

**2016 -- H 8149**

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LC005721  
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**STATE OF RHODE ISLAND**

**IN GENERAL ASSEMBLY**

**JANUARY SESSION, A.D. 2016**

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

**EXTENDING THE EXPIRATION DATE AND AMENDING THE MEMBERSHIP OF THE  
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, Bennett, Chippendale, Azzinaro, and Amore

Date Introduced: May 04, 2016

Referred To: House Health, Education & Welfare

1           RESOLVED, That the special legislative commission created by resolution No. 408  
2 passed by the House of Representatives at its January session, A.D. 2015, and approved June 18,  
3 2015, entitled "House Resolution Creating a Special Legislative Commission to Study the  
4 Creation of a Council to Coordinate Resources for Providing Care to Individuals with Rare  
5 Diseases" is hereby authorized to continue its study, and said commission shall expire on June 24,  
6 2019; and, be it further

7           RESOLVED, That the composition of said commission is hereby amended to consist of  
8 twenty (20) members: three (3) of whom shall be members of the Rhode Island House of  
9 Representatives, not more than two (2) from the same political party, to be appointed by the  
10 Speaker of the House; one of whom shall be the Director of the Rhode Island Department of  
11 Health, or designee; one of whom shall be the President of the Hospital Association of Rhode  
12 Island, or designee; two (2) of whom shall be individuals diagnosed with a rare disease, to be  
13 appointed by the Speaker of the House; one of whom shall be a caregiver of an individual  
14 diagnosed with a rare disease, to be appointed by the Speaker of the House; one of whom shall be  
15 the Associate Dean of Medicine for Public Health and Policy at the Alpert Medical School at  
16 Brown University, or designee; one of whom shall be the President of the Rhode Island Public  
17 Health Association, or designee; three (3) of whom shall be representatives of Rhode Island  
18 health insurance companies, to be appointed by the Speaker of the House; two (2) of whom shall

1 be representatives of the Pharmaceutical Industry, to be appointed by the Speaker of the House;  
2 one of whom shall be a representative of the biotech industry, to be appointed by the Speaker of  
3 the House; three (3) of whom shall be physicians, to be appointed by the Speaker of the House;  
4 and one of whom shall be a representative from a rare disease organization, to be appointed by  
5 the Speaker of the House; and be it further

6 RESOLVED, That the expiration date authorized by resolution No. 408 and passed by  
7 the House of Representatives at its January session, A.D. 2015, and approved June 24, 2015, be  
8 and the same is hereby rescinded.

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EXPLANATION  
BY THE LEGISLATIVE COUNCIL  
OF

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EXTENDING THE EXPIRATION DATE AND AMENDING THE MEMBERSHIP OF THE  
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- 1           This resolution would increase the membership of the special legislative commission to
- 2 study the creation of a council to coordinate resources for providing care to individuals with rare
- 3 diseases from nine (9) to twenty (20), and said commission would expire on June 24, 2019.

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