

CATALYSING

A CURE



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catalyse

To start or speed up a chemical reaction by acting as a catalyst

To make something start happening or start being successful

Foreword

Doddie Weir OBE was one of rugby’s most recognisable personalities. In 2017, the Scot revealed he was suffering from motor neuron disease (MND). From the moment he made his condition known, he committed himself to supporting fellow sufferers by raising funds for vital research, building awareness of MND, and giving hope to the MND community.

In November 2017, Doddie and his trustees launched the registered charity, My Name’s Doddie Foundation. The idea that started while sitting around Doddie’s kitchen table has developed into a high-performing, resilient and trusted charitable organisation that continues to grow at pace.

Funding research lies at the heart of everything we do; it’s what allows world-leading experts to investigate potential drugs, expedite new treatments and, fundamentally, work towards finding a cure for this disease.

The launch of our ambitious new research strategy ‘*Catalysing a Cure*’ outlines our continued commitment to our vision of a world free of MND, and to all people affected by MND.

As we look forward, 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.



Jill Douglas MBE
CEO



Ian Watt
Chair of Board of Trustees

Executive Summary

Our new research strategy 'Catalysing a Cure' has been developed in partnership with the MND community, ensuring that we focus on the research that will create the biggest impact for people living with MND. It sets out our intentions to build on our success to date and continue to fund, guide and enable the smartest, most efficient research to expedite the development of new treatments.

The next five years will see us drive forward a focused portfolio of translational research through our investment, partnering and influencing activities. We will continue to collaborate with all those who share our vision, explore opportunities to leverage additional funds for MND research and drive

the adoption of new approaches and ways of thinking to make progress together, faster. We will place a strategic focus on involving people affected by MND in everything we do, to ensure their needs and priorities are at the heart of our activities.

By the end of five years, we will have supported a diverse portfolio of new and encouraging treatments and fast-tracked those with the most promise towards the clinic. We will have innovated, collaborated and invested in the very best research in search of effective treatments to slow or stop disease progression, and to ultimately find a cure.

translational research

Translating scientific discoveries from the lab to the clinic

a cure for MND

A treatment or treatments that would restore normal life expectancy and quality of life for people living with the condition

therapeutic targets

Proteins, genes or systems in the body that can be acted on by a treatment, to change the course of a disease

Our Vision:

A world free of MND

Our Mission:

Fund, guide and enable the smartest, most efficient research to expedite the development of new treatments

Our Strategic Priorities:



Validate
therapeutic targets



Accelerate
new treatments



Improve
translation

Our Approach:



Invest
in cutting-edge translational research



Partner
with those who can help us achieve our vision



Influence
the research agenda



Involve
people affected by MND

Our Impact So Far

SINCE THE FOUNDATION WAS ESTABLISHED IN 2017 WE HAVE INVESTED IN A TARGETED PORTFOLIO OF RESEARCH, ALIGNED TO OUR VISION OF A WORLD FREE OF MND.

We have placed a strong focus on developing new treatments that could stop or slow the progression of MND, supporting a pipeline of promising approaches from early lab studies through to clinical trials.

pre-clinical studies

When treatments are tested in cell or animal models to assess whether they are likely to be safe and effective in humans

Where We Have Invested Our Funds



- Supporting clinical trials – £3.75m
- Improving translation – £440k
- Disease biology, including identifying causes of MND – £535k
- Identification of treatments that could be repurposed for MND – £750k
- National collaboration on translational research – £1m
- Pre-clinical development of new treatments – £1.3m

