

By: Representatives Turner, Arnold

To: Public Health and Human Services

HOUSE BILL NO. 1078

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 an academic
43 research institution in the state which receives grant funding for
44 rare disease research;



45 (b) At least one (1) geneticist licensed and practicing
46 in the State of Mississippi;

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

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

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

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

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

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

58 (i) A representative of health plan companies.

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

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

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



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

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

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

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

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

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

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



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

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

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

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

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

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

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



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

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

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

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

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

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

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

134 (f) One (1) patient representative.

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

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

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

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

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



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

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

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

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

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

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

