TennCare Sickle Cell Disease Report
January 15, 2023

BACKGROUND OF TENNESSEE PUBLIC CHAPTER NO. 186

PC 186 establishes that the Division of TennCare conduct an annual review of all medications, forms of treatment, and services for enrollees with a diagnosis of sickle cell disease who are eligible for coverage under the medical assistance program. The first Sickle-Cell Disease report was submitted to the legislature by TennCare on January 15, 2022. The Sickle-Cell Disease report (the report hereafter) will be submitted annually every January 15 to the legislature detailing TennCare's findings and any recommendations to the General Assembly based on those findings. TennCare must also publish the annual report to its website making it accessible to the general public. The purpose of the review is to determine if the available covered medications, treatments, and services are adequate to meet the needs of TennCare enrollees and whether TennCare should seek to add additional medications, treatments, or services. TennCare is required to solicit and consider input from the general public, with specific emphasis on input from persons or groups with knowledge and experience in sickle cell disease treatment.

Since the 2022 report, TennCare and its three Managed Care Organizations (MCOs) have had regular communications with TennCare enrollees and care providers from the Sickle Cell community. To further support the preparation of this report, TennCare and all three MCOs conducted Sickle Cell Provider Forums on December 14, 2022 and December 21, 2022. The report outlines the information required by PC 186.

OVERVIEW AND CONTEXT OF SICKLE CELL DISEASE

Sickle cell disease is a group of inherited red blood cell blood disorders. It is one of the most frequently inherited blood disorders in the United States affecting approximately 100,000 Americans[1]. The report describes the population demographics and healthcare utilization patterns of TennCare enrollees with sickle cell disease. It outlines clinical programs specifically designed to provide health care coordination and covers health care access and utilization patterns for individuals with sickle cell disease. The report discusses specific opportunities and challenges for this population, describes feedback received from stakeholders, and discusses the adequacy of TennCare covered medications, treatments, and services to meet the needs of enrollees with sickle cell disease. As of December 2022, TennCare provides healthcare coverage to approximately 1.7 million Tennesseans. All medical data provided in the report is based upon TennCare claims data from Calendar Year 2021 (CY2021).

[1] https://www.cdc.gov/ncbddd/sicklecell/data.html

TENNCARE SICKLE CELL DISEASE KEY POPULATION STATISTICS

Enrollee Demographics

Throughout 2021 TennCare provided healthcare coverage to over 1,400 enrollees diagnosed with sickle cell disease. Enrollees 0-21 years of age comprised 52.6% while enrollees over 21 years of age comprised 47.4%. The average enrollee age was 22 years. In 2021, there were 364 TennCare enrollees whose primary residence was in the East grand region, 365 in the Middle grand region, and 719 in the West grand region. Approximately 91% of the TennCare sickle cell disease population lives in urban areas and 9% in rural areas.[2]

Medical Services and Expenditures

In CY2021, TennCare expenditures for all medical services provided for enrollees with sickle cell disease totaled $33.7 million.[2] Table 1 shows the breakout of the total expenditures by categories of service.

TABLE 1 – Medical Expenditures by Cost Category [2]

Calendar Year	Cost Category	Total Cost
2021	Medication Costs	$13,529,178
2021	Professional Outpatient Services	$1,863,078
2021	Inpatient Services	$10,790,095
2021	Emergency Department Services	$1,587,613
2021	Labs and Ancillary Services	$5,237,302
2021	Other	$733,965
2021	TOTAL	$33,741,232

All enrollees with sickle-cell disease have a comprehensive medical and pharmacy benefit available through their TennCare coverage and are assigned a TennCare primary care provider. All three MCOs also offer a focused sickle cell care management program to assist enrollees if they wish to have the support. Approximately 66% of all outpatient services for these enrollees were provided by a Primary Care Provider or a Hematology/Oncology specialist.

TENNCARE PHARMACY BENEFIT FOR SICKLE CELL DISEASE

TennCare covers all drugs approved by the FDA for the coverage of sickle cell disease. This includes an extensive formulary of medications linked here:
https://www.optumrx.com/content/dam/openenrollment/pdfs/Tenncare/home-page/preferred-drug-list/Preferred%20Drug%20List%20(PDL).pdf

[2] Data from TennCare medical claims for CY 2021.

