

House Bill 2927

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 **as introduced**.

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 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; creating new provisions; and amending ORS 743A.067.

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 organizations that advocate for individuals with sickle cell disease;

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

(c) Community interest groups;

(d) Health care consumers;

(e) Clinical health care providers with knowledge and experience caring for and treating individuals with sickle cell disease;

(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

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 into consideration the geographic, demographic and cultural diversity of this state.

2 (4) The committee shall:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

34 (2) At least three shall serve for a term ending January 1, 2027.

35
36 **OREGON HEALTH AUTHORITY AND SICKLE CELL DISEASE**

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

40 (1) Provide, to the greatest extent practicable through community-based organizations,
41 or by other means, the following services:

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

44 (b) Social support and information services for individuals with sickle cell disease, in-
45 cluding services provided by regulated social workers, as defined in ORS 675.510, and com-

1 **munity health workers, as defined in ORS 414.025;**

2 **(c) Testing services for sickle cell disease;**

3 **(d) Genetic counseling;**

4 **(e) Assistance with applying for or accessing available reimbursements for medical ex-**
5 **penditures related to sickle cell disease;**

6 **(f) Education and counseling services following a newborn screening for sickle cell dis-**
7 **ease or trait; and**

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

10 **(2) Establish a system for providing information regarding the sickle cell trait to indi-**
11 **viduals who have the sickle cell trait or the parents or guardians of minor children who have**
12 **the sickle cell trait;**

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

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

20
21 **STUDY RELATED TO SICKLE CELL DISEASE**

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

25 **(a) Ways to improve access to health care, social support and other services for individ-**
26 **uals with sickle cell disease, including for individuals with sickle cell disease residing in areas**
27 **with:**

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

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

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

35 **(c) Ways to improve the coordination of health care services, including identifying avail-**
36 **able resources, for individuals with sickle cell disease who are transitioning from pediatric**
37 **to adult health care;**

38 **(d) Whether the state should establish a sickle cell disease registry, and if so, guidelines**
39 **and processes for establishing a registry, obtaining individual information, protecting data**
40 **privacy and using a state designated exchange; and**

41 **(e) Whether medications, treatments and services for individuals with sickle cell disease**
42 **covered by the Oregon Health Plan are sufficient to meet the needs of individuals with sickle**
43 **cell disease enrolled in the Oregon Health Plan or whether additional medications, treat-**
44 **ments or services need to be covered by the Oregon Health Plan.**

45 **(2) The committee shall submit a report in the manner provided by ORS 192.245, and may**

1 include recommendations for legislation, to the interim committees of the Legislative As-
2 sembly related to health care no later than June 30, 2024.

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

4
5 **HEALTH BENEFIT PLAN COVERAGE**
6 **FOR FERTILITY PRESERVATION SERVICES**
7

8 **SECTION 6.** ORS 743A.067, as amended by section 12, chapter 45, Oregon Laws 2022, is
9 amended to read:

10 743A.067. (1) As used in this section:

11 (a) “Contraceptives” means health care services, drugs, devices, products or medical procedures
12 to prevent a pregnancy.

13 (b) “Enrollee” means an insured individual and the individual’s spouse, domestic partner and
14 dependents who are beneficiaries under the insured individual’s health benefit plan.

15 (c) “Health benefit plan” has the meaning given that term in ORS 743B.005, excluding Medicare
16 Advantage Plans and including health benefit plans offering pharmacy benefits administered by a
17 third party administrator or pharmacy benefit manager.

18 (d) “Prior authorization” has the meaning given that term in ORS 743B.001.

19 (e) “Religious employer” has the meaning given that term in ORS 743A.066.

20 (f) “Utilization review” has the meaning given that term in ORS 743B.001.

21 (2) A health benefit plan offered in this state must provide coverage for all of the following
22 services, drugs, devices, products and procedures:

23 (a) Well-woman care prescribed by the Department of Consumer and Business Services by rule
24 consistent with guidelines published by the United States Health Resources and Services Adminis-
25 tration.

26 **(b) Fertility preservation for individuals with sickle cell disease.**

27 [(b)] (c) Counseling for sexually transmitted infections, including but not limited to human
28 immunodeficiency virus and acquired immune deficiency syndrome.

29 [(c)] (d) Screening for:

30 (A) Chlamydia;

31 (B) Gonorrhea;

32 (C) Hepatitis B;

33 (D) Hepatitis C;

34 (E) Human immunodeficiency virus and acquired immune deficiency syndrome;

35 (F) Human papillomavirus;

36 (G) Syphilis;

37 (H) Anemia;

38 (I) Urinary tract infection;

39 (J) Pregnancy;

40 (K) Rh incompatibility;

41 (L) Gestational diabetes;

42 (M) Osteoporosis;

43 (N) Breast cancer; and

44 (O) Cervical cancer.

45 [(d)] (e) Screening to determine whether counseling related to the BRCA1 or BRCA2 genetic

1 mutations is indicated and counseling related to the BRCA1 or BRCA2 genetic mutations if indi-
 2 cated.

3 [(e)] (f) Screening and appropriate counseling or interventions for:

4 (A) Tobacco use; and

5 (B) Domestic and interpersonal violence.

6 [(f)] (g) Folic acid supplements.

7 [(g)] (h) Abortion.

8 [(h)] (i) Breastfeeding comprehensive support, counseling and supplies.

9 [(i)] (j) Breast cancer chemoprevention counseling.

