



Eich cyf/Your ref P-06-1348

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

20 December 2023

Dear Jack,

The Petitions Committee wrote in October regarding healthcare for people living with Ehlers-Danlos syndromes (EDS) and Hypermobility spectrum disorders (HSD) in Wales. I advised I would ask my officials to review the additional queries provided by Ehlers Danloss Support UK (EDSUK) regarding access to healthcare for EDS and HSD patients.

EDSUK challenged whether appropriate referrals to rheumatology were being made and the status of EDS and HSD as rare diseases. I have sought further determination from the national clinical leadership in both rare diseases and musculoskeletal conditions.

In the absence of NICE or BSR guidance in this area, the EDS toolkit provided by Ehlers-Danloss Support UK advises that *“the key role of the GP at this moment in time is in diagnosing hEDS/HSD, validating the patient’s symptoms and co-ordinating care”*. This is completed through a thorough person-centred assessment as there are currently no specialist or specific medical tests for hEDS or HSD. It describes a range of interventions that should be available within the primary care team such as pharmacology and therapies.

In relation to referrals to secondary care, the toolkit describes criteria for escalation to secondary care genetic or rheumatology services when either the diagnosis is less clear or for consideration of the other, rare forms of EDS. These escalation criteria are consistent with the referral thresholds agreed by the all Wales medical genetic service. We fully expect these referral criteria to be considered.

The NHS Executive in Wales will soon consist of a National Strategic Network for musculoskeletal conditions and a rare disease implementation network. These networks will work collectively to explore how care pathways can be improved. The clinical leadership has advised they would be looking to work with the British Society of Rheumatologists, Ehlers Danlos Support UK and community pathways teams to productively consider these issues.

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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.

I hope this information is helpful.

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