

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.