10 [(j)] (k) Any contraceptive drug, device or product approved by the United States Food and Drug
 11 Administration, subject to all of the following:

12 (A) If there is a therapeutic equivalent of a contraceptive drug, device or product approved by
 13 the United States Food and Drug Administration, a health benefit plan may provide coverage for
 14 either the requested contraceptive drug, device or product or for one or more therapeutic equiv-
 15 alents of the requested drug, device or product.

16 (B) If a contraceptive drug, device or product covered by the health benefit plan is deemed
 17 medically inadvisable by the enrollee's provider, the health benefit plan must cover an alternative
 18 contraceptive drug, device or product prescribed by the provider.

19 (C) A health benefit plan must pay pharmacy claims for reimbursement of all contraceptive
 20 drugs available for over-the-counter sale that are approved by the United States Food and Drug
 21 Administration.

22 (D) A health benefit plan may not infringe upon an enrollee's choice of contraceptive drug, de-
 23 vice or product and may not require prior authorization, step therapy or other utilization review
 24 techniques for medically appropriate covered contraceptive drugs, devices or other products ap-
 25 proved by the United States Food and Drug Administration.

26 [(k)] (L) Voluntary sterilization.

27 [(L)] (m) As a single claim or combined with other claims for covered services provided on the
 28 same day:

29 (A) Patient education and counseling on contraception and sterilization.

30 (B) Services related to sterilization or the administration and monitoring of contraceptive drugs,
 31 devices and products, including but not limited to:

32 (i) Management of side effects;

33 (ii) Counseling for continued adherence to a prescribed regimen;

34 (iii) Device insertion and removal; and

35 (iv) Provision of alternative contraceptive drugs, devices or products deemed medically appro-
 36 priate in the judgment of the enrollee's provider.

37 [(m)] (n) Any additional preventive services for women that must be covered without cost
 38 sharing under 42 U.S.C. 300gg-13, as identified by the United States Preventive Services Task Force
 39 or the Health Resources and Services Administration of the United States Department of Health and
 40 Human Services as of January 1, 2017.

41 (3) A health benefit plan may not impose on an enrollee a deductible, coinsurance, copayment
 42 or any other cost-sharing requirement on the coverage required by this section. A health care pro-
 43 vider shall be reimbursed for providing the services described in this section without any deduction
 44 for coinsurance, copayments or any other cost-sharing amounts.

45 (4) Except as authorized under this section, a health benefit plan may not impose any re-

1 strictions or delays on the coverage required by this section.

2 (5) This section does not exclude coverage for contraceptive drugs, devices or products pre-
 3 scribed by a provider, acting within the provider's scope of practice, for:

4 (a) Reasons other than contraceptive purposes, such as decreasing the risk of ovarian cancer
 5 or eliminating symptoms of menopause; or

6 (b) Contraception that is necessary to preserve the life or health of an enrollee.

7 (6) This section does not limit the authority of the Department of Consumer and Business Ser-
 8 vices to ensure compliance with ORS 743A.063 and 743A.066.

9 (7) This section does not require a health benefit plan to cover:

10 (a) Experimental or investigational treatments;

11 (b) Clinical trials or demonstration projects, except as provided in ORS 743A.192;

12 (c) Treatments that do not conform to acceptable and customary standards of medical practice;

13 (d) Treatments for which there is insufficient data to determine efficacy; or

14 (e) Abortion if the insurer offering the health benefit plan excluded coverage for abortion in all
 15 of its individual, small employer and large employer group plans during the 2017 plan year.

16 (8) If services, drugs, devices, products or procedures required by this section are provided by
 17 an out-of-network provider, the health benefit plan must cover the services, drugs, devices, products
 18 or procedures without imposing any cost-sharing requirement on the enrollee if:

19 (a) There is no in-network provider to furnish the service, drug, device, product or procedure
 20 that is geographically accessible or accessible in a reasonable amount of time, as defined by the
 21 Department of Consumer and Business Services by rule consistent with the requirements for pro-
 22 vider networks in ORS 743B.505; or

23 (b) An in-network provider is unable or unwilling to provide the service in a timely manner.

24 (9) An insurer may offer to a religious employer a health benefit plan that does not include
 25 coverage for contraceptives or abortion procedures that are contrary to the religious employer's
 26 religious tenets only if the insurer notifies in writing all employees who may be enrolled in the
 27 health benefit plan of the contraceptives and procedures the employer refuses to cover for religious
 28 reasons.

29 (10) If the Department of Consumer and Business Services concludes that enforcement of this
 30 section may adversely affect the allocation of federal funds to this state, the department may grant
 31 an exemption to the requirements but only to the minimum extent necessary to ensure the continued
 32 receipt of federal funds.

33 (11) An insurer that is subject to this section shall make readily accessible to enrollees and
 34 potential enrollees, in a consumer-friendly format, information about the coverage of contraceptives
 35 by each health benefit plan and the coverage of other services, drugs, devices, products and proce-
 36 dures described in this section. The insurer must provide the information:

37 (a) On the insurer's website; and

38 (b) In writing upon request by an enrollee or potential enrollee.

39 (12) This section does not prohibit an insurer from using reasonable medical management tech-
 40 niques to determine the frequency, method, treatment or setting for the coverage of services, drugs,
 41 devices, products and procedures described in subsection (2) of this section, other than coverage
 42 required by subsection [(2)(g) and (j)] **(2)(h) and (k)** of this section, if the techniques:

43 (a) Are consistent with the coverage requirements of subsection (2) of this section; and

44 (b) Do not result in the wholesale or indiscriminate denial of coverage for a service.

45 (13) This section is exempt from ORS 743A.001.

