

By: Senator(s) Moran, Wiggins, Dearing,  
McMahan

To: Public Health and  
Welfare; Appropriations

SENATE BILL NO. 2463  
(As Sent to Governor)

1 AN ACT TO PROVIDE THAT THE UNIVERSITY OF MISSISSIPPI MEDICAL  
2 CENTER AS THE LEAD AGENCY, TOGETHER WITH THE STATE DEPARTMENT OF  
3 HEALTH, THE DIVISION OF MEDICAID AND THE MISSISSIPPI HEALTH  
4 INFORMATION NETWORK, SHALL COOPERATE WITH EACH OTHER IN PREPARING  
5 A COMPREHENSIVE REPORT ON THE STATE OF RARE DISEASES IN  
6 MISSISSIPPI, INCLUDING THE INCIDENCE OF RARE DISEASES IN THE  
7 STATE, THE STATUS OF THE RARE DISEASE COMMUNITY, AND TREATMENT AND  
8 SERVICES PROVIDED TO PERSONS WITH RARE DISEASES IN THE STATE; TO  
9 PROVIDE THAT THE REPORT SHALL BE PRESENTED TO THE CHAIRS OF  
10 CERTAIN LEGISLATIVE COMMITTEES NOT LATER THAN DECEMBER 1, 2019;  
11 AND FOR RELATED PURPOSES.

12 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MISSISSIPPI:

13 **SECTION 1.** The Legislature finds and declares:

14 (a) A rare disease is defined as a disease that affects  
15 fewer than two hundred thousand (200,000) people in the United  
16 States. Rare diseases are sometimes called orphan diseases.

17 There are seven thousand (7,000) known rare diseases affecting  
18 approximately thirty million (30,000,000) men, women and children  
19 in the United States;

20 (b) The exact cause for many rare diseases remains  
21 unknown. However, eighty percent (80%) of rare diseases are  
22 genetic in origin and can be linked to mutations in a single gene



23 or in multiple genes. Those diseases are referred to as genetic  
24 diseases. Genetic disease can be passed down from generation to  
25 generation, explaining why certain rare diseases run in families.  
26 It is also estimated that about half of all rare diseases affect  
27 children;

28 (c) A person suffering with a rare disease in  
29 Mississippi faces a wide range of challenges, including, but not  
30 limited to: delays in obtaining a diagnosis; misdiagnosis;  
31 shortage of medical specialists who are familiar with, and can  
32 provide treatment for, rare diseases; prohibitive cost of  
33 treatment; and the inability to access therapies and medication  
34 that are used by doctors to treat rare diseases but have not been  
35 approved by the federal Food and Drug Administration (FDA) for  
36 that specific purpose;

37 (d) In recent years, researchers have made considerable  
38 progress in developing diagnostic tools and treatment protocols  
39 for, and in discovering ways to prevent a variety of, rare  
40 diseases. However, much more remains to be done in the areas of  
41 rare disease research and the search for and development of new  
42 therapeutics; and

43 (e) It would be very beneficial to persons in  
44 Mississippi with rare diseases and to researchers who are trying  
45 to find ways to treat or prevent the occurrence of rare diseases  
46 to examine the existing data on rare diseases in Mississippi and  
47 compile it in a detailed report, which then could be analyzed and



48 used to educate medical professionals, government agencies and the  
49 public about rare diseases as an important public health issue,  
50 and to encourage and fund research in the development of new  
51 treatments for rare diseases.

52 **SECTION 2.** The University of Mississippi Medical Center  
53 (UMMC) as the lead agency, together with the State Department of  
54 Health, the Division of Medicaid and the Mississippi Health  
55 Information Network (MS-HIN), shall cooperate with each other in  
56 preparing a comprehensive report on the state of rare diseases in  
57 Mississippi, including the incidence of rare diseases in the  
58 state, the status of the rare disease community, and treatment and  
59 services provided to persons with rare diseases in the state. The  
60 State Department of Health, the Division of Medicaid and the  
61 MS-HIN shall provide to UMMC and each other all claims data and  
62 patient encounter data relating to the diagnosis and treatment of  
63 rare diseases and all related research and documentation relating  
64 to rare diseases, which shall be compiled, examined and analyzed  
65 in the report. The report shall be presented to the Chairs of the  
66 House Public Health and Human Services Committee, Senate Public  
67 Health and Welfare Committee, and the House and Senate Medicaid  
68 Committees not later than December 1, 2019.

69 **SECTION 3.** This act shall take effect and be in force from  
70 and after its passage.

