

State of North Carolina

ROY COOPER

GOVERNOR

FABRY DISEASE AWARENESS MONTH

2020

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, Fabry disease is a progressive inherited disorder that causes children and adults to experience many symptoms that diminish their quality of life, and can lead to premature death in adults due to stroke, kidney failure, and/or heart failure; and

WHEREAS, Fabry disease is caused by deficient activity of the lysosomal enzyme alpha-galactosidase A that results in buildup of lipids in the body, causing cell and organ damage; and

WHEREAS, symptoms can vary wildly, ranging from mild to severe; these symptoms can affect the whole body and may change over time; and

WHEREAS, there are two approved treatments available for Fabry disease but, because the disease is severely under-diagnosed, many people live without an accurate diagnosis or opportunity for treatment until after irreversible organ damage occurs; and

WHEREAS, newborn screening has now been performed in several countries, yielding a prevalence ranging from 1 in 1,368 to 1 in 8,882; this is a vastly different estimate than the earlier presumed prevalence of 1 in 40,000 to 1 in 117,000; and

WHEREAS, education and awareness are important in order to increase the recognition, diagnosis, understanding and management of Fabry disease; and

WHEREAS, health care providers and families should be aware of the many Fabry disease symptoms and, if warranted, obtain a GLA gene test that can definitively assess the presence of this treatable disorder; and

WHEREAS, the State of North Carolina encourages people in our communities to learn about Fabry disease and assess their family risk;

NOW, THEREFORE, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim April, 2020, as "FABRY DISEASE 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-fourth day of March 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.