

**Second Regular Session
Seventy-fourth General Assembly
STATE OF COLORADO**

REREVISED

*This Version Includes All Amendments
Adopted in the Second House*

LLS NO. 24-0065.02 Brita Darling x2241

SENATE BILL 24-042

SENATE SPONSORSHIP

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Senate Committees

Health & Human Services
Appropriations

House Committees

Health & Human Services
Appropriations

HOUSE
3rd Reading Unamended
May 3, 2024

HOUSE
Amended 2nd Reading
May 2, 2024

A BILL FOR AN ACT

101 **CONCERNING THE CREATION OF THE ARIE P. TAYLOR SICKLE CELL**
102 **DISEASE OUTREACH PROGRAM TO PROVIDE SUPPORT TO**
103 **INDIVIDUALS LIVING WITH SICKLE CELL DISEASE, AND, IN**
104 **CONNECTION THEREWITH, MAKING AN APPROPRIATION.**

SENATE
3rd Reading Unamended
April 17, 2024

SENATE
Amended 2nd Reading
April 16, 2024

Bill Summary

(Note: This summary applies to this bill as introduced and does not reflect any amendments that may be subsequently adopted. If this bill passes third reading in the house of introduction, a bill summary that applies to the reengrossed version of this bill will be available at <http://leg.colorado.gov>.)

The bill creates the Arie P. Taylor sickle cell disease outreach program (outreach program) in the department of public health and environment (department). To implement the outreach program, the bill

Shading denotes HOUSE amendment. Double underlining denotes SENATE amendment.
Capital letters or bold & italic numbers indicate new material to be added to existing law.
Dashes through the words or numbers indicate deletions from existing law.

requires the department, subject to available appropriations, to contract with one or more community-based nonprofit organizations (outreach organizations) to provide outreach and support services in the community to individuals living with sickle cell disease and their families.

The department shall contract with a third-party entity (administrator) to solicit applicants and administer the outreach program. On or before January 1, 2025, the department shall select one or more outreach organizations to implement the outreach program and shall give priority to community organizations with experience in providing services and support to the sickle cell community and that meet other criteria in the bill.

The outreach program may include informal counseling and health guidance, direction and support to individuals and their families in locating and accessing services in the community, outreach concerning activities and programs available to individuals and families living with sickle cell disease, peer support and referrals, advocacy regarding the interests of the sickle cell disease community, referrals for screening, and other services and support identified by the department.

The department shall approve the services provided through a contract and may consult with the university of Colorado school of medicine's sickle-cell anemia treatment and research center to identify needed services and supports.

Prior to the expiration of a contract, the outreach organization, in conjunction with the administrator, shall prepare and submit a written report to the department describing the impact of the outreach program provided under the contract, and the department shall provide the report to certain committees of the general assembly.

The bill repeals the outreach program after 5 years.

1 *Be it enacted by the General Assembly of the State of Colorado:*

2 **SECTION 1.** In Colorado Revised Statutes, **add** 25-1.5-121 as
3 follows:

4 **25-1.5-121. Arie P. Taylor sickle cell disease outreach program**
5 **- contracts - administration - report - legislative declaration -**
6 **definitions - repeal.** (1) THE GENERAL ASSEMBLY FINDS AND DECLARES
7 THAT:

8 (a) SICKLE-CELL ANEMIA IS A GENETIC DISORDER OF THE
9 HEMOGLOBIN IN RED BLOOD CELLS THAT CAUSES RED BLOOD CELLS THAT

1 CARRY OXYGEN TO STICK TOGETHER AFTER THE OXYGEN IS RELEASED,
2 CAUSING BLOCKAGES IN THE SMALL BLOOD VESSELS;

3 (b) THE MAIN SYMPTOMS OF SICKLE-CELL ANEMIA ARE ANEMIA
4 ANDEPISODES OF SEVERE PAIN CAUSED BY THE BLOCKAGES IN THE SMALL
5 BLOOD VESSELS; OVER TIME, PEOPLE WITH SICKLE-CELL ANEMIA ARE
6 INCREASINGLY AT RISK OF OTHER HEALTH COMPLICATIONS, AND THE
7 DISORDER DAMAGES THEIR ORGANS;

