Scottish Government submission of 6 September 2023

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

I refer you to your email of 24 July asking for the Scottish Government's views on the actions called for in petition PE2038. I have addressed the requests contained in the bullet points of the petition below.

- **Calling on the Scottish Parliament to urge the Scottish Government to commission suitable NHS services for those with hypermobile EDS (hEDS) and hypermobility spectrum disorders (HSD), and to consult with patients on their design and delivery.**

The Scottish Government is absolutely committed to ensuring that people living with a rare condition like hEDS and HSD are able to access the best possible care and support, and benefit from healthcare services that are safe, effective, and person-centred. It is the responsibility of the Scottish Government to set out policies which will tackle these issues, and it is expected all NHS Boards to provide high quality care accordingly. In general, it is the responsibility of NHS Boards to ensure sufficient workforce is in place to deliver safe services and the Scottish Government continue to support all NHS boards to ensure they do this.

Where specialist care and clinical expertise is available for rare conditions we are committed to making sure they are available to patients through the commissioning of specialist services. Diagnosis and patient care/symptom management for hEDS and HDS is provided by local and regional rheumatology services with the input of other specialities such as clinical genetics, chronic pain services and colorectal surgery as required. Where Scotland doesn't have such specialised treatment, there are options for patients to access the care they need, if available, elsewhere in the UK. The cross-border referral application would be made by the patients secondary care specialist or consultant if they deem that the treatment required is not available in Scotland. The application is evaluated by NHS National Services Division who then provide funding if the application shows that the

referral is to access a proven, evidence-based, specialist intervention, that is not available elsewhere in NHS Scotland. If the person in question does not yet have a secondary care specialist or consultant involved in their care, then this will fall under the responsibility of their GP.

During the development of the Scottish Rare Disease Action Plan, which was published last December, we engaged with the rare condition community and listened to the issues they raised, such as those highlighted in the petition.

The Action Plan is structured around the four shared priorities of the UK Rare Diseases Framework:

- faster diagnosis
- raising awareness
- better co-ordination of care
- improved access to specialist care

The actions that have been set out in this first iteration are to be worked on over the next 18 – 24 months, in collaboration with Scotland's NHS and with third-sector partners such as Genetic Alliance UK and other key stakeholders and patient groups. The actions will address issues around lack of sign posting, referral pathways and overall co-ordination of care for people with rare conditions, including those living with hEDS and HDS.

Another vital component to this is continuing to work with the rare condition community as we implement the Action Plan, to ensure that those with lived experience can tell us the most about what needs to change to improve their lives. This will include people who have conditions such as hEDS and HSD.

We are committed to raising awareness and education of rare conditions, such as hEDS and HSD, across all health care professionals, including physiotherapists and orthopaedic units. There are over 7,000 rare conditions and it is not possible for healthcare professionals to receive comprehensive training on every condition. However, it is important to ensure an understanding of rare conditions are part of the curriculum for trainee healthcare professionals. We are also seeking to

promote Continuing Professional Development linked to rare conditions which will be available throughout the career of a healthcare professional. There will also be work around appropriate signposting to reliable sources of information in order to help healthcare professionals navigate the complex clinical guidance that exists for many rare conditions.

I hope this response is helpful both to the Committee and to the petitioner.

Planning and Quality Division