



Eich cyf/Your ref P-06-1348
Ein cyf/Our ref EM/00507/24

Jack Sargeant MS
Chair - Petitions Committee
Senedd Cymru
Cardiff Bay
Cardiff
CF99 1SN

19 March 2024

Dear Jack,

Thank you for your letter of 23 February about Petition P-06-1348 Commission suitable NHS services in Wales for people with Ehlers-Danlos Syndrome (EDS) or hypermobility.

The role of the NHS Executive is to help ensure evidence-based approaches are utilised to improve patient outcomes and service sustainability and that learning is shared on a local, regional, and national level to drive the shift of resources locally in primary and community care.

The networks in place have built multi-disciplinary and multi-professional structures that provides credibility with the range of staff providing the services, and the patients in receipt of them.

The relevant networks relating to EDS are the networks for musculoskeletal conditions and rare diseases. The Musculoskeletal Strategic Network is in the process of appointing a Network Manager. The national clinical lead for Musculoskeletal Conditions is Dr Rob Letchford and he can be contacted at Robert.letchford@wales.nhs.uk. The intention is for a Musculoskeletal network to be created in the NHS Executive structure from 1st April 2024, but this is dependent on appointments. They will require time to bed in their structure and approach and 2024 will be a transition year for the Network to establish itself.

The national rare diseases implementation network is already in place. More information can be found here: [Rare Diseases - NHS Wales Executive](#). You can contact them via NHSWHC_RDIG@wales.nhs.uk.

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1SN

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:
0300 0604400

Gohebiaeth.Eluned.Morgan@llyw.cymru
Correspondence.Eluned.Morgan@gov.wales

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

The Welsh Government sets the strategic direction for quality of care and planning of services. We do not endorse specific approaches to treatment nor fund their advocacy. The logistical support requested for supporting the GP toolkit and would be for the NHS via the NHS Executive to consider.

I hope this helps clarify the remits of the relevant organisations.

Yours sincerely,

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

Eluned Morgan AS/MS

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services