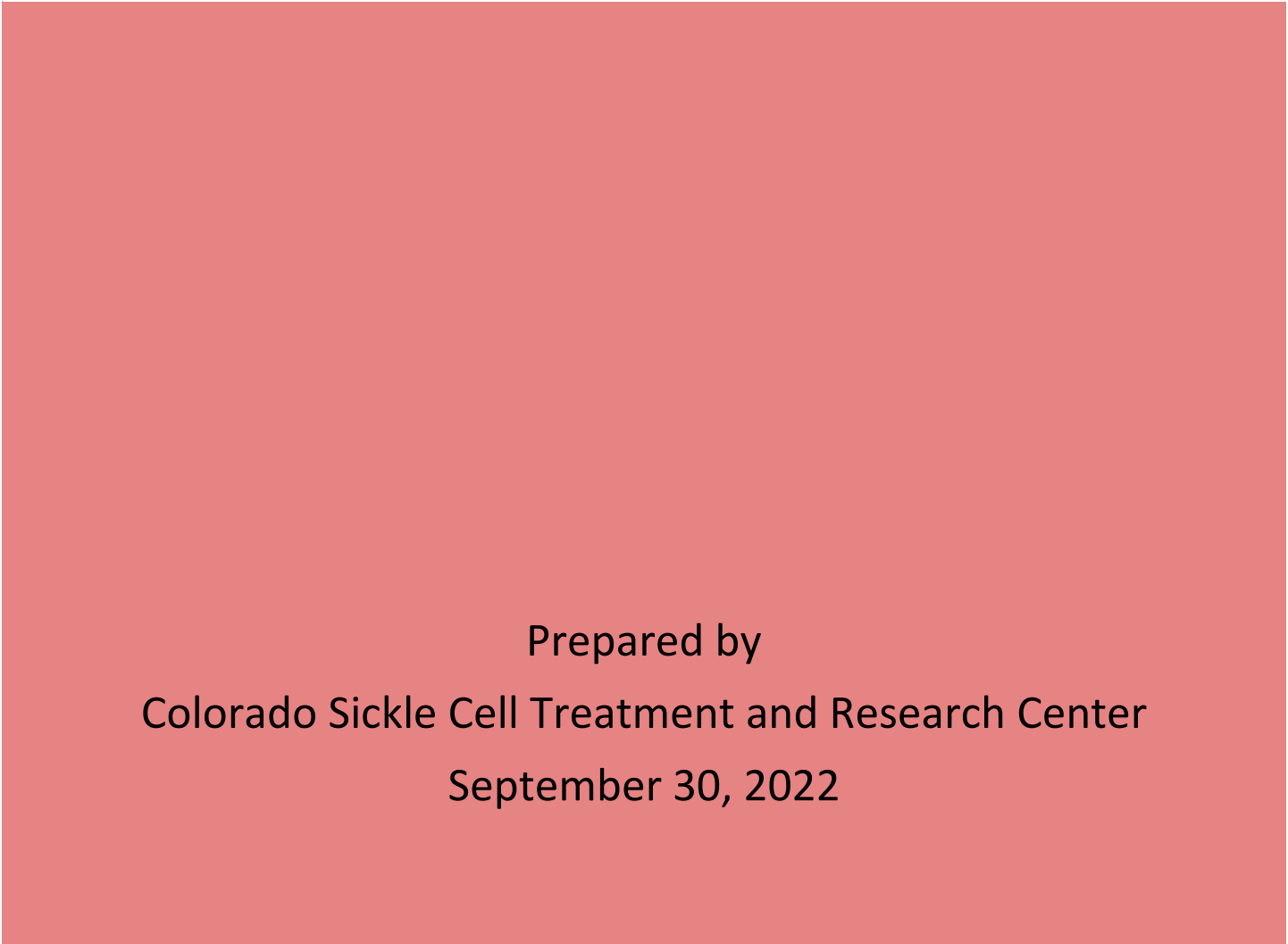


**COLORADO  
SICKLE CELL  
STATE ACTION PLAN  
2022-2023**



Prepared by  
Colorado Sickle Cell Treatment and Research Center  
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## I. BACKGROUND

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 ~450. 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.

