



Our ref: WQ92197

Samuel Kurtz MS
Senedd Constituency Member for Carmarthen West and South Pembrokeshire

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15 April 2024

Dear Samuel,

Thank you for your recent written question asking me how the Welsh Government is supporting research into motor neurone disease. Please accept my apologies for the delay responding.

Over the last year, there has been increased focus on ensuring Wales can play a greater role in research into Motor Neurone Disease (MND) and to offer people with MND access to new treatments, through clinical trials and other well-designed studies.

Health and Care Research Wales has been working closely with the South Wales MND Care and Research Network to ensure the research opportunities are embedded in care pathways. In North Wales, people will follow care pathways into English centres for both care and participation in research.

This work has been further enhanced by the appointment of the Health and Care Research Wales Specialty Lead for Neurology and Neurodegenerative diseases, whose role is to build networks across the NHS, increase the uptake of studies and actively engage with similar roles across the UK. There are currently nine MND research studies open and recruiting in Wales including the important MND SMART innovative drugs trial which has been specifically designed to speed up the time it takes to find medicines that can slow, stop, or reverse the progression of MND. Around 300 people (including people with MND, family members and carers) have participated in the studies, which range from trials for medicines, through to finding ways to improve the mental health guidance and support available for people with MND, their families and carers.

A UK 'MND Collaborative Partnership' has been funded (via a £4.25m grant) to kickstart collaborative efforts to end MND. The partnership brings together people living with MND, charities LifeArc, MND Association, MND Scotland and My Name's Doddie Foundation, Medical Research Council (MRC) and the NIHR, with leading researchers. [New motor neurone disease research offers hope for patients | King's College Hospital NHS Foundation Trust \(kch.nhs.uk\)](https://www.kch.nhs.uk/news/new-motor-neurone-disease-research-offers-hope-for-patients). Researchers and clinicians in Wales have been actively engaging with colleagues leading the partnership ensuring Wales is linked into developments and bring opportunities to patients but also researchers with an interest in the field.

My officials in the R&D Division and colleagues in the Health and Care Research Wales community have met with the MND Association on a number of occasions to discuss research into MND. I was delighted to host an event at the Senedd in May 2023, organised in collaboration with the MND Association, which enabled researchers and clinicians to raise the awareness of all the MND research activity taking place across Wales, but also provided an opportunity for the clinical, academic community to network with people with MND and their families.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'M. E. Morgan'.

Eluned Morgan AS/MS

Cabinet Secretary for Health and Social Care

Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol