



State of North Carolina

ROY COOPER
GOVERNOR

EHLERS DANLOS SYNDROME AWARENESS MONTH

2020

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, the Ehlers Danlos Syndromes (EDS) are a group of genetic disorders which can involve mutations in connective tissue that are characterized by hypermobility, skin hyperextensibility, and widespread chronic pain; and

WHEREAS, there are thirteen types of EDS that are characterized by distinctive features, with vascular Ehlers Danlos Syndrome being the most severe and fatal; and

WHEREAS, it is estimated that the prevalence of all types of the syndrome affect at least 1 in 5,000 people worldwide; and

WHEREAS, EDS is frequently misdiagnosed or undiagnosed, resulting in greater risks of serious injury, discomfort and disability for affected individuals; and

WHEREAS, early and accurate diagnosis can provide the opportunity to create life-saving medical plans and improve quality of life; and

WHEREAS, there is currently no cure or effective treatment for the various subtypes of EDS, in addition there is a lack of evidence-based guidelines for the management of this condition; and

WHEREAS, a network of organizations and support communities throughout North Carolina continue to educate the public and health care communities with research efforts of developing new levels of understanding, support, and improved treatments; and

WHEREAS, the State of North Carolina recognizes the medical specialists and patient advocates who work with individuals affected by Ehlers Danlos Syndromes, and encourages people to raise awareness in order to support and understand those who live with the challenges of these connective tissue disorders;

NOW, THEREFORE, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim May, 2020, as “**EHLERS SYNDROME AWARENESS MONTH**” in North Carolina, and commend its observance to all citizens.



Roy Cooper
Governor

IN WITNESS WHEREOF, I have hereunto set my hand and affixed the Great Seal of the State of North Carolina at the Capitol in Raleigh this twenty-eighth of April in the year of our Lord two thousand and twenty and of the Independence of the United States of America the two hundred and forty-fourth.