Currently, in the U.S., the American Society of Hematology Clinical Practice Guidelines on Sickle Cell Disease provide evidence-based, expert, consensus guidance for the treatment of sickle cell disease, linked here. TennCare references the most recent version of these guidelines. https://www.hematology.org/education/clinicians/guidelines-and-quality-care/clinical-practice-guidelines/sickle-cell-disease-guidelines

The recommendations address treatment of both adult and pediatric sickle cell disease. Treatment options for sickle cell disease are different for each patient and are based on individualized symptoms and care plans. Progressive organ damage is one of the primary causes of early death in the sickle cell population and the treatment of both the sickle cell disease and the chronic conditions that result from sickle cell disease is paramount for the long-term health of individuals with sickle cell disease. Many people with sickle cell disease will require lifelong supportive care such as red blood cell transfusions, pain management strategies, vaccinations, and antibiotic prophylaxis as part of their prevention plan for acute vaso-occlusive crises. Additionally, patients who experience acute vaso-occlusive crises will often require additional clinical care depending on the severity of their crisis. This care may be delivered in specialized sickle cell treatment centers, emergency rooms, or inpatient settings. Other patients may be placed on disease-modifying agents. Hydroxyurea (Droxia, Siklos, or Hydrea) has been and remains a key guideline-recommended agent for the treatment of sickle cell disease. Pharmaceutical-grade L-glutamine (Endari) received FDA approval for the treatment of sickle cell disease in July 2017. Crizanlizumab-tmca (Adakveo) and voxelotor (Oxbryta), were FDA-approved under rapid approval pathways for the treatment of sickle cell disease in November 2019. Both medications are covered for TennCare enrollees with sickle cell disease who meet the clinical coverage criteria for these treatments.

TennCare's pharmacy benefit focuses on providing effective and appropriate FDA-approved prescription drugs when medically necessary, including medications and related therapies used in the treatment of sickle cell disease. All medications that have an FDA-approval for treating sickle cell disease are covered by the TennCare formulary and have clinical criteria outlined to help support evidence-based coverage.

Currently, preferred formulary drugs used in the management of sickle cell disease are available to enrollees without prior authorization. Hydroxyurea and Droxia are recommended for use in the prevention of pain crises or vaso-occlusive episodes. Non-steroidal anti-inflammatory drugs such as prescription ibuprofen, oral diclofenac and topical gel, meloxicam, and ketorolac are readily available without authorization for use in the management of mild to moderate acute pain episodes. Oral antibiotics and vaccines for use in the prevention of infection are also available without prior approval.

Certain non-preferred medications, such as Siklos, Hydrea, Endari, Adakveo, and Oxbryta, require prior approval before a prescription can be dispensed. Droxia (hydroxyurea) is utilized to reduce the frequency of painful crises and the need for blood transfusions in patients with recurrent moderate to severe painful crises. Endari (l-glutamine powder) is indicated to reduce the acute

complications of sickle cell disease in adult and pediatric patients ≥ 5 years of age. Oxbryta (voxelotor) is FDA-approved for individuals with sickle cell disease ≥ 4 years of age and was granted priority review, fast track, orphan drug, rare pediatric disease, and breakthrough therapy designations. In October 2022, initial prior authorization criteria for the following sickle cell disease agents: Endari, Oxbryta, and Siklos was modified to only require a diagnosis > 3-month trial or intolerance of hydroxyurea, and weight-based dosing, if applicable (Endari) in an effort to improve access to care. This demonstrates TennCare's ongoing efforts to simplify and improve the prior authorization process and TennCare's request for feedback from providers who treat individuals with sickle cell disease.

The enrollee, physician, or an authorized agent can initiate routine utilization management processes such as prior approval and step therapy for ensuring requested drugs requiring prior approval meet the clinical criteria for medical necessity. Pre-approvals for drugs requiring authorization are processed within 24 hours of the initial request that includes identifying information, clinical reason for the use of the drug under review, and any previous treatment for the treated condition. If the review for a pharmacy service is denied, there remain multiple pathways to access medication services including peer to peer review, a 72-hour emergency supply, and a reconsideration of the original prior approval review via medical appeal. A peer-to-peer review is available to the prescriber for a clinical discussion or to gather more information on any pre-approval outcome. The prescriber can speak directly with a peer physician or pharmacist about their individual patient, patient's condition, and care options. If the request is emergent in nature, and prior approval is warranted, pharmacists can dispense up to a 72-hour emergency supply of the medication while it is under review at no cost to the enrollee.