Figure 1: 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



### Colorado Sickle Cell Treatment and Research Center

Anschutz Medical Campus, University of Colorado, Aurora, CO

The Colorado Sickle Cell Treatment and Research Center (“Sickle Cell Center”) was established by state legislative act in 1973 and since that time has facilitated coordinated clinical care, research and education activities across the state. The Sickle Cell Center is the primary source of specialty expertise and facilitation of comprehensive specialty care for both children and adults living with hemoglobinopathies. It also is contracted to facilitate the newborn screening hemoglobinopathies follow-up program for the states of Colorado and Wyoming. Basic, clinical and health services research conducted by the Center and its collaborators serves to elucidate the pathophysiology of sickle cell disease, develop and implement treatments and systems of care that prevent or minimize complications and that prolong and improve the quality of life as well as cure sickle cell disease. Research funding sources include NIH and other Federal agencies, industry, and foundations.

The Sickle Cell Center, as a state-based administrative entity within the School of Medicine at the University of Colorado, is uniquely positioned to serve as a site of coordination of healthcare-related activities in the state. It is independent of any given clinical facility, hospital, or healthcare system, has several funding streams, and can be the recipient of various grants, awards, contracts and donations in support of its efforts.

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 Sickle Cell Center provides salary support for a pediatric and adult hematologist who focus on patients with sickle cell disease and other hemoglobinopathies. The pediatric and adult hematologists collaborate closely, supported by a Center-supported transition coordinator, a medical social worker who is focused on adolescents and young adults in the context of a transition and transfer program.

## II. SUMMARY OF CURRENT STATE OF CLINICAL CARE

### Hemoglobinopathies Newborn Screening Program

All infants born in Colorado are screened for hemoglobinopathies. The Sickle Cell Center has continuously provided newborn screening short-term follow-up for hemoglobinopathies and hemoglobin traits 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 with a sickle cell specialist in the Children's Hospital Colorado system. This program is directed by a newborn screening follow-up nurse specialist and overseen by the Sickle Cell Center Director; these providers also provide consultation to the Colorado State Public Health Laboratory regarding lab testing and reporting.

### Clinical Care

The Sickle Cell Center serves as a coordinating organization for sickle cell activities across the state, but it is not an entity or physical site where healthcare is given. Approximately 400 adults and children with sickle cell disease are known to the Colorado Sickle Cell Center, the majority of whom receive ongoing specialty care in the Denver metropolitan primarily in the healthcare systems affiliated with the University of Colorado.

### *Pediatric Sickle Cell Care*

The majority of pediatric patients with sickle cell disease receive specialty sickle cell care in the Children's Hospital Colorado system, either on the main campus in the Denver metropolitan area (Aurora, a Denver suburb) or in Colorado Springs. Children's Hospital Colorado supports these clinics with dedicated advance practice provider, nursing and social work support. The Sickle Cell Center provides salary support for the pediatric hematologist who coordinates and provides much of clinical care at Children's Hospital Colorado, who also conducts specialty comprehensive care visits in the Colorado Springs affiliated clinic two-three times a year. Children usually receive inpatient care in the main Children's Hospital Colorado in Denver. 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 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.

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 Colorado for specialty services which are not available within the Kaiser system. This includes certain testing, e.g. transcranial Doppler and interventions, e.g. erythrocytapheresis. However, families are required to go to a Kaiser facility for tests and procedures when they are available, which presents challenges when trying to ensure families are able to complete these tests.

The Children's Hospital Colorado is the primary site of referral for the specialty management and follow-up of children with sickle cell disease and other hemoglobinopathies.

