PE2038/E: Commission suitable NHS services for people with hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders

Petitioner submission of 13 September 2024

We have new evidence to support the provision of suitable NHS services for people with hypermobile Ehlers-Danlos syndrome (hEDS) and hypermobility spectrum disorders (HSD). This evidence was presented by EDS UK, researchers Kathryn Berg and Dervil Dockrell and a range of Healthcare professionals at an exhibition in Holyrood on the 7-9 May 2024 during EDS awareness month and a roundtable hosted by Michael Marra MSP on the 4 September 2024.

Evidence that hEDS/HSD is not rare and evidence of lack of NHS services

hEDS/HSD are not rare types of Ehlers-Danlos syndromes, they are rarely diagnosed. A study of diagnosed prevalence in Northumberland, Frankel B et al 2023, showed that as many as 1 in 227 had a diagnosis. Demmler et al 2019 found that 1 in 500 people had a diagnosis of hEDS/HSD. That's between 11 and 24 thousand people living with hEDS/HSD in Scotland. These are only the people who actually have a diagnosis. Berg K and Dockrell D 2024 hEDS-START study found an average 20 year wait for diagnosis with 22% of people paying privately to get a diagnosis, 1 in 4 leaving Scotland to access hEDS/HSD related healthcare elsewhere and 1 in 7 being diagnosed in England. This demonstrates a clear failure to provide suitable NHS services for people with hEDS/HSD in Scotland.

National Services Division response PE2038/D

In October 2023, the Committee wrote to the National Services Division (NSD) to ask why the 2018 proposal for a specialist centre was rejected. They were also asked to confirm if the commitment from the NSD to produce a paper for regional directors of planning highlighting which issues and service gaps people with EDS and HSD encounter still stood. We are not aware of any paper being produced and there is no acknowledgement of this in their response.

We would also like to draw your attention to the suggested alternatives given by NSD to our original application for a specialist service "The reasons for non-progression included the lack of support for the proposal from the Scottish Society of Rheumatology, the need for initial assessment and treatment by local rheumatology services prior to referral to the national service and ***that care might be better delivered through the development of a set of clinical guidelines, a patient pathway of care or a networked community of practice***". This is exactly what we are trying to achieve but we are being told from Health Improvement Scotland there is not enough evidence to support SIGN guidelines. This is despite the evidence provided above and over 6,000 people providing their lived experience evidence in the hEDS START project.

Scottish Government response PE2038/C

The Scottish Government has cited the Scottish Rare Disease Action Plan (SRDAP) in its response. EDS UK has participated in events for SRDAP and has used these opportunities to advocate on behalf of members living with the rarer forms of EDS, recognising that the plan's broad actions to improve awareness of rare conditions more generally will, eventually, result in improvements in the experience of care for people with rare conditions. To maintain momentum we would welcome the opportunity to meet with officials to discuss EDS UK's current priorities and work progressing under the SRDAP as offered.

However, the development of specialist services for individual rare conditions is not within the scope of the SRDAP. The remit of Scotland's Rare Disease Implementation Board does not extend to decision making relating to the commissioning of specialist services, clinical pathways and guidelines in Scotland. Therefore, the SRDAP is not an appropriate route to address the urgent unmet clinical needs of the hEDS/HSD community in Scotland that this petition aims to tackle and is therefore not a solution. The evidence shows hEDS/HSD is not rare and is therefore not covered by the SRDAP.

What is happening in other UK nations

Through the EDS UK petitions, in May 2024 NHS Wales committed to co-creating a hypermobility pathway for primary care to help GPs diagnose and manage these conditions. Their Health Minister also gave EDS UK the contact for the Welsh Rare Disease Partnership to look at the rarer types of EDS. In England, a debate was held in Westminster and the Health and Secondary Care Minister offered a meeting with NHS England. The election was announced after the debate and so the meeting was postponed but we are confident this will be honoured. In Northern Ireland, we have meetings planned with MLAs to secure a similar debate.

What we need across the UK

Across all four nations we are seeking the following:

- A pathway for NHS diagnosis and care for hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders.
- NICE/SIGN guidelines for Ehlers-Danlos syndromes and hypermobility spectrum disorders.
- A coordinated, multidisciplinary approach to diagnosis and care for people with hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders and their associated co-morbidities.
- Support and training for healthcare professionals to deliver this.

What we have already done to provide a starting point

The hEDS-START study held a patient engagement event with EDS UK where a wish list for a pathway of care and a list of values to underpin a regional service in

Scotland were developed. This study provides a lived experience perspective and evidence base.

We also have the EDS UK GP toolkit which they are using in Wales as a basis for the primary care pathway.

We remain willing to engage with the Scottish Government in finding a solution for implementing the pathway, guidelines and training that are so desperately needed.