As new medications and therapeutic options for sickle cell disease are introduced to the clinical landscape, the TennCare medical and pharmacy benefit is routinely updated to allow for coverage of new medications as medically indicated. TennCare's formulary protocol is routinely advanced, as frequently as weekly, based on new drug availability, indications, route of administration, and according to nationally recognized guidelines, compendia, and established medical and pharmacy treatment standards. Routine updates safeguard access to critical medications for rare, chronic, and acute illness including sickle cell disease.

TennCare continues to follow the emerging clinical pipeline around new treatment options which advance rapidly. There have been significant developments in the treatment of sickle cell and research is ongoing to address the needs of sickle cell disease management. Many new treatment options, including gene therapy and stem cell transplantation, have been or are undergoing continued review by the FDA, which may provide the potential for a cure for sickle cell disease. TennCare closely tracks these emerging treatment options and the FDA approval processes based on review of clinical trials. On the horizon for FDA approval in late 2023, is lovotibeglogene autotemcel (LentiGlobin™), an experimental intravenous gene therapy showing promise in the management of painful crises. As new therapeutics are determined to be safe and effective, TennCare works quickly to ensure they are reviewed for potential inclusion in the TennCare benefit.

It is important to note that TennCare's covered outpatient pharmacy formulary is shaped based on input from the TennCare Pharmacy Advisory Committee (PAC). The TennCare PAC is comprised of members appointed by both executive and legislative representatives as outlined in state statute. The Committee makes recommendations regarding access to medications and related product guidance in conjunction with state clinicians. Committee members must be practicing primary or specialty physicians, pharmacists, or mid-level practitioners. The committee also includes enrollee advocates. In conjunction with TennCare clinicians, the PAC is responsible for developing, managing, updating, and administering the TennCare pharmacy formulary and review criteria.

Table 2 describes medication use by the population with sickle cell disease:

TABLE 2 – Medication Use by TennCare Enrollees with Sickle Cell Disease in 2021[2]

Calendar Year	Number of Enrollees Receiving Prescriptions	Percentage of Enrollees Receiving Prescriptions	Average number of Prescriptions for Enrollees
2021	1,208	88.1%	17.9

Table 3 describes opioid use by the population with sickle cell disease:

TABLE 3 – Opioid Use by TennCare Enrollees with Sickle Cell Disease in 2021[2]

Calendar Year	Number of Enrollees Receiving Opioids	Percentage of Enrollees Receiving Opioids	Number of Opioids Prescribed	Total Cost
2021	626	45.9	616,181	$197,962

Among patients with sickle cell disease, vaso-occlusive crises are recurrent and unpredictable attacks of acute pain. These pain crises are often treated with prescription analgesics, including topical and oral non-steroidal anti-inflammatory drugs and opioids. Each of these treatments are available for enrollees experiencing acute pain crisis and related and recurrent pain syndromes stemming from sickle cell disease progression.

TennCare provides additional accommodations for enrollees with sickle cell related to the opioid benefit. Enrollees with sickle cell disease can often experience acute pain crises and live with chronic pain related to their disease. All enrollees with sickle cell disease can access up to a 45-day supply of 60 Morphine Milligram Equivalents (MME) of opioids per day in any 90-day period for acute pain management. Additionally, enrollees with sickle cell experienced in opioids for the management of chronic pain are eligible to exceed the daily opioid threshold as prescribed by their provider up to 200 MME per day indefinitely with periodic review for ongoing medical need.

TENNCARE SICKLE CELL DISEASE POPULATION HEALTH AND CARE COORDINATION

TennCare provides a comprehensive Population Health program through its Managed Care Organizations for all enrollees, and especially those with sickle cell disease, to help coordinate care and support clinical needs.

Population Health and Care Coordination Programs

TennCare's Population Health program provides additional clinical support and care coordination for enrollees across the entire care continuum to offer health education, promote healthy behaviors, and disease self-management. Enrollees with additional needs can receive care coordination and thorough care management services through MCO care managers to help them access additional needed services. MCOs evaluate the entire enrollee population, according to the enrollee's clinical risk based on predictive modeling from medical diagnoses and service utilization. Enrollees can be engaged in care management through referrals, utilization management data, and health risk assessment results.

