



Mission Statement

To raise awareness of Ehlers-Danlos Syndrome and to provide support and education to all interested in the greater Oregon Area.

Who We Are:

We are a steadily growing group of patients with Ehlers-Danlos Syndrome along with families and friends in the greater Oregon area.

We seek to support one another in our journey with this challenging condition.

We meet several times per year. Please visit our website at www.oreds.org for details about meeting times and location.

Why Zebras?

"Zebra" is medical shorthand for a rare diagnosis. Some doctors are taught that when you hear hoofbeats, you assume horses, not zebras. So when interpreting symptoms, they assume the most common explanation. But sometimes the hoofbeats really are zebras! The zebra has become a symbol for underdiagnosed or rare conditions.

OREDS

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*Ehlers-Danlos
Syndrome isn't rare;
it is rarely diagnosed.*



About Ehlers-Danlos Syndrome:

Ehlers-Danlos Syndrome (EDS) is a genetic connective tissue disorder. There are 6 major types of EDS, each with a different set of symptoms or complications.

Connective tissue is found throughout the body, so EDS can present with a wide variety of symptoms causing unexpected complications.

EDS can look different across people, and symptoms can exist on a spectrum.


Symptoms include:

- Chronic pain
- Joints that frequently dislocate with minimal trauma
- Chronic fatigue
- Digestive complications
- Skin fragility that tears and/or bruises easily
- Fluctuations in heart rate or blood pressure, i.e. "dysautonomia"

Serious complications can include:

- Heart/organ rupture
- Chiari Malformation (brain stem descends into the spinal column)
- Permanent disability

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 Oregon Area
Ehlers-Danlos Support Group

 OREDS Boards List

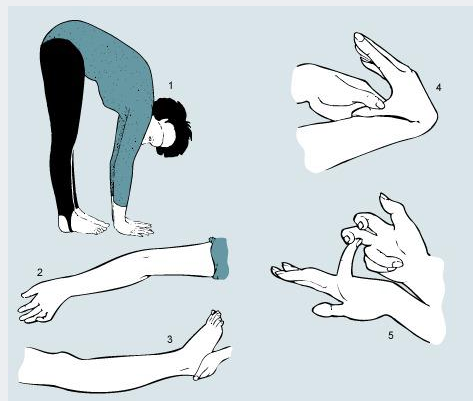
Diagnosis:

A geneticist can diagnose EDS, and genetic testing is available for many types. For the hypermobility type of EDS, a doctor will look at the Beighton Scale. A score of 5/9 or more shows hypermobility. The Beighton Scale is one piece of the puzzle in determining a diagnosis of EDS. To learn more on diagnosis, please visit our website.

The Beighton Scale:

*One point is given for each:

- ✓ Forward flexion of the trunk with knees fully extended so that the palms of the hand rest flat on the floor
- ✓ Hyperextension of the elbows beyond 10 degrees – one point each elbow
- ✓ Hyperextension of the knees beyond 10 degrees – one point each knee
- ✓ Passive apposition of the thumbs to the flexor aspect of the forearm – one point each hand
- ✓ Passive dorsiflexion of the little fingers beyond 90 degrees – one point each hand



**From www.EDNF.org/assessing-joint-hypermobility*

Support:

Many people with EDS may also experience depression and anxiety, which may have organic causes but can also be exacerbated by pain, fatigue, loss of functioning, and difficulty finding proper treatment and support.

EDS is often an invisible condition, with no external sign of the pain you experience. It can make you feel alone and confused. Finding an answer and knowing that there are others out there going through the same experience can be a great comfort.

At OR EDS, we believe that knowledge and hope come from human connections and common experience. We provide resources, education, and support for those diagnosed with EDS as well as those still seeking answers. There is help out there, and there is always hope.

