

RESOLUTION

WHEREAS, Ehlers-Danlos syndromes (EDS), including the most common type — Hypermobile Ehlers-Danlos syndrome, are a group of genetic disorders that affect the connective tissues in the body, which affect more than one in 5,000 people, regardless of age, race, or gender; and

WHEREAS, Symptoms commonly include joint hypermobility and dislocation; fragile, hyperextensible skin that bruises and scars easily; and tissue fragility, severe cases can be associated with unpredictable tearing of blood vessels and organs, leading to internal bleeding and other potentially life-threatening complications; and

WHEREAS, For people with EDS, their ligaments and joints are so loose so unstable that the muscles work twice as hard as the general population to hold their bodies together, leading to severe exhaustion; and

WHEREAS, All of these symptoms — joint laxity, joint pain, and exhaustion — can make learning with EDS an arduous task, particularly for younger students, since the physical act of writing can be extremely painful and difficult, forcing students to choose between answering questions with the fewest possible words or having their thumb joints slip in and out of place; and

WHEREAS, Since EDS is a rare condition, those living with EDS have taken to identifying themselves as zebras, in reference to the common medical idiom "when you hear hoofbeats, think horses not zebras"; and

WHEREAS, Ole A. Thorp Elementary School has established new pilot program focused on educational equity to help ensure two third grade students with EDS receive the education they rightly deserve from our public school system; and

WHEREAS, "Dazzle at School" — named after the term for a group of zebras — provides direct service to students by incorporating structured literacy intervention, occupational therapy, and assistive technology such as speech-to-text, as well as support and capacity building to help parents, schools, and teachers deliver an inclusive learning experience for students with EDS; and

WHEREAS, While there is currently no cure for EDS, treatment focuses on managing symptoms, preventing dangerous complications, and early and accurate diagnosis to provide opportunities for proper monitoring, timely medical interventions, and an improved quality of life; and

WHEREAS, Continued research is needed to better understand EDS; encouraging further studies can lead to breakthroughs in genetic testing, treatments, and other medical interventions, generating growth in the EDS knowledge base and bringing hope for a cure; and

WHEREAS, While research and clinical trials may take years or decades, the City Council, recognizing that inclusion is a fundamental responsibility of educators and that every child deserves the opportunity to shine, encourages Chicago Public Schools to support Dazzle at School, and expand the program to other public schools; now, therefore

BE IT RESOLVED, That we, the Mayor and the members of the Chicago City Council, gathered here this nineteenth day of April, 2023, do hereby designate May 2023 as Ehlers-Danlos Syndromes (EDS) Awareness Month in the City of Chicago, and recognize the groundbreaking work of the Dazzle at School program at Ole A. Thorp Elementary School; and

BE IT FURTHER RESOLVED That the City Council encourages Chicago Public Schools to create a toolkit for students with EDS, including by removing barriers to full inclusion, supplying assistive technology to schools, and allowing creative alternatives for gym and other physical education requirements.



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Alderman, 31st Ward