



Eich cyf/Your ref P-06-1348
Ein cyf/Our ref EM/01941/23

Jack Sargeant MS
Chair - Petitions Committee
Senedd Cymru
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16 August 2023

Dear Jack,

Thank you for your further letter of 14 July on behalf of the Petitions Committee regarding services for people with Ehlers-Danlos syndrome (EDS) and hypermobility spectrum disorders (HSD).

General consultant specialists are available within every Welsh Health Board and those living with a rare condition will receive quality multidisciplinary care as close to home as possible. Most patients with EDS will be under the care of a rheumatologist, who will have expertise in the area. As EDS is usually multisystem, a Multi-Disciplinary Team approach is best practice.

WHSSC commissions the diagnosis of EDS in children suspected of having EDS. Whilst children can be referred for diagnostic assessment, management and treatment for the condition will be through local clinicians. The specialised diagnostic service only considers children with classical, vascular or rare types of EDS and the children must be referred by a hospital specialist.

For adults the usual pathway would be within the responsibility of the health board within rheumatology. For some patients the high level of expertise required to treat patients is only available at a few centres within the United Kingdom. If there is a possibility a person may have a rare type of EDS, GPs can refer to the local genetics service for an assessment. If further investigation is required, further referral to the EDS National Diagnostic Service is available.

The Rare Diseases Implementation Group (RDIG) is currently scoping the opportunity regarding a virtual health hub for those impacted with Rare Diseases. It will look to provide

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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.

peer support and leadership opportunities, improve coordination of care and increase awareness of research studies.

RDIG are also supporting the SWAN clinic and the Paediatric Rare Disease MDT clinic in Cwm Taf Bro Morgannwg UHB, which aims to understand the impact of a named coordinator of care, amongst other objectives.

Welsh Government will work closely with the strategic clinical networks in the newly established NHS Wales Executive, to ensure we have the insight and support of networks to improve access to diagnosis and treatment for those with Rare Diseases, and in doing so increase awareness and training in these networks.

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