How Our Funding Has Helped to Expedite New Treatments

5

New treatments in pre-clinical studies

1

Treatment completed pre-clinical studies and progressed to clinical trial

7

Promising treatments tested in clinical trials

Our Impact in Numbers

28

Research projects funded

2

MND trial platforms in the UK supported and grown

15

UK MND centres supported by funding clinical trial staff time

2

New drug delivery techniques in development

£50m

Committed to MND research by the UK government

Our Impact So Far *cont.*

IN JUST FIVE YEARS, OUR RESEARCH PORTFOLIO AND IMPACT HAS GROWN AND EVOLVED. WE HAVE MADE IT A PRIORITY TO PARTNER WITH ALL THOSE WHO SHARE OUR VISION. BY PLAYING OUR PART IN NATIONAL COLLABORATIONS AND JOINING TOGETHER FUNDING FOR TARGETED RESEARCH, WE ARE HELPING TO DRIVE FORWARD THE RESEARCH LANDSCAPE.

A Timeline of Some of Our Key Research Investments

2018 Pre-Clinical Testing of Repurposed Drugs

Our funding helped researchers to select the first two treatments to be tested in MND-SMART, the UK's largest MND clinical trial.

2019 MND-SMART Platform Trial

We helped to expand MND-SMART by funding staff time at new trial centres, enabling patients to access the trial at more sites across the UK.

Funding partners:



2020 TRICALS Clinical Trials

Our funding has helped bring international trials from the European TRICALS consortium to the UK.

UK Funding partners:



2021 MND Translational Research Fund

We worked with other funders to establish a £1.5 million fund that has gone on to support three projects aiming to develop innovative treatments for MND.

Funding partners:



2022 MND Collaborative Partnership

By working in partnership with a consortium of funders, we have helped to build a unique £6.25 million national collaboration that will accelerate the search for a cure.

Funding partners:



Our Impact So Far *cont.*

Driving Forward New Treatments

We have supported a range of innovative projects to help develop effective treatments to slow or stop the progression of MND.

Drug Repurposing



Along with MND Scotland, My Name's Daddie Foundation co-funded our lab studies that showed that the drug terazosin, currently used to treat other conditions, could also be effective in MND. To progress this promising finding, the Foundation is funding a pilot study to test the treatment in people living with MND, which is now underway in Oxford.

Professor Tom Gillingwater,
University of Edinburgh



Left to right: **Dr Nikky Huang, Dr Helena Chaytow**
and **Professor Tom Gillingwater**

Developing Gene Therapies



Left to right: **Doddie Weir** and **Professor Chris Shaw**



My Name's Daddie Foundation was the first funder to believe in our novel therapeutic approach. They funded our early work to develop a gene therapy treatment to reduce the toxic build-up of a protein called TDP-43 in the motor neurons of people living with MND. We are now testing whether we can develop this as a single injection to provide lifelong protection against TDP-43 toxicity.

Professor Chris Shaw, King's College London

Accelerating Progress Together

We know that collaboration is essential to accelerate progress, so we have played an important role in bringing the MND community together.

Campaigning



My Name's Daddie Foundation has been a driving force behind our unique partnership of charities, people living with MND and researchers, that has successfully lobbied government to commit transformational funding for MND research. This is just the start. We will continue to ensure MND research gets the long-term funding it needs to bring new treatments to people like me, faster.

Dave Setters, Living with MND



Building Consensus



In close collaboration with MND Association and Medicines Discovery Catapult, we convened an independent working group of MND experts. Through a series of workshops, we developed a framework of guiding principles for the research community, to raise the standard of pre-clinical MND research and accelerate the development of new treatments.

Project partners:



Catalysing a Cure: Our New Strategy

As we enter a new phase of our research programme, we remain absolutely committed to our mission: to fund, guide and enable the smartest, most efficient research to expedite the development of new treatments for MND.

Where We Are Now

Today, there is huge momentum in MND research. For the first time ever, there is real hope that there are effective treatments to slow or stop disease progression on the horizon.

Our understanding of the biology that underpins MND is growing rapidly, and many breakthroughs are being translated into potential new treatments. What's more, in the UK we have excellent clinical trial infrastructure, so new treatments can be rapidly tested in people living with MND.

