

## HRSA Sickle Cell Disease Treatment Demonstration Program

### COLORADO STATE ACTION PLAN

Date submitted: 10/16/2025

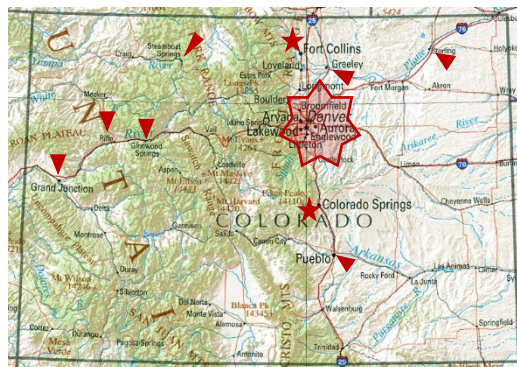
Covering the action period of Jan-Dec 2026

#### I. Statewide Sickle Cell Disease (SCD) Data

The state of Colorado is home to several diverse populations, including 262,000 African Americans and 1,297,000 of Hispanic heritage (<http://www.census.gov/quickfacts>), with a rapidly growing community of over 45,500 African immigrants (<http://www.migrationpolicy.org/data/state-profiles/state/demographics/CO>). Based on population estimates and available data, the number of individuals in Colorado living with sickle cell disease is thought to be ~400. Most live along the Front Range of Colorado in the Denver metropolitan area, Colorado Springs 60 miles to the south and Fort Collins 65 miles to the north. Each year there are 16-20 infants born in Colorado with a hemoglobinopathy, of which 10-15 have sickle cell disease, all of which are detected by universal newborn screening.

Figure: Known locations of patients with sickle cell disease. Denver metropolitan area where most patients reside is shaded in red.

- ★ - Other cities with specialty practices that see sickle cell pts
- ▼ - Other location of known sickle cell patients



These data reflect information available to providers in the two major healthcare systems [Childrens' Hospital Colorado (CHCO) and University of Colorado Health (UCHealth)] which provide specialty services to the majority of individuals with sickle cell disease in Colorado. In 2021, Colorado joined the Sickle Cell Data Collection program funded by the Centers for Disease Control and Prevention (CDC), and is in the process of establishing state-based surveillance for sickle cell disease. Although preliminary, data from that evolving system support an estimate of ~400

individuals with sickle cell disease, 75% of which live in 3 large counties along the Front Range. As this surveillance system develops, more statewide data regarding the sickle cell population will be available.

## II. Overview of Organizations

Lead organization submitting the plan on behalf of the state:

University of Colorado Sickle Cell Program (CU Sickle Cell Program):

Effective July 2025, State of Colorado funding through the University of Colorado School of Medicine for the Colorado Sickle Cell Treatment and Research Center was discontinued. This resulted in the loss of the Center's full-time administrator and adult research program manager positions, infrastructure support, and eliminated salary support for the Center director and the primary pediatric and adult hematologists providing care for sickle cell patients at the Children's Hospital Colorado (CHCO) and the University of Colorado Hospital (UCH). With loss of personnel and essential administrative functions and support Center programs, the Sickle Cell Center was closed.

Clinical care continues at CHCO and UCH as sickle cell specialty care has been embedded within those systems for many years, although the implications of the loss of salary support for the academic faculty caring for these patients remains unclear.

Other funding sources continue for the next fiscal year for the State of Colorado Hemoglobinopathies Newborn Screening (NBS) Short Term Follow-up Program and the Colorado Sickle Cell Transition Program, with the promise of support from the Department of Pediatrics for the 2 positions in these programs. Mechanisms are in place and/or are being sought to continue both adult and pediatric sickle cell disease clinical research, as well as collaboration with basic science laboratories at CU and across the country.

The newly-formed CU Sickle Cell Program is coordinated by the Sickle Cell Center's former director, Dr. Kathryn Hassell. This program represents an effort to sustain remaining sickle cell-oriented programs and activities while seeking funding for ongoing and future program development. Although there is no administrative support, some office space and a website have been retained for remaining programs, and monthly virtual meetings are held to maintain engagement of University faculty and personnel involved in sickle cell disease. These meetings also include the leadership of the Colorado Sickle Cell Association, the primary community-based organization in Colorado.

University of Colorado (CU) Sickle Cell Program  
University of Colorado Anschutz Medical Campus  
Education 2 South  
13121 E. 17th Ave  
Aurora, Colorado 80045  
Website: <https://medschool.cuanschutz.edu/sickle-cell-center>

Key Staff Members:

Kathryn Hassell, MD            Program Coordinator; PSCRC State Lead  
Professor of Medicine, Division of Hematology  
[kathryn.hassell@cuanschutz.edu](mailto:kathryn.hassell@cuanschutz.edu)

Christopher McKinney, MD    Lead Hematologist, Pediatric Sickle Cell Services at Children's Hospital Colorado  
Associate Professor of Pediatrics, Hematology Section  
[Christopher.McKinney@childrenscolorado.org](mailto:Christopher.McKinney@childrenscolorado.org)

Gemlyn George, MD            Lead Hematologist, Adult Sickle Cell Clinical Program, University of Colorado Hospital  
Assistant Professor of Medicine, Division of Hematology  
[gemlyn.george@cuanschutz.edu](mailto:gemlyn.george@cuanschutz.edu)

Donna Holstein, RN            Colorado and Wyoming Hemoglobinopathies Newborn Screening Short-Term Follow-Up Program  
[donna.holstein@cuanschutz.edu](mailto:donna.holstein@cuanschutz.edu)

