

P-06-1348 Commission suitable NHS services in Wales for people with EDS or hypermobility spectrum disorders, Correspondence – Petitioner to Committee, 18.09.23



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

Natasha Evans-Jones
Lead engagement and community volunteer for Wales
Area coordinator for North Wales
Student social worker
Ehlers-Danlos Support UK

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Dear Eluned,

Thank you for your letter regarding our petition calling for the funding or commissioning of suitable services for those with hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders (hEDS/HSD).

Within your letter you state that patients with hEDS/HSD should be under a local rheumatologist to help manage their care. Unfortunately, currently most health boards within Cymru decline all referrals for local rheumatology stating that they do not deal with hEDS/HSD. I have evidence of this including letters sent to our members who have been bounced back, and emails from rheumatologists stating this. It is best practice to refer to rheumatology to get diagnosis and support, but unfortunately for hundreds of patients with hEDS/HSD in Cymru, they are left with no care as rheumatologists are refusing to see them. Many of the patients with hEDS/HSD must pay themselves for private healthcare to gain any diagnosis or support, if they can afford it. If a patient needs support from a specialist service in England, then they must apply for individual patient funding. In my experience this is very rarely given, and often the application to these specialist centres needs support of local rheumatology, of which most patients are not able to access.

Within your last two letters you state that hEDS/HSD is classed as a rare disease so would be included under the Welsh rare disease awareness plan 2022. Demmler et al (2019) found that hEDS/HSD is around 1 in 500 in Cymru and therefore no longer classed as a rare disease. There are 13 types of EDS, 12 of those are classed as rare diseases. The rarer types are covered by genetic diagnosis services as they have a gene that can be tested. hEDS/HSD do not currently have a genetic test, so diagnosis would be through physical presentation.

Without access to local rheumatology many patients in Cymru are being let down by the NHS. We need to fund or commission specific services for people with hEDS/HSD.

Yours sincerely,

Natasha Evans-Jones (she/her)
Lead Engagement Volunteer and Area Co-ordinator