

# MAINE STATE LEGISLATURE

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# 131st MAINE LEGISLATURE

## FIRST REGULAR SESSION-2023

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Legislative Document

No. 1083

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H.P. 678

House of Representatives, March 9, 2023

### **An Act to Amend the Membership of the Rare Disease Advisory Council**

(EMERGENCY)

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Reported by Representative MEYER of Eliot for the Joint Standing Committee on Health and Human Services pursuant to Resolve 2021, chapter 177, section 8.

Reference to the Committee on Health and Human Services suggested and ordered printed pursuant to Joint Rule 218.

A handwritten signature in cursive script that reads "Robert B. Hunt".

ROBERT B. HUNT  
Clerk

1           **Emergency preamble.** Whereas, acts and resolves of the Legislature do not  
2 become effective until 90 days after adjournment unless enacted as emergencies; and

3           **Whereas**, a council coordinator to provide administrative support to the Rare Disease  
4 Advisory Council is currently being appointed and members of the council will soon be  
5 appointed; and

6           **Whereas**, to minimize disruption of membership and ensure that members of the  
7 council with direct experience of a single-gene disorder will be appointed at the beginning  
8 of the council's activities, this legislation must take effect immediately; and

9           **Whereas**, in the judgment of the Legislature, these facts create an emergency within  
10 the meaning of the Constitution of Maine and require the following legislation as  
11 immediately necessary for the preservation of the public peace, health and safety; now,  
12 therefore,

13 **Be it enacted by the People of the State of Maine as follows:**

14           **Sec. 1. 22 MRSA §1700-B, sub-§2, ¶L**, as enacted by PL 2021, c. 740, §2, is  
15 repealed.

16           **Sec. 2. 22 MRSA §1700-B, sub-§2, ¶M**, as enacted by PL 2021, c. 740, §2, is  
17 repealed.

18           **Sec. 3. 22 MRSA §1700-B, sub-§2, ¶N**, as enacted by PL 2021, c. 740, §2, is  
19 amended to read:

20           N. One representative of an organization dedicated to providing services to persons  
21 with rare diseases;

22           **Sec. 4. 22 MRSA §1700-B, sub-§2, ¶O** is enacted to read:

23           O. One person 18 years of age or older who has had or has a single-gene disorder;

24           **Sec. 5. 22 MRSA §1700-B, sub-§2, ¶P** is enacted to read:

25           P. One person 18 years of age or older who has had or has a rare disease that is not a  
26 single-gene disorder;

27           **Sec. 6. 22 MRSA §1700-B, sub-§2, ¶Q** is enacted to read:

28           Q. One parent or guardian who has a child with a single-gene disorder; and

29           **Sec. 7. 22 MRSA §1700-B, sub-§2, ¶R** is enacted to read:

30           R. One parent or guardian who has a child with a rare disease that is not a single-gene  
31 disorder.

32           **Emergency clause.** In view of the emergency cited in the preamble, this legislation  
33 takes effect when approved.

34   **SUMMARY**

35           This bill is a recommendation from the Advisory Panel to Better Understand and Make  
36 Recommendations Regarding the Implications of Genome-editing Technology for the  
37 Citizens of the State established pursuant to Resolve 2021, chapter 177. It changes the  
38 membership of the Rare Disease Advisory Council to require one of the members who is

1 18 years of age or older with a rare disease to be a person who has or has had a single-gene  
2 disorder and to require one of the members who is a parent or guardian of a child with a  
3 rare disease to be a parent or guardian of a child with a single-gene disorder. The members  
4 of the Rare Disease Advisory Council have not yet been appointed.