

**HOUSE . . . . . No. 3714**

**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>William N. Brownsberger</i>	<i>Second Suffolk and Middlesex</i>
<i>Thomas J. Calter</i>	<i>12th Plymouth</i>
<i>James M. Cantwell</i>	<i>4th Plymouth</i>
<i>Edward F. Copping</i>	<i>10th Suffolk</i>
<i>Josh S. Cutler</i>	<i>6th Plymouth</i>
<i>Marjorie C. Decker</i>	<i>25th Middlesex</i>
<i>Geoff Diehl</i>	<i>7th Plymouth</i>
<i>Shawn Dooley</i>	<i>9th Norfolk</i>
<i>Carole A. Fiola</i>	<i>6th Bristol</i>
<i>Colleen M. Garry</i>	<i>36th Middlesex</i>
<i>Carlos Gonzalez</i>	<i>10th Hampden</i>
<i>Jonathan Hecht</i>	<i>29th Middlesex</i>
<i>Hannah Kane</i>	<i>11th Worcester</i>
<i>Joseph D. McKenna</i>	<i>18th Worcester</i>
<i>Michael O. Moore</i>	<i>Second Worcester</i>
<i>Mathew Muratore</i>	<i>1st Plymouth</i>
<i>Shaunna L. O'Connell</i>	<i>3rd Bristol</i>

<i>Michael J. Rodrigues</i>	<i>First Bristol and Plymouth</i>
<i>David M. Rogers</i>	<i>24th Middlesex</i>
<i>Richard J. Ross</i>	<i>Norfolk, Bristol and Middlesex</i>
<i>Alan Silvia</i>	<i>7th Bristol</i>
<i>Brian M. Ashe</i>	<i>2nd Hampden</i>
<i>Ruth B. Balsler</i>	<i>12th Middlesex</i>

**HOUSE . . . . . No. 3714**

---

By Mr. Heroux of Attleboro, a petition (subject to Joint Rule 12) of Paul R. Heroux and others for legislation to authorize the commissioner of the Department of Public Health to appoint a rare disease advisory council to coordinate statewide efforts for the study of the incidences of rare diseases within the Commonwealth. Public Health.

---

**The Commonwealth of Massachusetts**

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

An Act to create a Massachusetts rare disease advisory council.

*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; 2  
23 rare disease survivor over the age of 18; 2 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 Rare New England; 1 representative from the Coalition for Pediatric Pain; 1 representative  
26 from an accountable care organization certified by the health policy commission; 1  
27 representative from a health care organization involved in rare disease care, which  
28 predominantly serves minority or underserved populations; 1 representative from each licensed  
29 health care agency category that provides care for rare disease survivors; 1 representative from  
30 an organization that provides respite care services for caregivers of rare disease survivors; and 1  
31 educator licensed in the commonwealth, who provides or coordinates educational services for  
32 rare disease survivor under the age of 18; 1 representative from the New England Newborn  
33 Screening Program.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

83 (c) Notwithstanding any general or special law to the contrary, the advisory council may  
84 request and receive medical records and information otherwise considered confidential;  
85 provided, that no medical records or information provided to the advisory committee shall  
86 contain any individually identifiable patient information. Such records or information received  
87 by the advisory council shall not be considered public records as defined in section 7 of chapter  
88 4.

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

94 (e) On or before March 1, 2016, the advisory council shall provide a preliminary report  
95 to the general court, the governor, and state agencies by filing the same with the clerks of the  
96 house of representatives and the senate and the executive office for administration and finance.

97 The preliminary report shall include, but is not limited to, an estimate the financial, informational  
98 and other resources needed to achieve the goals and duties of the advisory council.

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

108 SECTION 2. The rare disease advisory council established by section 230 of chapter 111  
109 of the General Laws shall have its