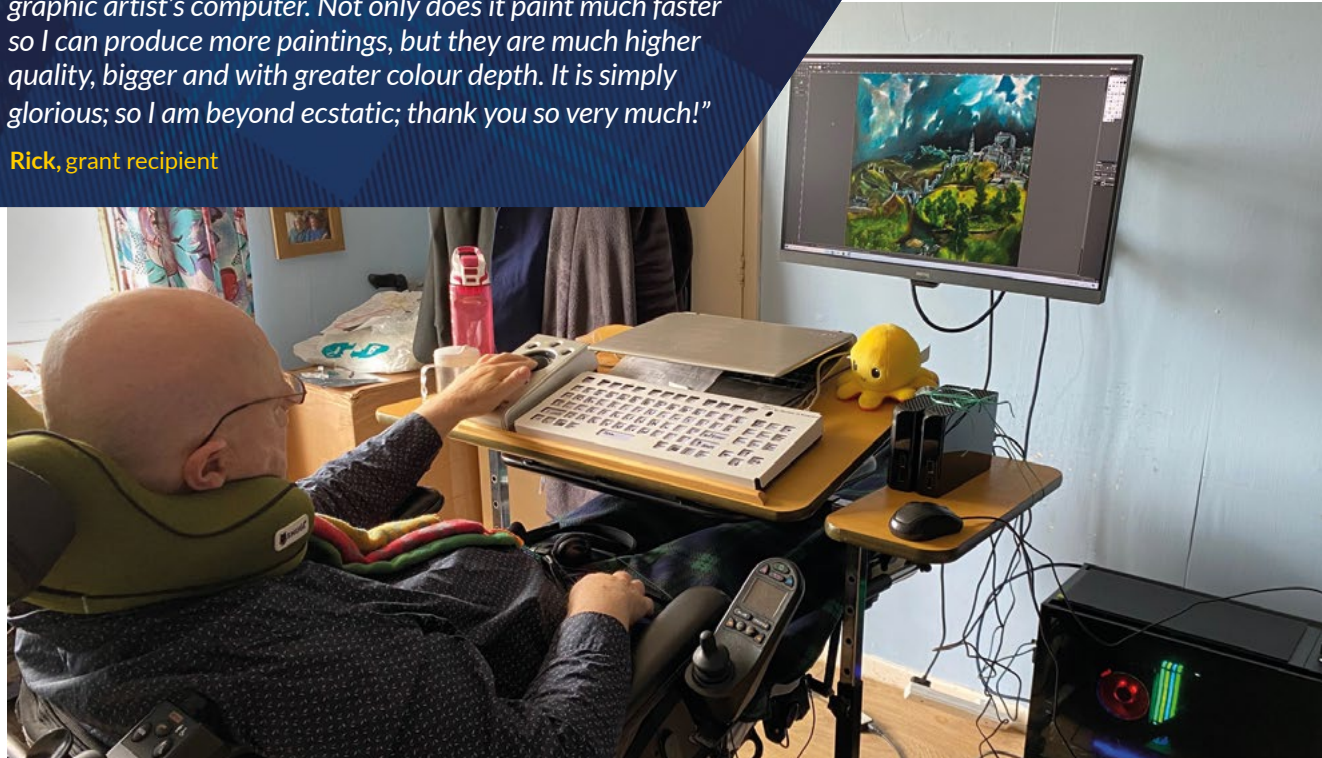
“The stairlift that Doddie’s foundation kindly helped fund was finally installed yesterday...thanks to all involved; it will make a huge difference.”

Roger, grant recipient



“I am Rick, once an academic and educator, now an artist living with MND and painting without brushes, using a computer. I am incredibly grateful to the My Name’s Doddie Foundation for the grant which helped me to replace my poor old overheating laptop with a wonderful purpose-built graphic artist’s computer. Not only does it paint much faster so I can produce more paintings, but they are much higher quality, bigger and with greater colour depth. It is simply glorious; so I am beyond ecstatic; thank you so very much!”

Rick, grant recipient



These are two example’s of Rick’s stunning work. See more on his Flickr page at www.flickr.com/photos/drrickzt

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'.

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.

Sheela Upadhyaya

Sheela is a rare disease strategic advisor and is passionate about securing high quality care outcomes for patients with rare diseases. She has extensive experience in understanding the issues that stakeholders face when developing and bringing new treatments to patients trying to secure access for medicines. Sheela sits on the board of the World Orphan Drug Congress and has participated in several European projects in rare diseases. She is also chair elect for the ISPOR Rare Disease Special Interest Group. Sheela has co-authored several papers that discuss HTA methods for assessing value of orphan medicines and presented at many conferences on the subject.

Sheela has a passion for partnership working and believes that collaboration is the key to delivering high quality outcomes for all.

Matt Cooper

Matt has been involved in clinical research for over 20 years in industry, academia and the NHS, including time at AstraZeneca, Bradford Teaching Hospitals NHS Trust, the National Cancer Research Network and as an Exec Director of the NIHR Clinical Research Network. He is currently General Manager, Oncology at Panthera Biopartners. He lives in North Yorkshire, enjoys running in the countryside with his English Pointer and coaches Ripon Rugby Club U15 girls.

Stuart Paul

Stuart is a Chartered Accountant who spent more than 20 years in investment management. He has served on the boards of several companies and charities. Stuart played schoolboy rugby with Doddie and they toured New Zealand together with the Scottish Schools team in 1988.

