EDS
EHLERS-DANLOS SUPPORT UK

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

14/4/24

Dear Eluned,

Thank you for your letter. As advised, we have emailed Dr Rob Letchford (MSK clinical lead), and the rare disease implementation network. We plan to meet with both soon and agree that a collaboration with them both will be helpful.

Within an earlier letter that HSD/ HEDS can be managed through using the GP toolkit. Although this is correct in practice this has rarely happened. I support those with EDS/HSD and most GP’s do not feel confident enough to use the toolkit, and often refuse to diagnose. With rheumatology also refusing to see those patients with any hypermobility they are left to pay private or go without care. This is wholly unacceptable. If the plan is to continue to refuse patients referrals to rheumatology, will GPs be getting additional training so that they can support patients best?

We understand that unfortunately there is no treatment for EDS/HSD due to it being a genetic condition. But there are support services that can help a person’s wellbeing and quality of life. Support services like pain management, occupational therapy, and physio at the early stages of symptoms allow patients to better manage their EDS/ HSD symptoms. But with EDS/HSD it is usually on average 19 years until a diagnosis is given. With rheumatology refusing to see patients, and GP’s not being confident in using the GP toolkit patients are left longer and often deteriorate in their condition. Long term this has an economic impact, for example less ability to work and contribute to the economy.

EDS/ HSD does not have a pathway for care, with EDS/HSD affecting around 1/500 people (Demmler et al, 2019) we think it’s time that a care pathway is created. Patients are being left without diagnosis, support, and care. How would we go about creating this?

Yours sincerely,

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