

Scottish Government submission of 12 October 2023

PE2038/C: Commission suitable NHS services for people with hypermobile Ehlers-Danlos syndrome and hyper mobility spectrum disorders

Engagement with individuals living with hEDS and HSD has mainly been in two areas.

Individuals attended engagement events as part of the development of the Scottish Action Plan for Rare Diseases where we heard from members of the community about their lived experience.

The Scottish Government's Rare Diseases Policy Team receive correspondence from those living with rare conditions through the Ministerial and Corporate Correspondence system. Such correspondence describing lived experience powerfully bring to life the challenges of living with a rare condition. These stories bring an important focus, not only raising awareness of individual rare conditions such as hEDS and HSD; but ensure the experiences of individual citizens are heard and their experience informs our thinking and future policies. The Scottish Government are listening, and will put lived experience at the heart of our actions to improve the lives of people in Scotland living with a rare condition in developing strategic policy for the NHS in Scotland.

With regards engagement with Ehlers-Danlos Support UK (EDS-UK), we can assure the Committee that it is the Rare Disease Implementation Boards's intention to hold a number of "involvement meetings" early in 2024 which will be widely advertised. The Scottish Government has funded Genetic Alliance UK to carry out these meetings on our behalf.

The Scottish Government are also considering what additional stakeholder engagement activities may be required throughout 2024.

Officials would be happy to meet with EDS UK to explore their current priorities and discuss the work progressing under the current Rare Disease Action Plan. Finally, we'd invite EDS UK to contact Natalie Frankish (Policy and Engagement Manager for Scotland - Genetic Alliance UK) who is a member of the Scottish Governments Rare

Disease Implementation Board (RDIB) and who could represent their views at the RDIB.

Planning and Quality Division