### *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 or in Colorado Springs at Memorial Hospital. The Sickle Cell Center provides salary support for the adult hematologist who coordinates and provides clinical care at University of Colorado Hospital (UCH); outreach clinical services are also available in Glenwood Springs, CO. Adults followed in the UCHealth system in the Denver area who require an emergency department visit are seen at UCH on the AMC campus or one of the many affiliated urgent care sites, 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 UCHealth hematology/oncology groups, and receive care in the emergency department care and are hospitalized at Memorial Hospital and Poudre Valley Hospital, respectively. All UCHealth hospitals share a common electronic medical record (EPIC).

Subspecialty sickle cell services uniquely offered at AMC campus in the Denver area includes liver MR imaging for iron content. Chronic erythrocytapheresis (red cell exchange) with minor antigen-matched RBCs is available at UCH on the AMC campus and in Colorado Springs at Memorial Hospital. For patients seen at UCH on the AMC campus, an individualized emergency department initial care plan is created and placed in their UCHealth EPIC record, although this can only be seen by providers within the UCHealth-affiliated institutions. Other specialty providers on the AMC campus (renal, hepatology, cardiopulmonary, pain, orthopedics) have gained experience in the assessment and management of sickle cell disease complications. 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.

As of 2022, 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. 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,

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" where some parts of an 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 medical system. UCH and Sickle Cell Center experts provide consultative support when requested, and transfer for a higher level of inpatient care at UCH on the AMC campus is available if needed.

### *Primary Care*

There are no primary care clinics or providers within the Colorado Children's or UCHealth systems specifically targeting individuals with sickle cell disease. Thus, care for these patients can be spread across a variety of clinic systems and providers, many of which are not actively involved in the Sickle Cell Center and have variable experience in the management of sickle cell disease. This may include Children's Hospital Colorado primary care clinic, Kaiser, various pediatric 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. In general, the primary care providers for the children defer all issues not related to routine immunizations to the pediatric sickle cell hematologist.

For adults living with sickle cell disease, a collaboration has been established with a community primary care and pain management clinic, 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 17 patients as of mid-2022. This primary care clinic offers primary care, pain management, specialty care as recommended by hematologists, physical therapy and psychological services/counseling.

#### *Colorado Sickle Cell Center Transition Program*

The Sickle Cell Center's Transition 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 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 up to the 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 Children's Hospital Colorado Transition Governance Board.

#### Sickle Cell Community-Based Organizations

The Colorado Sickle Cell Association (<https://cscadenver.godaddysites.com>), 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. 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 include patient and family holiday parties and a 5K run fundraiser. The Sickle Cell Association partners with the Colorado Sickle Cell Center 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 provider educational events. The group is an active partner in projects conducted by the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), and recently completed a year-long community health worker training program. The Ella Mae Bransom Sickle Cell Association (<https://www.ellamae.org>), a sister organization based in Colorado Springs, provides services and assistance to individuals with sickle cell disease and their families in southern Colorado, and conducts an annual fundraiser to support research.

#### Medicaid Surplus Funding Program

The Colorado Sickle Cell Center has been awarded funding from the State of Colorado Medicaid surplus through CU Medicine, the faculty practice organization for the University of Colorado. These funds have renewed annually, most recently in July 2022, which permits the Sickle Cell Center to continue salary support for sickle cell specialty practitioners to permit them to use their time 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 2022, a portion of this funding is being used to support further develop the Sickle Cell Center's 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 identify, catalogue and post healthcare resources, educational material, decision tools, and other materials on the Sickle Cell Center's state website, which will be updated and maintained.

### **III. PRIORITIES, GOALS AND STRATEGIES 2022-2023**

**First Priority: To work with sites of specialty and primary healthcare to ensure that high-quality, evidence- and guideline-based services are offered to all persons in Colorado living with sickle cell disease across the lifespan**

**Second Priority: To improve awareness of the resources available in Colorado to individuals with sickle cell disease and their families to manage the impact of the disease across the lifespan, including access to healthcare, community-based services, and school/work**

