

By: Senator(s) Blackwell, Boyd

To: Public Health and Welfare

SENATE BILL NO. 2156

1 AN ACT TO CREATE THE MISSISSIPPI RARE DISEASE ADVISORY  
 2 COUNCIL AT THE UNIVERSITY OF MISSISSIPPI MEDICAL CENTER; TO  
 3 DECLARE CERTAIN LEGISLATIVE FINDINGS RELATING TO RARE DISEASES; TO  
 4 PRESCRIBE THE MEMBERSHIP AND DUTIES OF THE COUNCIL; TO REQUIRE THE  
 5 COUNCIL TO SUBMIT AN ANNUAL REPORT TO THE GOVERNOR AND  
 6 LEGISLATURE; TO REQUIRE THE GOVERNOR TO APPOINT MEMBERS OF A BOARD  
 7 OF DIRECTORS FOR THE GOVERNANCE OF THE COUNCIL; TO REQUIRE THE  
 8 BOARD OF DIRECTORS TO EMPLOY AN EXECUTIVE DIRECTOR FOR THE  
 9 COUNCIL; AND FOR RELATED PURPOSES.

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

11 **SECTION 1.** The Legislature finds and declares that:

12 (a) A rare disease, sometimes called an "orphan  
 13 disease," is defined as a disease that affects fewer than two  
 14 hundred thousand (200,000) people.

15 (b) There are seven thousand (7,000) known rare  
 16 diseases affecting more than twenty-five million (25,000,000) men,  
 17 women and children in the United States.

18 (c) While the exact cause for many rare diseases  
 19 remains unknown, eighty percent (80%) of rare diseases are genetic  
 20 in origin and can be linked to mutations in a single gene or in



21 multiple genes, which can be passed down from generation to  
22 generation.

23 (d) People with rare diseases face many challenges,  
24 including delays in obtaining a diagnosis, misdiagnosis, shortages  
25 of medical specialists who can provide treatment, and lack of  
26 access to therapies and medication used to treat rare diseases.

27 (e) An advisory council composed of qualified  
28 professionals and persons living with rare diseases could educate  
29 medical professionals, governmental agencies, legislators and the  
30 public about rare diseases as an important public health issue and  
31 encourage and secure funding for research for the development of  
32 new treatments for rare diseases.

33 **SECTION 2.** (1) The Mississippi Rare Disease Advisory  
34 Council is established at the University of Mississippi Medical  
35 Center for the purpose of advising the Legislature and other  
36 governmental agencies, departments, commissions and authorities on  
37 the needs of individuals living in Mississippi with a rare  
38 disease.

39 (2) The board of directors created under Section 4 of this  
40 act shall appoint the following members of the council, which must  
41 reflect the diversity of the state population:

42 (a) At least one (1) representative from academic  
43 research institutions in the state which receive grant funding for  
44 rare disease research;



45 (b) At least one (1) geneticist licensed and practicing  
46 in the State of Mississippi who is a licensed medical doctor or  
47 has otherwise obtained a doctorate in a related field;

48 (c) At least one (1) physician with experience treating  
49 rare diseases who are practicing in the state;

50 (d) At least one (1) person having a rare disease who  
51 are eighteen (18) years of age or older;

52 (e) At least one (1) caregiver of a person with a rare  
53 disease;

54 (f) At least two (2) representatives of a rare disease  
55 patient organization that operates in this state;

56 (g) A pharmacist with experience with drugs used to  
57 treat rare diseases;

58 (h) A representative of the biotechnology industry; and

59 (i) A representative of health plan companies.

60 (3) The initial meeting of the council must occur before  
61 October 1, 2024. The council shall meet on a regular basis, as  
62 determined by the board of directors, in person or via an online  
63 meeting platform.

64 (4) (a) Each member of the council shall serve a term of  
65 three (3) years. If a vacancy occurs on the council, the board of  
66 directors shall appoint, in a timely manner, a person to serve the  
67 remainder of the term of the vacated member.

68 (b) Subject to the availability of funding, members of  
69 the council may receive per diem, as authorized under Section



70 25-3-69, and be reimbursed for traveling expenses and mileage, as  
71 provided under Section 25-3-41.

72 **SECTION 3.** (1) The council shall perform the following  
73 duties:

74 (a) Convene public hearings, make inquiries and solicit  
75 comments from the general public in Mississippi to assist the  
76 council with developing a first year landscape of rare diseases in  
77 the state.