We are now perfectly poised to enter a new era of translation. That is, translating our increased understanding of the underlying disease biology into effective new treatments.

Our new research strategy will see My Name's5 Doddie Foundation support a focused portfolio of translational research. We will invest in cutting-edge science, partner with those who share our vision, use our voice to influence the research agenda and involve people affected by MND in everything we do.

OUR ROLE IN THE LANDSCAPE

We will act as a catalyst for the development of new treatments, investing in early-stage, innovative projects with the potential for huge impact. Our aim is to help researchers build the evidence that's needed to demonstrate the potential of new treatments, encouraging others to support and invest in their onward development.



**WE WON'T STOP
UNTIL OUR VISION
IS A REALITY:
A WORLD THAT'S
TRULY FREE
OF MND.**

Our Goals

Short-Term Goal

We are close to developing effective treatments to slow or stop the progression of certain kinds of MND. A huge amount of progress has been made in recent years and many novel targets are now being validated and potential treatments are being tested in clinical trials.

We will continue to support and encourage this progress, to accelerate the development of effective treatments for all people living with MND. We will also support the development of new treatments for the symptoms of MND, where they could transform the lives of people living with the condition.



Short-Term Goal:

Treatments to slow or stop progression of MND and better manage symptoms

Long-Term Goal

Our ultimate goal is to find a cure for MND. It's highly likely that we will need to develop multiple approaches to cure MND, each suitable for a specific kind of the disease. This will require a deeper understanding of the disease that will help to reveal novel targets for future curative treatments. It is also likely to require innovation in other research areas such as earlier detection and diagnosis of MND, so that treatments can be administered as early as possible in the disease course.

Over the coming years, we will partner with others and drive forward innovative research in the search for these cures.



Long-Term Goal:

Treatments to cure MND

Objectives of Our 5-Year Strategy By the End of 2028, We Will Have:

INVESTED IN THE ROBUST VALIDATION OF NOVEL TARGETS

prioritising those with the most potential to underpin future therapeutic strategies

SUPPORTED THE DEVELOPMENT OF NEW TREATMENTS

gathering the critical data needed to convince collaborators and investors of their potential

DEVELOPED STRATEGIES TO IMPROVE TRANSLATION

of lab discoveries to the clinic, to accelerate progress in the search for a cure



Our new strategy 'Catalysing a Cure' is ambitious; it focuses on bringing new treatments to people living with MND, faster. It is underpinned by what matters most to our community and recognises that the people living with this devastating condition do not have time to wait. We believe that effective treatments to slow or stop disease progression aren't too far away. By working closely with our remarkable research community and supporting the adoption of new approaches and ways of thinking, we will accelerate the journey towards making these treatments a reality.



