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Ehlers-Danlos Syndrome Network C.A.R.E.S., Inc.

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~What is it?

- Ehlers Danlos Syndrome (EDS) is a group of heritable connective tissue disorders affecting about 1 in 10,000 -15,000 . It is characterized by (joint) hyper mobility, skin extensibility(stretchy skin) and tissue fragility (scarring & bruising).
- It is caused by faulty collagens. Collagens provide structure and strength to connective tissue throughout the body. Type III collagen is mostly found in skin, blood vessels, and internal organs.
- There are six major types of Ehlers-Danlos Syndrome. The different types of EDS are classified according to their manifestations of signs and symptoms.
- Many EDS patients have signs and symptoms from several types making diagnosis hard.
- There is no cure and no treatment for Ehlers-Danlos Syndrome.

Most Common Types...

Classical Type

- The Classical Type is **one of the most common forms** of Ehlers-Danlos Syndrome The Classical Type of EDS is characterized by highly elastic, soft, and doughy skin; unusual scarring; and loose joints.
- People with the Classical Type have smooth, velvety skin that is stretchy, fragile, and easily bruised, wide scarring.
- People with this condition also have loose joints with an unusually large range of movement (hypermobility). As a result, joints are prone to dislocation, sprains, and the early-onset arthritis, hiatal hernias and cervical insufficiency.

Hypermobility Type

- The most common sign is an unusually large range of joint movements called hypermobility. Both large and small joints are unstable, and certain joints (such as the shoulder, knee, and jaw) tend to dislocate frequently. Pain is chronic.
- Ruptures of tendons, vessels and internal organs.
- Soft or velvety skin with normal or slightly increased extensibility and spontaneous or easily induced tears or ruptures of skin, tendons, ligaments, vessels, or other internal organs.

Vascular Type of EDS (vEDS)- Most Severe Type

- The Vascular Type of EDS is characterized by possible arterial or organ rupture as a result of spontaneous rupture of vessels or organs due to the result of even minor trauma.
- The Vascular Type of EDS is the **most serious form** of Ehlers-Danlos Syndrome.
- Life expectancy is shortened.

Other Types of EDS : Kyphoscoliosis Type, Arthrochalasia Type, Dermatosparaxis Type, Tenascin-X Deficient Type

What causes It?

- There are numerous types of EDS, all caused by changes in one of several genes. The manner in which EDS is inherited depends on the specific gene involved.
- Although there is much information regarding the changes in genes that cause EDS and their various inheritance patterns, the exact gene mutation for all types of EDS is not known.

How do you know you have it ?

- Clinical symptoms such as extreme joint looseness and unusual skin qualities, along with family history, can lead to a diagnosis of EDS.
- Specific tests, such as skin biopsies are available for diagnosis of certain types of EDS, including vascular type. A skin biopsy involves removing a small sample of skin and examining its microscopic structure.. Blood tests and urine tests are available for some types.
- Management of all types of EDS may include genetic counseling to help the affected individual and their family understand the disorder and its impact on other family members and future children.
- Prenatal diagnosis is available for specific forms of EDS, including kyphoscoliosis type and vascular type. However, prenatal testing is only a possibility in these types if the underlying defect has been found in another family member.

How is it treated?

- Medical therapy relies on managing symptoms and trying to prevent further complications.
- There is no cure for EDS. There is no treatment
- Surgery, although discouraged, is sometimes necessary to repair joint damage caused by repeated dislocations. Bracing is often prescribed.
- Physical therapy teaches individuals how to strengthen muscles around joints and may help to prevent or limit damage.

Does it affect life ?

- The outlook for individuals with EDS depends on the type of EDS with which they have been diagnosed.
- Symptoms vary in severity and the frequency of complications changes on an individual basis.
- Some individuals have few symptoms while others are severely restricted in their daily life.
- Most individuals will have a normal lifespan, however, those with EDS vascular type, have an increased risk of fatal complications.
- Constant bruises, skin wounds, and trips to the hospital take their toll on both affected children and their parents.
- Prior to diagnosis parents of children with EDS have found themselves under suspicion of child abuse.
- Some people with EDS are not diagnosed until well into adulthood and, in the case of EDS vascular type, occasionally not until after death due to complications of the disorder.



WHAT IS Ehlers-Danlos Syndrome Network C.A.R.E.S.,INC. ?

EDS Network Cares is a **non-profit organization** established and driven by EDS patients and family members who share a belief in, and a passion for research and education. This **all-volunteer network** is led by devoted volunteers whose primary goal is to make a difference in the lives of people who are suffering each and every day from Ehlers-Danlos Syndrome.

Our mission is to help improve the quality of life for people who have Ehlers-Danlos Syndrome, through research, education and support.

We believe.....

- By supporting research, effective management techniques will be developed and ultimately, a cure will be found.
- Through support, we meet the needs of those who deserve personal attention in crisis and in grief.
- Through education and advocacy, we promote awareness, understanding and ensure access to treatment.

Our 1st Research Project:!

The EDS family is a tight-knit community, a community that has lost too many members during the past few years. In 2009/2010, we had an opportunity to turn our feelings of helplessness into hope by funding a critical research project: the Ehlers-Danlos syndrome mouse model.

The development of this particular mouse model enables researchers to explore treatment options using an already FDA-approved medication to reduce the fragility of the vascular system. Additionally this project enables researchers to better understand the genetic mechanism involved in not only the vascular type of EDS, but potentially all types of EDS and other connective tissue disorders in which collagen proteins are affected.

Our funding contribution supported a continuation of Dr. Hal Dietz' Altered Cytokine Signaling in Vascular Ehlers Danlos Syndrome (VEDS) study at Johns Hopkins.

Rarely are people given the opportunity to directly fund a treatment for such a devastating disease—a disease that currently has no cure or treatment. Ehlers-Danlos Syndrome Network C.A.R.E.S. was proud to be a part of such important research.

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