

#### **Autism and Ehlers-Danlos Syndrome**

#### What is Ehlers-Danlos Syndrome (EDS)?

- EDS is a hereditary connective tissue disorder.
- ◆ There are 13 subtypes one of which is hyper-mobile EDS - (hEDS)

#### What is hEDS?

- ♦ hEDS characterized by:
  - generalized hyper mobility of joints
- Additional associated features include but are not limited to:
  - Dysautonomia (e.g., Postural Orthostatic Tachycardia Syndrome (POTS) )
  - ◆ Proprioceptive impairment
  - Orthopedic issues (e.g, sprains)
  - ◆ Pain
  - ◆ Fatigue
  - Sleep issues
  - ♦ Sensory sensitivities
  - ♦ Hypotonia
  - ♦ Functional GI disorders

# What might dysautonomia look like if my child can't tell me with words how they are feeling?

- "Challenging behaviors" (e.g., lying down and refusing to move)
- Resistance to changing position / transitions
- ♦ Refusing activities
- ♦ Seeking proprioceptive inputs

## Can hEDS become more apparent with age?

♦ Yes! Research suggests that a large portion of girls do not seek medical care until puberty when the symptoms and consequent problems seem to increase

#### What is the relationship between Autism and hEDS?

- ♦ Research suggests a significant correlation between diagnoses of hEDS and Autism
- ◆ A recent study reported that 6% of hEDS patients in the study sample were also diagnosed with Autism (a much higher percentage than expected in the general public)

### Should I ask my doctor / my child's doctor about EDS?

- Do you / your child have joint hypermobility?
  - ♦ If you answered "yes," mentioning EDS to your / your child's doctor is recommended
  - If you answered "no," there is likely no need to do so

## Why should I ask my doctor / my child's doctor about EDS?

- ◆ The features often associated with hEDS may have significant impact on health.
- Monitoring and management of symptoms can greatly improve quality of life and engagement in daily activities

#### How is hEDS diagnosed?

- hEDS is a clinical diagnosis that involves screening for hyper mobility using a tool called the Beighton Scale
- A doctor familiar with hEDS will assess for additional factors such as family history and soft skin

## Where can I find more information about EDS?

https://www.ehlers-danlos.com
And EDS link to Autism: https://doi.org/
10.2147/NDT.S290494