



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

22 January 2024

Dear Eluned,

Thank you for your letter of the 20 December 2023 with your carefully considered response concerning our petition for better care for those with Ehlers-Danlos syndrome/hypermobility spectrum disorder (EDS/ HSD) in Wales. Thank you also for the opportunity to put comments through the petitions committee, both of which we warmly appreciate.

We welcome the reference to our GP toolkit hosted until recently by the RCGP, which we know has helped GPs using it. The toolkit is now available on our website <https://gptoolkit.ehlers-danlos.org/> We also welcome the opportunity to work with National Strategic Network for musculoskeletal conditions and the rare disease implementation network collectively, to explore how care pathways can be improved. We are delighted that the clinical leadership will work with ourselves, the British Society of Rheumatologists and community pathways teams to productively consider these issues. This is great news.

We have the following questions in response to your letter.

1. How will we move this important discussion forwards? How can we engage with the other specialists within the multidisciplinary team across primary and secondary care that are involved in managing EDS/HSD? It is critical that the people involved in this pivotal discussion fully represent the complexity and multisystemic nature of the condition. We need to have representation from other specialists including physiotherapists, gastroenterologists, neurologists, gynaecologists etc. Will the clinical leadership you have sought further determination from, set a date for us to meet? What is the timeline for the change to a National Strategic Network?
2. Whilst we wait for this important discussion, our GP toolkit, in the absence of NICE or BSR guidance in this area, is the only tool available and therefore the only way of aiding accurate and timely diagnoses and effective treatment plans. Will there be opportunities to formalise links to it to ensure that all healthcare professionals and not only GPs are aware of the toolkit? Is there funding available to help promote it and host it on relevant Continuing Medical Education platforms?

Thank you again for your looking into this issue and for the committee's ongoing support. We look forward to your response.

Yours sincerely,

Natasha Evans-Jones (She/her)
Lead engagement and community volunteer for Wales
Area coordinator for North Wales

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