



Press Release

Issued: Thursday 16 January 2020

Landmark trial seeks people with MND to test potential treatments

Hundreds of people living with motor neurone disease are being invited to take part in one of the UK's most comprehensive clinical trials in a generation.

The UK-wide trial – called MND-SMART – aims to find treatments that can slow, stop or reverse disease progression.

The long-term study will ensure that new medicines can be tested for years to come, researchers say.

Motor neurone disease (MND), also known as amyotrophic lateral sclerosis or ALS, is a progressive condition that causes muscle to waste away.

It occurs when nerve cells called motor neurons, which send messages from the brain and spinal cord to the body's muscles, stop working properly.

More than 1500 people are diagnosed with MND in the UK each year. There is no cure and half of people die within two years of diagnosis.

MND-SMART will include as many people with the condition as possible, regardless of how the disease or current treatments affect them. The trial has been developed to find effective medicines more quickly.

Typical clinical trials focus on a single drug - patients receiving the active drug are compared with those who receive an inactive substance, known as the placebo.

MND-SMART will allow more than one treatment to be tested against a shared placebo group so that patients have a higher likelihood of receiving an active treatment.

The clinical trial is designed to be adaptive so that the researchers can modify their approach according to emerging results. New drugs can be added once the trial has started, while medicines that prove ineffective can be dropped.

Initially researchers will test drugs that are already licensed for use in other conditions to check whether they offer any benefit for people with MND.

This repurposing of existing drugs avoids some of the lengthy approvals processes associated with new drugs and could cut years off the time taken for the medications to become available to people with MND through the NHS.

People with MND are invited to register interest in the trial at www.MND-SMART.org. The first participants will be seen in Edinburgh with other clinics across the UK joining during 2020.

The trial has been developed by people with MND and clinical trial experts from across the UK. This includes specialists from the Euan MacDonald Centre for MND Research at the University of Edinburgh, University College London and the University of Warwick.

MND-SMART is supported by the Euan MacDonald Centre, substantial private donations, MND Scotland and the My Name's 5 Daddie Foundation.



@EdinburghUni



edinburghuniversity



@UniversityOfEdinburgh



@university-of-edinburgh

Euan MacDonald, who is living with MND and co-founder of the Euan MacDonald Centre for MND Research with his father Donald, said: "This is the result of 10 years of hard work and collaboration and we are thankful to those involved. Clinical trials like this provide hope that people around the world with MND will one day have access to safe and effective treatments."

Dr Suvankar Pal, Neurologist and MND-SMART Co-Investigator, said: "We are extremely grateful to the people with MND who have helped us design the trial and we believe their involvement will mean far more people will be able to take part."

"Listening to people with MND means we have developed MND-SMART to have very few exclusion criteria. We have also included the option of video calls to reduce the number of times people have to make the tiring journey to a clinic."

Lawrence Cowan, Chair of MND Scotland, said: "This is an historic moment in our fightback against motor neurone disease and because of the incredible generosity of our supporters, MND Scotland has invested £1.5 million into MND-SMART."

Doddie Weir, founder of My Name's Doddie Foundation said: "The support we have received since we launched the Foundation has been incredible and has made it possible for us to invest in this exciting new trial. MND-SMART gives patients some hope, and that is what I have campaigned for since I received my diagnosis three years ago."

For further information, please contact: Guy Atkinson, Press and PR Office, 0131 650 6357, guy.atkinson@ed.ac.uk