Response from the Department of Health and Social Care, December 2019
From: Department of Health and Social Care [mailto:DoNotReply@dhsc.gov.uk]
Sent: 02 December 2019 16:33
To: Karen Huntley <karen.huntley@healthwatchcalderdale.co.uk>
Subject: Your recent correspondence

Our ref: DE-1193118

Dear Miss Huntley,

Thank you for your correspondence of 8 October about hypermobility syndromes. I have been asked to reply, and I apologise for the delay in doing so.

In January 2018, NHS England published its Implementation Plan for the UK Strategy for Rare Diseases; this can be found on the NHS England website at: https://www.gov.uk/government/publications/uk-strategy-for-rare-diseases-2019-update-to-the-implementation-plan-for-england

NHS England announced its new genomic medicine service in October 2018. As part of this service, the first National Genomic Test Directory was launched in 2019 and can be found on the NHS website at: https://www.england.nhs.uk/publication/national-genomic-test-directories/

The hypermobile conditions Ehlers-Danlos Syndrome (EDS), osteogenesis imperfecta and Stickler syndrome are included in the Test Directory. The Test Directory will be updated every year to keep pace with scientific and technological advances. NHS England also commissions highly specialised services for three inheritable hypermobile disorders, including a complex EDS diagnostic service for adults and children at two centres in England, London North West University Healthcare NHS Trust and Sheffield Children's NHS Foundation Trust.

UK charities can also give support to patients. For example, the Ehlers-Danlos Society, www.ehlers-danlos.com, is a community of patients, caregivers, healthcare professionals, and supporters, dedicated to saving and improving the lives of those affected by EDS, hypermobility spectrum disorders (HSD) and related conditions. The Society supports collaborative research and education initiatives, awareness campaigns, advocacy, community-building, and care for the EDS and HSD population. It has a freephone international helpline for advice, although it should be noted that it cannot give medical advice. The Society's telephone numbers and contact form can be found at: www.ehlers-danlos.com/about-us

The charity Ehlers-Danlos Support UK, www.ehlers-danlos.org, also provides support and information to those in the UK whose lives are touched by EDS. The free helpline is 0800 9078518 (Tues and Fri) or it can also be contacted on 020 8736 5604 (Mon to Fri).

Both charities are members of Genetic Alliance UK, which works to improve the lives of patients and families affected by rare, genetic and undiagnosed conditions and has over 200 patient organisations as members. It produces information for patients, families and anyone interested in genetic conditions. More information about its work can be found at www.geneticalliance.org.uk.

Now that Parliament has been dissolved before the General Election, the Department cannot comment further on this matter. What happens on the issue of services and support for people with hypermobility disorders in the future will be a matter for the incoming Government.

I am sorry I cannot be more directly helpful.

Yours sincerely,

Millie Pritchard

Ministerial Correspondence and Public Enquiries
Department of Health and Social Care