

By: Representatives McKnight, Mickens

To: Public Health and Human Services

HOUSE BILL NO. 616

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 two (2) representatives from academic  
43 research institutions in the state which receive grant funding for  
44 rare disease research;



- 45                   (b) At least two (2) geneticists licensed and  
46 practicing in the State of Mississippi;
- 47                   (c) At least one (1) genetic counselor practicing in  
48 the state;
- 49                   (d) One (1) registered nurse or advanced practice  
50 registered nurse with experience treating rare diseases who is  
51 licensed and practicing in the state;
- 52                   (e) At least two (2) physicians with experience  
53 treating rare diseases who are practicing in the state;
- 54                   (f) At least two (2) hospital administrators or their  
55 designees, from hospitals in the state which provide care to  
56 persons diagnosed with a rare disease, one (1) of whom must  
57 represent a hospital in which the scope of services focuses on  
58 rare diseases of pediatric patients;
- 59                   (g) At least two (2) persons having a rare disease who  
60 are eighteen (18) years of age or older;
- 61                   (h) At least one (1) caregiver of a person with a rare  
62 disease;
- 63                   (i) At least three (3) representatives of a rare  
64 disease patient organization that operates in this state;
- 65                   (j) A pharmacist with experience with drugs used to  
66 treat rare diseases;
- 67                   (k) A representative of the biotechnology industry;
- 68                   (l) A representative of health plan companies; and



69 (m) A member of the scientific community who is engaged  
70 in rare disease research, including, but not limited to, a medical  
71 researcher with experience conducting research on rare diseases.

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

76 (4) (a) Each member of the council shall serve a term of  
77 three (3) years. If a vacancy occurs on the council, the board of  
78 directors shall appoint, in a timely manner, a person to serve the  
79 remainder of the term of the vacated member.

80 (b) Subject to the availability of funding, members of  
81 the council may receive per diem, as authorized under Section  
82 25-3-69, and be reimbursed for traveling expenses and mileage, as  
83 provided under Section 25-3-41.

84 **SECTION 3.** (1) The council shall perform the following  
85 duties:

86 (a) Convene public hearings, make inquiries and solicit  
87 comments from the general public in Mississippi to assist the  
88 council with developing a first year landscape of rare diseases in  
89 the state.

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



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

97 (d) Research and make recommendations to state agencies  
98 and insurers that provide services to persons with a rare disease  
99 on the impact of coverage, cost-sharing, tiering or other  
100 utilization management procedures on the provision of treatment  
101 and care services.

102 (e) Research and identify priorities relating to  
103 treatments and services provided to persons with rare diseases in  
104 Mississippi, and develop policy recommendations that include  
105 safeguards against discrimination for these populations on these  
106 and related issues.

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

109 (g) Evaluate and make recommendations to improve  
110 Medicaid coverage for approved treatment and medications for rare  
111 disease patients.

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

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



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

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

126 (2) The council shall submit an annual report on its  
127 activities to the Governor and Legislature before July 1 of each  
128 year, with the first report being due before July 1, 2025. The  
129 report must describe the activities and progress made by the  
130 council on the duties prescribed under this section and give an  
131 update on the status of funding for the council, including  
132 information on grant applications and which grants were accepted,  
133 used and have remaining balances. The report also must include  
134 recommendations on ways to address the needs of people living with  
135 rare diseases in the State of Mississippi.

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

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

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

142 (c) The State Insurance Commissioner or the  
143 commissioner's designee;



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

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

147 (f) One (1) patient representative.

148 (2) The board of directors shall perform the following  
149 duties:

150 (a) Establish policies for swiftly appointing members  
151 of the council;

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

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

155 (3) The initial meeting of the board of directors must occur  
156 before October 1, 2024. Subsequent meetings of the board must be  
157 held on a regular basis and in a format, as determined by the  
158 executive director.

159 (4) (a) Each member of the board of directors shall serve a  
160 term of three (3) years. If a vacancy occurs on the board, the  
161 remaining members of the board of directors shall appoint, in a  
162 timely manner, a person to serve the remainder of the vacated  
163 term. A vacancy on the board does not affect the power of the  
164 remaining members of the board to execute its work.

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



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

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

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