#### **GOALS AND STRATEGIES TO ACHIEVE THESE PRIORITIES:**

**GOAL 1:** Continuously identify specific providers, clinics, facilities and healthcare systems (sites of care) where individuals with sickle cell disease seek healthcare service, including sickle cell hematological care, sickle cell-related specialty care e.g. ophthalmology, cardiopulmonary, obstetrics, and non-sickle cell-related care e.g. primary care

**Strategy 1.1:** Maintain a central database of sites of care known to the Colorado Sickle Cell Center, as identified by individuals and their families, by community members and organizations, and during transition from pediatric-oriented to adult-oriented healthcare

Strategy 1.1.1: Provide the opportunity for individuals, families and community members to identify other sites of care during healthcare encounters or by contacting the Colorado Sickle Cell Center via its website, by email or by phone

Strategy 1.1.2: Collaborate with community-based organizations to identify sites of care for individuals who are not seen within known sites of care

Strategy 1.1.3: Create a Colorado sickle cell provider listserv by obtaining email addresses as the primary method of communication with providers, key personnel in clinics, facilities and healthcare systems for dissemination of information regarding resources

**Strategy 1.2:** Contact known sites of care initially and at least annually to be sure database information is correct, to provide information about how to access the website and its content, how to obtain consultation from sickle cell experts in Colorado, and to request feedback about other needs or opportunities for further interaction/support

**Strategy 1.3:** Convene an annual “Sickle Cell Provider Summit” 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.

**GOAL 2:** Support sites of care in an effort to provide high-quality, evidence- and guideline-based healthcare for individuals with sickle cell disease across the lifespan

**Strategy 2.1:** Maintain an updated centralized resource on the Colorado Sickle Cell Center’s website containing contemporary guidelines and clinical decision support, providing:

Strategy 2.1.1: Downloadable PDFs and/or links to sources of guidance for the management of individuals with sickle cell disease, including newborn screening follow-up recommendations, pediatric and adult hematology specialty care, other specialty care, primary and obstetrical care

Strategy 2.1.2: Contact information for sickle cell disease experts in Colorado, including access for routine and urgent consultation

Strategy 2.1.3: A listing of the known sites of care, including primary care and other specialty care providers who serve sickle cell patients

Strategy 2.1.4: Information highlighting newly-approved drugs or recommended management strategies

**Strategy 2.2:** Disseminate educational opportunities to the identified sites of care via the Colorado sickle cell provider listserv

Strategy 2.1.1: Offer 2-4 educational interactive webinars per year for all Colorado sites of care, focusing on topics of interest to providers in Colorado

Strategy 2.1.2: Consider continuing education credit for activities, including the webinars

Strategy 2.1.3: Advertise to those in the database as well as listservs as available listservs for educational institutions and other professional groups as appropriate

Strategy 2.1.4: Announce other educational meetings, webinars, archived presentations as they become available via the listserv

**GOAL 3:** Enhance awareness of sickle cell disease and coverage for appropriate healthcare services provided by administrator of major healthcare systems and insurers, including the Children's Hospital Colorado system, UHealth system, Colorado State Medicaid programs, Medicare, Denver Health Medical Center, Colorado Kaiser Permanente and any other systems in which sickle cell patients seek care.

**Strategy 3.1:** Identify and work with case managers within systems/plans to increase awareness of the complexities of sickle cell disease management and the need for individuals and their families to have access to sites of care with appropriate expertise

**Strategy 3.2:** Identify and collaborate with transition coordinators within systems/plans to develop processes to facilitate the transition from pediatric-oriented care to adult-oriented care as well as actual transfer of care

**Strategy 3.3:** Communicate annually with the state Medicaid Medical Director and key personnel regarding standard and new management recommendations, including FDA approval of new therapies, curative therapies and policy statements regarding treatment strategies.

**Strategy 3.4:** Include stakeholders from governmental and private insurers as well as administrators of major healthcare systems in the annual Sickle Cell Provider Summit

**GOAL 4:** Increase awareness of and facilitate linkages to community-based organizations in Colorado that have or potentially could support a variety of needs for individuals with sickle cell disease and their families.

