

House Bill 3527

Sponsored by Representatives WEIDNER, NOSSE; Representative HACK

SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure **as introduced**.

Establishes Task Force on Lysosomal Storage Disorder Screenings to study feasibility of and barriers to pilot project using certain screening technologies. Directs task force to report findings to Legislative Assembly.

Sunsets task force on December 31, 2016.

Declares emergency, effective on passage.

A BILL FOR AN ACT

1
2 Relating to Task Force on Lysosomal Storage Disorder Screenings; and declaring an emergency.

3 **Be It Enacted by the People of the State of Oregon:**

4 **SECTION 1. (1) The Task Force on Lysosomal Storage Disorder Screenings is established,**
5 **consisting of seven members appointed as follows:**

6 (a) **The President of the Senate shall appoint one member from among the members of**
7 **the Senate.**

8 (b) **The Speaker of the House of Representatives shall appoint one member from among**
9 **the members of the House of Representatives.**

10 (c) **The Governor shall appoint five members as follows:**

11 (A) **One member who represents the Oregon Health and Science University;**

12 (B) **The Director of the Oregon Health Authority, or a designee of the director;**

13 (C) **Two members who are health care professionals knowledgeable about lysosomal**
14 **storage disorders and the screening and treatment for lysosomal storage disorders; and**

15 (D) **One member who is a parent of a child who has a lysosomal storage disorder.**

16 (2) **The task force shall study the feasibility of and barriers to a pilot project to use**
17 **screening technologies not yet approved by the federal Food and Drug Administration to**
18 **screen infants for lysosomal storage disorders.**

19 (3) **The task force may request data from the Oregon Health and Science University and**
20 **the Oregon Health Authority that the task force determines is necessary to carry out the**
21 **duties described in subsection (2) of this section.**

22 (4) **Members of the Legislative Assembly appointed to the task force are nonvoting**
23 **members of the task force and may act in an advisory capacity only.**

24 (5) **A majority of the voting members of the task force constitutes a quorum for the**
25 **transaction of business.**

26 (6) **Official action by the task force requires the approval of a majority of the voting**
27 **members of the task force.**

28 (7) **The task force shall elect one of its members to serve as chairperson.**

29 (8) **If there is a vacancy for any cause, the appointing authority shall make an appoint-**
30 **ment to become immediately effective.**

NOTE: Matter in **boldfaced** type in an amended section is new; matter [*italic and bracketed*] is existing law to be omitted. New sections are in **boldfaced** type.

1 **(9) The task force shall meet at times and places specified by the call of the chairperson**
2 **or of a majority of the voting members of the task force.**

3 **(10) The task force may adopt rules necessary for the operation of the task force.**

4 **(11) The task force shall submit a report in the manner provided by ORS 192.245, and**
5 **may include recommendations for legislation, to the interim committees of the Legislative**
6 **Assembly related to health care no later than September 15, 2016.**

7 **(12) The Oregon Health Authority shall provide staff support to the task force.**

8 **(13) Members of the task force who are not members of the Legislative Assembly are not**
9 **entitled to compensation, but may be reimbursed for actual and necessary travel and other**
10 **expenses incurred by them in the performance of their official duties in the manner and**
11 **amounts provided for in ORS 292.495. Claims for expenses incurred in performing functions**
12 **of the task force shall be paid out of funds appropriated to the Oregon Health Authority for**
13 **purposes of the task force.**

14 **(14) All agencies of state government, as defined in ORS 174.111, are directed to assist**
15 **the task force in the performance of its duties and, to the extent permitted by laws relating**
16 **to confidentiality, to furnish such information and advice as the members of the task force**
17 **consider necessary to perform their duties.**

18 **SECTION 2.** **Section 1 of this 2015 Act is repealed on December 31, 2016.**

19 **SECTION 3.** **This 2015 Act being necessary for the immediate preservation of the public**
20 **peace, health and safety, an emergency is declared to exist, and this 2015 Act takes effect**
21 **on its passage.**

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