Initial health assessments are offered and conducted with every enrollee within ninety days of becoming TennCare eligible. These health assessments help TennCare enrollees learn about their potential health risks and partner with their MCO for the services and clinical care needed to help address these risks. Health assessment information is used to connect individual enrollees with appropriate intervention approaches and maximize the impact of the services provided.

Using all of these clinical inputs, MCOs stratify all enrollees into different risk level programs ranging from minimal clinical risk to high clinical risk. Each risk-level has targeted supports that match their risk and identified needs. Some examples of risk stratifications include:

- ***No Risk*** (Wellness): enrollees with no identified health risks
- ***Low Risk:*** includes enrollees with rising risk and chronic health care needs, as well as low risk maternity
- ***High Risk****:* includes enrollees with high-risk needs (complex case management and chronic care management), as well as high risk maternity

Enrollees with sickle cell disease are included into the stratification along with the entire population. Individuals with sickle cell disease may be stratified in the low-risk or high-risk programs reflecting their underlying sickle cell disease and the accompanying chronic conditions. Most individuals with sickle cell disease would fall into the high-risk category.

Care Coordination is impactful for enrollees with sickle cell disease as it assists with acute healthcare needs, health service needs, or risks which need immediate attention. The goal of Population Health and Care Coordination Services is to make sure enrollees get the services they need to prevent or reduce adverse health outcomes. The care management team can also work

ENROLLEE STORY

An adult female with SCD living in West TN was referred to case management due to high inpatient utilization. Her Nurse Case Manager contacted her and successfully engaged her in case management. She had suffered with Sickle Cell Disease her entire life, along with several complications including chronic pain, osteonecrosis of bilateral hips, stroke, vitamin D deficiency, pulmonary embolism, osteoporosis, and anxiety. She received monthly therapeutic apheresis, which is a blood exchange process that removes abnormal cells.

Due to the chronic pain caused by SCD, she also required assistance with her Activities of Daily Living (ADLs). She had received CHOICES services since 2018, and her mother provided the needed care through the Consumer Direction program. Her Nurse Case Manger reached out to her CHOICES Care Coordinator, to discuss her frequent hospitalizations and which medical needs may require further assistance. She was engaged with a SCD Clinic and saw them on at least a monthly basis. Her Nurse Case Manager discussed ways to help manage her SCD, including the importance of regular checkups, vaccinations, adequate hydration, staying cool when it's hot and warm when it's cold, but most importantly, reporting early signs and symptoms to her SCD provider to prevent a pain crisis. She recently started having increased pain and called her SCD provider's office to report this and received outpatient IV fluids and pain management. This early reporting prevented an SCD crisis and hospital admission.

The case manager also worked closely with the enrollee to help her coordinate care with several specialists as she was experiencing several other issues that required medical attention. With the help of the care manager, she established care and completed several medical appointments and diagnostic testing that was recommended.

Due to SCD affecting every aspect of her life, she has also experienced financial barriers. She needed additional community resources for food and vision. The MCO Health Navigator was again consulted to assist with providing these resources. She also struggles with anxiety and her Nurse Case Manager aided with self-management education including positive thoughts, meditation, quiet spaces, and deep breathing exercises. She was educated on the importance of compliance with her Psychiatric appointments as well as her medication regimen. They also discussed strategies that have been helpful when she experiences panic attacks. She is now very motivated and determined to better manage her conditions. She is continuing to meet with her Nurse Case Manager as well as her CHOICES Care Coordinator and has had no further inpatient admissions since engaging with case management. This integrated collaboration has allowed her to continue working towards meeting her goal of better managing her health.

with an enrollee's primary care provider to help communication with specialists and other care providers as well as to provide wrap around care and support for the enrollee.

Clinical care coordination teams generally consist of a Nurse Case Manager, Behavioral Health Case Manager, Behavioral Health Peer Support, Social Worker, Dietitian, Health Educator, Long Term Services and Supports Care Coordinator, Pharmacy Specialist, Medical Director, Health Navigator, and Enrollee Resource Coordinator.

Patient Outreach and Engagement

TennCare utilizes a variety of methods to conduct outreach to enrollees. The MCOs outreach to individuals telephonically, by interactive voice response (IVR), secure enrollee portals, and by mail. MCOs conduct face-to-face interactions, teleconference calls, and text messaging when appropriate and with enrollee consent. MCOs also partner with providers in a collaborative effort to reach or re-engage individuals. TennCare provides the ability for an enrollee to speak with a registered nurse 24-hours a day for help finding doctors, schedule appointments, get to urgent care centers or walk in clinics, or speak directly with a doctor's office about their health care needs.