8 (c) ACCORDING TO THE 2022-23 "COLORADO SICKLE CELL STATE
9 ACTION PLAN" PREPARED BY THE COLORADO SICKLE CELL TREATMENT
10 AND RESEARCH CENTER AT THE UNIVERSITY OF COLORADO SCHOOL OF
11 MEDICINE, APPROXIMATELY FOUR HUNDRED FIFTY PEOPLE IN COLORADO
12 ARE LIVING WITH SICKLE-CELL ANEMIA, ALTHOUGH THIS NUMBER LIKELY
13 UNDERCOUNTS THE POPULATION LIVING WITH SICKLE CELL DISEASE;

14 (d) DUE TO THE EFFECTS OF SICKLE CELL DISEASE, INCLUDING
15 EPISODES OF DEBILITATING PAIN, MANY INDIVIDUALS LIVING WITH
16 SICKLE-CELL ANEMIA AND THEIR FAMILIES NEED SERVICES AND SUPPORT
17 IN THE COMMUNITY TO MANAGE THEIR HEALTH CONDITION AND DAILY
18 LIVES;

19 (e) ARIE PARKS TAYLOR WAS THE FIRST AFRICAN AMERICAN
20 WOMAN TO SERVE AS A WOMEN IN THE AIR FORCE, "WAF", CLASSROOM
21 INSTRUCTOR AND OFFICER; TO BE ELECTED TO SERVE IN THE HOUSE OF
22 REPRESENTATIVES OF THE COLORADO GENERAL ASSEMBLY; TO SERVE AS
23 THE CLERK AND RECORDER FOR THE CITY AND COUNTY OF DENVER OR
24 ANY COUNTY IN COLORADO; AND TO SERVE AS THE CHIEF CLERK OF THE
25 DENVER ELECTION COMMISSION;

26 (f) PASSIONATE ABOUT THE CONCERNS OF INDIVIDUALS LIVING
27 WITH SICKLE-CELL ANEMIA, DURING HER TIME IN THE GENERAL ASSEMBLY

1 REPRESENTATIVE TAYLOR SPONSORED LEGISLATION THAT CREATED THE
2 SICKLE-CELL ANEMIA TREATMENT AND RESEARCH CENTER AT THE
3 UNIVERSITY OF COLORADO SCHOOL OF MEDICINE, WHICH PROVIDES
4 SUPPORT AND TREATMENT FOR INDIVIDUALS WITH SICKLE CELL DISEASE
5 AND CONDUCTS RESEARCH RELATING TO SICKLE CELL DISEASE; AND

6 (g) CREATING AN OUTREACH PROGRAM BY PARTNERING WITH ONE
7 OR MORE COMMUNITY-BASED NONPROFIT ORGANIZATIONS TO ENHANCE
8 SERVICES AND SUPPORT IN THE COMMUNITY FOR INDIVIDUALS WITH SICKLE
9 CELL DISEASE AND THEIR FAMILIES WILL HELP ENSURE A BETTER QUALITY
10 OF LIFE FOR THESE COLORADANS.

11 (2) AS USED IN THIS SECTION, UNLESS THE CONTEXT OTHERWISE
12 REQUIRES, "OUTREACH PROGRAM" MEANS THE ARIE P. TAYLOR SICKLE
13 CELL DISEASE OUTREACH PROGRAM CREATED IN SUBSECTION (3) OF THIS
14 SECTION.

15 (3) _____ THERE IS CREATED IN THE DEPARTMENT THE ARIE P.
16 TAYLOR SICKLE CELL DISEASE OUTREACH PROGRAM. THE PURPOSE OF THE
17 OUTREACH PROGRAM IS TO PROVIDE SERVICES AND SUPPORT IN THE
18 COMMUNITY TO INDIVIDUALS LIVING WITH SICKLE CELL DISEASE AND
19 THEIR FAMILIES.

