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HOUSE RESOLUTION

2           WHEREAS, Ehlers-Danlos Syndrome (EDS) is a group of  
3 inherited disorders characterized by excessive looseness and  
4 instability of the joints, fragile and hyperelastic skin that  
5 bruises, scars, and tears easily, and major blood vessels that  
6 can disintegrate catastrophically; the overall prevalence of  
7 all types of Ehlers-Danlos Syndrome is estimated at 1 in 5,000  
8 births worldwide, representing over 75,000 Americans and 1.5  
9 million globally; and

10           WHEREAS, Some forms of Ehlers-Danlos Syndrome involve  
11 serious, life-threatening, or fatal complications; major blood  
12 vessels, organs, and the aorta can tear or rupture  
13 unpredictably, causing acute pain, internal bleeding, shock,  
14 and premature death; life can be foreshortened for those with  
15 this vascular type: the average life span is only to the  
16 forties and tragically, many die in their teens; and

17           WHEREAS, It is the mission Ehlers-Danlos National  
18 Foundation (EDNF) to provide information and advocacy for  
19 people living with Ehlers-Danlos Syndrome and to provide a  
20 network of support and knowledge to the medical profession,  
21 greater healthcare community, and public at large; currently,  
22 there is little research dedicated to EDS outside of research  
23 funded by EDNF; increased interest, study, and understanding of  
24 EDS and its genetic connections will generate breakthroughs  
25 that may provide better screening, treatments, and a cure; and

26           WHEREAS, There is neither screening nor a cure for  
27 Ehlers-Danlos Syndrome and individual symptoms must be  
28 evaluated and cared for appropriately; physical and  
29 occupational therapy, evaluation, and intervention by  
30 rehabilitation specialists is often required to address basic  
31 life tasks; appropriate therapy and treatment is especially  
32 essential for EDS in children; early and accurate diagnosis

1 will provide the opportunity to create life-saving emergency  
2 medical plans, ensure proper cardiac monitoring, and allow for  
3 the optimum quality of life for EDS families; and

4 WHEREAS, Ehlers-Danlos Syndrome is frequently misdiagnosed  
5 or undiagnosed for decades, resulting in greater discomfort and  
6 disability; the vascular form may only be recognized with the  
7 advent of an often-fatal medical emergency; for some, the  
8 diagnosis only accompanies autopsy; earlier recognition can  
9 prevent many of these premature and tragic deaths and allow  
10 earlier and more effective management of EDS; and

11 WHEREAS, Increased awareness of Ehlers-Danlos Syndrome in  
12 the medical profession will allow earlier diagnosis,  
13 treatment, and care to ensure hope of a better life and  
14 participation in society; the reduced disability, pain, and  
15 expense will offer tangible positive effects and an enhanced  
16 quality of life for EDS families; and

17 WHEREAS, It is imperative that additional funding be  
18 dedicated to research this under-recognized and  
19 under-diagnosed condition; by fostering and funding further  
20 studies of EDS, new understanding of syndrome processes and  
21 therapeutic interventions can be acquired; current work at the  
22 National Institutes of Health and other research institutions  
23 can be expanded and increased, generating an increased  
24 knowledge base; and

25 WHEREAS, In memory of all of our families and friends who  
26 have died from Ehlers-Danlos Syndrome, the Ehlers-Danlos  
27 National Foundation will continue to educate and fund research  
28 so that someday we will see a brighter day; therefore, be it

29 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE  
30 NINETY-FOURTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that  
31 we designate the month of May 2006 as Ehlers-Danlos Syndrome

1 Awareness Month; and be it further

2           RESOLVED, That a suitable copy of this resolution be sent  
3 to the Ehlers-Danlos Foundation.