

# HEALTH AND HUMAN SERVICES (HHS)

Resolution HHS-22-58

## SUPPORTING RARE DISEASES

WHEREAS, the National Black Caucus of State Legislators (NBCSL) supports increased representation of the rare disease community in state government to ensure that legislation or regulations that impact people living with rare diseases, which are often chronic and debilitating, are well-informed;

WHEREAS, in the United States a rare disease is defined as an illness or condition that affects fewer than 200,000 people;

WHEREAS, an estimated 25 - 30 million Americans are affected by over 7,000 rare diseases, many of which are serious or life-threatening and almost half of which affect children;

WHEREAS, Congress passed the Orphan Drug Act of 1983 to successfully encourage investment in the development of drugs to treat rare conditions, as these conditions were previously underrepresented in medical research and drug development, however over 90 percent of rare diseases still lack an FDA-approved treatment;

WHEREAS, people living with rare diseases face significant barriers to care, including years-long journeys to diagnosis, limited treatment and coverage options, lack of medical specialists for their conditions, and the economic burdens of managing their disease;

WHEREAS, these challenges faced by the larger rare disease community exacerbate existing health disparities for Black Americans living with rare diseases, such as social determinants of health, underrepresentation in clinical research trials, and disparate access to affordable healthcare;

WHEREAS, due to the sheer number of rare diseases, it is challenging for elected officials and agencies to have a full understanding of all rare diseases;

WHEREAS, the NBCSL acknowledges that it is crucial for laws and regulations affecting those living with rare diseases to be developed with input from stakeholders who understand the unique diagnostic, treatment, and access challenges that rare disease patients and their families face;

WHEREAS, Rare Disease Advisory Councils (RDACs) are advisory bodies created through state legislation that provide representation for the rare disease community in state government, with council membership including patients, advocates, physicians, researchers, and other experts;

# HEALTH AND HUMAN SERVICES (HHS)

Resolution HHS-22-58

WHEREAS, RDACs are typically responsible for examining treatment and services provided to people living with rare diseases in a state, including obstacles to care, and presenting recommendations to state legislatures, health departments, and agencies to improve the health outcomes and quality of life of the rare disease community; and

WHEREAS, over 20 states have enacted RDACs since 2015, ensuring that laws and regulations that impact the rare disease community or state efforts to address barriers among this vulnerable population are carried out with the medical, scientific, and technical input of the councils.

THEREFORE BE IT RESOLVED, that the National Black Caucus of State Legislators (NBCSL) recognizes the need for increased awareness, education, and research regarding rare diseases;

BE IT FURTHER RESOLVED, that the NBCSL maintains that the unique needs of the rare disease community, including the needs of Black Americans living with rare diseases, should be addressed in collaboration with rare disease stakeholders;

BE IT FURTHER RESOLVED, that the NBCSL supports the establishment and continued support of Rare Disease Advisory Councils in all 50 states; and

BE IT FINALLY RESOLVED, that a copy of this resolution be transmitted to the President of the United States, the Vice President of the United States, members of the United States House of Representatives and the United States Senate, and other federal and state government officials and agencies as appropriate.

**SPONSOR: Representative Toni Rose (TX)**

**Committee of Jurisdiction: Health and Human Services (HHS) Policy Committee**

**Ratified in Plenary Session: December 2, 2021**

**Ratification certified by: Representative Billy Mitchell (GA), NBCSL President**