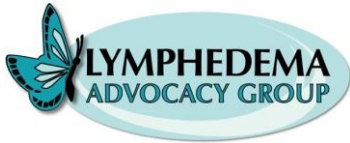




Alone we are rare. Together we are strong.[®]



April 4, 2024

The Honorable Tate Reeves
Governor of Mississippi
State Capitol
Jackson, MS 39205

RE: Support for Senate Bill 2156 (Blackwell) – Establishes a Rare Disease Advisory Council in the State of Mississippi

Dear Governor Reeves,

The 18 undersigned organizations representing individuals with rare diseases in Mississippi, write in support of Senate Bill 2156 (Blackwell), which would establish a Rare Disease Advisory Council (RDAC) in the state, giving a voice to the estimated 1-in-10 individuals living with a rare disease in Mississippi.

As defined by the Orphan Drug Act, any condition that affects fewer than 200,000 Americans¹ is considered rare. Overall, there are more than 10,000 known rare diseases, affecting an estimated 30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many

¹ [United States Food & Drug Administration, Rare Diseases at FDA](https://www.fda.gov/orphan)

1779 MASSACHUSETTS AVENUE NW, SUITE 500
WASHINGTON, DC 20036
T 202-588-5700 ■ F 202-588-5701

7 KENOSIA AVENUE
DANBURY, CT 06810
T 203-744-0100 ■ F 203-263-9938

1900 CROWN COLONY DRIVE, SUITE 310
QUINCY, MA 02169
T 617-249-7300 ■ F 617-249-7301

rarediseases.org ■ orphan@rarediseases.org

NORD[®] and its icon are registered trademarks of the National Organization for Rare Disorders. NORD is a registered 501(c)(3) charity organization.

unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's complex needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

With diverse membership and broad community support, a Mississippi RDAC will serve as a valuable resource as our health care system evolves. A strong RDAC can help relieve burdens on the state by expeditiously delivering direct feedback, solutions, and resources to Mississippi government decision makers with one community voice. Without an RDAC, Mississippi laws and regulations that affect the rare community will be developed without the consultation of rare disease stakeholders, leaving this vulnerable population at greater risk for poor health and economic outcomes.

The legislation proposes to house the RDAC within the University of Mississippi Medical Center. It is not uncommon for a RDAC to engage the support of an academic institution within the State to accomplish its goals. In fact, of the 27 existing RDACs, four are associated with an institution of higher learning. The support of the University will be useful as the Council works to fulfill its 11 duties including creating and disseminating a first-year landscape or survey of the rare disease population to help identify unmet needs of the rare disease patients, caregivers, and providers in the state and developing recommendations to improve patient access to and quality of rare disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services.

Our 18 organizations and Mississippi's rare disease community are eager to welcome Mississippi to the community of 27 states that have given their rare disease patients a stronger voice in state government by creating a Rare Disease Advisory Council (RDAC). Those states include most of Mississippi's neighbors, Alabama, Louisiana, and Tennessee, as well as Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Maine, Maryland, Massachusetts, Minnesota, Missouri, Nevada, North Carolina, New Hampshire, New Jersey, New York, Ohio, Pennsylvania, South Carolina, Utah, Virginia, and West Virginia.

On behalf of the undersigned organizations, **we urge you to sign this critical piece of legislation into law, elevating the voice of the rare disease community in Mississippi.** For any questions, please feel free to contact Carolyn Sheridan with the National Organization for Rare Disorders via email at csheridan@raredisases.org. Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders®
AiArthritis
The ALS Association
American Cancer Society Cancer Action Network (ACSCAN)
American Partnership for Eosinophilic Disorders
Cystic Fibrosis Research Institute (CFRI)
Dravet Syndrome Foundation
HCU Network America
The Leukemia & Lymphoma Society
Lymphedema Advocacy Group
Mellie J Foundation



Alone we are rare. Together we are strong.®

Mississippi Metabolics Foundation
The Myositis Association (TMP)
National Marrow Donor Program (NMDP)
National MPS Society
National Niemann-Pick Disease Foundation
Neuropathy Action Foundation (NAF)
United MSD Foundation

CC:

Anne Hall Brashier, Chief of Staff to the Governor
David Maron, Acting Deputy Chief of Staff & Chief Legal Council to the Governor
Cory Custer, Deputy Chief of Staff, External Affairs to the Governor
Hunter Estes, Director of Communications to the Governor
Shelby Wilcher, Press Secretary to the Governor



Alone we are rare. Together we are strong.®