Michael Regier, MSW        Coordinator, Colorado Sickle Cell Transition Program; PSCRC State Coordinator  
[michael.regier@cuanschutz.edu](mailto:michael.regier@cuanschutz.edu)

Summary of Services Provided:

State of Colorado Hemoglobinopathies NBS Short-Term Follow-Up Program:

All infants born in Colorado are screened for hemoglobinopathies. The Sickle Cell Center historically provided newborn screening short-term follow-up for hemoglobinopathies and hemoglobin traits under contract to the State of Colorado since universal screening was implemented in January 1979. Currently this program continues through CU Medicine with administrative support from the Department of Pediatrics. All infants with hemoglobinopathies in Colorado and Wyoming are followed by this program until they have their first appointment with a sickle cell specialist in the CHCO or other healthcare system. This program is directed by a newborn screening follow-up nurse specialist and overseen by Dr. Kathryn Hassell; these providers also provide consultation to the Colorado State Public Health Laboratory regarding lab testing and reporting.

Funding for this program is partially supported by contract with the Colorado Department of Health and Environment (CDPHE), with additional salary support from CU Medicine's Medicaid Upper Payment Limit (UPL) Program for ongoing activities related to community engagement and training to support families of infants identified with sickle cell disease and grant support from the Colorado Sickle Cell Data Collection (SCDC) Project, a national CDC Surveillance project.

Colorado Sickle Cell Transition Program:

This program serves approximately 80 individuals with sickle cell disease aged 12-26, and their families, to facilitate and support transition from pediatric to adult healthcare. The full-time state transition coordinator, a medical social worker, meets with youth and their families at the time of hematology clinic visits (in any healthcare system) to regularly assesses readiness, knowledge, and skills to manage healthcare and interactions with the healthcare system. Ongoing contact is also maintained via phone, text, and virtual or in-person visits outside the clinic setting, sustained with individuals after transfer to adult care through age 26. At the individual's request, the coordinator will accompany them to pediatric and adult appointments in any healthcare setting in Colorado, and will facilitate communication with sites of care, insurers, schools/work sites regarding policies, identifying resources and developing tools to support transition in these systems. System improvements are also implemented through participation in groups such as the CHCO Transition Governance Board and in a variety of UCHealth adult sites of care across Colorado, including Kaiser Permanente Colorado and other non-University systems.

Funding for this program is provided by the CU Medicine's Medicaid UPL Program, the Colorado SCDC Surveillance project, as well as from the Pacific Sickle Cell Regional Collaborative (PSCRC) Program, a HRSA grant program.

Lead Community-Based Organization:

Colorado Sickle Cell Association

6825 E Tennessee Ave # 639  
Denver, CO 80224  
Phone: 303-333-2606

Website: [https:// cosicklecellassoc.org](https://cosicklecellassoc.org)

Key Staff Members:

Donna Dixon            Executive Director  
Lee Allen, Jr            President

Summary of Services Provided:

The Colorado Sickle Cell Association, established in 1974, is a community-based organization with a mission to coordinate and provide services and support to the sickle cell patient and their families in the state of Colorado. The Board of Director's meets monthly to ensure they are always moving forward with their projects. The Association has been mentoring 2 young people to assume leadership roles in 2025 and has established a pipeline for "junior" board members to engage in direction-setting, organization and conduct of the Association's activities.

Year-round services include sponsored blood drives, community education and advocacy, collaboration and patient referrals, empowerment and advocacy groups and emergency assistance to fulfill their vision to educate, support, empower and advocate for the sickle cell patients and their families in the state of Colorado. Annual events also include patient and family holiday parties, and a 5K run fundraiser.

In July 2025, the Colorado Sickle Cell Association was awarded State of Colorado funding to provide enhance community engagement services as a result of the Arie P. Taylor Act, passed by the Colorado State Legislature in 2024. The primary initial activities include development of a sickle cell community health worker program, facilitation of sickle cell trait testing with appropriate counseling, and "train the trainer" activities for members of the community to support families with infants and children diagnosed with sickle cell disease.

In the course of these activities, the Colorado Sickle Cell Association partners with the CU Sickle Cell Program and Children's Hospital Colorado on projects to improve access to care, increase awareness of sickle cell disease and trait, and to co-sponsor community and health care provider

educational events. They participate in the development of the statewide sickle cell surveillance system as a funded partner in the CDC’s Sickle Cell Data Collection program, contributing perspective on important outcomes to be assessed and developing videos and podcasts to be used to disseminate information about sickle cell disease to the affected community and general public. The Association is also an active partner with the PSCRC, contributing to work in Colorado and the Pacific Region in this HRSA-funded program.

**III. Available Community Services and Partners**

| Name or organization  | Type of organization:                   | Partnership status:  | Comments/notes  |
|---|---|--|---|
| Center for Cancer and Blood Disorders<br>Children’s Hospital Colorado<br>Primary clinic: Aurora, CO<br>Affiliated clinic: Colorado Springs, CO          | Pediatric SCD Clinic                    | Established partnership  | Specialty hematological services for children and young adults with sickle cell disease have been provided by Children’s Hospital Colorado for 50 years, serving ~250 children with SCD               |
| Blood Disorders Clinic<br>University of Colorado Hospital<br>Primary clinic: Aurora, CO<br>Affiliated clinics: Colorado Springs, CO<br>Fort Collins, CO | Adult SCD Clinic                        | Established partnership with primary clinic<br>Forming partnership with affiliated clinics | Primary site of specialty hematological services for adults with sickle cell disease, which been provided by the University of Colorado Hospital for more than 40 years, serving ~180 adults with SCD |
| Arvada West Family Medicine Clinic<br>Arvada, CO  | Primary care and pain management clinic | Established partnership  | PCP services provided by NPs with training in management of SCD as well as chronic pain. Co-management of ~10-12 adults with SCD in collaboration with Blood Disorders Clinic at UCH                  |

