

Senate Resolution 619

By: Senator Williams of the 19th

#### A RESOLUTION

1 Recognizing May as Ehlers-Danlos Syndrome Awareness Month; and for other purposes.

2 WHEREAS, Ehlers-Danlos Syndrome is a group of genetic disorders involving mutations  
3 in connective tissue characterized by looseness, instability, and dislocations of the joints,  
4 fragile and often hyperelastic skin that bruises, scars, and tears easily, and unpredictable  
5 arterial and organ rupture causing acute pain, excessive internal bleeding, shock, stroke, and  
6 premature death; and

7 WHEREAS, there are six major types of Ehlers-Danlos Syndrome that are characterized by  
8 distinctive features, with life being shortened for individuals with the vascular type due to  
9 the possibility of arterial or organ rupture; it is estimated that the prevalence of all types of  
10 Ehlers-Danlos Syndrome is 1 in 5,000 births worldwide; and

11 WHEREAS, a network of worldwide support groups has proven of great benefit to  
12 individuals with Ehlers-Danlos Syndrome; these organizations not only put people in touch  
13 with other individuals managing life with Ehlers-Danlos Syndrome, but also are vital in  
14 providing up to date information to the medical profession and public at large; and

15 WHEREAS, currently there is little research being undertaken into Ehlers-Danlos Syndrome;  
16 however, there continues to be hope that genetic testing and research will be increased; by  
17 encouraging further studies of Ehlers-Danlos Syndrome, new understanding, interventions,  
18 and improved treatments can be acquired; current work at the National Institutes of Health  
19 and other research institutions can be expanded and increased, generating a growth in the  
20 knowledge base and bringing hope for a cure; and

21 WHEREAS, there is neither routine screening nor a cure for Ehlers-Danlos Syndrome;  
22 individuals must seek a diagnosis from a knowledgeable health care provider; and

23 WHEREAS, individual symptoms must be evaluated and cared for appropriately; physical  
24 and occupational therapy evaluation and intervention may be required to address basic life  
25 tasks; early and accurate diagnosis can provide the opportunity to create life-saving  
26 emergency medical plans, ensure proper monitoring, and improve quality of life and support  
27 for Ehlers-Danlos Syndrome families in the State of Georgia; and

28 WHEREAS, Ehlers-Danlos Syndrome is frequently misdiagnosed or undiagnosed for  
29 decades, sometimes generations, resulting in greater discomfort and disability for individuals  
30 and offspring; improved knowledge of the vascular form can prevent generations of  
31 premature and tragic deaths and increased knowledge of all types can allow earlier and more  
32 effective management of Ehlers-Danlos Syndrome, increasing hope of a better quality of life,  
33 increasing participation in society, and reducing disability, pain, and medical expense for  
34 Ehlers-Danlos Syndrome families in the State of Georgia; and

35 WHEREAS, in memory of all the families and friends who have died from Ehlers-Danlos  
36 Syndrome, the network of Ehlers-Danlos Syndrome organizations will continue to educate  
37 and raise money for research so that someday we will see a brighter day.

38 NOW, THEREFORE, BE IT RESOLVED BY THE SENATE that the members of this body  
39 recognize May as Ehlers-Danlos Syndrome Awareness Month.

40 BE IT FURTHER RESOLVED that the Secretary of the Senate is authorized and directed  
41 to make appropriate copies of this resolution available for distribution to members of the  
42 public and the press.