

An Act

SENATE BILL 24-042

BY SENATOR(S) Buckner and Fields, Coleman, Exum, Bridges, Cutter, Ginal, Gonzales, Hinrichsen, Kolker, Marchman, Mullica, Priola, Roberts, Rodriguez, Winter F., Zenzinger;
also REPRESENTATIVE(S) English and Bacon, Herod, Amabile, Bird, Boesenecker, Brown, deGruy Kennedy, Duran, Epps, Froelich, Hamrick, Hernandez, Jodeh, Joseph, Kipp, Lieder, Lindsay, Lukens, Mabrey, Marvin, McCormick, Ortiz, Ricks, Rutinel, Sirota, Story, Valdez, Vigil, Weissman, Willford, Woodrow, Young, McCluskie.

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

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

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

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

Capital letters or bold & italic numbers indicate new material added to existing law; dashes through words or numbers indicate deletions from existing law and such material is not part of the act.

THAT:

(a) SICKLE-CELL ANEMIA IS A GENETIC DISORDER OF THE HEMOGLOBIN IN RED BLOOD CELLS THAT CAUSES RED BLOOD CELLS THAT CARRY OXYGEN TO STICK TOGETHER AFTER THE OXYGEN IS RELEASED, 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;

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

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

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

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

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

(b) (I) 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.

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

(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.

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

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

DISEASE IN COLORADO;

(II) HAS EXPERIENCE PROVIDING THE SERVICES AND SUPPORT 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.

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

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

(II) INFORMAL COUNSELING AND GUIDANCE ON HEALTH BEHAVIORS;

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

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

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

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

(VIII) ANY OTHER SERVICES AND SUPPORT AS DETERMINED BY THE 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 AND DURATION OF THE CONTRACT.

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

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

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

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

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

(b) THE DEPARTMENT SHALL PROVIDE THE REPORT TO THE HOUSE OF REPRESENTATIVES HEALTH AND HUMAN SERVICES COMMITTEE AND THE SENATE HEALTH AND HUMAN SERVICES COMMITTEE, OR THEIR SUCCESSOR COMMITTEES. THE DEPARTMENT MAY INCLUDE WITH THE REPORT INFORMATION KNOWN TO THE DEPARTMENT CONCERNING THE OUTCOMES OF THE SERVICES AND SUPPORT PROVIDED, AS WELL AS OTHER RELEVANT INFORMATION CONCERNING THE IMPACT OF THE OUTREACH PROGRAM ON

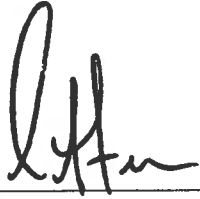
INDIVIDUALS LIVING WITH SICKLE CELL DISEASE AND THEIR FAMILIES.

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

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

SECTION 3. Safety clause. The general assembly finds, 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.



Steve Fenberg
PRESIDENT OF
THE SENATE



Julie McCluskie
SPEAKER OF THE HOUSE
OF REPRESENTATIVES

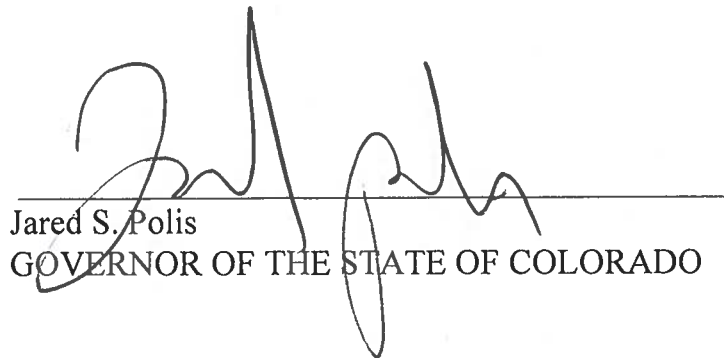


Cindi L. Markwell
SECRETARY OF
THE SENATE



Robin Jones
CHIEF CLERK OF THE HOUSE
OF REPRESENTATIVES

APPROVED Monday June 3rd 2024 at 1:20 pm
(Date and Time)



Jared S. Polis
GOVERNOR OF THE STATE OF COLORADO