|   |                                      |   |   |
|---|--------------------------------------|---|---|
| Road To Me Recovery Services  | Counseling/pain management services  | Established partnership                       | Partner of Arvada West Family Medicine providing counseling, psychological support and chronic pain management for individuals with SCD   |
| Colorado Kaiser Permanente Denver, CO   | Adult SCD Care<br>Adult Primary Care | Established partnership                       | Beginning in 2022, adults covered by Colorado Kaiser Permanente plans receive inpatient and outpatient specialty sickle cell care from Kaiser hematologists who have received training in sickle cell disease management. Patients are admitted to Kaiser system hospitals for inpatient care and primary care is also provided within the Kaiser system. UCH and Sickle Cell Center experts provide consultative support when requested. |
| Colorado Sickle Cell Association Denver, CO   | CBO                                  | Co-Lead Organization, Established partnership | See description in Section II   |
| Ella Mae Bransom Sickle Cell Association<br><a href="https://www.ellamae.org">https://www.ellamae.org</a> | CB)                                  | Other: Enhancing partnership                  | The Sickle Cell Center and Colorado Sickle Cell Association have a long-standing collaboration with the EMB Sickle Cell Association but further engagement of this CBO in specific activities will be pursued as they serve Colorado Springs, where a significant subset of individuals with sickle cell disease receive care and services  |
| Center for Public Health Innovation (CPHI), CI International  | Statewide Sickle Cell Surveillance   | Established partnership                       | This Colorado institute has been awarded the CDC grant to develop and implement a statewide surveillance system for sickle cell disease. Member of the Sickle Cell Center and Colorado Sickle Cell Association are active participants in this program  |
| Colorado Sickle Cell Anemia Advisory Committee  | Governor-Appointed State Committee   | Established partnership                       | This committee was established when the Sickle Cell Center was established by legislative act in 1973 to review activities of the Center as a state entity and provide a report to the Governor when  |

|   |   |                     |  |
|---|---|---------------------|--|
|   |   |                     | needed. Members include a defined number medical providers, representatives of community organizations, members of the affected community, and the general public, appointed by the Governor’s office. |
| Denver Health and Hospitals<br>Denver, CO | Pediatric and Adult<br>Primary Care<br>Adult SCD Care | Forming partnership | This “safety net hospital” system is utilized by some individuals and families with sickle cell disease, often based on Medicaid plan assignment.  |

**IV. Current Care**

**1. Safe Transition from Pediatric to Adult Care:**

As described in Section II, the Colorado Sickle Cell Transition Program serves individuals with sickle cell disease aged 12-26, and their families, to facilitate and support transition from pediatric to adult healthcare regardless the site of healthcare. Engagement by the full-time state transition coordinator includes ongoing contact meeting with youth and their families via phone, text, and virtual or in-person visits outside the clinic setting to regularly assesses readiness, knowledge, and skills to manage healthcare and interactions with the healthcare system. This contact is sustained with individuals after transfer to adult care, through age 26. At the individual’s request, the coordinator will accompany them to pediatric and adult appointments in any healthcare setting in Colorado, and will facilitate communication with sites of care, insurers, schools/work sites regarding policies, identifying resources and developing tools to support transition in these systems. The coordinator also works with pediatric and adult providers in various healthcare settings to optimize transition processes within their systems, increasing awareness of barriers and identifying opportunities to overcome them.

This program addresses health equity as individuals in the transition age group, and their families, receive support services from the Transition Program coordinator regardless of where they are receiving healthcare or health insurance status. The coordinator also advocates on behalf of the individual in transition as they interact with healthcare systems when needed.

The development of the Colorado Sickle Cell Association's Community Health Worker Program will further enhance the support for adolescents and young adults to assist them with navigating the challenges of living with sickle cell disease during the transition from childhood to adult opportunities and responsibilities in the healthcare, family life, school, and employment.

## **2. Care Across the Lifespan:**

### State of Colorado Hemoglobinopathies Newborn Screening (NBS) Short-Term Follow-Up Program:

As described in Section II, all infants born in Colorado are screened for hemoglobinopathies. The Sickle Cell NBS Short-Term Follow-Up Program provides newborn screening short-term follow-up for infants detected by the state NBS program to have a hemoglobinopathy or a hemoglobin trait under contract to the State of Colorado since this universal screening was implemented in Colorado in January 1979. All infants with hemoglobinopathies are followed by this program until they have their first appointment scheduled with a sickle cell specialist in the Children's Hospital Colorado system. This program ensures the initial consultation is completed for all infants with sickle cell disease and other hemoglobinopathies. Clinical guidance and family educational materials are sent to the primary care provider of infants identified with sickle cell or other hemoglobin traits, along with information regarding genetic counseling services available to interested families.

This program addresses health equity as the infants in Colorado identified by the NBS program, funded by the State of Colorado, receives these coordinated follow-up services at no charge.

### Clinical Care:

The majority of affected children with sickle cell disease receive specialty pediatric care in the Children's Hospital Colorado system and the majority of adults receiving specialty care at the University of Colorado Health system in their respective blood disorders clinics located on the Anschutz Medical Campus in the Denver metropolitan area. Both health systems also provide specialty care through affiliated sites on Colorado Springs (children and adults) and in Fort Collins (adults). The pediatric and adult hematologists collaborate closely, supported by the Transition Program coordinator who is a medical social worker focused on adolescents and young adults aged 12-26. Monthly meetings are held to discuss ongoing clinical issues, needs and opportunities for improvement.

