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## What is Ehlers-Danlos Syndrome?

Ehlers-Danlos Syndrome (EDS) is a condition that is as black and white as the zebra ribbon that symbolizes the condition. Individuals with the condition are considered medical zebras because of how the condition mimics other conditions. At one time, EDS was considered to be rare; however, now it is considered to be underdiagnosed. Due to awareness and ongoing professional programs, recognition of EDS is improving.

EDS is caused by a defect in the structure, production, or processing of collagen or proteins that interact with collagen, such as mutations in the COL5A or COL3A genes. Not all mutations have been identified for all the subtypes of EDS.

Individuals who are affected by this genetic connective tissue disorder can exhibit many signs such as joint hypermobility, fragile or soft skin, elastic skin, chronic fatigue and pain, spinal issues, neuropathic pain, joint instability, tendon ruptures, easy or unexplained bruising, chronic headaches, arterial dissection, easy bleeding, unexplained fractures and dislocations, and more. Because of these symptoms, this genetic disorder can be a life altering or deadly condition.

Not all who have EDS are affected the same way, which causes it to be misunderstood and underdiagnosed.

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## About CEDSA

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Center for Ehlers-Danlos Syndrome Alliance (CEDSA) is founded on the principals that children are our future and individuals with EDS need a strong, supportive voice to improve their medical care, education, rights, and overall quality of life.

CEDSA works to help parents understand issues and treatment options for their children with EDS. We work with schools to find resolutions to education issues.

CEDSA advocates are driven to warrant justice for parents who have been wrongfully accused of child abuse and educate agencies as to how EDS can be mistaken for child abuse.

CEDSA's Board of Directors believes that all of our volunteers, medical and professional advisors, and associate consultants work as a team. The wonderful volunteers are the hub of the team! They truly make a difference by providing the coping and success tools to improve life with EDS.

As a non-profit organization, CEDSA relies on the generosity of others and fundraising awareness events in order to provide the multitude of programs that help individuals with EDS and other co-morbid conditions. See our website for the complete list of programs and services that CEDSA offers.

### *Center for Ehlers Danlos Syndrome Alliance*

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# How to get an IEP for your child

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## Center for Ehlers Danlos Syndrome Alliance Inc.

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[www.CEDSA.org](http://www.CEDSA.org)

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## Steps of the initial IEP process

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Attempting to obtain an Individualized Education Program (IEP) for your child can sometimes feel challenging and overwhelming. The following are steps a parent should take in requesting an IEP process.

1. Obtain a letter from your primary doctor with your child's diagnoses.
2. Write a letter to the school requesting an IEP evaluation, due to your child's health impacting their education.
3. Take the letter to the school with a copy that they can sign for your records verifying they received the request.
4. The school will hold the first meeting shortly after they receive the request. This meeting will be to review data and have you sign a document called a REED to test your student.
5. Within 60 days or less, the school must complete the REED testing and have a final determination meeting. At this meeting the school must present an eligibility statement and if needed a draft IEP.



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## REED testing

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Each student that is being evaluated for an IEP will need to be tested. You can request evaluations in the following areas:

- Cognitive and education functional testing\* (*Normally done by a school psychologist*)
- Visual motor integration, convergence and overall vision\*\*\*
- Occupational and Physical Therapy \*\*
- Adaptive Physical Education\*\*\*
- Adaptive Technology\*\*\*
- Audiology
- Behavioral and School Social Worker Assessments
- Speech Articulation, Environmental, Speech Pragmatics, and Non-Verbal Social Skills\*\*\*

\* Normally done for the initial IEP and every 3 years including senior year.

\*\* Only in relation to school function.

\*\*\* Recommended for students with EDS

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## Tips to follow during the IEP evaluation process

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The Americans with Disabilities Act (ADA) guarantees those with an identified disability equal access to all public (and some private) places as those who are not disabled. Public schools are included in this law.

- Keep a journal of conversations and meetings. (Who, when, where, etc.)
- No verbal agreements or denials. All should be put in writing.
- Ask for all requests to be documented on the Prior Written Notice.
- Allow the school nurse to access the student's medical records of his/her PCP for an Individual Health Plan and to have an overview for the IEP meeting.
- READ the Procedural and Safeguard Handbook given to you at the REED meeting.

## Advocacy Service

CEDSA offers free advocacy service and IEP consults for those families with students who have EDS or other closely related co-morbid conditions. Please call our advocacy coordinators office to arrange a time to speak with an advocate. (989) 872-3372