

Senate Bill 274

By: Senators Orrock of the 36th, Miller of the 49th, Hufstetler of the 52nd, Butler of the 55th, Henson of the 41st and others

A BILL TO BE ENTITLED  
AN ACT

1 To amend Title 31 of the Official Code of Georgia Annotated, relating to health, so as to  
2 create the Advisory Council on Rare Diseases; to provide for legislative findings; to provide  
3 for definitions; to provide for membership; to provide for terms of office; to provide for  
4 purposes, duties, and responsibilities of the advisory council; to provide for related matters;  
5 to repeal conflicting laws; and for other purposes.

6 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

7 **SECTION 1.**

8 Title 31 of the Official Code of Georgia Annotated, relating to health, is amended by adding  
9 a new chapter to read as follows:

10 "CHAPTER 50

11 31-50-1.

12 The General Assembly finds that:

13 (1) Rare diseases in the United States are defined as conditions impacting less than  
14 200,000 people;

15 (2) It is estimated that there are 7,000 rare diseases affecting 30 million Americans, or  
16 7 to 8 percent of the population, according to the National Organization for Rare  
17 Disorders (NORD); and

18 (3) In 2018, of the 59 new drugs approved by the United States Food and Drug  
19 Administration (FDA), 34 of those drugs were for rare diseases.

20 31-50-2.

21 As used in this chapter, the term:

22 (1) 'Advisory council' means the Advisory Council on Rare Diseases established  
23 pursuant to Code Section 31-50-3.

24 (2) 'Rare disease' has the same meaning as defined in 21 U.S.C. Sec. 360bb.

25 31-50-3.

26 (a) There is established the Advisory Council on Rare Diseases. The advisory council  
27 shall be housed within an academic research institution in this state that has a dedicated  
28 focus on rare disease research or that has received grant funding to support the  
29 advancement of rare disease research that is approved by the Department of Public Health.

30 (b) The advisory council shall be composed of the following members:

31 (1) A physician licensed and practicing in this state with experience researching,  
32 diagnosing, or treating rare diseases, appointed by the Governor;

33 (2) A medical researcher with experience conducting research concerning rare diseases,  
34 appointed by the Governor;

35 (3) A registered professional nurse or advanced practice registered nurse licensed and  
36 practicing in this state with experience treating rare diseases, appointed by the Lieutenant  
37 Governor;

38 (4) One survivor of a rare disease, appointed by the Lieutenant Governor;

39 (5) One member who represents a rare disease foundation, appointed by the Speaker of  
40 the House of Representatives;

41 (6) One representative from each academic research institution in this state that receives  
42 any grant funding for rare disease research, appointed by the Speaker of the House of  
43 Representatives;

44 (7) The chairperson of the Board of Public Health, or his or her designee, who shall serve  
45 as an ex officio, nonvoting member of the advisory council; and

46 (8) The chairperson of the Board of Human Services, or his or her designee, who shall  
47 serve as an ex officio, nonvoting member of the advisory council.

48 (c) Members appointed pursuant to paragraphs (1) through (6) of subsection (b) of this  
49 Code section shall serve for a term of three years, and no member shall serve more than  
50 two consecutive terms.

51 (d) Members of the advisory council shall receive no compensation for their services but  
52 shall be allowed actual and necessary expenses in the performance of their duties. Any  
53 legislative members of the advisory council shall receive the allowances provided for in  
54 Code Section 28-1-8. Citizen members shall receive a daily expense allowance in the  
55 amount specified in subsection (b) of Code Section 45-7-21 as well as the mileage or  
56 transportation allowance authorized for state employees. Members that are state officials  
57 or state employees shall receive no compensation for their services on the advisory council  
58 but shall be reimbursed for expenses incurred in the performance of their duties as  
59 members of the advisory council in the same manner as reimbursements are made in their

60 capacity as state officials or state employees. The funds necessary for the reimbursement  
 61 of the expenses of state officials, other than legislative members, and state employees shall  
 62 come from funds appropriated to or otherwise available to their respective departments.

63 (e) The advisory council shall select a chairperson from among its members.

64 (f) Administrative support and other services required by the advisory council shall be  
 65 provided by the Department of Public Health and the academic research institution.

66 (g) The chairperson shall convene the first meeting of the advisory council no later than  
 67 September 30, 2019. A majority of the councilmembers shall constitute a quorum.  
 68 Following the first meeting, the advisory council shall meet upon the call of the chairperson  
 69 or upon the request of a majority of councilmembers.

70 31-50-4.

71 (a) The purpose of the advisory council shall be to:

72 (1) Promote collaboration between rare disease organizations, clinicians, policymakers,  
 73 and academic research centers to better understand the incidence and prevalence of rare  
 74 diseases in Georgia;

75 (2) Identify gaps in the diagnosis and treatment of rare diseases;

76 (3) Serve as a comprehensive and accessible source of information on rare diseases in  
 77 Georgia; and

78 (4) Advise the Governor and the General Assembly on research, diagnosis, treatment,  
 79 and education related to rare diseases.

80 (b) The advisory council shall have the following duties and responsibilities:

81 (1) Advise on coordinating state-wide efforts for the study of the incidence of rare  
 82 diseases within the state and the status of the rare disease community; and

83 (2) Report to the General Assembly not later than December 1, 2019, and annually  
 84 thereafter, on the activities of the advisory council and its findings and recommendations  
 85 regarding rare disease research and care in this state, including any recommendations for  
 86 statutory changes and amendments to the structure, organization, and powers or duties  
 87 of the advisory council."

## 88 **SECTION 2.**

89 All laws and parts of laws in conflict with this Act are repealed.