Staff and providers affiliated with the CU Sickle Cell Program continuously provide and encourage incorporation of best practices for the management of individuals with sickle cell disease. Specific activities including consultation/decision support, technical assistance, and education within their specific areas of focus e.g. NBS, transition, pediatric and adult care. This targeted effort increases recognition of barriers and gaps in care and helps to drive improvement to address health inequities.

#### *Pediatric Specialty Care*

The primary source of pediatric sickle cell specialty care is through Children’s Hospital Colorado, who also conducts specialty comprehensive care visits in the Colorado Springs affiliated clinic two-three times a year. When receiving comprehensive care, the children are often seen by a physician, nurse, social worker, geneticist, nutritionist, psychologist, and in some instances a dentist.

Specialty sickle cell services including transcranial Doppler, cardiac and liver MR imaging for iron content, acute and chronic erythrocytapheresis (red cell exchange) with partially minor antigen-matched RBCs, and stem cell (bone marrow) transplantation and gene therapy as a standard-of-care procedure. Research studies are often available for novel inpatient and outpatient interventions, new approaches to stem cell transplantation, and gene therapy.

Children typically receive inpatient care in the main Children’s Hospital Colorado on the Anschutz Medical Campus in the Denver area. For children who live in an outlying area, families are asked to bring their child to the Children’s Hospital in Denver or Colorado Springs at least annually for a comprehensive visit, and follow-up care is coordinated through the local primary care provider. They are generally transferred from outside facilities for an increased level of expert care if hospitalization is required.

Children covered by Kaiser insurance are allowed to be seen at Children’s Hospital for specialty inpatient and outpatient services which are not available within the Kaiser system. This includes certain testing, e.g. transcranial Doppler and interventions, e.g. erythrocytapheresis. However, families may be required to go to a Kaiser facility for some tests and procedures when they are available within the Kaiser system, which may present challenges when trying to ensure completion of these tests.

#### *Pediatric Primary Care*

There are no primary care clinics or providers within the Children’s or Hospital system specifically targeting individuals with sickle cell disease. Thus, primary care for these patients can be spread across a variety of clinic systems and providers which are not actively involved in the CU Sickle Cell Program. This may include Children’s Hospital Colorado primary care clinic, Kaiser, various pediatric practices, “indigent care” clinics including the Denver Health and Hospitals system (“safety net” healthcare system) and the Metropolitan Community Provider network, which includes federally-qualified healthcare centers. In general, the primary care providers for the children defer most issues not related to routine immunizations to the pediatric sickle cell hematologist.

#### *Adult Specialty Care*

The majority of adult patients with sickle cell disease receive specialty sickle cell care in the University of Colorado Health (UCHealth) system, most on the Anschutz Medical Campus (AMC) in the Denver metropolitan area, in Colorado Springs at Memorial Hospital and in Fort Collins at

Poudre Valley Hospital, both UCHHealth affiliates. Outreach clinical services are also available in Glenwood Springs, CO. Adults followed in the UCHHealth system in the Denver area who require an emergency department visit are seen at UCH on the AMC campus or one of the affiliated urgent care sites or hospitals, and are usually admitted to UCH if hospitalization is required. Adults followed in the UCH system in Colorado Springs or Fort Collins are followed by local UCHHealth hematology/oncology groups, and receive care in the emergency department care and are hospitalized at Memorial Hospital and Poudre Valley Hospital, respectively. All UCHHealth hospitals share a common electronic medical record (EPIC) and, increasingly, information from Children’s Hospital Colorado and other hospitals can be seen through the “Care Everywhere” EPIC feature.

Subspecialty sickle cell services uniquely offered at the AMC in the Denver area includes liver MR imaging for iron content. Chronic erythrocytapheresis (red cell exchange) with full minor antigen-matched RBCs is available at UCH on the AMC campus and in Colorado Springs at Memorial Hospital. Standardized emergency department and inpatient sickle cell order sets and clinical care pathways are available at UCH on the AMC campus. Other specialty providers on the AMC (renal, hepatology, cardiopulmonary, pain, orthopedics) have gained experience in the assessment and management of sickle cell disease complications. Standard-of-care stem cell transplantation and gene therapy can be done for young adults at the Children’s Hospital. Research studies are available for novel inpatient and outpatient interventions; new approaches to stem cell transplantation and gene therapy are available through the Children’s Hospital for young adults.

Adults covered by Kaiser Permanente Colorado plans receive inpatient and outpatient specialty sickle cell care from Kaiser hematologists who have received training in sickle cell disease management, representing ~10 individuals. Patients are admitted to Kaiser system hospitals for inpatient care and primary care is also provided within the Kaiser system. UCH and CU Sickle Cell Program experts provide consultative support and technical assistance as requested.

Some individuals choose to receive specialty care in practices in Denver, Colorado Springs, and Fort Collins, most often with providers in the Rocky Mountain Cancer Center network, and in other part of the state, closer to where they reside or attend school. These practices use various hospitals in different healthcare systems across Colorado, some of which are linked through the “Care Everywhere” through which outside electronic medical record (EMR) can be viewed if the institution uses EPIC. Some individuals seek, or are assigned, to receive care in the Denver Health facilities, Colorado’s “safety net” hospital system. UCH experts provide consultative support when requested, and individuals are transferred for a higher level of inpatient care (e.g., for exchange transfusion) at UCH on the AMC campus when needed.

