

**HOUSE . . . . . No.**

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**The Commonwealth of Massachusetts**

PRESENTED BY:

***Paul R. Heroux***

*To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:*

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

An Act to create a Massachusetts rare disease advisory council.

PETITION OF:

NAME:

DISTRICT/ADDRESS:

*Paul R. Heroux*

*2nd Bristol*

*Jay Livingstone*

*8th Suffolk*

**HOUSE . . . . . No.**

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By Mr. Heroux of Attleboro, a petition (subject to Joint Rule 12) of Paul R. Heroux and Jay Livingstone for legislation to create a rare disease advisory council. Public Health.

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**The Commonwealth of Massachusetts**

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**In the Year Two Thousand Fourteen**  
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An Act to create a Massachusetts rare disease advisory council.

*Whereas*, The deferred operation of this act would tend to defeat its purpose, which is to establish forthwith a rare disease advisory council, therefore it is hereby declared to be an emergency law, necessary for the immediate preservation of the public convenience.

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

1 SECTION 1. Chapter 111 of the General Laws is hereby amended by adding the  
2 following section:-

3 Section 230. (a) For the purposes of this section, the following words shall have the  
4 following meanings, unless the context clearly requires otherwise:-

5 "Rare disease", shall mean any disease or condition which affects less than 200,000  
6 people in the United States.

7 "Rare disease care", shall mean the academic research of a rare disease or the medical  
8 treatment of individuals diagnosed with a rare disease.

9 (b) (1) The commissioner of the Department of Public Health shall appoint a rare disease  
10 advisory council to coordinate statewide efforts for the study of the incidence of rare disease  
11 within the commonwealth and the status of the rare disease community. The advisory council  
12 shall consist of the following members: the commissioner, or a designee from the department of  
13 Public Health, who shall serve as chair; up to 7 physicians actively involved in rare disease care,  
14 from among the following fields (i) neurology, (ii) cardiology, (iii) primary care, (iv) orthopedics  
15 and (v) emergency care (vi) hematology (vii) genetics; 1 registered nurse or nurse practitioner  
16 actively involved in rare disease care; 1 hospital administrator, or a designee, from each hospital  
17 in the commonwealth actively involved in rare disease care; 2 representatives from the

18 department of public health actively involved in providing public education on rare disease or  
19 chronic disease ; 1 representative from a rehabilitation facility that provides rare disease care; 1  
20 rare disease survivor over the age of 18; 1 caregiver of a rare disease survivor under the age of  
21 18; 1 representative from the Rare Disease United Foundation of Massachusetts; 1 representative  
22 from an accountable care organization certified by the health policy commission; 1  
23 representative from a health care organization involved in rare disease care, which  
24 predominantly serves minority or underserved populations; 1 representative from each licensed  
25 health care agency category that provides care for rare disease survivors; 1 representative from  
26 an organization that provides respite care services for caregivers of rare disease survivors; and 1  
27 educator licensed in the commonwealth, who provides or coordinates educational services for  
28 rare disease survivor under the age of 18.

29 (2) Each member of the advisory council shall serve for a term of 3 years, or until the  
30 member's successor is appointed by the commissioner. The advisory council shall meet  
31 periodically, but at least 4 times annually. The members of the advisory council shall serve  
32 without compensation; provided, however that the members shall be reimbursed for actual  
33 expenses reasonably incurred in the performance of their duties as members. The commissioner  
34 shall provide the advisory council with suitable accommodations for its meetings and may,  
35 subject to appropriation, provide administrative support to assist the advisory council.