**Strategy 4.1:** Disseminate information about services and support offered by the Colorado sickle cell community-based organizations to the Colorado sickle cell provider listserv and healthcare entities, as well as provide contact information and a link on the Colorado Sickle Cell Center website



**Strategy 4.2:** Maintain up-to-date information about organizations that provide support to Coloradans for transportation, housing, assistance with access to Medicaid and other healthcare coverage, school and work accommodation, and other needs via the Colorado Sickle Cell Center website

**Strategy 4.3:** Maintain ongoing regular communication and collaboration between sickle cell community-based organization and the Sickle Cell Center in order to facilitate activities and programs, including those outlined in this State Plan

#### **IV. KEY PARTICIPANTS AND POTENTIAL PARTNERS**

##### Coordinating Organization:

Colorado Sickle Cell Treatment and Research Center  
University of Colorado, Aurora, CO

##### Known Sites of Pediatric Specialty Care:

Children’s Hospital Colorado System  
Hospitals/Outpatient Clinics  
Main Campus: Aurora, CO  
Affiliated Facilities: CO Springs, CO

##### Known Sites of Adult Specialty Care:

University of Colorado Health (UCHealth) System  
Hospitals/Outpatient Clinics  
Main Campus: Aurora, CO  
Affiliated Hospitals: CO Springs, Fort Collins, CO  
Denver Health and Hospitals System  
Hospital/Outpatient Clinics: Denver Metro  
Rocky Mountain Cancer Centers  
Outpatient Clinics: Various locations in CO

##### Known Sites of Primary Care Providers

Kaiser Permanente Colorado  
Outpatient Clinics: Various locations across Colorado  
Metropolitan Community Provider Network (MCPN)  
withEvery Child Pediatrics  
Denver Health Medical Center  
Children’s Hospital Colorado Primary Care Clinics  
Peak Vista Pediatrics  
Arvada West Family Medicine (primary care and pain management, focused on adolescents/adults)

##### Community Support Groups

Colorado Sickle Cell Association Denver, CO	Ella Mae Bransom Sickle Cell Support Group Colorado Springs, CO
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##### Colorado State Medicaid Program

Department of Health Care Policy and Finance: Health First Colorado, 40+ managed care plans

##### Colorado Department of Health and Environment Laboratory

Newborn Screening for Hemoglobinopathies

## V. STATE ACTION PLAN DEVELOPMENT OPPORTUNITIES IN 2022-2023

There are a number of opportunities for enhancement of healthcare in Colorado for individuals of all ages living with sickle cell disease and their families. However, state action planning in Colorado will initially focus on the healthcare and other systems which serve adults as well as in the area of transition and transfer for adolescents and young adults from pediatric-oriented to adult-oriented healthcare. The following activities are planned for the next year (August 2022-August 2023), targeting the sites with larger number of patients in addition to ongoing efforts to locate and reach out to providers and practice sites that have fewer patients, eventually creating a virtual interactive network of communication and sharing of resources.

### ADULT CARE

#### University of Colorado Healthcare System (UCHealth) Specialty Care

##### *University of Colorado Hospital (UCH), Aurora, CO*

The majority of adults living with sickle cell disease receive their specialty inpatient and outpatient care at UCH in Aurora. There are a number of opportunities to improve the quality of care and patient experience, some of which are currently in development in collaboration with UCH groups including hospitalists and hematology providers including APPs, nurses and pharmacists; and social workers.