#### *Primary Care*

There are no primary care clinics or providers within the UCHHealth system specifically serving individuals with sickle cell disease. Primary care for these patients can be spread across a variety of clinic systems and providers, many of which are not actively involved in the CU Sickle Cell

Program and have variable levels of experience in the management of sickle cell disease. This may include primary care clinics in the UCHHealth system, various family medicine or internal medicine practices, and “indigent care” clinics including the Denver Health and Hospitals system (“safety net” healthcare system) and the Metropolitan Community Provider network, which includes federally-qualified healthcare centers.

For adults living with sickle cell disease, a collaboration has been established with a private community primary care and pain management clinic which serves Medicaid patients, Arvada West Family Medicine, located in the northwestern Denver metro area. A co-management model has been established between UCH and the primary care provider, which has served 11 patients in 2025. This primary care clinic offers primary care, pain management, specialty care as recommended by hematologists, and physical therapy. Psychological and mental health support is offered by a clinical partner, Road to Me Recovery Services, and Aurora Mental Health Services and similar agencies have been identified who have served those living with sickle cell disease.

All of these activities address health equity and access to quality care by communication, education and dissemination of best practices between various clinical sites of care that may be accessed by individuals based on geographical location, insurance coverage, and personal preferences. The CU Sickle Cell Program serves to facilitate this networking and assist with the further development and support of these systems. Linkages to the community and CBOs are achieved through monthly virtual meetings with the CU Sickle Cell Program to increase awareness of ongoing health care activities across Colorado and an opportunity to learn of gaps in care that need to be addressed.

### **3. Provider education and workforce development:**

#### Provider Education:

##### *Colorado Sickle Cell Summit*

The Sickle Cell Center had annually convened a Colorado Sickle Cell Summit, held virtually since the COVID pandemic, to include all stakeholders to review current status of sickle cell disease in Colorado, provide an update on sentinel advances in management, and provide a forum for communication and collaboration. This annual event has drawn 40-60+ participants, including physicians, ANPs, nurses, social workers, health care system administrators, CHWs, community-based organizations and state agencies, trainees, students, and individuals with sickle cell disease and family members. Two-three hours of educational updates on best practices for sickle cell care are followed by a community forum in which short presentations by participants are arranged to increase awareness of and connections between with various programs and resources in Colorado.

Due to the recent changes in sickle cell infrastructure at the University, the Summit will be deferred to Spring 2026.

*Educational Webinars*

As new providers working, or with an interest, in sickle cell disease are identified they are invited to webinars hosted by the Pacific Sickle Cell Regional Collaborative. Sickle cell experts from Colorado regularly contribute presentations to this webinar series annually.

*CU Sickle Cell Program and Colorado Sickle Cell Association members continuing education*

Ongoing annual continuing education of sickle cell providers at all levels is encouraged and supported by their home organization via attendance (virtual or in-person) to relevant professional meetings. These include the annual American Society of Hematology meetings, SCDA and other national sickle cell meetings, American Public Health Laboratories (APHL) newborn screening meeting, the annual symposium of the Health Care Transition Research Consortium and the Annual Chronic Illness and Disability Conference Transition from Pediatric to Adult-based Care hosted by Texas Children's Hospital and Baylor University School of Medicine.

Workforce Development:

The Sickle Cell Center and its staff continuously strive to identify and support providers in healthcare settings where individuals with sickle cell disease seek care, including those with and outside the Children's Hospital and UHealth systems.

*Professional mentorship:*

- > Colorado Hemoglobinopathies NBS follow-up staff provide consultation and technical assistance to genetic counselors, primary care providers (MD/DO, ANP, RN) and the State Department of Health (public health lab staff) in process development and improvement for NBS
- > CU Sickle Cell Program staff and providers contribute to orientation of new specialty clinical staff (APPs, RNs, erythrocytapheresis personnel) and clinical social services providers, as well as offering ongoing technical support for process improvement and resource development.
- > Senior clinical members of the CU Sickle Cell Program mentor physicians adopting new leadership positions in sickle cell clinical services
- > The Colorado Sickle Cell Transition Program coordinator provides consultation and technical assistance to practitioners (MD/DO, ANP, RN, SW) seeking to integrate and improve transition processes in their practices
- > Ongoing co-management of adult sickle cell patients between the UCH Hematology, Arvada West Family Medicine (ANP) and Road To Me Recovery Services (SW), including technical assistance and education.
- > The CU Sickle Cell Program adult hematologists work with Arvada West Family Medicine Clinic (ANP, RN, ANP trainees) to continue to develop co-management strategies for adults with sickle cell disease and seek to establish new relationships with primary care providers serving sickle cell patients to expand this model in other clinical settings to reach out to primary care providers and clinics to encourage and support ongoing co-management.

> The annual virtual Colorado Sickle Cell Summit described above also serves to facilitate connections between providers, service organizations and agencies, and individuals with sickle cell disease across the state.

*Participation in Health Care Professional Education Programs and Forums:*

> CU Sickle Cell Program-affiliated hematologists lecture in the curriculum and training programs for a variety of health care professionals at a stage when they may consider a clinical focus in sickle cell disease. This includes lectures for medical, ANP, student and pharmacy students, as well as physicians in residency and hematology fellowship training, when invited by curriculum and training program directors.

> CU Sickle Cell Program and Colorado Sickle Cell Association members routinely participate in a panel discussion in the University of Colorado School of Medicine Hematology Course for medical students.

> CU Sickle Cell Program staff and providers offer statewide educational webinars and in-person didactic sessions to clinical providers in practices and healthcare systems which serve or are considering serving sickle cell patients, improving their capacity and willingness care for individuals with sickle cell disease.