Jessica Lee
Director of Research

Our Strategic Priorities in Focus: Validate Therapeutic Targets

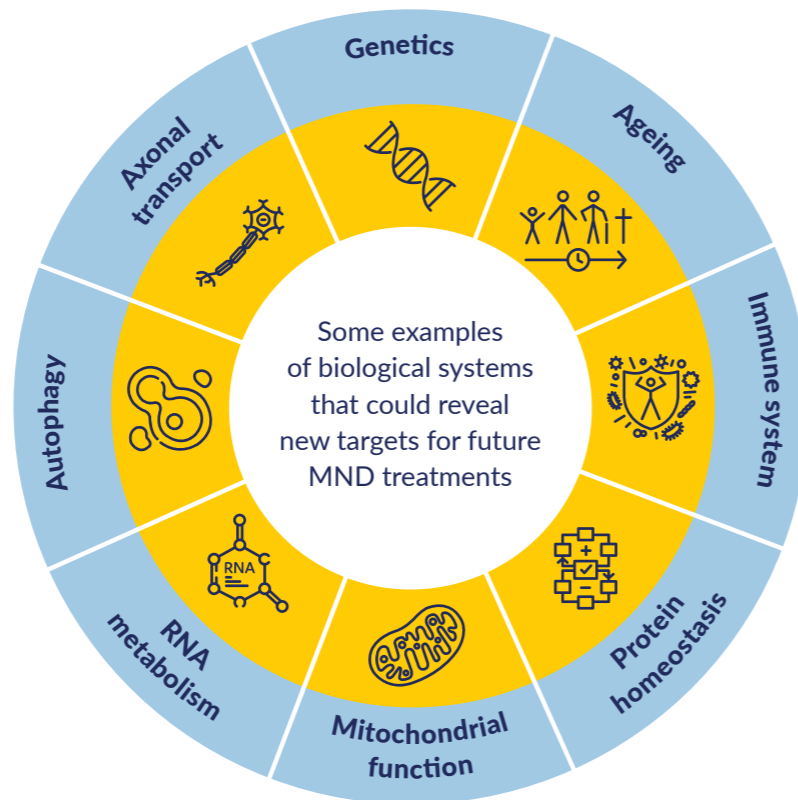


Our understanding of MND biology has grown significantly over the past decade, revealing many potential targets that are now being pursued by drug developers. To drive further progress in the search for effective treatments and a cure, we will continue to invest in research that aims to identify and robustly validate new targets.

Searching For New Therapeutic Avenues

There are many biological systems that could reveal promising targets for new treatments. Better understanding of these systems and how they impact MND is key to identifying future therapeutic strategies and helping in our search for a cure.

We want to support the development of treatments that could be effective for as many people living with MND as possible. So, we will prioritise searching for targets related to mechanisms that underpin the development and progression of MND in most people with the condition.



To Tackle This Strategic Priority, We Will:

- Invest in innovative research to identify and validate novel therapeutic targets
- Develop strategic initiatives in priority areas to focus efforts, engage new partners, leverage funding and accelerate progress
- Learn from innovation in other conditions and work across disease boundaries to drive new approaches and ways of thinking

Accelerate New Treatments



Drug discovery and development in MND has been challenging, with limited success to date. However, we believe this is changing. Recent progress in the field means that MND is ripe for translation and can lead the way for other neurodegenerative conditions.

We will drive forward a portfolio of potential new treatments, partnering with others to create a vibrant and engaged MND drug discovery community. We will act as a catalyst to bring together academics, industry, charities and investors to accelerate new treatments.

Building a Diverse Treatment Portfolio

We will adopt a portfolio approach. Just like building a financial investment portfolio, we will support the development of a diverse range of innovative treatments. By supporting many different approaches, there is more chance of us finding those that will ultimately be effective.

When our researchers have demonstrated that a new treatment shows promise, we will ensure it is fast-tracked through the drug discovery and development process by helping to leverage further funds and support for its onward development.

To Tackle This Strategic Priority, We Will:

- Invest in the development and pre-clinical testing of new treatments, enabling our researchers to gather robust data on safety and efficacy
- Support the development of UK experimental medicine and clinical trial infrastructure so new treatments can be tested in people living with MND in the most efficient way
- Assist the onward development of promising treatments by ensuring the right collaborations and funding are in place



Our Strategic Priorities in Focus *cont.* Improve Translation

Many new treatments for MND have shown great potential in the lab but failed to slow or stop disease progression when tested in people living with MND. Translation from the lab to the clinic needs to be improved.

Our Enablers to Improve Translation

Earlier Detection and Diagnosis:

In pre-clinical lab models, treatments are administered as soon as MND symptoms appear, however in humans this is more difficult as it can take more than a year to get an MND diagnosis. Earlier detection of MND would improve translation of results to the clinic.

Better Biomarkers:

There are currently no validated biological readouts (or “biomarkers”) to tell us if a new treatment is working. These would improve the way we test and predict which treatments are likely to work in people living with MND.

