



Sample letter- be sure to personalize the letter and change the highlighted portions to fit who you are requesting the proclamation from.

DATE

NAME OF GOVERNMENT OFFICIAL

ADDRESS

Dear _____,

As a concerned resident of [STATE/COUNTY/Town] and a person affected by Ehlers-Danlos Syndrome, I am asking [STATE/COUNTY/TOWN] to help raise awareness of Ehlers-Danlos Syndrome by issuing a Proclamation declaring May to be Ehlers-Danlos Syndromes Awareness Month in [STATE/COUNTY/TOWN].

Ehlers-Danlos Syndromes are a group of inherited connective tissue disorders that greatly affect the body in many ways. Connective tissues are found everywhere in the body. They are made up of strong proteins that allow for body tissue to be stretched, and then return to a normal position and function. In patients with Ehlers-Danlos Syndromes, there are problems with the proteins of the connective tissue that can cause the tissues to be fragile and/or overly stretchy, causing pain and damage.

There are 13 different types of Ehlers-Danlos Syndrome, each with unique manifestations. They can result in symptoms such as joint hypermobility, where joints are loose and unstable, and thus can dislocate easily. Skin can also be hyperextensible, causing it to be fragile, velvety, and hyperelastic, resulting in bruises, scars, and skin tears. Many with Ehlers-Danlos Syndrome also have musculoskeletal problems such as chronic, early-onset, debilitating pain, scoliosis, and poor muscle tone. Some with Ehlers-Danlos Syndrome also deal with comorbid conditions such as mast cell disorders and dysautonomia.

It is estimated that between 1 in 2,500 - 5,000 people worldwide live with Ehlers-Danlos Syndrome.



[If desired, insert your story here in a short paragraph. Less is more, so keep it simple. This is optional.]

Although there is no cure for Ehlers-Danlos Syndrome, increased awareness and research offer hope for greater understanding, faster diagnosis, improved medical care, and improved quality of life for patients and their families.

I have attached a sample proclamation along with a Top 10 Facts Sheet on Ehlers-Danlos Syndromes. The proclamation was drafted by Dysautonomia Support Network, a 501(c)(3) non-profit that is committed to empowering, educating, and advocating for those affected by dysautonomia and its related conditions. More information about the organization and Ehlers-Danlos Syndromes can be found online at www.dysautonomiasupport.org.

Please let me know if your office is able to help us raise awareness of Ehlers-Danlos Syndromes by issuing the attached proclamation declaring May to be Ehlers-Danlos Syndromes Awareness Month in **(STATE/COUNTY/TOWN)**. If possible, we would like to have you present the proclamation publicly. If there is any other information you need or if you have any questions, please feel free to contact me at **(YOUR PHONE NUMBER)**

Respectfully,

YOUR NAME

YOUR ADDRESS

YOUR CONTACT INFORMATION