

Ehlers-Danlos Syndrome is Not a Crime, It's Genetic!

Press Release

from the Office Eugene Wilson, Chairman

November 27, 2013

Child abuse charges are a fear for all families who have Ehlers-Danlos Syndrome (EDS) and there is little protection for them. The accusations can come from a variety of sources including schools, truancy officers, members of the medical community, and others whom fail to fully understand EDS. Families with this often misunderstood medical condition have enough to battle besides charges that can destroy the sanctity of their family.

Center for Ehlers-Danlos Syndrome Alliance (CEDSA) has been helping families with this (nightmare) situation for the past few years. During this time, we have been working on developing an informational network that will help those within Children Protective Services (CPS) to understand Ehlers-Danlos Syndrome. This information will also be available to the medical community and schools to help guard the family unit.

Recently, several families reached out to the media for help to bring this to the public's attention. We applauded those families and fully supported them in their darkest hours. Their fight is just like many that we've worked with and are currently helping. CEDSA has seen an increase in these types of cases and in September we saw the need to escalate our CPS awareness campaign.

In December, we will release a video about the campaign detailing how the program will operate. We anticipate releasing the video the week prior to Christmas. The program is set to launch off in 2014. If you are interested in helping with the campaign please email staff@cedsa.org with a detailed message on how you want to participate.

If you are a family with EDS that CPS is investigating, email our advocacy team at EDSadvocates@cedsa.org and our compassionate team will be glad to assist you and your family. CEDSA is always proud to help. We understand your daily struggles as most of our staff and volunteers have EDS.

Ehlers-Danlos Syndrome is not a crime, it's genetic! Do not make having EDS a crime by calling it child abuse. For additional updates on this and other news articles from CEDSA please visit our homepage at www.CEDSA.org or call our office at (989) 872-3372.

Sincerely

