

1 HJR115
2 182787-2
3 By Representatives Weaver, Hanes, Lovvorn, Ball, Williams (P),
4 Fridy and Harper
5 RFD: Rules
6 First Read: 02-MAR-17

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8 ESTABLISHING THE ALABAMA RARE DISEASE ADVISORY
9 COUNCIL.

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11 WHEREAS, rare diseases affect approximately 400,000
12 citizens in Alabama; there is no collaboration among rare
13 disease groups to provide these people a voice in state
14 government; and

15 WHEREAS, a council of knowledgeable professionals in
16 this area could help Alabama leaders better understand and
17 address the needs of rare disease patients; and

18 WHEREAS, progress in health care for all state
19 citizens is a critical concern for this body; appropriate
20 measures can be taken on a state level that can positively
21 impact Alabama citizens with rare diseases; now therefore,

22 BE IT RESOLVED BY THE LEGISLATURE OF ALABAMA, BOTH
23 HOUSES THEREOF CONCURRING, That there is created the Rare
24 Disease Advisory Council within the School of Medicine of the
25 University of Alabama at Birmingham to advise the Governor and
26 the Legislature on research, diagnosis, treatment, and
27 education relating to rare diseases.

1 (a) The appointing authorities shall coordinate
2 their appointments to assure that the membership of the
3 council is inclusive and reflects the racial, gender,
4 geographic, urban, rural, and economic diversity of the state.

5 (b) The membership of the council shall consist of
6 the following:

7 (1) One physician affiliated with the University of
8 South Alabama appointed by the Governor who is licensed and
9 practicing in Alabama with experience researching, diagnosing,
10 or treating rare diseases.

11 (2) One pediatrician appointed by the Governor who
12 is licensed and practicing in Alabama with experience
13 researching, diagnosing, or treating rare diseases.

14 (3) One medical researcher appointed by the Governor
15 who has experience conducting research concerning rare
16 disease.

17 (4) One registered nurse or advanced practice
18 registered nurse appointed by the Governor who is licensed and
19 practicing in Alabama with experience treating rare diseases.

20 (5) One pediatric nurse practitioner appointed by
21 the Governor who is licensed and practicing in Alabama with
22 experience treating rare diseases.

23 (6) One hospital administrator, or designee,
24 appointed by the Governor, from a pediatric hospital in
25 Alabama that cares for patients with rare diseases.

1 (7) One hospital administrator, or designee,
2 appointed by the Governor, from a hospital in Alabama that
3 cares for patients with rare diseases.

4 (8) One representative appointed by the Governor
5 from each academic research institution in Alabama that
6 receives any grant funding for rare disease research.

7 (9) One representative from each of the seven
8 Congressional districts who resides in the district, appointed
9 by the Governor, and who represents an IRS-established
10 non-profit rare disease foundation.

11 (10) The State Health Officer shall be an ex officio
12 member of the council.

13 (11) One member of the Senate appointed by the
14 President Pro Tempore of the Senate.

15 (12) One member of the Senate appointed by the
16 Senate Minority Leader.

17 (13) One member of the House of Representatives
18 appointed by the Speaker of the House of Representatives.

19 (14) One member of the House of Representatives
20 appointed by the Minority Leader of the House of
21 Representatives.

22 (c) The council shall have all of the following
23 duties:

24 (1) Discuss strategies to improve understanding of
25 the diagnosis, treatment, and impact of rare diseases.

26 (2) Collect data on rare diseases including the cost
27 and economic impact for people in Alabama.

1 (3) Coordinate rare disease collaborations across
2 Alabama, including academic medical centers, investigators,
3 relevant funding agencies, biotech companies, and advocacy
4 groups.

5 (4) Highlight collaborations and synergy between
6 clinicians and investigators, academic medical centers, state
7 and federal funding agencies, biotech and pharmaceutical
8 companies, and non-profit research and medical institutions.

9 (5) Report findings to the Alabama Legislature
10 annually with the goal to address changes in rare disease
11 policies that will positively impact citizens and the state.

12 (d) Members shall be appointed for terms of three
13 years. No member shall serve more than two consecutive terms.
14 A member shall serve until his or her successor is appointed
15 and qualified.

16 (e) Initial appointments to this council shall be
17 made within 60 days of the adoption of this resolution.

18 (f) Upon the recommendation of the Dean of the
19 School of Medicine of the University of Alabama at Birmingham,
20 the Governor shall appoint the chair of the council.

21 (g) Total membership of the council consists of the
22 number of members serving on the council not including vacant
23 positions. A quorum shall consist of a simple majority of
24 total membership and shall be sufficient to conduct the
25 transaction of business of the council.

26 (h) The council shall meet at least quarterly.

1 (i) Council members shall receive no compensation
2 for their services.