



A Proclamation by the Governor

WHEREAS, Ehlers-Danlos Syndrome is a group of genetic disorders involving mutations in connective tissue characterized by looseness, instability, and dislocations of the joints, fragile and often hyper-elastic skin that bruises, scars, and tears easily, unpredictable arterial and organ rupture causing acute pain, excessive internal bleeding, shock, stroke, and premature death. It is estimated the prevalence of all types of Ehlers-Danlos Syndrome is 1 in 5,000 births worldwide; and

WHEREAS, a network of worldwide support groups have proved of great benefit to individuals with Ehlers-Danlos Syndrome. Not only do these organizations put people in touch with other individuals managing life with Ehlers-Danlos Syndrome, they are also vital in providing up-to-date information to the medical profession and public-at-large. At this stage there is little research being undertaken into Ehlers-Danlos Syndrome, however, there continues to be hope that genetic testing and research will be increased; and

WHEREAS, there is neither routine screening nor a cure for Ehlers-Danlos Syndrome, individuals must seek a diagnosis from a knowledgeable health care provider. Early and accurate diagnosis can provide the opportunity to create life-saving emergency-medical plans, ensure proper monitoring, and improve quality of life and support for Ehlers-Danlos Syndrome families in the State of Nevada; and

WHEREAS, Ehlers-Danlos Syndrome is frequently misdiagnosed or undiagnosed for decades, sometimes generations, resulting in greater discomfort and disability for individuals and offspring; improved knowledge of the vascular form can prevent generations of premature and tragic deaths and increased knowledge of all types allow earlier and more effective management of Ehlers-Danlos Syndrome, increasing hope of a better quality of life, increased participation in society, reduced disability, pain, and medical expense for Ehlers-Danlos Syndrome families in the State of Nevada. In memory of all our families and friends who have died from Ehlers-Danlos Syndrome the network of Ehlers-Danlos Syndrome organizations will continue to educate and raise money for research, so that someday we will see a brighter day;

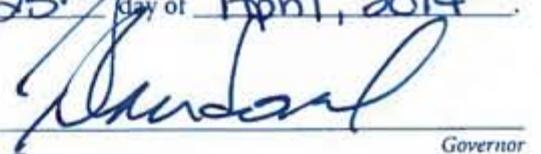
NOW, THEREFORE, I, BRIAN SANDOVAL, GOVERNOR OF THE STATE OF NEVADA, hereby proclaim May 2014 as

EHLERS-DANLOS SYNDROME AWARENESS MONTH



In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of Nevada to be affixed at the State Capitol in Carson City, this 25th day of April, 2014.

By the Governor:


Governor


Secretary of State

By _____
Deputy