

House Bill 918

By: Representatives Cheokas of the 138<sup>th</sup>, Cooper of the 43<sup>rd</sup>, Newton of the 123<sup>rd</sup>, and Stephens of the 164<sup>th</sup>

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 provide for the establishment of the Georgia Rare Disease Advisory Council; to provide for  
3 legislative findings; to provide for membership; to provide for the duties and powers of the  
4 advisory council; to provide for an annual report; to provide for related matters; to repeal  
5 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  
9 enacting a new Chapter 50, which is reserved, to read as follows:

10 "CHAPTER 50

11 31-50-1.

12 The General Assembly finds that:

13 (1) A rare disease, sometimes called an orphan disease, is defined as a disease that  
14 affects fewer than 200,000 people in the United States;

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- 15 (2) There are more than 7,000 known rare diseases affecting approximately 25-30  
16 million Americans, more than half of which are children;
- 17 (3) More than 90 percent of rare diseases do not have a federal Food and Drug  
18 Administration (FDA) approved treatment;
- 19 (4) While the exact cause of many rare diseases remains unknown, many rare diseases  
20 are genetic in origin and can be linked to mutations in a single gene, or in multiple genes,  
21 which can be passed down from generation to generation;
- 22 (5) People with rare diseases face many challenges, including delays in obtaining an  
23 accurate diagnosis, finding a health care provider with expertise in their condition, and  
24 a lack of affordable access to therapies and medications used to treat rare diseases; and
- 25 (6) A state based advisory council composed of qualified professionals and persons  
26 living with rare diseases and their caregivers could educate medical professionals,  
27 government agencies, legislators, and the public about rare diseases as an important  
28 public health issue and encourage research into the development of new ways to diagnose  
29 and treat rare diseases. Reserved.

30 31-50-2.

- 31 (a) There is hereby established the Georgia Rare Disease Advisory Council within the  
32 department.
- 33 (b) The advisory council shall be composed of the following members, appointed by, and  
34 serving at the pleasure of, the Governor:
- 35 (1) A chairperson, who shall not be a state employee;
- 36 (2) One representative from an academic research institution in the state that receives  
37 grant funding for rare disease research;
- 38 (3) One representative from the Division of Medical Assistance Plans of the Department  
39 of Community Health;

- 40 (4) One representative from the Division of Family and Children Services of the  
41 Department of Human Services;
- 42 (5) One geneticist licensed and practicing in Georgia;
- 43 (6) One registered nurse or advanced practice registered nurse licensed and practicing  
44 in Georgia with experience treating rare diseases;
- 45 (7) One physician practicing in Georgia with experience treating rare diseases;
- 46 (8) Two patients who have a rare disease;
- 47 (9) One caregiver of a person with a rare disease;
- 48 (10) One representative of a rare disease patient organization that operates in Georgia;
- 49 (11) One representative from the biopharma industry;
- 50 (12) One representative from a health plan company; and
- 51 (13) One licensed social worker practicing in Georgia with experience working with rare  
52 disease patients.
- 53 (c) All members of the advisory council shall be full-time residents of Georgia.
- 54 (d) The advisory council shall meet upon the call of the chairperson and shall meet no less  
55 than quarterly, either in person or via virtual means. The advisory council shall provide  
56 opportunities for the public to provide input.
- 57 (e) Members of the advisory council shall receive no compensation for their services but  
58 shall be allowed actual and necessary expenses in the performance of their duties. Any  
59 legislative members of the advisory council shall receive the allowances provided for in  
60 Code Section 28-1-8. Citizen members shall receive a daily expense allowance in the  
61 amount specified in subsection (b) of Code Section 45-7-21, as well as the mileage or  
62 transportation allowance authorized for state employees. Members who are state officials  
63 or state employees shall receive no compensation for their services on the advisory council  
64 but shall be reimbursed for expenses incurred in the performance of their duties as  
65 members of the advisory council in the same manner as reimbursements are made in their  
66 capacity as state officials or state employees. The funds necessary for the reimbursement

67 of the expenses of state officials, other than legislative members, and state employees shall  
68 come from funds appropriated to or otherwise available to their respective departments.

69 31-50-3.

70 (a) The purpose of the advisory council shall be to advise the General Assembly and other  
71 state agencies and departments, as appropriate, on the needs of individuals with rare  
72 diseases living in Georgia.

73 (b) The advisory council shall conduct the following activities to benefit rare disease  
74 patients in Georgia:

75 (1) Convene public hearings, make inquiries, and solicit comments from the general  
76 public in Georgia to assist the advisory council with a first-year landscape or survey of  
77 the needs of rare disease patients, caregivers, and providers in the state;

78 (2) Consult with health care experts to develop policy recommendations to improve  
79 patient access to quality rare disease specialists, affordable and comprehensive health  
80 care coverage, better access to clinical trials, expansion of telehealth services, relevant  
81 diagnostics, timely treatment and to make recommendations to state agencies and insurers  
82 that provide services to persons with a rare disease on the impact of prior authorization,  
83 cost-sharing, tiering, or other utilization management procedures on the provision of  
84 treatment and care for patients;

85 (3) Evaluate and make recommendations to implement necessary improvements to  
86 Georgia newborn screening programs;

87 (4) Publish on the advisory council's website a list of existing, publicly accessible  
88 resources on research, diagnosis, treatment, and educational materials for health care  
89 providers relating to the rare diseases in Georgia; and

90 (5) Research and identify best practices to reduce health disparities and achieve health  
91 equity in the research, diagnosis, and treatment of rare diseases in Georgia.

92 (c) The advisory council may solicit and accept donations, gifts, grants, property, or  
93 matching funds from any public or private source for the use by the council in conducting  
94 the activities required pursuant to subsection (b) of this Code section.

95 31-50-4.

96 No later than June 30, 2023, and annually thereafter, the advisory council shall submit a  
97 report to the Governor and the General Assembly. Such annual report shall:

98 (1) Detail the activities and progress of the advisory council in the prior year;

99 (2) Provide an update on the status of funding of the advisory council, including any  
100 grant funds which were solicited, accepted, or used, and any remaining balances; and

101 (3) Provide recommendations to the Governor and General Assembly on ways to address  
102 the needs of people living with rare diseases in Georgia.

103 Prior to submission, a draft of the annual report shall be made available for public comment  
104 and discussed at an open public meeting."

105 **SECTION 2.**

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