

# City of Philadelphia



Council of the City of Philadelphia  
Office of the Chief Clerk  
Room 402, City Hall  
Philadelphia

(Resolution No. 230593)

## RESOLUTION

Authorizing the Committee on People with Disabilities and Special Needs to hold hearings regarding the issues, challenges, and misdiagnoses for children and their families dealing with Ehlers-Danlos syndromes.

WHEREAS, Ehlers-Danlos syndromes (“EDS”) are a group of genetic disorders that affect the connective tissues – primarily the skin, joints, and blood vessel walls; people who have EDS usually have overly flexible joints and stretchy skin; and

WHEREAS, EDS occurs due to variations of more than 19 genes that are present at birth, with the specific gene affected determining the type of EDS; some cases result from new variations occurring during early development, while others are inherited; and

WHEREAS, The hypermobile type of EDS affects at least one in 5,000 people globally and other types occur at lower frequencies, yet the prognosis depends on the specific disorder and a cure is not yet known; and

WHEREAS, Due to the rare nature of EDS, a growing number of families and individuals are experiencing misdiagnoses which may cause delays in care, mistreatment, or false allegations of child abuse; and

WHEREAS, Any concern raised about possible child abuse should always be considered carefully; however, features of EDS can look like injuries consistent with cases of physical abuse; and

WHEREAS, In January 10, 2021, The Ehlers-Danlos Society held a virtual awareness event titled “*Pediatric Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders: Exploring The Impact of Misdiagnosis,*” so that people could share their experiences and develop perspectives around misdiagnoses, their causes, and the role non-profit organizations and charities can play to support better understanding in communities, among clinicians, and in social services; and

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*RESOLUTION NO. 230593 continued*

WHEREAS, Philadelphia is known as a global leader in healthcare, from the nation's first hospital (Pennsylvania Hospital) to the home of three children's hospitals (Children's Hospital of Philadelphia, St. Christopher's Hospital for Children, and Shriners Children's Philadelphia), and it is important to raise the awareness of this problem so that the world's leading healthcare institutions and clinicians can help to address this issue; now, therefore, be it

RESOLVED, that the Council of the City of Philadelphia does hereby authorize the Committee on People with Disabilities and Special Needs to hold hearings regarding the issues, challenges, and misdiagnoses for children and their families dealing with Ehlers-Danlos syndromes.

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*RESOLUTION NO. 230593 continued*

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*RESOLUTION NO. 230593 continued*

CERTIFICATION: This is a true and correct copy of the original Resolution, Adopted by the Council of the City of Philadelphia on the fourteenth day Of September, 2023.

Darrell L. Clarke  
PRESIDENT OF THE COUNCIL

Michael A. Decker  
CHIEF CLERK OF THE COUNCIL

Introduced by: Councilmember Vaughn

Sponsored by: Councilmembers Vaughan, Bass, Gilmore Richardson,  
Driscoll, Squilla, Gauthier, Brooks, Lozada, Thomas and  
Phillips