P-06-1348 Commission suitable NHS services in Wales for people with EDS or hypermobility spectrum disorders, Correspondence – Petitioner to Committee, 27.06.23

EHLERS-DANLOS SUPPORT UK

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

petitions@senedd.wales

27 June 2023

RE: Your reference P-06-1348

Dear Mr Sargeant,

Thank you for sharing the letter, dated 19 June 2023, from Eluned Morgan AS/MS, Minister for Health and Social Services, in response to our petition about NHS services for people with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD).

While the true prevalence of EDS and HSD is unknown, the conditions are likely to affect between 600 and 6,400 people in Wales[1].

We are pleased to hear that 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.

We welcome the Wales Rare Diseases Action Plan 2022 - 2026 and are pleased to hear that The Rare Disease Implementation Group has made progress with all of its priorities in the last year. We would be grateful for more information on how and when this work will impact those with EDS and HSD in Wales and would be pleased to attend a meeting with the Department of Health and Social Services to discuss further.

The current experiences of our members indicate that people with EDS and HSD in Wales do not have access to any 'services for people with rare conditions', which Ms Morgan stated as being the responsibility of The Welsh Health Specialised Services Committee (WHSSC). Their website lists 'Rare Diseases' as a commissioned service but the location(s) of this service and the pathway to access it is unclear for people with symptoms of EDS or HSD. It would be helpful for our helpline staff and volunteers in Wales to learn about the commissioned rare disease services so that they can signpost patients accordingly.

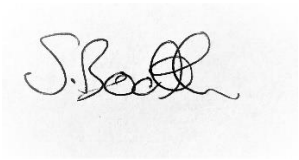
[1] Demmler JC, Atkinson MD, Reinhold EJ*, et al*
Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK: a national electronic cohort study and case–control comparison
BMJ Open 2019;**9:**e031365. doi: 10.1136/bmjopen-2019-031365

If the rare disease service is based on a genomic medicine service, it is unlikely to be of benefit to those with hypermobile EDS (hEDS) or HSD at present, as a genetic basis for these conditions is yet to be identified.

It is our experience that health boards are not commissioning appropriate community-based or secondary care EDS and HSD services at present. In line with the Welsh Government's 'A Healthier Wales' plan, hospital-based rheumatology departments are specifically declining referrals for patients with 'hypermobility' (which includes those with most types of EDS and HSD) in favour of management in primary and community care. This includes those with complex needs. This is slowing down the time to diagnosis of EDS and HSD, which goes against the Wales Rare Disease Action Plan. We would like to understand what alternative pathways are available to these patients with complex needs.

Thank you.

Yours sincerely,



Susan Booth
Chief Executive Officer

Natasha Evans-Jones
Lead Engagement Volunteer for Wales