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

# PREAMENDED

This Unofficial Version Includes Committee Amendments Not Yet Adopted on Second Reading

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 Appropriations **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 <u>http://leg.colorado.gov</u>.)

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 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;

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

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

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

(f) PASSIONATE ABOUT THE CONCERNS OF INDIVIDUALS LIVING
 with sickle-cell anemia, during her time in the general assembly
 Representative Taylor sponsored legislation that created the

-3-

SICKLE-CELL ANEMIA TREATMENT AND RESEARCH CENTER AT THE
 UNIVERSITY OF COLORADO SCHOOL OF MEDICINE, WHICH PROVIDES
 SUPPORT AND TREATMENT FOR INDIVIDUALS WITH SICKLE CELL DISEASE
 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 <u>REQUIRES, "OUTREACH PROGRAM" MEANS THE ARIE P. TAYLOR SICKLE</u>
12 CELL DISEASE OUTREACH PROGRAM CREATED IN SUBSECTION (3) OF THIS
13 SECTION.

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

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

(b) SUBJECT TO AVAILABLE APPROPRIATIONS, ON OR BEFORE
JANUARY 1, 2025, THE DEPARTMENT SHALL CONTRACT WITH ONE OR MORE
COMMUNITY-BASED NONPROFIT ORGANIZATIONS \_\_\_\_\_ TO PROVIDE
COMMUNITY-BASED SERVICES AND SUPPORT TO INDIVIDUALS LIVING WITH
SICKLE CELL DISEASE AND THEIR FAMILIES.

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

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

6 (I) HAS A MINIMUM OF TEN YEARS' EXPERIENCE IN PROVIDING 7 SERVICES AND SUPPORT IN COLORADO TO INDIVIDUALS LIVING WITH 8 SICKLE CELL DISEASE AND THEIR FAMILIES, SPECIFICALLY IN THE DENVER 9 METROPOLITAN AREA OR COLORADO SPRINGS, WHICH AREAS OF THE 10 STATE HAVE THE HIGHEST NUMBER OF INDIVIDUALS LIVING WITH SICKLE 11 CELL DISEASE IN COLORADO;

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

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

18 DEPENDING UPON THE AMOUNT OF AVAILABLE (5) (a) 19 APPROPRIATIONS AND THE NEEDS TO BE ADDRESSED THROUGH A 20 CONTRACT, THE COMMUNITY-BASED SERVICES AND SUPPORT PROVIDED 21 THROUGH THE OUTREACH PROGRAM MAY INCLUDE THE FOLLOWING 22 SERVICES AND SUPPORT PROVIDED BY A COMMUNITY-BASED NONPROFIT 23 ORGANIZATION OR BY COMMUNITY HEALTH WORKERS OR SOCIAL 24 WORKERS EMPLOYED BY THE COMMUNITY-BASED NONPROFIT 25 ORGANIZATION:

26 (I) CULTURALLY APPROPRIATE HEALTH EDUCATION AND
 27 INFORMATION CONCERNING SICKLE CELL DISEASE AND LIVING WITH SICKLE

-5-

1 CELL DISEASE;

2 (II) INFORMAL COUNSELING AND GUIDANCE ON HEALTH
3 BEHAVIORS;

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

9 (IV) OUTREACH TO THE SICKLE CELL DISEASE COMMUNITY 10 CONCERNING ACTIVITIES AND PROGRAMS AVAILABLE TO INDIVIDUALS 11 LIVING WITH THE EFFECTS OF SICKLE CELL DISEASE AND THEIR FAMILIES; 12 (V) PEER SUPPORT SERVICES AND REFERRALS FOR INDIVIDUALS 13 AND FAMILIES LIVING WITH SICKLE CELL DISEASE IN THE LOCAL 14 COMMUNITY;

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

19 (VII) REFERRALS FOR SICKLE-CELL ANEMIA SCREENING; AND
20 (VIII) ANY OTHER SERVICES AND SUPPORT AS DETERMINED BY THE
21 DEPARTMENT.

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

1 AND DURATION OF THE CONTRACT.

2 (6) (a) PRIOR TO THE EXPIRATION OF A CONTRACT, A
3 COMMUNITY-BASED NONPROFIT ORGANIZATION IMPLEMENTING THE
4 OUTREACH PROGRAM SHALL PREPARE AND <u>SUBMIT</u> A WRITTEN REPORT TO
5 THE DEPARTMENT DESCRIBING:

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

8 (II) THE NUMBER OF INDIVIDUALS AND FAMILIES IMPACTED
9 THROUGH THE SERVICES AND SUPPORT;

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

15 (IV) THE LOCATION WHERE THE SERVICES AND SUPPORT WAS16 PROVIDED.

17 (b) THE DEPARTMENT SHALL PROVIDE THE REPORT TO THE HOUSE 18 OF REPRESENTATIVES \_\_ HEALTH AND HUMAN SERVICES COMMITTEE AND 19 THE SENATE HEALTH AND HUMAN SERVICES COMMITTEE, OR THEIR 20 SUCCESSOR COMMITTEES. THE DEPARTMENT MAY INCLUDE WITH THE 21 REPORT INFORMATION KNOWN TO THE DEPARTMENT CONCERNING THE 22 OUTCOMES OF THE SERVICES AND SUPPORT PROVIDED, AS WELL AS OTHER 23 RELEVANT INFORMATION CONCERNING THE IMPACT OF THE OUTREACH 24 PROGRAM ON INDIVIDUALS LIVING WITH SICKLE CELL DISEASE AND THEIR 25 FAMILIES.

26 (7) This section is repealed, effective July 1, 2030.

27 SECTION 2. Safety clause. The general assembly finds,

-7-

determines, and declares that this act is necessary for the immediate
 preservation of the public peace, health, or safety or for appropriations for
 the support and maintenance of the departments of the state and state
 institutions.