

## RARE DISEASE 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 thirty million Americans; and

WHEREAS: Many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected. Thousands of residents of Georgia are among those affected by rare diseases since nearly one in ten Americans have rare diseases; and

WHEREAS: While nearly 330 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between eleven and fourteen million people according to the Food and Drug Administration, there are well over fifteen 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 at all by the public so that patients and their families must bear a large share of the burden for things such as raising funds for research; and

WHEREAS: The National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2009, and patients, medical professionals, researchers, government officials, and companies developing treatments for rare diseases are joining together to focus attention on rare diseases as a public health issue on that day; now

THEREFORE: I, SONNY PERDUE, Governor of the State of Georgia, do hereby proclaim February 28, 2009 as RARE DISEASE DAY in Georgia.

In witness thereof, I have hereunto set my hand and caused the Seal of the Executive Department to be affixed this 3<sup>rd</sup> day of February in the year of our Lord two thousand nine.