36 (c) The advisory council shall advise the general court, the governor, and the  
37 commissioner on the incidence of rare disease within the commonwealth and the status of the  
38 rare disease community. To achieve its purpose, the advisory council shall:

39 (1) Undertake a statistical and qualitative examination of the incidence and causes of rare  
40 disease and develop a profile of the social and economic burden of rare disease in the  
41 commonwealth;

42 (2) Receive and consider reports and testimony from individuals, the department,  
43 community-based organizations, voluntary health organizations, healthcare providers, and other  
44 public and private organizations within the commonwealth, or recognized nationally as having  
45 expertise in rare disease care, in order to learn about their contributions to rare disease care and  
46 possibilities for the improvement of rare disease care in the commonwealth;

47 (3) Develop methods to publicize the profile of the social and economic burden of rare  
48 disease in the Commonwealth;

49 (4) Identify research-based strategies effective in preventing and controlling risks of co-  
50 morbidities for rare disease, based on available scientific evidence a;

51 (5) Determine the impact that delayed or inappropriate treatment of rare disease has on  
52 the quality of patients' lives and the associated economic burden on both patients and the  
53 Commonwealth;

54 (6) Study the economic burden of early treatment of rare disease with regard to quality of  
55 care, insurance reimbursement, rehabilitation, and related services;

56 (7) Determine best practices for ensuring that the public and healthcare providers are  
57 sufficiently informed of the most effective strategies for recognizing and treating rare disease;

58 (8) Evaluate the current system of rare disease treatment and develop recommendations  
59 to increase rare disease survival rates;

60 (9) Research and determine the most appropriate method to collect rare disease data,  
61 which shall include a record of the cases of rare disease occurring in the commonwealth and  
62 such information concerning these cases as the advisory committee deems necessary and  
63 appropriate to conduct thorough and complete epidemiological surveys of rare disease diagnosed  
64 in the commonwealth, subject to all applicable privacy laws and protections;

65 (10) Identify best practices for rare disease care from other states and at the national level  
66 that will improve rare disease care in the commonwealth, including the feasibility of, and a  
67 proposed structure for, developing a rare disease information and patient support network in the  
68 commonwealth;

69 (11) Identify and obtain any sources of public or private funding available to improve  
70 rare disease care in the commonwealth or to advance the mission of the advisory council;

71 (12) Develop a registry of all rare diseases diagnosed within the commonwealth to aid in  
72 determining any genetic or environmental contributors to rare diseases; and

73 (13) Develop and maintain a comprehensive rare disease plan for the commonwealth,  
74 which shall utilize any information and materials received or developed by the advisory council  
75 pursuant to paragraphs (1) to (12), inclusive, and which shall include information specifically  
76 directed toward the general public, state and local officials, state agencies, private organizations  
77 and associations, and businesses and industries.

78 (c) Notwithstanding any general or special law to the contrary, the advisory council may  
79 request and receive medical records and information otherwise considered confidential;  
80 provided, that no medical records or information provided to the advisory committee shall  
81 contain any individually identifiable patient information. Such records or information received  
82 by the advisory council shall not be considered public records as defined in section 7 of chapter  
83 4.

84 (d) The advisory council may apply for and receive on behalf of the commonwealth any  
85 funds, including appropriations, grants, bequests, gifts or contributions, from any source, which  
86 shall be deposited in a separate account and may be expended by the majority vote of the  
87 council, without further appropriation, in accordance with chapter 29 and any rules or regulations  
88 promulgated thereunder.

89 (e) On or before March 1, 2015, the advisory council shall provide a preliminary report  
90 to the general court, the governor, and state agencies by filing the same with the clerks of the  
91 house of representatives and the senate and the executive office for administration and finance.  
92 The preliminary report shall include, but is not limited to, an estimate the financial, informational  
93 and other resources needed to achieve the goals and duties of the advisory council.

94 (f) On or before March 1, 2016, and annually thereafter, the advisory council shall file a  
95 report with the clerks of the house of representatives and the senate and the executive office for  
96 administration and finance, which shall include, but is not limited to: (i) a summary of the  
97 current state of comprehensive rare disease plan for the commonwealth; (ii) those actions taken  
98 and progress made toward achieving implementation of the comprehensive rare disease plan; (iii)  
99 an accounting of all funds received by the council, and the source of those funds; (iv) an  
100 accounting of all funds expended by the council; and (iv), to the extent practicable, an estimate  
101 of any cost savings on the part of individuals and the commonwealth that will occur upon full  
102 implementation of the comprehensive rare disease plan and accompanying programs.

103 SECTION 2. The rare disease advisory council established by section 230 of chapter 111  
104 of the General Laws shall have its first meeting within 180 days of the effective date of this act.