

Open Letter from the Board of Directors of EDS Today

Regarding: ABC's Primetime Medical Mysteries, Air Date January 24, 2007

No Freak Show

Key words: Ehlers-Danlos, medical mysteries, Garry Turner, Dylan, ABC

On Wednesday, January 24, 2007, the United States broadcast network ABC highlighted Ehlers-Danlos Syndrome in its "Medical Mysteries" series. The online EDS community awaited the airing with some concern. Typically, Ehlers-Danlos Syndrome, when it is presented in the media at all, is presented in a sensationalistic fashion. Such treatment of EDS goes back to the days of circus side shows. Would ABC be responsible in its portrayal of people with EDS? That their promotional material highlighted a performer from England's "Circus of Horrors" did not bode well.

Frequently, people with Ehlers-Danlos Syndrome are encouraged to perform as contortionists. Probably, most of these people are unaware of their condition, as few doctors are educated enough to diagnose it. And those who are aware tend not to know how dangerous repeated dislocation of the joints is for their future well-being and mobility. That lack of knowledge is the direct result of doctors not taking EDS seriously, of treating EDS as just an amusing side show. It is perceived as extremely rare and/or not a serious or life threatening disorder—in part because of sensationalistic shows, where contortionists show off tricks of their joints and skin. Most physicians hear no more than a passing mention of EDS while they are in training, and that mention often reinforces the "Circus Freak" stereotyping of EDS. As Garry Turner, who was showcased in "Medical Mysteries," found out, often it is the doctors who are the first audience for the Ehlers-Danlos Syndrome side show, interested in the patient only to the extent that an extreme case of what is already a rare disorder is available to poke and prod and measure. Because of this portrayed oddity, EDS is not taken as a legitimate, serious disorder.

And that attitude is dangerous, as the story of David Bowen makes clear.

After a childhood of odd injuries, David was fighting for his life in the children's ICU. His pediatrician, just returned from vacation, contacted the doctors there, and called his mother, Cathy, with the latest word.

"The doctors there think Dave has Ehlers-Danlos Syndrome."

"What is that?" Cathy asked.

The pediatrician's answer: "It's what the circus people have, where they can bend in a pretzel."

"David can't bend in a pretzel!" Cathy reeled as she realized: "They're looking at my son as a circus freak!"

That same day, a geneticist finally examined David, giving him a cursory glance and suggesting that he had Vascular-type Ehlers-Danlos Syndrome (VEDS). VEDS is the most often lethal form of EDS, and has clear symptoms. But doctors looking at EDS

as a circus performance had completely missed the diagnosis because David was not unusually hypermobile.

In David's case, his doctors' stereotypical vision of EDS led to a failure of diagnosis and ultimately to his death at age 14. But the view of EDS as a freak show interferes with diagnosis, treatment, and socialization across the board. Children who exhibit EDS symptoms—hypermobile joints or, like Garry, stretchy skin—are pushed by peers to demonstrate over and over again their special "gift." Why not? After all, it is so entertaining. But it is also causing damage every single time. Many people with EDS, such as Dylan (who was also presented during the show), have limited mobility by the time they are adults. When parents first ask doctors about issues related to hypermobility, if the doctor shares the popular view of EDS as entertainment, they will be told that there is nothing to worry about. It is imperative that medical professionals understand the [symptoms of Ehlers-Danlos](#), the classifications, and need for preventative care. If doctors were more aware of EDS, then children such as the anonymous young man "performing" on YouTube would know better than to injure themselves, as Dr. Nazli McDonnell points out.