

Plain Text Resource Ehlers Danlos Syndrome (EDS) Awareness Month

Slide 1

The first slide has a zebra print border and the LUNA project logo is in the bottom right hand corner. There are 2 white rectangles with black text on them. The first says Ehlers Danlos Syndrome (EDS) Awareness Month and underneath this the second says EE·LUHZ DAN·LOS SIN·DROWM

Slide 2 What is EDS?

Ehlers Danlos Syndrome (EDS) is an inherited connective tissue disorder. It occurs due to a genetic mutation in an individual's DNA. In the case of EDS this mutation means that the protein collagen is formed incorrectly making it weaker than it should be.

Collagen is a connective tissue that is present all over the body, holding everything together. Some of the areas impacted by collagen include: your skin, digestive system, bones, blood vessels, muscles, and tendons. It's the most abundant protein in the human body!

There are at least 16 different types of collagen and there are 13 types of EDS. Depending on where the mutation sits, it'll cause different forms of EDS each with different symptoms.

There is a small black outline of a DNA molecule on the page.

Slide 3 Types of EDS

As mentioned previously there are 13 types of EDS. Some of which are rarer than others. The most common is hEDS whilst certain types of EDS such as vEDS and aEDS are much rarer.

Hypermobile EDS (hEDS)
Classical EDS (cEDS)
Classical-like EDS (clEDS)
Cardiac-valvular EDS (cvEDS)
Vascular EDS (vEDS)
Arthrochalasia EDS (aEDS)
Dermatosparaxis EDS (dEDS)
Kyphoscoliotic EDS (kEDS)
Brittle Cornea Syndrome (BCS)
Spondylodysplastic EDS (spEDS)
Musculocontractural EDS (mcEDS)
Myopathic EDS (mEDS)
Periodontal EDS (pEDS)

Each different type is in a different colour font and they are spread randomly across the slide

Slide 4 Symptoms of EDS

The symptoms of EDS vary for each specific type of EDS but some of the symptoms include:

Joint hypermobility
Frequent dislocations/subluxations
Easy bruising
Chronic pain
Fragile, stretchy skin
Prolapses
Atrophic scarring
Hernias
Dental problems eg. overcrowding
Delayed healing
Heart valve issues

Each different symptom is in a different colour font and they are spread randomly across the slide

Slide 5 Explaining EDS

Imagine that your body is held together with glue (connective tissue).

For a person without EDS that glue is like superglue (functional connective tissue), good quality and strong. But for people with EDS it's like that glue is pritt stick (faulty connective tissue), it is weak and doesn't do a very good job of holding your body together. Collagen is the 'glue' in your body and it is literally everywhere and that's why EDS affects so many areas of the body

There is an illustration of a grayscale bottle of glue in the top right hand corner

Slide 6 EDS & Comorbidities

Many other conditions appear to commonly occur alongside Ehlers Danlos Syndrome. These are known as comorbidities and can include:

Dysautonomia
MCAS (Mast Cell Activation Syndrome)
Gastroparesis
Chiari malformation
Adrenal insufficiency
CCI (Cranio-cervical Instability)
Chronic Fatigue
Anxiety
Sleep Disorders

Each different comorbidity is in a different colour font and they are spread randomly across the slide

Slide 7

Like every chronic illness EDS exists on a spectrum of severities. Each person with EDS will be impacted differently by the condition.

Some will be able to lead a relatively “normal” life with minimal adjustments. Others will manage their condition through physio and medication. Whilst others will be severely disabled by their condition and its comorbidities often reliant upon mobility aids, medical devices such as feeding tubes or catheters, and medication to function.

The nature of EDS also exists on a fluctuating scale so a person’s capabilities may differ from one day to the next based on their symptoms and/or injuries from dislocations.

Slide 8 Why the Zebra?

The Zebra became a symbol for those with EDS as in the medical field junior doctors are often told “when you hear hoofbeats behind you, don’t expect to see a zebra.” Which implies that you should be looking for the more common and usual, not the surprising, diagnosis. But for those with EDS this is not the case. People with EDS are the unexpected. The symbol of the zebra acts to represent that sometimes when you hear hoofbeats, it really is a zebra.

When you see a zebra, you know it’s a zebra—but no two zebras have identical stripes just as no two people with EDS have identical symptoms or presentation.

There is a picture of a zebra in the bottom left corner

Slide 9 Favourite creators with EDS

There is a photo of each of the following 6 people, with their name, and instagram handles.

There are:

Lauren-@edsnoodle

Lori- @budtobloomlori

Ella- @edsvsella

Jess- @chronicallyjess1

Lauren- @potsofhope

Lacey- @more.than.midodrine

The LUNA logo is situated in the top right corner