- Systems Changes
  - o Increase of awareness of and utilization of standardized inpatient sickle cell order sets and the Agile MD inpatient clinical care pathway in hospitals across the UCHealth system
  - o Solidify working relationships with specific subspecialty faculty (renal, pulmonary, hepatology, pain, ortho) with an interest in sickle cell disease who are willing to accept specific referrals of sickle cell patients
  - o Continue to advocate for social work support for sickle cell patients at UCH
  - o Explore potential UCH funding for services to be provided by the Colorado Sickle Cell Association trained community health workers
- Provide mentoring and education as needed to adult hematology APPs, nurses, social workers or other providers newly assigned to the UCH Blood Disorders Clinic
- Develop a proposal requesting resources and financial support from UCH to further solidify a formal collaborative sickle cell clinical program to optimize care
- Identify mechanisms to obtain input from individuals using the emergency department, in collaboration community-based organizations, to be integrated into an evaluation of utilization and outcomes data, in order to provide providers with feedback and opportunities for improvement

##### *Memorial Hospital, Colorado Springs, CO and Poudre Valley Hospital, Fort Collins, CO*

- Meet with specialty provider group to assess opportunities for additional consultative support, the provision of additional resources (education, decision tools, etc), collaboration in QI/research activities
- Identify specific issues for ED and inpatient sickle cell care which might be addressed by education, decision tools, order sets and/or quality improvement efforts with support from the Sickle Cell Center

##### *UCHealth System-Wide*

- Identify location in shared EMR system (EPIC) for individualized care plans that can be accessed by all affiliated hospital-based EDs as well as the numerous newly-acquired free-standing urgent care centers
- Identify processes to incorporate pain management plans devised by the co-managing community clinic partner into EPIC in a readily accessible location, as this clinic is not currently in the UCHealth system nor with access to a shared EMR
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## Other Healthcare Systems Specialty Care

### *Kaiser Permanente*

- Offer education and ongoing consultative support to Kaiser hematologists as needed in the management of sickle cell disease patients. This may include an annual routine formal consultation at UCH, at the discretion of the Kaiser hematologist.
- Offer education and ongoing consultative support to Kaiser emergency department and hospital providers as needed for the management of sickle cell disease patients in these settings

### *Private Hematology/Oncology Practices*

- Offer resources (guidelines, networking, consultation) to practices who are currently seeing even a single sickle cell patient or a practice which an individual with sickle cell disease might like to use based on location/convenience/insurance requirements

## State-Wide Clinical Practice Efforts

- Explore mechanisms to share individualized care and pain management plans through the “Care Everywhere” feature of EPIC for those unaffiliated healthcare systems currently linked through this mechanism, which includes Denver Health Medical Center, the principle “safety net” hospital in Denver, and Kaiser, as well as several other major hospital systems.
- Encourage all providers to join Project ECHO teleconferences and other educational activities
- Increase awareness and dissemination of information regarding the services and resources available through the Colorado Sickle Cell Association and Ella Mae Bransom Sickle Cell Association
- Continue support of transitioning youth to known or new potential sites of specialty care and/or establish distant co-management strategies with local providers, based on their choice of school or employment location anywhere in Colorado. This includes participation of the state transition coordinator in clinic visits as requested by the youth in transition, regardless of hospital system or clinic location

## PEDIATRIC CARE

### Children’s Hospital Colorado System-Aurora

- Continue close collaboration with the other pediatric hematologists who provide care to sickle cell disease patients admitted to the hematology service.
- Identify and solidify working relationships with specific subspecialty faculty (renal, pulmonary, hepatology, pain, ortho) and hospital staff through the Sickle Cell Collaborative at Children’s Hospital Colorado by meeting 2-3 times per year.
- Maintain and update care pathways, guidelines, order sets for inpatients and emergency department
- Continue close relationship with bone marrow transplant to provide a cure through bone marrow transplant or gene therapy
- Quality Improvement Activities – Outpatient Hemoglobinopathy Clinics
  - o Assess and maintain focus on utilization of hydroxyurea, L-glutamine (Endari) and blood transfusion therapies to modify disease
  - o Assess and track TCD uptake by families
  - o Continue efforts to reduce “no-show” rate by collaborating with scheduling
  - o Participate in the pediatric emergency care network funded HRSA project to decrease time to opiates for pain in the emergency department
  - o Work with the blood bank at Children’s Hospital Colorado to gain more ethnically diverse blood donors
- Continue to encourage collaboration with the Colorado Sickle Cell Association to sponsor blood drives