*Technical Assistance:*

> Colorado Sickle Cell Transition Program coordinator works with providers (MD, ANP, RN, SW) in various healthcare systems to develop and improve approaches and policies addressing to transition within their systems

> Participation by CU Sickle Cell Program providers and staff in the development of standardized order sets and treatment protocols, clinical care pathways, clinical tools and health care policy regarding pediatric and adult sickle cell care. This has been provided for the CHCO and UHealth systems as well as for Colorado Kaiser Permanente, Arvada West Family Medicine and Denver Health and Hospitals.

> Facilitation of awareness of and networking between resources available to the sickle cell population in Colorado through forums such as the annual Colorado Sickle Cell Summit and at events co-hosted by the CU Sickle Cell Program and the Colorado Sickle Cell Association.

**4. Partnerships and care coordination:**

Sickle Cell Community-Based Organizations

In addition to ongoing activities with the Colorado Sickle Cell Association in Denver described in Section II above and throughout this plan, the CU Sickle Cell Program also supports the Ella Mae Bransom Sickle Cell Association (<https://www.ellamae.org>), a sister organization based in Colorado Springs. This CBO provides services and assistance to individuals with sickle cell disease and their families in southern Colorado, and conducts an annual fundraiser to support research and community SCD awareness and education offered by the Sickle Cell Center staff during these events.

Both community-based organizations are invited to join the CU Sickle Cell Program staff for a monthly virtual meeting to share information about issues facing those with sickle cell disease, strategize, prioritize and plan activities and events.

#### Medicaid Surplus Funding Program

The CU Sickle Cell Program has been awarded funding from the State of Colorado Medicaid Upper Payment Limit (UPL) program through CU Medicine, the faculty practice organization for the University of Colorado Hospital. These funds have been renewed annually, most recently in July 2025, which permits the CU Sickle Cell Program to continue salary support for sickle cell specialty practitioners to use time and effort to implement changes in communication and collaboration between the various parts of the health systems that impact those with sickle cell disease. Beginning in July 2025, a portion of this funding is being used to support further enhance the Colorado Sickle Cell Transition Program. Goals are to improve the access to and coordination of care across Colorado for the state's Medicaid recipients, including projects and programs outlined in this State Plan. Another focus of this work is to support the development of new sites for primary care for adults with potential expansion of the Arvada West Family Medicine Clinic. A third area of emphasis is the development and presentation of the "Empower: Training Champions for Sickle Cell" curriculum for community members who will serve families with infants and children with sickle cell disease, led by the Colorado Sickle Cell Association and support by the Hemoglobinopathies NBS Follow-up staff member.

Colorado Sickle Cell Anemia Advisory Committee: As noted in the Partners Table, this committee consists of medical professionals, representatives of community organization, and general public members from both the affected communities and those interested in sickle cell disease. Twice- or thrice-yearly meetings were held to review the activities of the former Sickle Cell Center. This provides a forum for input from the stakeholders represented on the committee to recognize needs and gaps in service, but also networking and collaboration for identification of resources, solutions to ongoing challenges and advocacy. The committee has the opportunity to make a report to the Governor's office after each meeting. The current chairperson of the committee is the father of two children living with sickle cell disease. With the closure of the Sickle Cell Center, clarification will be sought about this committee, in hopes that it can continue to advise the CU Sickle Cell Program.

#### Colorado Sickle Cell Data Collection (Statewide Surveillance):

The Center for Public Health Innovations (CPHI) is an institute of CI International based in Colorado that is participating in the CDC's Sickle Cell Data Collection program, receiving funds to develop a state-wide surveillance system for sickle cell disease. Members of the CU Sickle Cell Program, Colorado Sickle Cell Association and Colorado Department of Health and Environment NBS Program participate in the design and validation of the surveillance system, as well as the interpretation and plans for dissemination of the surveillance data as it is obtained.

**5. Community empowerment:**

- > Program development by the Colorado Sickle Cell Association (primary CBO) newly funded by State of Colorado support in the areas of a community health worker program, sickle cell trait testing, and “train the trainer” program.
- > Major sickle cell events (e.g. Sickle Cell Summit) in Colorado are planned from the very early stages through collaboration between the CU Sickle Cell Program, Colorado Sickle Cell Association, and other relevant stakeholders as needed for the specific event. This includes setting the agenda, venue, and timing, and planning and contributing specific content.
- > CBO and sickle cell disease patient representation and participation is routinely sought for projects including HRSA’s Sickle Cell Regional Collaborative Program and the CDC Sickle Cell Data Collection surveillance programs
- > The Colorado Sickle Cell State Advisory Committee membership includes individuals with sickle cell disease and/or their family members and representation from community organizations serving the sickle cell population; committee leadership roles are often filled by individuals with sickle cell disease and family members.
- > The Colorado Sickle Cell Summit provides a state-wide forum for community members and organizations to express needs and goals for those living with sickle cell disease and to increase awareness of their resources among providers and other stakeholders
- > Individuals with sickle cell disease and their families are regularly engaged to participate in a medical school hematology session and to provide perspective during provider educational activities. Individuals have also been invited to participate in forums at regional and national healthcare professional meetings.
- > The CU Sickle Cell Program actively seeks to identify opportunities for utilization of community resources, including potential contracts or other funding options for community-based resources such as the trained community health workers

## V. Planned Activities to Improve SCD Care

### Specific Plans for 2026:

The overall focus for 2026 will be to identify and implement strategies to ensure that high-quality and coordinated sickle cell programs, activities and resources remain available to those living with sickle cell disease across Colorado. With the closure of the Sickle Cell Center, concerted efforts by individuals/entities engaged in sickle cell disease will be made to leverage remaining resources to ensure the clinical programs, health systems improvements, educational/awareness efforts and community engagement continue. The CU Sickle Cell Program will serve as a platform for coordination for these individuals and efforts, recognizing limitations in capacity without administrative or financial support.

