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STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2014

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A N A C T

RELATING TO HUMAN SERVICES - RARE DISEASE COMMUNITY SUPPORT,
RESOURCE COORDINATION, AND QUALITY OF LIFE ACT OF 2014

Introduced By: Representatives Kazarian, Amore, Slater, Diaz, and O'Brien

Date Introduced: January 15, 2014

Referred To: House Health, Education & Welfare

It is enacted by the General Assembly as follows:

1 SECTION 1. Title 40 of the General Laws entitled "HUMAN SERVICES" is hereby
2 amended by adding thereto the following chapter:

3 CHAPTER 23

4 RARE DISEASE COMMUNITY SUPPORT, RESOURCE COORDINATION, AND QUALITY

5 OF LIFE ACT OF 2014

6 **40-23-1. Rhode Island rare disease community support. Resource coordination, and**
7 **quality of life act of 2014. – Purpose and declarations. – (a) The Rhode Island general**
8 **assembly hereby finds, determines, and declares that rare disease survivors face early causes of**
9 **mortality, death and permanent, long-term disability in Rhode Island; state resources are not**
10 **coordinated for survivors and their family caregivers to provide for better access to appropriate**
11 **state social services; and health coverage is often denied or restricted upon diagnosis, treatments**
12 **are not usually covered, and information on locally-based clinical trials are not well-promoted. If**
13 **these resources are better coordinated, mortality will be reduced, quality of life will improve,**
14 **necessity of accessing state resources may decline overtime, and the ability for rare disease**
15 **survivors to live independently will increase.**

16 (b) The Rhode Island general assembly further finds that the establishment of a state rare
17 disease community advisory council will ensure that state-of-the-art information on rare disease
18 education, treatment, and access to care is available to health care providers and survivors. This

1 advisory council will serve as a consensus group designed to coordinate efforts in state resources,
2 private entities, and social services, including bringing additional monies to the state to fund
3 improvements in the treatment of rare diseases.

4 **40-23-2. Rare disease community advisory council - Membership.** – (a) The director
5 of the department of human services shall appoint an advisory council to serve as a statewide
6 commission designed to coordinate efforts for the rare disease community. The director may
7 assign staff, upon availability of funds, to assist the advisory council and shall provide it with
8 suitable accommodations for its meetings. Members appointed to the advisory council shall
9 include:

10 (1) Up to five (5) physicians actively involved in rare disease care from the following
11 fields:

12 (i) Neurology;

13 (ii) Cardiology;

14 (iii) Primary care;

15 (iv) Orthopedics; and

16 (v) Emergency care.

17 (2) One registered professional nurse or nurse practitioner actively involved in rare
18 disease care;

19 (3) One hospital administrator or designee from each hospital that provides care to rare
20 disease survivors;

21 (4) One representative each from the public health field actively involved in public health
22 education on rare disease or chronic conditions management from the department of human
23 services and the department of health.

24 (5) One representative from a rehabilitation facility that provides services to rare disease
25 survivors;

26 (6) One rare disease survivor over the age of eighteen (18).

27 (7) One caregiver of a pediatric rare disease survivor;

28 (8) One representative from the rare disease united foundation;

29 (9) One representative from Rhode Island quality partners or state-recognized quality
30 improvement organization (QIO);

31 (10) One representative from a minority health organization involved in rare disease care;

32 (11) One representative from each licensed health care agency category that provides care
33 for rare disease survivors;

34 (12) One representative from an organization that provides respite care services for rare

1 disease caregivers; and

2 (13) One licensed educator involved in providing or coordinating educational services to
3 a rare disease pediatric survivor.

4 (b) The advisory council shall advise the Rhode Island general assembly, the governor,
5 and the director of the department of human services, and have the following duties;

6 (1) Undertake a statistical and qualitative examination of the incidence and causes of rare
7 diseases and develop a profile of the social and economic burden of rare diseases in Rhode Island;

8 (2) Receive and consider reports and testimony from individuals, the state department of
9 health, community-based organizations, voluntary health organizations, healthcare providers, and
10 other public and private organizations statewide and of national significance to rare diseases to
11 learn more about their contributions to rare disease treatment and their ideas for the improvement
12 of rare disease care in Rhode Island;

13 (3) Develop methods to publicize the profile of rare disease burden in Rhode Island;

14 (4) Identify research-based strategies that are effective in preventing and controlling risks
15 of co-morbidities for rare disease based on the science available from rare disease related
16 organizations;

17 (5) Determine the burden that delayed or inappropriate treatment has on the quality of
18 patients' lives and the associated financial burden on them and the state;

19 (6) Study the economic impact of early rare disease treatment with regard to quality of
20 care, reimbursement issues, and rehabilitation, and related services;

21 (7) Research and determine how to ensure that the public and healthcare providers are
22 sufficiently informed of the most effective strategies for rare disease awareness and care;

23 (8) Evaluate the current system of treatment and develop recommendations to improve all
24 aspects of increasing rare disease survival rates;

25 (9) Research and determine the most appropriate method to collect data which shall
26 include a record of the cases of rare diseases that occur in Rhode Island and such information
27 concerning the cases as it shall deem necessary and appropriate in order to conduct thorough and
28 complete epidemiological surveys of rare diseases diagnosed in Rhode Island and to apply
29 appropriate preventative and control measures where possible;

30 (10) Identify best practices on rare disease care in other states and at the federal level that
31 will improve rare disease care in Rhode Island, including the feasibility and proposed structure of
32 developing a rare disease information and patient support network;

33 (11) Research and obtain any public or private funding available to improve rare disease
34 care in Rhode Island;

1 (12) Complete and maintain a statewide comprehensive rare disease plan to the general
2 public, state and local officials, various public and private organizations and associations,
3 business and industries, agencies, potential funders, and other community resources;

4 (13) Develop a registry of all rare diseases diagnosed within the state to determine any
5 genetic and environmental contributors to rare diseases; and

6 (14) Identify and facilitate specific commitments to help implement the plan and all
7 advisory council activities.

8 (c) The members of the advisory council shall serve without compensation; provided,
9 however the members shall be reimbursed for their reasonable costs of attendance, including, but
10 not limited to mileage and parking fees.

11 (d) The advisory council shall convene within one hundred and eighty (180) days of the
12 effective date of this chapter, and shall submit a preliminary report to state agencies, the general
13 assembly and the governor annually. The reports shall address the plans, actions, and resources
14 needed to achieve its goals and progress in achieving implementation of the plan to reduce the
15 burden from rare diseases in Rhode Island. The reports shall include an accounting of funds
16 expended, funds received from grants, and anticipated funding needs and related cost savings for
17 full implementation of recommended plans and programs.

18 Any health care information requested or obtained by the advisory council or otherwise
19 in the performance of its duties, shall be provided in a format that does not contain individually-
20 identifiable information.

21 SECTION 2. This act shall take effect upon passage.

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EXPLANATION
BY THE LEGISLATIVE COUNCIL
OF

A N A C T

RELATING TO HUMAN SERVICES - RARE DISEASE COMMUNITY SUPPORT,
RESOURCE COORDINATION, AND QUALITY OF LIFE ACT OF 2014

1 This act would establish the “Rhode Island rare disease community advisory council”
2 within the department of human services in order to aid the state in developing an action plan that
3 addresses the coordination of resources to efficiently provide care for Rhode Islanders living with
4 rare diseases and their family caregiver. The members would serve without compensation,
5 however, they would be reimbursed for their reasonable costs of attendance.

6 This act would take effect upon passage.

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