Ian Watt

Ian is CEO of Fosroc International Ltd, the sponsors of Fosroc super 6 and the Scottish under 20s rugby academies which he was instrumental in setting up, with a vision to helping young players contribute to Scotland's rugby. He has a passion for rugby where he was introduced to Doddie and they became firm friends. He is married and enjoys time with family, skiing and fitness.

Our team



Jill Douglas

Chief Executive Officer

Jill manages the day to day activity of the charity, working closely with trustees. Jill is also a respected sports broadcaster.



Nicola Roseman

Chief Financial Officer

Nicola is ACCA and CIPD qualified with extensive global experience. Nicola 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 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.



Paul Thompson

Director of Fundraising

Paul is responsible for delivering the income needed to continue and grow our research and support programmes. Paul has twenty years' experience in a range of fundraising roles at National UK health charities.



Alex Glynne-Percy

Digital Marketing Lead

Alex handles digital communication with our brilliant supporters and partners via our social media, mailing list and website. Alex has a background in PR, social media and e-commerce.



Rachel Sharp

Fundraising Manager

Rachel looks after all the wonderful supporters and fundraisers who get in touch to help raise vital awareness and funds towards fighting MND.



Olivia Bird

Research and Grants Officer

Olivia manages applications for funding, peer review and monitors the progress of our research projects. Olivia is knowledgeable about medical research and holds a PhD in pharmacology.



Mia Noquet

Fundraising Assistant

Mia works alongside Rachel, looking after the Foundation's fantastic fundraisers and supporters. Mia has a degree in Government, Policy and Society, and has built fundraising experience through volunteer placements.



Jessica Lee

Director of Research

Jess is the Foundation's Director of Research. She is responsible for driving the Foundation's research activities forward. Jess has previously established and led international research programmes, working with patients, academia, industry and clinical teams to accelerate medicines discovery in areas of patient need.



Jessica Scott

PA

Jessica has extensive experience working in charities, with her most recent post being at St Columba's Hospice. Prior to that she lived in London where she worked for the Royal Africa Society. She is responsible for helping the Trustees with the Board Governance, as well as supporting the wider team.

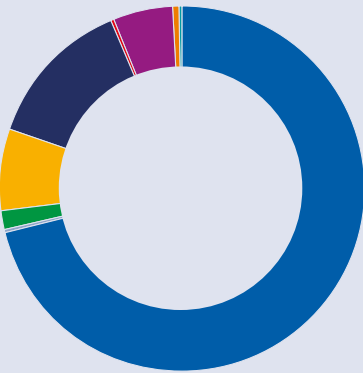
Financial summary

2021 marked a resumption of many of the MND research projects we support, with some being suspended for several months in 2020. We also saw a return to more in-person fundraising activities and are grateful for the wonderful efforts of our supportive community.

In 2022 we have committed to our research prioritisation exercise to focus our research strategy for which the Foundation is well positioned to invest in further MND projects to accelerate the development of new treatments.

How we've spent the money raised:

	14 months to 31 December 2021		12 months to 31 October 2020	
Donations to medical research and individuals	£2,443,147	71%	£821,111	63%
Administration cost	£14,529	0%	£17,866	1%
Legal professional	£51,068	1%	£57,827	4%
Medical research consultant	£251,558	7%	£89,109	7%
Marketing cost – consultancy	£454,909	13%	£192,079	15%
Marketing cost – goods	£7,767	0%	£15,904	1%
Salaries	£180,988	5%	£96,085	7%
Trustees travel	£22,469	1%	£5,946	0%
Bank charges	£5,047	0%	£716	0%
	£3,431,482		£1,296,643	



Visual representation of expenditure in the 14 months to 31 October 2021

- Donations to medical research and individuals
- Administration cost
- Legal professional
- Medical research consultant
- Marketing cost – consultancy
- Marketing cost – goods
- Salaries
- Trustees travel
- Bank charges

In the 14 months to 31 December 2021:

58p out of every £1

was spent on funding our work in research and care of MND sufferers*

£1,103,712

has been raised by direct marketing activities (£2.43 for every £1 spent)

50% of donations

came from charitable websites such as JustGiving, Virgin Money and Enthuse

* The reduction from the previous year is due to an increase in reserves covering future years of Medical Research commitments

What's next?

The support we receive continues to be incredible. Over the past year, we have focused on growing our infrastructure to make us a sustainable organisation and this will continue to be our priority.

We will give people a range of ways to get involved and make sure they understand how their support makes research possible. From Doddie's Clubhouse to Doddie Aid and from expanding our running programme to finding volunteers who can represent us up and down the country, we will have something for everyone no matter what their interests are or where they live. Areas for potential growth include expanding our engagement with corporate partners through our Business Club and launching a free will scheme to encourage people to consider leaving a gift in their will to support future research.

As well as continuing to deliver on our promise of investing in research, the coming year will see the launch of a comprehensive research strategy. This will outline our journey towards a cure for MND and will take into account the opinions of members of the MND community, including people with MND and their families.



How you can help

Make a donation

Make a regular donation to further research and improve the lives of those living with MND by joining Doddie's Clubhouse. Find out more at: myname5doddie.co.uk/doddie-s-clubhouse

Or you can make a one-off donation 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, Easyfundraising and AmazonSmile. To discover more about the various ways that you can help support My Name's 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's 5 Doddie Foundation news, events and research? Sign up to our newsletter here: <http://eepurl.com/dwqEh1>

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