



Guest Editorial

Hailey Kao

In the Eyes of a Zebra

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Editor's Note: As a holiday gift to our readers, we continue our annual tradition of turning over the November/December editorial pen to a child or young person. This year, we are most grateful to have Hailey Kao from Voorhees, NJ, share her story.

Hello, my name is Hailey Kao. I am 11 years old and I have EDS, hypermobile form. EDS stands for Ehler's Danlos Syndrome, but I like EDS better because it is way easier to say. EDS is very hard to deal with because it affects everything that I do. EDS affects all the collagen in my body. It is a connective tissue disease. It is not contagious; I got it from my mother. She has EDS, too.

The zebra is the symbol for EDS. Zebras are all different, and no two zebras have the same pattern type. Just like zebra patterns, EDS symptoms are unique to each person. At one point, my EDS symptoms were so bad, I asked Santa for a service dog. I was diagnosed with EDS at the age of 1.5 years by a doctor who dealt with difficult cases at Children's Hospital of Philadelphia (CHOP). It took a long time for the doctors to diagnosis me because they thought my mother was crazy. I mean, I know she is crazy (just kidding!), but that is beside the point.

I started receiving physical therapy (PT) and occupational therapy (OT) right away. Therapy was boring, but it really does help. I have been in and out of OT and PT most of my life. There is no cure for EDS, and I will be stuck with PT and OT forever. As a result of my experiences, I want to be a physical therapist when I grow up.

These last couple of years have been rough. As I have gotten older, my EDS symptoms have gotten worse. I have had to spend a lot of time in PT and OT, in school, and at Weisman Rehabilitation Hospital. I have missed out on tons of fun things due to my



Hailey Kao, with her emotional support dog, Daisy. Printed with permission from Hailey Kao and her mother, Regina Kao.

EDS, like roller skating, birthday parties, fun and fitness day, sports, and all the other things normal kids do.

There are many things in my life that my EDS makes not fun. EDS makes school not fun. EDS makes me hurt a lot, and I miss out on the things that all the other kids get to do. This year, I am unable to participate in gym due to my EDS. Gym was my favorite subject, and I can't do it in middle school because I might get hurt. Gym is no longer fun because I will never get to do it again while I am in school.

Writing is also difficult for my hands, but not my brain. I love writing. EDS makes my hands tired and painful. I am having trouble keeping up this year. I must have adults write for me at times; that really stinks.

Also, I must have a lot of stuff adjusted so I can go to school. My locker has to have a different lock on it, my seating has to be adjusted, and so do my assignments. EDS makes school

complicated and boring. It stinks to have EDS and to be in middle school.

Everyday things are challenging because my joints get tired. When they get tired, I can't even do the simple stuff. EDS is always with me; it never leaves and always pops up at the worst time. EDS is always there and always ruins my good days. I want to leave you with the following visual, so you can better understand my journey.

When you ask a disabled kid if they are fine, it's usually always, "Yeah, I'm fine." Stop and really think about that answer because that answer is the wall that stops you from seeing what we really go through every day. The more hurdles there are, the stronger and bigger the wall. To help you understand better, think about the following scenario. You are walking on a rocky beach that you think ends, but it never does. The pain shoots through your whole body, and it spreads like a flame. There might be breaks in the sharp stone path, but not for long.

Even though EDS has brought me pain and difficulty, it has also brought me so many blessings. EDS has brought some of the most amazing people into my life. People who lift me up, cheer me on to do the impossible. People who find the light in my darkness and always help me see past my EDS.

EDS has also brought me my best friend, Daisy. She is my emotional support dog and my best buddy. She is always there at the end of a bad day. She listens to me without saying any of those cheesy phrases like, "It could be worse," "You're fine," or "Turn the other cheek honey and look at the bright side." She lets me get out all the bad feelings that come with having EDS. It is important to have someone to talk with and cry on when things are not going the way they should be. Daisy makes it easier to live with the daily challenges of EDS. ■