Patient Stratification Strategies:

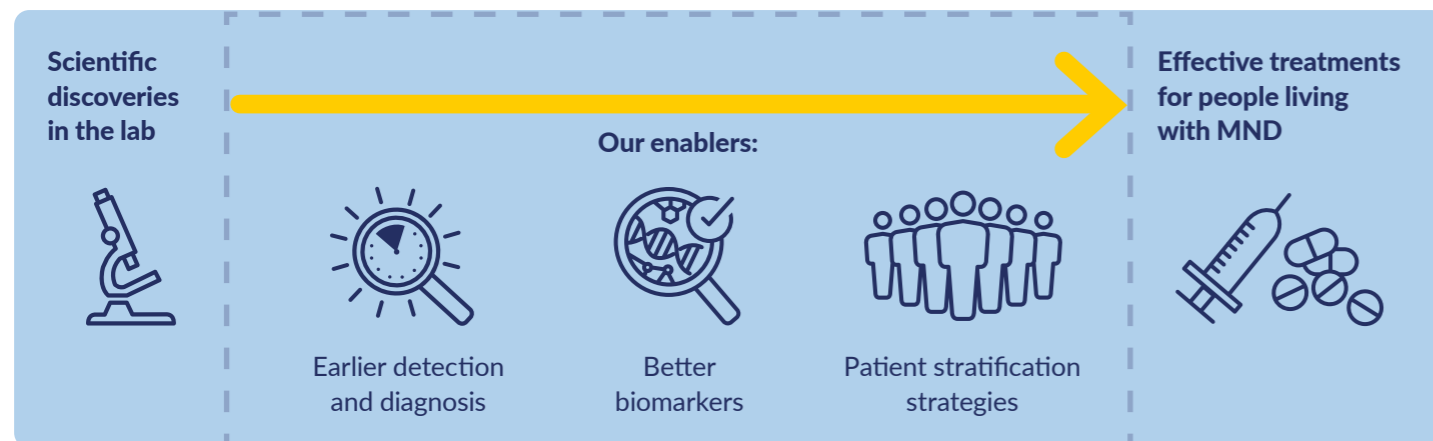
MND presents and progresses differently in each person. By grouping patients according to characteristics of their disease (“patient stratification”), individuals could be offered the treatments that would be most effective for them.

To Tackle This Strategic Priority, We Will:

- Create collaborations and strategic initiatives to enable earlier detection and diagnosis of MND, learning from progress made in other diseases
- Encourage the incorporation of biomarker and patient stratification approaches in all our research projects, to improve the chances of findings being successfully translated from the lab to the clinic
- Continue to explore and encourage the adoption of new ways to improve translation



PEOPLE LIVING
WITH MND
DO NOT HAVE
TIME TO WAIT.



Our Approach



Invest in cutting-edge translational research

- Invest in the very best cutting-edge translational research projects through a competitive grant scheme
- Take an entrepreneurial approach by investing in a portfolio of the most promising drug discovery projects across academia and biotech
- Launch strategic initiatives that encourage collaboration and drive the adoption of new approaches and ways of thinking



Partner with those who can help us achieve our vision

- Partner with other funders to generate bigger funding pots and create more impact by investing in research, together
- Create collaborations with the right expertise and resources in place to fast-track the onward development of promising treatments



Influence the research agenda

- Influence the scientific and political agenda to boost investment and support for translational MND research
- Guide and shape the research agenda by bringing together leading minds at our biannual Scientific Advisory Meetings to enable critical assessment of the latest trends and accelerate adoption of the most promising research approaches



