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LC000901/SUB A
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STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2015

H O U S E R E S O L U T I O N

**CREATING A SPECIAL LEGISLATIVE COMMISSION TO STUDY THE CREATION OF A
COUNCIL TO COORDINATE RESOURCES FOR PROVIDING CARE TO INDIVIDUALS
WITH RARE DISEASES**

Introduced By: Representatives Kazarian, and Amore

Date Introduced: February 04, 2015

Referred To: House Health, Education & Welfare

1 RESOLVED, That a special legislative commission be and the same is hereby created
2 consisting of nine (9) members: three (3) of whom shall be members of the Rhode Island House
3 of Representatives, not more than two (2) from the same political party, to be appointed by the
4 Speaker of the House; one of whom shall be the Director of the Rhode Island Department of
5 Health, or designee; one of whom shall be the Executive Director of the Rhode Island Hospital
6 Association, or designee; one of whom shall be an individual diagnosed with a rare disease, to be
7 appointed by the Speaker of the House; one of whom shall be a caregiver of an individual
8 diagnosed with a rare disease, to be appointed by the Speaker of the House; one of whom shall be
9 the Associate Dean of Medicine for Public Health and Policy at the Alpert Medical School at
10 Brown University, or designee; and one of whom shall be the President of the Rhode Island
11 Public Health Association, or designee.

12 In lieu of any appointment of a member of the legislature to a permanent advisory
13 commission, a legislative study commission, or any commission created by a General Assembly
14 resolution, the appointing authority may appoint a member of the general public to serve in lieu
15 of a legislator, provided that the Majority Leader or the Minority Leader of the political party
16 which is entitled to the appointment, consents to the member of the general public.

17 The purpose of said commission shall be to make a comprehensive study and proffer
18 recommendations for coordinating the efforts of state resources, private entities, and social
19 services in order to efficiently provide care for Rhode Islanders living with rare diseases and their

1 caregivers.

2 Forthwith upon passage of this resolution, the members of the commission shall meet at
3 the call of the Speaker of the House and organize and shall select a chairperson.

4 Vacancies in said commission shall be filled in like manner as the original appointment.

5 The membership of said commission shall receive no compensation for their services.

6 All departments and agencies of the state shall furnish such advice and information,
7 documentary and otherwise, to said commission and its agents as is deemed necessary or
8 desirable by the commission to facilitate the purposes of this resolution.

9 The Speaker of the House is hereby authorized and directed to provide suitable quarters
10 for said commission; and be it further

11 RESOLVED, That the commission shall report its findings and recommendations to the
12 House of Representatives no later than March 24, 2016, and said commission shall expire on June
13 24, 2016.

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EXPLANATION
BY THE LEGISLATIVE COUNCIL
OF

H O U S E R E S O L U T I O N

CREATING A SPECIAL LEGISLATIVE COMMISSION TO STUDY THE CREATION OF A
COUNCIL TO COORDINATE RESOURCES FOR PROVIDING CARE TO INDIVIDUALS
WITH RARE DISEASES

- 1 This resolution would create a nine (9) member special legislative study commission
- 2 whose purpose it would be to study and make recommendations for coordinating the necessary
- 3 resources to provide care to individuals with rare diseases, and who would report back to the
- 4 House no later than March 24, 2016, and whose life would expire on June 24, 2016.

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