82nd OREGON LEGISLATIVE ASSEMBLY--2023 Regular Session

A-Engrossed

House Bill 2927

Ordered by the House March 31
Including House Amendments dated March 31

Sponsored by Representative NELSON, Senator WOODS, Representative BYNUM, Senator FREDERICK; Representatives HUDSON, REYNOLDS, Senator MEEK (Presession filed.)

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.

Establishes Statewide Steering Committee on Sickle Cell Disease. Requires committee, with regards to sickle cell disease, to establish statewide network of stakeholders, provide education services, identify funding sources and make recommendations.

Requires Oregon Health Authority, in consultation with committee, to provide social support and other services for individuals with sickle cell disease, establish system to provide information to individuals, or parents or guardians of individuals, who have sickle cell trait, maintain webpage with resources for health care providers regarding care and treatment of individuals with sickle cell disease and conduct annual review of treatment plans and services provided for individuals with sickle cell disease eligible for medical assistance under Oregon Health Plan.

Requires committee, in consultation with authority, to study ways to provide outreach and improve access to and coordination of health care, social support and other services for individuals with sickle cell disease, whether to establish sickle cell disease registry and whether medications, treatments and services for individuals with sickle cell disease covered by Oregon Health Plan are sufficient. Directs committee to submit findings to interim committees of Legislative Assembly related to health care no later than [*June*] **November** 30, 2024.

[*Requires health benefit plans to cover fertility preservation for individuals with sickle cell disease.*]

A BILL FOR AN ACT

Relating to sickle cell disease.

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

STATEWIDE STEERING COMMITTEE ON SICKLE CELL DISEASE

SECTION 1. (1) The Statewide Steering Committee on Sickle Cell Disease is established within the Oregon Health Authority.

(2) The Director of the Oregon Health Authority shall appoint at least 11 but not more than 15 members to serve on the committee. Members on the committee must be individuals who represent:

(a) Local or national community-based organizations with experience providing direct support services to individuals with sickle cell disease in Oregon;

(b) Interest or support groups that work with individuals with sickle cell disease;

(c) Community-based organizations that advocate for individuals with sickle cell disease;

(d) Health care consumers;

(e) Clinical health care providers with knowledge and experience caring for and treating individuals with sickle cell disease, including hematologists, emergency physicians and primary care physicians;

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.

(f) Pediatric clinics that provide care to or treat children with sickle cell disease;

(g) Academic institutions involved with sickle cell disease research or providing care to or treating individuals with sickle cell disease; and

(h) Hospitals that provide care to or treat individuals with sickle cell disease.

(3) In appointing members under subsection (2) of this section, the director shall take into consideration the geographic, demographic and cultural diversity of this state.

(4) The committee shall:

(a) Establish a statewide network of stakeholders who provide care to or treat individuals with sickle cell disease;

(b) Establish partnerships with relevant institutions and community groups;

(c) Educate individuals with sickle cell disease, health care providers and the public about health care and treatment options for individuals with sickle cell disease;

(d) Identify funding sources, including federal, state and private sources, for implementing or supporting any recommendations made under paragraph (e) of this subsection; and

(e) Make recommendations regarding actions, studies, policies, laws or regulations to advance the care and treatment of individuals with sickle cell disease.

(5) A majority of the members of the committee constitutes a quorum for the transaction of business.

(6) Official action by the committee requires the approval of a majority of the members of the committee.

(7) The committee shall elect a chairperson from among its members.

(8) The committee shall meet at the call of the chairperson or of a majority of the members of the committee.

(9) The committee may adopt rules necessary for the operation of the committee.

(10) The term of office of each member of the committee is four years, but a member serves at the pleasure of the director. Before the expiration of the term of a member, the director shall appoint a successor whose term begins January 1 next following. A member is eligible for reappointment. If there is a vacancy for any cause, the director shall make an appointment to become immediately effective for the unexpired term.

