

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. Nearly one in ten Americans are affected by rare diseases, thousands of whom are residents of Georgia; and
- WHEREAS: While nearly 330 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between 11 and 14 million people 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 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, 2010, 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, 2010 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 10th day of February in the year of our Lord two thousand ten.