78 (b) Consult with experts on the board of directors,  
79 council and externally, as needed, on rare diseases to develop  
80 policy recommendations to improve access and quality of care for  
81 health insurance, education and treatment in the state.

82 (c) Research and make policy recommendations to the  
83 Legislature on access to insurance, specialists and other needed  
84 services for patients with rare diseases.

85 (d) Research and make recommendations to state agencies  
86 and insurers that provide services to persons with a rare disease  
87 on the impact of coverage, cost-sharing, tiering or other  
88 utilization management procedures on the provision of treatment  
89 and care services.

90 (e) Research and identify priorities relating to  
91 treatments and services provided to persons with rare diseases in  
92 Mississippi, and develop policy recommendations that include  
93 safeguards against discrimination for these populations on these  
94 and related issues.



95           (f) Evaluate and make recommendations to improve the  
96 state's newborn screening program.

97           (g) Evaluate and make recommendations to improve  
98 Medicaid coverage for approved treatment and medications for rare  
99 disease patients.

100           (h) Publish a list of existing, publicly accessible  
101 resources on research, diagnosis, treatment and education relating  
102 to those rare diseases in Mississippi, including publishing the  
103 information on a state webpage.

104           (i) Collect additional research topic areas from the  
105 public to inform future studies and reports on which the council  
106 can work for the state.

107           (j) Establish policies for training academic  
108 institutions, state agencies, health care professionals and others  
109 to foster a greater understanding of rare diseases in Mississippi.

110           (k) Identify a mechanism for sharing best practices for  
111 health care providers to ensure they are informed adequately of  
112 the most effective strategies for recognizing and treating rare  
113 diseases in Mississippi.

114           (2) The council shall submit an annual report on its  
115 activities to the Governor and Legislature before July 1 of each  
116 year, with the first report being due before July 1, 2025. The  
117 report must describe the activities and progress made by the  
118 council on the duties prescribed under this section and give an  
119 update on the status of funding for the council, including



120 information on grant applications and which grants were accepted,  
121 used and have remaining balances. The report also must include  
122 recommendations on ways to address the needs of people living with  
123 rare diseases in the State of Mississippi.

124 **SECTION 4.** (1) The council will be governed by a board of  
125 directors, which shall be comprised of the executive director and  
126 the following members appointed by the Governor:

127 (a) The State Health Officer or the officer's designee;

128 (b) The Executive Director of the Division of Medicaid  
129 or the director's designee;

130 (c) The State Insurance Commissioner or the  
131 commissioner's designee;

132 (d) The State Superintendent of Public Education or the  
133 superintendent's designee;

134 (e) One (1) representative of industry; and

135 (f) One (1) patient representative.

136 (2) The board of directors shall perform the following  
137 duties:

138 (a) Establish policies for swiftly appointing members  
139 of the council;

140 (b) Develop policies for frequency of meetings; and

141 (c) Determine a mechanism for remaining in contact in  
142 between regularly scheduled meetings of the board.

143 (3) The initial meeting of the board of directors must occur  
144 before October 1, 2024. Subsequent meetings of the board must be



145 held on a regular basis and in a format, as determined by the  
146 executive director.

147 (4) (a) Each member of the board of directors shall serve a  
148 term of three (3) years. If a vacancy occurs on the board, the  
149 remaining members of the board of directors shall appoint, in a  
150 timely manner, a person to serve the remainder of the vacated  
151 term. A vacancy on the board does not affect the power of the  
152 remaining members of the board to execute its work.

153 (b) Subject to the availability of funding, members of  
154 the board of directors may receive per diem, as authorized under  
155 Section 25-3-69, and be reimbursed for traveling expenses and  
156 mileage, as provided under Section 25-3-41.

157 **SECTION 5.** (1) The Mississippi Rare Disease Advisory  
158 Council will be under the direction of an executive director, who  
159 will be appointed by the board of directors. The executive  
160 director, who may not be employed by the federal or state  
161 government, shall oversee the board and lead the council.

162 (2) The executive director may solicit funds on behalf of  
163 the council. The council shall establish a method to securely  
164 hold and distribute funds.

165 **SECTION 6.** This act shall take effect and be in force from  
166 and after July 1, 2024.

