



BY THE GOVERNOR OF THE STATE OF GEORGIA

## A PROCLAMATION

### RARE DISEASES DAY

- WHEREAS: There are nearly 7,000 diseases and conditions considered rare, each affecting fewer than 200,000 individuals in the United States. While each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans; and
- WHEREAS: Many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected. Nearly one in ten Americans are affected by rare diseases, thousands of whom are residents of Georgia; and
- WHEREAS: Treatment for many rare diseases is insufficient, as are social networks to support individuals with rare diseases and their families. While many days are dedicated to sufferers of individual diseases like AIDS, Breast Cancer, and others, sufferers of rare diseases like Adenoid Cystic Carcinoma, Urea Cycle Disorder, Progeria, or Acquired von Willebrand's Disease, and Mal de Debarquement Syndrome were not recognized until 2009; and
- WHEREAS: Only five percent of rare diseases have approved drug treatments. While nearly 450 orphan drugs and biologics have been approved for the treatment of rare diseases, according to the Food and Drug Administration, there are well over 15 million Americans with rare diseases who have no treatment specific to their disease; and
- WHEREAS: Individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and
- WHEREAS: Some rare diseases, such as "Lou Gehrig's disease" and Huntington's disease, are relatively well known, but many others are not known by the public so that patients and their families must bear a large share of the burden for challenges such as raising funds for research; and
- WHEREAS: Groups and non-government entities like the National Organization for Rare Disorders recognize that it takes a dedicated team to tackle these challenges and celebrate all who come together in support of the rare disease community, including medical professionals, researchers, government officials, advocates, and biotech companies developing orphan drugs for rare diseases. On February 29, 2016, the national observance of Rare Disease Day focuses attention on the unsung heroes who commit themselves to rare diseases as a public health issue; now
- THEREFORE: I, NATHAN DEAL, Governor of the State of Georgia, do hereby proclaim February 29, 2016, as RARE DISEASES DAY in Georgia.

In witness thereof, I have hereunto set my hand and caused the Seal of the Executive Department to be affixed this 11<sup>th</sup> day of January in the year of our Lord two thousand sixteen.

*Nathan Deal*

GOVERNOR

ATTEST

*Chris W. Riley*

CHIEF OF STAFF

