

# State of North Carolina

# **ROY COOPER**

**GOVERNOR** 

## EHLERS-DANLOS SYNDROME AND HYPERMOBILITY SPECTRUM DISORDERS AWARENESS MONTH

2023

#### BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

### **A PROCLAMATION**

WHEREAS, the Ehlers-Danlos Syndrome (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 13 types of EDS that are characterized by distinctive features, with vascular Ehlers-Danlos Syndrome being the most severe and fatal; and

WHEREAS, hypermobility spectrum disorders (HSD) are connective tissue disorders that cause joint hypermobility, instability, injury, and pain; other problems such as fatigue, headaches, GI problems, and autonomic dysfunction are often seen as part of HSD; and

WHEREAS, it is estimated that the prevalence of all types of EDS 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, and 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 to develop 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 Syndrome and hypermobility spectrum disorders, 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, 2023, as "EHLERS-DANLOS SYNDROME AND HYPERMOBILITY SPECTRUM DISORDERS AWARENESS MONTH" in North Carolina, and commend its observance to all citizens.

Roy Cooper

**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 day of April in the year of our Lord two thousand and twenty-three and of the Independence of the United States of America the two hundred and forty-seventh.