The plans delineated in this section address the specific areas of focus. However, this will be in the context of background work to sustain/increase underlying financial and administrative support of the various programs and activities themselves, which is not detailed.

#### 1. Safe Transition from Pediatric to Adult Care:

Annual and recurring activities of the Sickle Cell Center's transition program, serving individuals from 12-26 years of age, will continue as described in Sections II and IV. Specific information on activities and/or new projects in 2023 are described below:

> Finalization of an updated Medicaid handout to describe processes for maintaining Medicaid when appropriate in adolescence and obtaining adult coverage. Anticipating changes to Medicaid due to changes in federal law, ALL Medicaid recipients' eligibility will be assessed twice per year. Draft of the handout has been included in the transition handbook.

- Transition coordinator will utilize information from the Colorado Medicaid website and the Colorado Department of Health Care Policy and Finance (HCPF) website, to keep handout updated.
- Completion of tool by end of 2026
- Outcome: dissemination of information to individuals and families engaged in the Colorado Sickle Cell Transition Program

> Creation a "memorandum of understanding" describing expectations around the activities of the transition program between individuals and families with sickle cell disease and the transition coordinator, to be signed by all at the start of the program, with an updated version for the adult individual to sign when they turn 18

- Transition coordinator to develop content, in collaboration with pediatric and adult providers
- Completion of documents by end of 2026
- Outcome: Once available, the MOU will be signed with all new participations and current participants at the time of their next encounter with the transition coordinator

> Introduction of an iPad for use in CHCO sickle cell clinic for patients to complete a Transition Readiness self-assessment prior to seeing the provider which would auto-populate the EMR and be immediately available for review and discussion during the clinic visit.

- Ongoing pilot in a Thursday morning comprehensive sickle cell clinic
- Outcome: use of the iPad by patients in the transition program to complete Transition Readiness self-assessment on an annual basis during a clinic visit. This is in addition to the use of Transition Readiness tools and other assessments made by the transition coordinator and providers

> Creation of an annually updated transition handbook to describe processes for multiple aspect of transition, including maintaining Medicaid, Disability and Vocational Rehabilitation Services, and state/federal educational services. Handbook prepared in print and will be available virtually on the CU Sickle Cell Program website

- Transition coordinator to gather information from stakeholders and service partners
- Annual handbook updates virtually, with printed copies as warranted for distribution at events
- Outcome: dissemination of information to individuals and families engaged in the Colorado Sickle Cell Transition Program

## **2. Care Across the Lifespan:**

Despite losses in available resources and supporting infrastructure with the closure of the Sickle Cell Center in 2025, those working in sickle cell disease will strive to maintain annual and recurring activities as described in Sections II and IV, including plans for Transition (as described in #1 above) and for further development of a CHW program (as described in #4 below). Specific information regarding ongoing and/or new projects are described below:

> Participation in UCH sickle-cell directed efforts for inpatient care and discharge planning

- Dr. George and Mr. Regier will continue to educate and guide UCH Hospital Medicine inpatient service by participating in weekly multidisciplinary rounds for inpatients with sickle cell disease, including those of transition age
- Re-engage in the review of Agile MD Sickle Cell Inpatient Care Pathway and specific sickle cell order set utilization
- Facilitate communication and engagement between UCH hospital discharge planners and the new CHW program when available from the Colorado Sickle Cell Association (CBO)
- Facilitate communication and engagement between UCH hospital personnel and potential resources including Department of Vocational Rehabilitation and other agencies, initiated prior to discharge, to address anticipated needs at home after discharge
- Outcomes: utilization of consistent standard, high-quality care, directly impacting this through participation in weekly rounds, utilization of current tools, and increasing resources including access to CHWs and other post-discharge resources.

> Optimize benefits of co-management program between UCH Blood Disorders Clinic and Arvada West Family Medicine

- Assess outcomes by measuring ED and hospital utilization patterns for co-managed sickle cell patients before and since sustained participation in this model
- Facilitate at least twice-yearly virtual comprehensive case-review conferences, with continued interval communication as needed to address individual patient needs as they arise
- Dr. Hassell to provide support for program development and staff education for possible expansion to an additional site of primary care in south Denver
- Outcome: Determination of impact of this co-management approach leading to implementation of changes that may improve outcomes and quality of care

> Development and implementation of transition programming at the Children’s Hospital Colorado, as outlined in #1 above.

### **3. Provider education and workforce development:**

Despite recent changes, annual/recurring activities and events described in Section IV for education, workforce development and technical assistance will continue. Specific information is provided below:

#### Provider Education

> Annual Virtual Colorado Sickle Cell Summit

- Educational topics selected in collaboration with the CU Sickle Cell Program, Colorado Sickle Cell Association and other partners; 2.5 hours of presentations
- Content determined, speakers identified in early 2026; virtual event to occur in late spring 2026
- Outcome: providers of all types (primary and specialty care, physicians, APPs, nurses, social workers and other healthcare workers) will receive updated information about management of sickle cell disease and resources in Colorado

> Dr. Hassell and/or Mr. Regier will contribute a region-wide PSCRC webinar, topic to be determined

> Drs. Hassell, McKinney and George will continue to provide peer education regarding sickle cell disease (care conferences, lectures) within and outside the University systems.

