



# Euan MacDonald Centre for Motor Neuron Disease Research

A network of 250 leading MND scientists, clinicians and health professionals across Scotland

Motor neuron disease (MND; also known as amyotrophic lateral sclerosis, ALS) affects cells in the brain and spinal cord, causing progressive muscle weakness and paralysis.

MND is usually fatal within 2-3 years. Lifetime risk is 1 in 300. There is no cure or effective treatment.

Our mission is to transform, through research, the outcomes for people living with MND and related conditions

We do this by:

TRAINING the next generation of MND researchers

COLLABORATING across research disciplines, and between clinicians & scientists

ENGAGING people with lived experience, and promoting awareness of MND

|      | Our community  | World-class research  |                  |
|------|--|---|------------------|
| 17   | Years in operation   | <b>Leveraged</b> in competitive MND research funding from                                       | £60M             |
| 50   | Principal Investigators at the<br>Universities of Edinburgh, Dundee<br>St Andrews, Aberdeen & Glasgow<br>including 18 Professors | charities, governments and industry  Peer-reviewed research  publications related to MND        | >400             |
| >100 | early-career researchers   | People recruited to the   | <b>&gt; 0</b> F0 |
| 50   | NHS staff, including consultant neurologists, specialist nurses & clinical trial teams   | clinical drugs trial MND-SMART,<br>open at 22 sites across the UK  Spinout company, SpeakUnique | >850<br>1        |
| 5    | <b>Fellows</b> of the Royal Society of Edinburgh   | Editors-in-chief<br>of scientific journals  | 3                |

#### Training the next generation of MND researchers

50+ PhD & MSc students 50+

Postdoctoral researchers, with dedicated postdoc network 30+

PhDs funded to date

10+

Awardees of national training fellowships in last 5 years

#### A cherished sense of community



We are deeply indebted to our founders Euan MacDonald MBE and Donald MacDonald CBE.

Their vision and unwavering commitment to the Centre over two decades has been inspirational to our members.



We are proud to work closely with Euan's Guide, the award-winning disabled access charity that was founded by Euan, with his sister Kiki.

Donald (L) and Euan (R) in 2007

# MND-SMART Clinical trials for MND

"I am so grateful to have the opportunity to take part...I feel strongly that the only way forward to lessening the impact of this condition is through research." Participant in Orkney



MND-SMART is open at 22 sites across all 4 home nations, and is the UK's largest-ever MND drugs trial, having recruited >850 participants to date, including from remote UK islands.

MND-SMART has an innovative "multi-arm, multi-stage" design. Multiple drugs can be tested at the same time, providing definitive answers in half the time of conventional trials.

MND-SMART is widely accessible to diverse ethnic populations, and is co-produced with people living with MND, to make it as easy as possible to take part, e.g. couriering drugs to people's homes.

#### Bench-to-bedside collaborative research

Across our network we are experts in investigating MND in multiple modalities including cognitive assessment, human stem cells, post-mortem tissue and small animal models. We study adult-onset MND and the childhood form spinal muscular atrophy (SMA).

Using our industry-standard robotic drug screening technology, we can test hundreds of compounds using automated sample handling & image analysis. We work together to validate leads. Promising drugs will be tested in MND-SMART.



### Scotland's national platform to empower people with MND



Clinical Audit Research Evaluation

Scotland pioneered the firstever national register of people with MND.

CARE-MND captures details of 99.8% of cases via a world-leading MND nursing service.

CARE-MND facilitates equity of care, plus access to demographic, medication & intervention data.

75% consent to research, giving Scotland a uniquely 'research-ready' population.

# Voice technology spinout company



SpeakUnique is a University spinout that develops voice banking technology to allow people to create a personalised synthetic voice for use in communication aids.

This means people can retain their identity and communicate in a voice that sounds like their own, even when natural speech is not possible.

## Building national & international partnerships





We work closely with UK MND charities, and are members of UK & European networks including the UK MND Research Institute.

We have published research with >350 scientists worldwide in the last 5 years

