

HCR 4 STAFF MEASURE SUMMARY

Carrier: Rep. McIntire

House Committee On Rules

Action Date: 03/05/25

Action: Be Adopted.

Vote: 7-0-0-0

Yeas: 7 - Boshart Davis, Bowman, Drazan, Elmer, Kropf, Pham H, Valderrama

Fiscal: No fiscal impact

Revenue: No revenue impact

Prepared By: Melissa Leoni, LPRO Analyst

Meeting Dates: 3/5

WHAT THE MEASURE DOES:

This measure designates May 2025 as Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders Awareness Month.

ISSUES DISCUSSED:

- The experiences of people who have Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorders (HSD)
- Elevating awareness of EDS and HSD

EFFECT OF AMENDMENT:

No amendment.

BACKGROUND:

Ehlers-Danlos syndromes (EDS) are a group of 13 heritable connective tissue disorders that together affect 1 in 5,000 people. Each type of EDS has its own set of symptoms, but some features are seen across all types of EDS, including joint hypermobility, skin hyperextensibility, and tissue fragility.

Hypermobility spectrum disorders (HSD) are connective tissue disorders that cause joint hypermobility, instability, injury, and pain. Other symptoms of HSD include fatigue, headaches, gastrointestinal problems, and autonomic dysfunction.

There is no cure for any type of EDS or HSD, and the conditions are managed by addressing a person's symptoms. EDS and HSD can cause a variety of symptoms in many different areas of the body, so people with these conditions often require multiple providers in different specialties to manage their care.

Access to medical professionals who are knowledgeable about EDS and HSD is limited in Oregon. A lack of awareness about EDS and HSD in the United States and across the world stands in the way of diagnosis, management, and research of these conditions. Awareness about EDS and HSD by both medical professionals and the general public can help improve the lives of people living with EDS and HSD in Oregon.