### Children's Hospital Colorado Springs

- Continue to hold outreach clinics every 3-4 months to develop comprehensive plans and provide consultation
- Determine local provider needs and provide resources
- Assess access to current sickle cell guidelines, algorithms and management protocols at main Children's Hospital Colorado
- Assess optimal location of admission (Colorado Springs or CHCO on AMC in Aurora)
- Be available for urgent issues
- Verify similar testing can be offered
- Attempt to maintain the same standards of care

### Kaiser Permanente

- Continue co-management with primary care providers with primary responsibility for acute and chronic care falling to sickle cell providers at Children's Hospital Colorado
- Continue transfer of sickle cell patients for inpatient management

### Denver Health

- Provide comprehensive care to patients assigned to Denver Health
- Provide inpatient care to patients assigned to Denver Health.

## ACROSS-THE-LIFESPAN COLLABORATION

### Partnership with Medicaid

- Identify primary liaison to assist navigation of the multitude of managed care plans under this program
- Transition program to develop a hand-out and resources about adult Medicaid to assist youth when transferring from pediatric to adult care
- Better understand and help patients maneuver various policies for assignment to a particular plan that would include care within the Children's Hospital Colorado or UHealth systems
- Explore dissemination of NHBLI guidelines, American Society of Hematology (ASH) guidelines or state-specific adaptation of basic best practices across the various plans
- Work with the Colorado Medicaid program to develop an annual report regarding sickle cell statewide utilization data and outcomes

### Partnership with Primary Care Providers

- Contact all known and newly-identified providers/practices/clinic systems which serve sickle cell patients to assess opportunities to support
- Target Project ECHO-like teleconferences at least one a year to primary care providers
- Identify a location easily accessed in EPIC Care Everywhere which shows treatment and plans
- Assure providers outside Care Everywhere and EPIC receive information about every patient visit
- Receive calls from outside providers and develop co-management plans
- Continue support of transitioning youth to known or new potential sites of primary and specialty care

### Partnership with Colorado State Department of Health and Environment (CDPHE)

- Continue collaboration with the CDPHE Newborn Screening Laboratory to sustain quality hemoglobinopathies testing and follow-up
- Continue collaboration with CDPHE efforts to education primary care providers about newborn screening and appropriate follow-up for sickle cell disease

### Partnership with Community Based Organizations

- Identification of high priority areas for clients (careers, parenting) and resources available to assist where needed
- Increased awareness of and dissemination of information about community-based organizations at all sites of care across Colorado
- Further develop transition program components which are anchored in community and family support
- Collaboration between the Sickle Cell Center transition program and the Colorado Sickle Cell Association to increase awareness among youth and young adults about the Association's programs and activities.
- Continued collaboration between Children's Hospital Colorado social worker and CBO to clients
- Updating of "Sickle Cell 101" – basic education and materials provided by CBO to clients
- Collaborative efforts to identify funding for the Colorado Sickle Cell Association trained community health workers, include possible funding from UCH for services.
- Optimizing communication in community at large – social media, positive messaging, oneSCDvoice

### Additional Specific Activities:

- Continued use of telehealth in specialty and primary care setting for patients who desire this form of healthcare when appropriate and as supported by healthcare systems and clinics.
- Annual in-person provider "summit" for education and networking: open to all types of providers
- Colorado Project ECHO-like teleconferences ~2-4/year – primary method of outreach to ED, hospitalists, primary care and specialty care
  - o Establish process for reaching out (letter vs email vs other? to newly-identified providers, including invitation to Colorado and Regional ECHO Calls
  - o Rotate focus of Colorado ECHO calls (hospitalist, ED, primary care, specialty care)
- Dissemination of resources and clinical/decision support information via the Sickle Cell Center state website:
  - o Clinical resources including primary, hematology and other specialty care
  - o Agencies
  - o Community-based organizations
- Annual community-targeted in-person education conference co-sponsored by the Sickle Cell Center and community-based organizations
- Participate in activities related to the development of state-wise surveillance for sickle cell disease funded by CDC