



Summer Newsletter 2020

Despite the challenges posed by Covid-19, it's been an incredible six months for the Euan MacDonald Centre! Years of research and preparation have resulted in the launch of two major initiatives: our innovative clinical trial MND-SMART, and our first spin-out company, SpeakUnique. Read on to find out more about both.

Like everyone we've been doing our best to adapt to the change in circumstances, and although trial recruitment and lab experiments have had to pause, our researchers have been busy continuing their research at home. We've been speaking to research participants via telephone and video calls, analysing data, reading about the latest findings from around the world, writing up results for publication in scientific journals, and preparing new bids for funding. We are poised and excited to resume hands-on research activity as soon as we can.

The effects of Covid-19 have been particularly felt by people living with MND. Read on for an excellent blog from our founder Euan MacDonald.

A massive thank you to everyone who supports us!

Launch of MND clinical trial

In January we launched one of the most innovative and comprehensive MND trials in a generation - MND-SMART. But we also had to pause recruitment due to COVID-19.

Read about:

- [the trial launch](#)
- [our first participant](#)
- [recruitment pausing due to COVID-19](#)



Fundraising

You can now raise money for MND research without leaving the house. Raise funds whilst you shop online and at no extra cost to you through www.easyfundraising.org.uk

[Find out more and sign up...](#)



Research into inherited MND

Aberdeen PhD student and Centre researcher Jade Howard, is researching family experiences of inherited forms of MND. She is recruiting people across the UK to take part.

[Find out more about Jade's research...](#)



SpeakUnique goes live

Our first spin-out company is helping people around the world who've lost, or are at risk of losing, their voice due to medical conditions such as MND.

SpeakUnique creates personalised synthetic voices online for use in communication aids. The voices created are identifiably an individual's own voice. The technology is the result of a research project during which over 1600 people from all over Scotland and the UK generously donated their voices.

[Visit www.speakunique.co.uk](http://www.speakunique.co.uk)
[Find out more about the launch...](#)

CARE MND research published

Our CARE-MND platform contains the details of 99% of people with MND in Scotland. It is helping to improve clinical care across the country by enabling healthcare professionals to audit the provision of MND care and treatment and empowering people to take part in MND research.

The following two studies have recently published the results of research carried out using data from the platform:

Riluzole prescribing study

A team of researchers recently reviewed data around the prescription, use and discontinuation of the drug riluzole for people with MND in Scotland. Their findings encourage clinicians to offer riluzole to everyone newly diagnosed and provides helpful information for understanding why people may stop taking the drug.

[Read the full article on riluzole...](#)

Cognitive assessments audit

Many people with MND experience changes and difficulties in their thinking (cognition) and behaviour. The early detection of these symptoms is critical for many reasons including their impact on care givers and life expectancy. Researchers audited cognitive and behavioural assessments in Scotland to see whether best practice is being followed.

[Read about the audit results....](#)





And finally.....

Our founder Euan MacDonald has written an excellent blog in response to COVID-19 for his charity Euan's Guide. His passion for life shines through and here at the Euan MacDonald Centre we see that same passion applied to finding treatments for MND.

[Read Euan's Blog](#)

www.euanmacdonaldcentre.org



The Euan MacDonald Centre for Motor Neurone Disease Research

is based at the University of Edinburgh and is a not-for-profit, charitable network of over 200 researchers across Scotland.

We use research to improve the lives of people living with motor neurone disease (MND) and related conditions.

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