



Eich cyf/Your ref P-06-1348  
Ein cyf/Our ref EM/01475/23

Jack Sargeant MS  
Chair - Petitions Committee  
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19 June 2023

Dear Jack,

Thank you for your letter of 25 May on behalf of the Petitions Committee regarding services for people with Ehlers-Danlos syndrome (EDS) and hypermobility spectrum disorders (HSD).

I am aware that EDS and HSD are classed as rare conditions. The Welsh Health Specialised Services Committee (WHSSC) plans and secures services for people with rare conditions and it is the responsibility of health boards to manage the access and referral to services as appropriate.

The Welsh Government is committed to improving the lives of those impacted with a Rare Disease in Wales and recognises the substantial challenges, including equity of care, management and if available, treatment faced by people.

The Wales Rare Diseases Action Plan 2022 - 2026 - NHS Wales Executive sets out a number of priorities that aim to improve the accessibility and quality of care individuals receive, and these priorities are aligned with the rest of the United Kingdom. They include:

- Priority 1: Helping patients get a final diagnosis faster
- Priority 2: Increasing awareness of rare diseases amongst healthcare professionals
- Priority 3: Better coordination of care
- Priority 4: Improving access to specialist care, treatment, and medicines

The Rare Disease Implementation Group is working towards the delivery of these objectives, and in the last year have made progress with all priorities. In addition, there are

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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.

ongoing investigations regarding the opportunity for a virtual health hub/Wales Rare Disease centre that will provide remote support to those with Rare Diseases.

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