HOUSE DOCKET, NO. 945 FILED ON: 1/14/2015

HOUSE . . . . . No. 1977

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*
James M. Cantwell	*4th Plymouth*
Josh S. Cutler	*6th Plymouth*
Viriato M. deMacedo	*Plymouth and Barnstable*
Geoff Diehl	*7th Plymouth*
Benjamin B. Downing	*Berkshire, Hampshire, Franklin and Hampden*
Gloria L. Fox	*7th Suffolk*
Denise C. Garlick	*13th Norfolk*
Joseph D. McKenna	*18th Worcester*
Paul McMurtry	*11th Norfolk*
Michael O. Moore	*Second Worcester*
Tom Sannicandro	*7th Middlesex*
Frank I. Smizik	*15th Norfolk*
Chris Walsh	*6th Middlesex*

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HOUSE . . . . . No. 1977

By Mr. Heroux of Attleboro, a petition (accompanied by bill, House, No. 1977) of Paul R. Heroux and others for legislation to establish a rare disease advisory council. Public Health.

The Commonwealth of Massachusetts

In the One Hundred and Eighty-Ninth General Court
(2015-2016)

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.