20 _____
21 (4) (a) THE DEPARTMENT SHALL SOLICIT APPLICATIONS FROM
22 COMMUNITY-BASED NONPROFIT ORGANIZATIONS THAT ARE CAPABLE OF
23 IMPLEMENTING THE OUTREACH PROGRAM. _____

24 (b) (I) ON OR BEFORE JANUARY 1, 2025, THE DEPARTMENT SHALL
25 CONTRACT WITH ONE OR MORE COMMUNITY-BASED NONPROFIT
26 ORGANIZATIONS _____ TO PROVIDE COMMUNITY-BASED SERVICES AND
27 SUPPORT TO INDIVIDUALS LIVING WITH SICKLE CELL DISEASE AND THEIR

1 FAMILIES.

2 (II) THE GENERAL ASSEMBLY SHALL APPROPRIATE TWO HUNDRED
3 THOUSAND DOLLARS FOR THE OUTREACH PROGRAM, WHICH AMOUNT
4 SHALL INCLUDE ADMINISTRATIVE COSTS NOT TO EXCEED EIGHT PERCENT.

5 (c) THE DEPARTMENT SHALL DETERMINE THE INITIAL TERM OF A
6 CONTRACT, NOT TO EXCEED TWO YEARS, AND SHALL APPROVE THE
7 SERVICES AND SUPPORT TO BE INCLUDED IN A CONTRACT.

8 (d) IN AWARDING A CONTRACT, THE DEPARTMENT SHALL GIVE
9 PRIORITY TO A COMMUNITY-BASED NONPROFIT ORGANIZATION THAT:

10 (I) HAS A MINIMUM OF TEN YEARS' EXPERIENCE IN PROVIDING
11 SERVICES AND SUPPORT IN COLORADO TO INDIVIDUALS LIVING WITH
12 SICKLE CELL DISEASE AND THEIR FAMILIES, SPECIFICALLY IN THE DENVER
13 METROPOLITAN AREA OR COLORADO SPRINGS, WHICH AREAS OF THE
14 STATE HAVE THE HIGHEST NUMBER OF INDIVIDUALS LIVING WITH SICKLE
15 CELL DISEASE IN COLORADO;

16 (II) HAS EXPERIENCE PROVIDING THE SERVICES AND SUPPORT
17 DESCRIBED IN SUBSECTION (5)(a) OF THIS SECTION; AND

18 (III) IS ENGAGED IN FUNDRAISING FOR AND RAISING AWARENESS
19 OF THE NEEDS OF INDIVIDUALS LIVING WITH SICKLE CELL DISEASE AND
20 THEIR FAMILIES AND MAINTAINS A NETWORK OF PERSONS ABLE TO
21 PROVIDE PEER ASSISTANCE AND RESOURCES TO THOSE INDIVIDUALS.

22 (5) (a) DEPENDING UPON _____ THE NEEDS TO BE ADDRESSED
23 THROUGH A CONTRACT, THE COMMUNITY-BASED SERVICES AND SUPPORT
24 PROVIDED THROUGH THE OUTREACH PROGRAM MAY INCLUDE THE
25 FOLLOWING SERVICES AND SUPPORT PROVIDED BY A COMMUNITY-BASED
26 NONPROFIT ORGANIZATION OR BY COMMUNITY HEALTH WORKERS OR
27 SOCIAL WORKERS EMPLOYED BY THE COMMUNITY-BASED NONPROFIT

1 ORGANIZATION:

2 (I) CULTURALLY APPROPRIATE HEALTH EDUCATION AND
3 INFORMATION CONCERNING SICKLE CELL DISEASE AND LIVING WITH SICKLE
4 CELL DISEASE;

5 (II) INFORMAL COUNSELING AND GUIDANCE ON HEALTH
6 BEHAVIORS;

7 (III) DIRECTION AND SUPPORT TO INDIVIDUALS AND THEIR
8 FAMILIES IN LOCATING AND ACCESSING SERVICES IN THE COMMUNITY TO
9 ADDRESS THEIR NEEDS, INCLUDING NONMEDICAL NEEDS SUCH AS HOUSING,
10 FOOD, EDUCATION, TRANSPORTATION, EMPLOYMENT, LEGAL SERVICES,
11 AND OTHER SUPPORT;

12 (IV) OUTREACH TO THE SICKLE CELL DISEASE COMMUNITY
13 CONCERNING ACTIVITIES AND PROGRAMS AVAILABLE TO INDIVIDUALS
14 LIVING WITH THE EFFECTS OF SICKLE CELL DISEASE AND THEIR FAMILIES;

15 (V) PEER SUPPORT SERVICES AND REFERRALS FOR INDIVIDUALS
16 AND FAMILIES LIVING WITH SICKLE CELL DISEASE IN THE LOCAL
17 COMMUNITY;

