

Second Regular Session
Seventy-fourth General Assembly
STATE OF COLORADO

INTRODUCED

LLS NO. 24-0065.02 Brita Darling x2241

SENATE BILL 24-042

SENATE SPONSORSHIP

Buckner and Fields, Coleman, Exum

HOUSE SPONSORSHIP

English, Bacon, Herod

Senate Committees
Health & Human Services

House Committees

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.**

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 requires the department, subject to available appropriations, to contract with one or more community-based nonprofit organizations (outreach

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.

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

10 CARRY OXYGEN TO STICK TOGETHER AFTER THE OXYGEN IS RELEASED,

1 CAUSING BLOCKAGES IN THE SMALL BLOOD VESSELS;

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

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

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

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

25 (f) PASSIONATE ABOUT THE CONCERNS OF INDIVIDUALS LIVING
26 WITH SICKLE-CELL ANEMIA, DURING HER TIME IN THE GENERAL ASSEMBLY
27 REPRESENTATIVE TAYLOR SPONSORED LEGISLATION THAT CREATED THE

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

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

10 (2) AS USED IN THIS SECTION, UNLESS THE CONTEXT OTHERWISE
11 REQUIRES:

12 (a) "ADMINISTRATOR" MEANS THE THIRD-PARTY ENTITY
13 CONTRACTED WITH THE DEPARTMENT TO ADMINISTER THE OUTREACH
14 PROGRAM PURSUANT TO SUBSECTION (3)(b) OF THIS SECTION.

15 (b) "OUTREACH PROGRAM" MEANS THE ARIE P. TAYLOR SICKLE
16 CELL DISEASE OUTREACH PROGRAM CREATED IN SUBSECTION (3) OF THIS
17 SECTION.

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

23 (b) THE DEPARTMENT SHALL CONTRACT WITH A THIRD-PARTY
24 ENTITY TO ADMINISTER THE OUTREACH PROGRAM.

25 (4) (a) THE ADMINISTRATOR SHALL SOLICIT APPLICATIONS FROM
26 COMMUNITY-BASED NONPROFIT ORGANIZATIONS THAT ARE CAPABLE OF
27 IMPLEMENTING THE OUTREACH PROGRAM AND SHALL PRESENT QUALIFIED

1 APPLICANTS TO THE DEPARTMENT.

2 (b) SUBJECT TO AVAILABLE APPROPRIATIONS, ON OR BEFORE
3 JANUARY 1, 2025, THE DEPARTMENT SHALL CONTRACT WITH ONE OR MORE
4 COMMUNITY-BASED NONPROFIT ORGANIZATIONS PRESENTED BY THE
5 ADMINISTRATOR TO PROVIDE COMMUNITY-BASED SERVICES AND SUPPORT
6 TO INDIVIDUALS LIVING WITH SICKLE CELL DISEASE AND THEIR FAMILIES.

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

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

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

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

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

24 (5) (a) DEPENDING UPON THE AMOUNT OF AVAILABLE
25 APPROPRIATIONS AND THE NEEDS TO BE ADDRESSED THROUGH A
26 CONTRACT, THE COMMUNITY-BASED SERVICES AND SUPPORT PROVIDED
27 THROUGH THE OUTREACH PROGRAM MAY INCLUDE THE FOLLOWING

1 SERVICES AND SUPPORT PROVIDED BY A COMMUNITY-BASED NONPROFIT
2 ORGANIZATION OR BY COMMUNITY HEALTH WORKERS OR SOCIAL
3 WORKERS EMPLOYED BY THE COMMUNITY-BASED NONPROFIT
4 ORGANIZATION:

5 (I) CULTURALLY APPROPRIATE HEALTH EDUCATION AND
6 INFORMATION CONCERNING SICKLE CELL DISEASE AND LIVING WITH SICKLE
7 CELL DISEASE;

8 (II) INFORMAL COUNSELING AND GUIDANCE ON HEALTH
9 BEHAVIORS;

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

15 (IV) OUTREACH TO THE SICKLE CELL DISEASE COMMUNITY
16 CONCERNING ACTIVITIES AND PROGRAMS AVAILABLE TO INDIVIDUALS
17 LIVING WITH THE EFFECTS OF SICKLE CELL DISEASE AND THEIR FAMILIES;

18 (V) PEER SUPPORT SERVICES AND REFERRALS FOR INDIVIDUALS
19 AND FAMILIES LIVING WITH SICKLE CELL DISEASE IN THE LOCAL
20 COMMUNITY;

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

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

26 (VIII) ANY OTHER SERVICES AND SUPPORT AS DETERMINED BY THE
27 DEPARTMENT.

1 (b) IN DETERMINING THE SERVICES AND SUPPORT INCLUDED IN A
2 CONTRACT, THE DEPARTMENT MAY CONSULT WITH THE SICKLE-CELL
3 ANEMIA TREATMENT AND RESEARCH CENTER, CREATED IN SECTION
4 23-21-203, TO IDENTIFY THE COMMUNITY-BASED SERVICES AND SUPPORT
5 THAT IS LIKELY TO HAVE THE GREATEST IMPACT ON THE INDIVIDUALS AND
6 FAMILIES SERVED THROUGH THE OUTREACH PROGRAM GIVEN THE AMOUNT
7 AND DURATION OF THE CONTRACT.

8 (6) (a) PRIOR TO THE EXPIRATION OF A CONTRACT, A
9 COMMUNITY-BASED NONPROFIT ORGANIZATION IMPLEMENTING THE
10 OUTREACH PROGRAM SHALL PREPARE AND SUBMIT, IN CONJUNCTION WITH
11 THE ADMINISTRATOR, A WRITTEN REPORT TO THE DEPARTMENT
12 DESCRIBING:

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

15 (II) THE NUMBER OF INDIVIDUALS AND FAMILIES IMPACTED
16 THROUGH THE SERVICES AND SUPPORT;

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

22 (IV) THE LOCATION WHERE THE SERVICES AND SUPPORT WAS
23 PROVIDED.

24 (b) THE DEPARTMENT SHALL PROVIDE THE REPORT TO THE HOUSE
25 OF REPRESENTATIVES PUBLIC AND BEHAVIORAL HEALTH AND HUMAN
26 SERVICES COMMITTEE AND THE SENATE HEALTH AND HUMAN SERVICES
27 COMMITTEE, OR THEIR SUCCESSOR COMMITTEES. THE DEPARTMENT MAY

1 INCLUDE WITH THE REPORT INFORMATION KNOWN TO THE DEPARTMENT
2 CONCERNING THE OUTCOMES OF THE SERVICES AND SUPPORT PROVIDED,
3 AS WELL AS OTHER RELEVANT INFORMATION CONCERNING THE IMPACT OF
4 THE OUTREACH PROGRAM ON INDIVIDUALS LIVING WITH SICKLE CELL
5 DISEASE AND THEIR FAMILIES.

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

7 **SECTION 2. Safety clause.** The general assembly finds,
8 determines, and declares that this act is necessary for the immediate
9 preservation of the public peace, health, or safety or for appropriations for
10 the support and maintenance of the departments of the state and state
11 institutions.