#### Work Force Development

> The Colorado Sickle Cell Association’s new community health worker program has already trained 3 new community health workers who will be able to serve the sickle cell community in Colorado

> The Colorado Sickle Cell Association’s “Empower: Training Champions for Sickle Cell” Program is educating community members, including those living with sickle cell disease, to provide guidance to families with infants with sickle cell disease about living with the disease and support them as they face challenges

#### **4. Partnerships and care coordination:**

Existing partnerships and efforts to improve care coordination as outlined in Section IV will be sustained, including ongoing partnership activities for the Medicaid Surplus Funding (UPL) Project, the Colorado Sickle Cell Anemia Advisory Committee and the Colorado Sickle Cell Data Collection surveillance projects. Specific information is provided below:

> Community blood drives held by the Colorado Sickle Cell Association in coordination with Vitalant Regional Blood Center (for the adult chronic transfusion program) and Children’s Hospital Colorado Blood Bank (for the pediatric chronic transfusion program). The CSCA has also partnered with the Red Cross to increase its donor pool.

- Outcome: Increase the donor pool for fully-minor antigen matched blood for sickle cell patients

> Build a partnership between the Colorado Sickle Cell Association’s trained sickle cell community health workers and the CHCO and UHealth system

> Maintain partnership between the Colorado Kaiser Permanente health care system and UHealth regarding management of adult sickle cell patients and transitioning youth.

> Continue to pursue partnership with Denver Health Medical System, Denver’s “safety net” hospital where some individuals with sickle cell disease seek or are assigned care by Medicaid

- Analysis of Colorado SCDC (surveillance) data to assess the number of individuals with sickle cell disease in the Denver Health system and their healthcare utilization
- Offer technical assistance and education for providers
- Outcome: Individuals and families affected by sickle cell disease who seek or are assigned care in the Denver Health system will receive high-quality, evidence-based management of their sickle cell disease.

> Colorado Sickle Cell Anemia Advisory Committee meetings to be attended by the CU Sickle Cell Program Coordinator and other members

#### **5. Community empowerment:**

Established partnerships and annual and recurring activities as described in Section IV will be sustained. Specific information is described below:

> Direct contributions to improvements in the healthcare system and provider education by the Colorado Sickle Cell Association and individuals and families affected by sickle cell disease will be facilitated through numerous activities as previously described, including

- participation in medical school hematology course

- planning for major sickle cell events (e.g. Sickle Cell Summit, Sickle Cell Center 50<sup>th</sup> Anniversary Celebration), including setting the agenda, specific content, venue and timing
  - CBO and sickle cell disease patient representation and participation in HRSA's Sickle Cell Regional Collaborative Program including monthly regional meetings and the CDC Sickle Cell Data Collection surveillance programs through monthly operational meetings and quarterly advisory committee meetings
  - leadership roles on the Colorado Sickle Cell Anemia Advisory Committee
- > The Colorado Sickle Cell Association will lead the planning and conduct of community events and programs, including
- blood drives
  - annual 5K Walk/Run fundraiser and backpack give-away
  - scholarship program for individuals with sickle cell disease seeking education or vocational training beyond high school
  - continue website improvement
  - speaking to parents and medical professionals at the Rare Disease Fair at CHCO

> **OPTIONAL: Other Statewide Priority-Areas**

## VII. Additional Information

### **Important facilitators to care within the state:**

Dedicated pediatric and adult hematologists affiliated with the Colorado Sickle Cell Center who are willing go beyond daily clinical care to champion improvements within their health care systems and across Colorado.

The Colorado Sickle Cell Center, as an academic administrative entity in the University of Colorado School of Medicine, was able to facilitate communication and coordinate various activities across health care settings and outside health care systems, and played a role across the lifespan from the newborn screening program through pediatrics, transition and adult care. It also provided modest financial support to academic providers so they could more fully focus on the development and implementation of various sickle cell activities and opportunities. It is hoped the CU Sickle Cell Program can continue some amount of coordination, advocacy and facilitation statewide, even in the absence of infrastructure and financial support.

A strong relationship between the CU Sickle Cell Program and the Colorado Sickle Cell Association, the primary sickle cell community-based organization, and the Association's recent legislative funding, opens new opportunities for collaboration to develop processes to better serve those with sickle cell disease.

Increasing number of health care providers outside the traditional academic University system, particularly for adults, permitting greater flexibility for individuals when choosing where to live, work or attend school in Colorado

### **Important barriers to care within the state:**

Children's Hospital Colorado and University of Colorado Hospital/UCHealth, the primary sites of specialty sickle cell care for children and adults with sickle cell disease, historically provide limited resources (e.g. social work services) for the sickle cell population.

Challenges to increasing the knowledge base and use of best practices for sickle cell disease management outside the primary academic clinical care systems, including identification of opportunities to provide education and technical assistance to busy practitioners, particularly in practices with relatively few sickle cell patients.

Identifying adequate funding to sustain engagement of sickle cell champions to lead health systems changes, dissemination of education and best practices, and community engagement

### **Notable setbacks to the work:**

As noted above, the closure of the Colorado Sickle Cell Center in 2025. In addition, the primary sources of remaining funding for sickle cell programs are either year-to-year (Colorado Sickle Cell NBS Follow-Up Program) or are expected to be discontinued in mid-2026 (UPL Medicaid Program, which is the primary source of funding for the Colorado Sickle Cell Transition Program), creating significant challenges with planning for future activities.

|  |
|--|
|  |
|--|