

**HOUSE . . . . . No. 1171**

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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:
<i>Paul R. Heroux</i>	<i>2nd Bristol</i>
<i>Shawn Dooley</i>	<i>9th Norfolk</i>
<i>Mathew Muratore</i>	<i>1st Plymouth</i>
<i>Richard J. Ross</i>	<i>Norfolk, Bristol and Middlesex</i>

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By Mr. Heroux of Attleboro, a petition (accompanied by bill, House, No. 1171) of Paul R. Heroux and others for legislation to establish a rare disease advisory council. Public Health.

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[SIMILAR MATTER FILED IN PREVIOUS SESSION  
SEE HOUSE, NO. 1977 OF 2015-2016.]

**The Commonwealth of Massachusetts**

\_\_\_\_\_  
**In the One Hundred and Ninetieth General Court  
(2017-2018)**  
\_\_\_\_\_

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 which affects fewer than 200,000 people in the  
6 United States, which has status as an "orphan"disease for research purposes, or is known to be  
7 substantially under diagnosed and unrecognized as a result of lack of adequate diagnostic and  
8 research information."

9           “Rare disease care”, shall mean the academic research of a rare disease or the medical  
10 treatment of individuals diagnosed with a rare disease.

11           (b) (1) The commissioner of the Department of Public Health shall appoint a rare disease  
12 advisory council to coordinate statewide efforts for the study of the incidence of rare disease  
13 within the commonwealth and the status of the rare disease community. The advisory council  
14 shall consist of the following members: the commissioner, or a designee from the department of  
15 Public Health, who shall serve as chair; up to 11 physicians actively involved in rare disease  
16 care, from among the following fields: Pediatrician, Primary Care Doctor, Emergency Care  
17 Doctor, Geneticist, Metabolic Specialist, Psychologist, Gastroenterologist, Neurologist,  
18 Cardiologist, Hematologist, and Orthopedic Physician; 1 registered nurse or nurse practitioner  
19 actively involved in rare disease care; 1 hospital administrator, or a designee, from each hospital  
20 in the commonwealth actively involved in rare disease care; 2 representatives from the  
21 department of public health actively involved in providing public education on rare disease or  
22 chronic disease ; 1 representative from a rehabilitation facility that provides rare disease care; 1  
23 rare disease survivor over the age of 18; 1 caregiver of a rare disease survivor under the age of  
24 18; 1 representative from the Rare Disease United Foundation of Massachusetts; 1 representative  
25 from an accountable care organization certified by the health policy commission; 1  
26 representative from a health care organization involved in rare disease care, which  
27 predominantly serves minority or underserved populations; 1 representative from each licensed  
28 health care agency category that provides care for rare disease survivors; 1 representative from  
29 an organization that provides respite care services for caregivers of rare disease survivors; and 1  
30 educator licensed in the commonwealth, who provides or coordinates educational services for

31 rare disease survivor under the age of 18; 1 representative from the New England Newborn  
32 Screening Program.

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

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

43 (1) Undertake a statistical and qualitative examination of the incidence and causes of rare  
44 disease and develop a profile of the social and economic burden of rare disease in the  
45 commonwealth;

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

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

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

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

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

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

62 (8) Evaluate the current system of rare disease treatment to develop recommendations to  
63 increase rare disease survival rates and improve quality of life;

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

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

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

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

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

82 (c) Notwithstanding any general or special law to the contrary, the advisory council may  
83 request and receive medical records and information otherwise considered confidential;  
84 provided, that no medical records or information provided to the advisory committee shall  
85 contain any individually identifiable patient information. Such records or information received  
86 by the advisory council shall not be considered public records as defined in section 7 of chapter  
87 4.

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

93 (e) On or before March 1, 2016, the advisory council shall provide a preliminary report  
94 to the general court, the governor, and state agencies by filing the same with the clerks of the

95 house of representatives and the senate and the executive office for administration and finance.  
96 The preliminary report shall include, but is not limited to, an estimate the financial, informational  
97 and other resources needed to achieve the goals and duties of the advisory council.

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

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