(11) Members of the committee are not entitled to compensation, but may be reimbursed from funds available to the authority, for actual and necessary travel and other expenses incurred by them in the performance of their official duties in the manner and amounts provided for in ORS 292.495.

SECTION 2. Notwithstanding the term of office for members of the Statewide Steering Committee on Sickle Cell Disease specified in section 1 (10) of this 2023 Act, of the members first appointed to the committee:

(1) At least three shall serve for a term ending January 1, 2025.

(2) At least four shall serve for a term ending January 1, 2026.

(3) At least four shall serve for a term ending January 1, 2027.

OREGON HEALTH AUTHORITY AND SICKLE CELL DISEASE

SECTION 3. The Oregon Health Authority, in consultation with the Statewide Steering Committee on Sickle Cell Disease established under section 1 of this 2023 Act, shall:

(1) Provide, to the greatest extent practicable through community-based organizations,

or by other means, the following services:

(a) Educational programs regarding sickle cell disease for individuals with sickle cell disease;

(b) Social support and information services for individuals with sickle cell disease, including services provided by regulated social workers, as defined in ORS 675.510, and community health workers, as defined in ORS 414.025;

(c) Testing services for sickle cell disease;

(d) Genetic counseling;

(e) Assistance with applying for or accessing available reimbursements for medical expenses related to sickle cell disease;

(f) Education and counseling services following a newborn screening for sickle cell disease or trait; and

(g) Any other program or service that decreases the need for individuals with sickle cell disease to use acute care services;

(2) Establish a system for providing information regarding the sickle cell trait to individuals who have the sickle cell trait or the parents or guardians of minor children who have the sickle cell trait;

(3) Maintain a webpage that is accessible through a link on the home page of the authority's website that provides a list of resources for health care providers to improve the providers' understanding, care and treatment of individuals with sickle cell disease or who have the sickle cell trait; and

(4) Conduct an annual review of all medications, treatment plans and services provided for individuals with sickle cell disease who are eligible for medical assistance under the Oregon Health Plan and provide the review to the committee.

STUDY RELATED TO SICKLE CELL DISEASE

SECTION 4. **(1) The Statewide Steering Committee on Sickle Cell Disease, in consultation with the Oregon Health Authority, shall study:**

(a) Ways to improve access to health care, social support and other services for individuals with sickle cell disease, including for individuals with sickle cell disease residing in areas with:

(A) A higher number of individuals with sickle cell disease; and

(B) No or few health care providers with knowledge or experience in providing care or treatment to individuals with sickle cell disease;

(b) Ways to engage with community-based events or organizations that connect or provide community members with health care services or information regarding health care services to provide outreach to individuals with sickle cell disease and education on accessing health care services and living with sickle cell disease;

(c) Ways to improve the coordination of health care services, including identifying available resources, for individuals with sickle cell disease who are transitioning from pediatric to adult health care;

(d) Existing sickle cell disease registries and evaluate whether the state should establish a sickle cell disease registry, and if so, guidelines and processes for establishing a registry, obtaining individual information, protecting data privacy and using a state designated ex-

change;

(e) Whether medications, treatments and services for individuals with sickle cell disease covered by the Oregon Health Plan are sufficient to meet the needs of individuals with sickle cell disease enrolled in the Oregon Health Plan or whether additional medications, treatments or services need to be covered by the Oregon Health Plan;

(f) Ways to provide fertility preservation treatments for individuals with sickle cell disease; and

(g) Ways to establish a toll-free information hotline for individuals with sickle cell disease.

(2) The committee shall submit a report in the manner provided by ORS 192.245, and may include recommendations for legislation, to the interim committees of the Legislative Assembly related to health care no later than November 30, 2024.

SECTION 5. Section 4 of this 2023 Act is repealed on January 2, 2025.

UNIT CAPTIONS

SECTION 6. The unit captions used in this 2023 Act are provided only for the convenience of the reader and do not become part of the statutory law of this state or express any legislative intent in the enactment of this 2023 Act.