



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

5 December 2023

Dear Eluned,

Thank you for your letter concerning our petition for better care for those with Ehlers-Danlos syndrome/ hypermobility spectrum disorder (EDS/ HSD). I would like to thank you for taking our concerns seriously- we are delighted that a review will be taking place and are very keen to see the outcome of your investigation.

We would like to ask who the leads are that you will be speaking to? There are 13 types of EDS, 12 are rare, and the hypermobile EDS/HSD types are known to be more common affecting 1 in 500 people in Wales (Demmler et al 2019 <https://pubmed.ncbi.nlm.nih.gov/31685485/>). This study demonstrates that hEDS/HSD is a common condition, and it also demonstrates that it does not only affect the musculoskeletal system and soft tissues. There are many co-morbidities as this chronic condition affects the connective tissue throughout the body. Therefore, we would like to know if the leads that are to be consulted in your review will also include experts from other specialities to provide a true reflection of the issues faced by people with EDS in Wales? We have a medical advisory panel of specialists in EDS/ HSD and are happy to ask them for their input on this issue.

We would also like to ask how many referrals from GPs to rheumatology are being refused across Wales? Those with EDS/ HSD in Wales are still being routinely being denied care under rheumatology. We know from our members that nearly all referrals are bounced back to GPs. Therefore, most people if they can afford it, pay to see a rheumatologist privately. This is the same for physiotherapy and other Musculoskeletal (MSK) services. The Getting It Right First Time Rheumatology report of 2021 recommended that people with non-inflammatory conditions (such as EDS/HSD) are cared for in primary or community care. EDS is not an inflammatory condition, but it is a connective tissue disorder (CTD) and musculoskeletal (MSK) condition causing multi-systemic issues. Both MSK and CTD conditions normally fall under the remit of rheumatology.

We would also like to ask how many people in Wales with the rarer types of EDS are being funded to access treatment in England? We know that the types of EDS that have a genetic marker are able to be referred to specialist centres in Sheffield and London. We would like to know how well this is working and are all GPs in Wales aware that this is an option?

There is no clear pathway for anyone with any type of EDS in Wales. There are diagnostic difficulties with hEDS/HSD in particular as there is no genetic test for them. Across the UK it is estimated that it takes around 19 years from symptoms beginning to diagnosis, this is being exacerbated by rheumatology refusing to see anyone with hypermobility in Cymru. Therefore how will primary and community care be supported in making accurate diagnosis and providing good treatment plans? The only toolkit we are aware of is our own GP toolkit. <https://gptoolkit.ehlers-danlos.org/> Will your investigation include what guidance and advice is in place to support healthcare professionals across a range of specialties to diagnose and manage EDS/HSD effectively?

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I met with Joel James MS recently and he is also supporting us to have a drop in the Senedd to open up discussions about the inequalities experienced by Welsh patients. Joel has also stated that he will be contacting each health board in Cymru to see their reasoning behind not seeing those with hypermobility. We are currently waiting for an update on these approaches and a date for the drop in. We hope that these questions will help to shape your investigation and we would be willing to help in any way possible. People with EDS/HSD in Wales desperately need a proper plan and resource in place to support them living with this painful and debilitating condition. We look forward to hearing from you soon.

Yours sincerely,

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