Involve people affected by MND

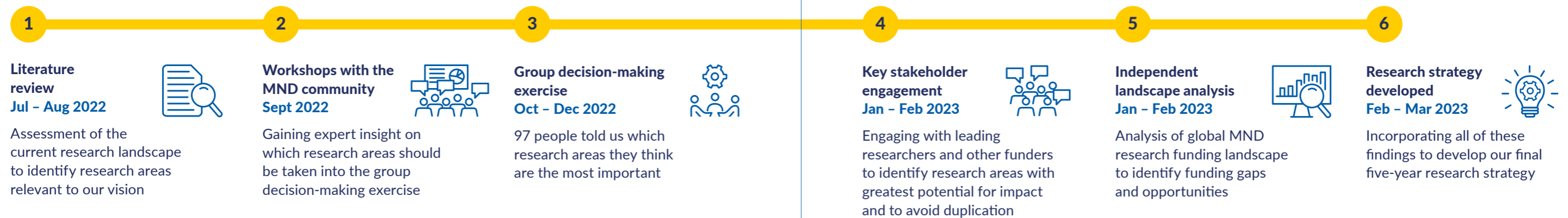
- Involve people living with MND, their families and carers in everything we do, to ensure their needs and priorities are at the heart of our activities
- This will include reviewing our funding applications and advising us on how to best implement our strategy



We will take an iterative approach to deliver our strategy by developing annual action plans that guide our activities, responding flexibly to changes in the research landscape.

How We Developed Our Research Strategy

We believe the MND community should play a vital role in shaping our activities, and it's important to us that we are prioritising the topics that matter most to them. So, we undertook a collaborative exercise to set our priorities. Over 100 people from all corners of the MND community took part in this exercise, including people living with MND, families, carers, healthcare professionals and researchers from academia and industry.



Our Group Decision-Making Exercise

Based on our initial research and discussions with the MND community, we put together a list of 21 key research areas that could contribute to our vision of a world free of MND. Then, we developed an online survey to ask which of these 21 research areas mattered most to the community.

- 13 of the 21 research areas reached consensus as being important research areas for the Foundation. These were the focus of our subsequent engagement with key stakeholders and independent landscape analysis

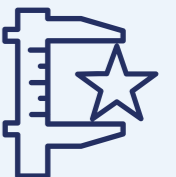
- 8 out of the 21 research areas did not reach consensus, so we are keeping a watching brief and working with other funders to ensure they're not forgotten about

To help us develop our strategy, we partnered with the healthcare consultancy, Costello Medical. The full methodology and results from this exercise can be found on our website.

Measuring and Communicating Our Impact

We are committed to analysing and communicating the impact of the research we fund. The next five years will see us develop an impact evaluation framework against which we will report annually, so you can see how we are addressing our strategic priorities and working to achieve our objectives.

We will work closely with our funded researchers to understand the importance of their research and how it could impact people living with MND. We will share these findings in a clear and understandable manner so that the entire MND community can learn how our work is progressing.



How You Can Help

We can only continue to drive forward research towards our vision of a world free of MND with your help. Whether you come along to one of our special events, sign up to run a marathon, or get your company involved as a partner, you are joining our community and we hugely appreciate it.

BE PART OF THE CURE

Join Doddie Aid

Doddie Aid is a virtual mass-participation exercise event founded by former Scotland captain, Rob Wainwright, every January. Sign up on the Doddie Aid app, claim your free district snood and get logging your miles. All exercise counts, with the winning district being the one with the most miles at the end of the event.

Sign Up For Doddie's Clubhouse

The Clubhouse is a great way to regularly support the work of the Foundation. Members receive exclusive content, a unique pin badge, car sticker and commemorative clubhouse items.

Join the Business Club

Our Business Club provides an opportunity for business leaders to grow their networks with peers from various business backgrounds, over their shared passion for supporting the Foundation.

Leave a Gift in Your Will

You can help ensure our research continues to tackle MND by leaving a gift in your will to My Name's 5 Doddie Foundation. Letting us know of a gift you intend to leave in your will allows us to plan research funding into the future.

For information or advice on all of the above and more, visit our website or get in touch via email at info@myname5doddie.co.uk.



GET INVOLVED

Email us at
research@myname5doddie.co.uk
if you would like to get involved
with our research.

**MY
NAME'S
DODDIE**
foundation

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

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