18 (VI) ADVOCACY REGARDING THE INTERESTS OF THE SICKLE CELL
19 DISEASE COMMUNITY THROUGH PARTNERSHIPS WITH THE GENERAL
20 PUBLIC, STATE AND LOCAL GOVERNMENT ENTITIES, HEALTH-CARE
21 PROVIDERS, AND OTHER COMMUNITY-BASED ORGANIZATIONS;

22 (VII) REFERRALS FOR SICKLE-CELL ANEMIA SCREENING; AND

23 (VIII) ANY OTHER SERVICES AND SUPPORT AS DETERMINED BY THE
24 DEPARTMENT.

25 (b) IN DETERMINING THE SERVICES AND SUPPORT INCLUDED IN A
26 CONTRACT, THE DEPARTMENT MAY CONSULT WITH THE SICKLE-CELL
27 ANEMIA TREATMENT AND RESEARCH CENTER, CREATED IN SECTION

1 23-21-203, TO IDENTIFY THE COMMUNITY-BASED SERVICES AND SUPPORT
2 THAT IS LIKELY TO HAVE THE GREATEST IMPACT ON THE INDIVIDUALS AND
3 FAMILIES SERVED THROUGH THE OUTREACH PROGRAM GIVEN THE AMOUNT
4 AND DURATION OF THE CONTRACT.

5 (6) (a) PRIOR TO THE EXPIRATION OF A CONTRACT, A
6 COMMUNITY-BASED NONPROFIT ORGANIZATION IMPLEMENTING THE
7 OUTREACH PROGRAM SHALL PREPARE AND SUBMIT A WRITTEN REPORT TO
8 THE DEPARTMENT DESCRIBING:

9 (I) THE TYPE AND AMOUNT OF SERVICES AND SUPPORT PROVIDED
10 TO THE COMMUNITY PURSUANT TO THE OUTREACH PROGRAM;

11 (II) THE NUMBER OF INDIVIDUALS AND FAMILIES IMPACTED
12 THROUGH THE SERVICES AND SUPPORT;

13 (III) THE CHARACTERISTICS OF THE INDIVIDUALS RECEIVING
14 SERVICES AND SUPPORT, INCLUDING WHETHER THE SERVICES OR SUPPORT
15 WAS PROVIDED TO ADULTS OR CHILDREN WITH SICKLE CELL DISEASE OR
16 THEIR FAMILY MEMBERS, BUT EXCLUDING PERSONALLY IDENTIFYING
17 INFORMATION REGARDING THE INDIVIDUALS; AND

18 (IV) THE LOCATION WHERE THE SERVICES AND SUPPORT WAS
19 PROVIDED.

20 (b) THE DEPARTMENT SHALL PROVIDE THE REPORT TO THE HOUSE
21 OF REPRESENTATIVES HEALTH AND HUMAN SERVICES COMMITTEE AND
22 THE SENATE HEALTH AND HUMAN SERVICES COMMITTEE, OR THEIR
23 SUCCESSOR COMMITTEES. THE DEPARTMENT MAY INCLUDE WITH THE
24 REPORT INFORMATION KNOWN TO THE DEPARTMENT CONCERNING THE
25 OUTCOMES OF THE SERVICES AND SUPPORT PROVIDED, AS WELL AS OTHER
26 RELEVANT INFORMATION CONCERNING THE IMPACT OF THE OUTREACH
27 PROGRAM ON INDIVIDUALS LIVING WITH SICKLE CELL DISEASE AND THEIR

1 FAMILIES.

2 (7) THIS SECTION IS REPEALED, EFFECTIVE JULY 1, 2030.

3 **SECTION 2. Appropriation.** For the 2024-25 state fiscal year,
4 \$200,000 is appropriated to the department of public health and
5 environment for use by the division of administration and support. This
6 appropriation is from the general fund and is based on an assumption that
7 the division will require an additional 0.1 FTE. To implement this act, the
8 division may use this appropriation for the Arie P. Taylor sickle cell
9 disease outreach program.

10 **SECTION 3. Safety clause.** The general assembly finds,
11 determines, and declares that this act is necessary for the immediate
12 preservation of the public peace, health, or safety or for appropriations for
13 the support and maintenance of the departments of the state and state
14 institutions.