At a minimum, enrollees in a low-risk category receive at least four communications each year, addressing self-management education increasing the knowledge of their chronic health

condition. These communications emphasize the importance of medication adherence and appropriate behavioral changes, the management of the emotional aspect of their health condition, and self-efficacy and support. MCOs also offer individual support for self-management if the enrollee desires it, including health coaching and a 24/7 NurseLine. Low-risk enrollees who would like engagement with a care manager can also opt-in to care management and receive interactive support.

Enrollees in the high-risk program receive intensive care coordination. Monthly interactive contacts by the MCO nurture the development of a supportive enrollee and health coach relationship, disease specific management skills, development and implementation of an individualized care plan, problem solving techniques, self-efficacy, and referrals to link the enrollee with medical, social, educational, and other programs and services to address any identified needs. Enrollees may choose to opt-out of any of these care coordination programs.

ENROLLEE STORY

An adult male with Sickle Cell Disease in West TN was identified for case management due to his risk for inpatient readmission related to his SCD. The member lives with his mother, who is his primary caregiver. An MCO Nurse Case Manager (NCM) outreached and completed an initial assessment with him and his mother focusing on healthcare services and health related social needs. The initial assessment identified barriers to care that the family was facing. The case manager immediately began working with the family to address these needs and develop a plan of care.

First, his mother gained a better understanding of the importance of the member's pain management of SCD. Together, his mother worked with the NCM to ensure the member could access prescribed opioid pain medications. The care team engaged the MCO Pharmacy Specialist on the prior authorization process, expiration dates, and provider communication to prevent a lapse of coverage. The pharmacy specialist also explained how to the mother could be reimbursed for out-of-pocket expenses if needed.

Next, the NCM worked with the family to understand how diet, mental health, and lifestyle adjustments could help reduce sickle cell crises and manage the iron overload from frequent blood transfusions. An MCO dietitian provided education on a well-balanced diet and supplements to discuss with the hematologist to best support his SCD. They discussed high iron foods, how to avoid overconsumption, and ways to pair them with other foods to reduce the absorption of iron. They also made a dietary plan that was practical to help the member increase his intake of nutrients during times of fatigue. The NCM also supported the member remain connected with his hematologist and made all appointments

Lastly, the NCM screened for health related social needs and identified that the family was facing financial barriers related to payment of utilities. His mother was referred to Southwest Human Resource Agency (SWHRA) and received $250 towards their utility bill which helped greatly.

The member was proud that he did not experience any crises during the time he was engaged with the NCM. Since his case closure, he has not had any further inpatient hospitalizations. He has visited the emergency room only once for a blood transfusion that was preceded by a hematology appointment. He and his mother now have the necessary education, tools, and resources to support his goals to better manage his health.

Support for Non-Medical Risk Factors

TennCare MCOs use a variety of supports to assess for non-medical risk factors. Enrollees are screened for social determinants of health needs during interactive contacts. When needs are identified, specific referrals and resources are provided to begin addressing these needs.

MCOs also use Online Social Services Search Engines and Portals. SDOH platforms provide an online directory of social service

organizations that are accessed by Case Management as well as by enrollees and providers. Individuals can search for free and reduced cost services by zip code. Service domains include food, housing, education, transportation, legal support, and others. Each domain contains sub-categories to address specific needs such as skills and training, utility assistance, and food delivery.

Non-emergency medical transportation (NEMT) is a covered benefit for TennCare enrollees attending an approved service that helps provide access to care when they document that they do not have access to transportation. The program offers three levels of service, curb-to-curb, door-to-door, and bed-to-bed. NEMT includes pharmacy visits to pick up prescriptions.

Each MCOs has utilized innovative solutions to offer on-demand rides for enrollees with certain NEMT needs. For example, the MCOs have partnered with ride-sharing companies to offer on-demand ride shares in addition to traditional NEMT transportation options to better meet the needs of sickle cell disease enrollees when sickle cell disease clinics identify transportation needs for their patients.

ADDITIONAL MCO-SPECIFIC INITIATIVES FOR SICKLE CELL DISEASE

In addition to the programs described above that all TennCare MCOs provide, each MCO has specific care coordination programs to ensure appropriate access to care and improved health outcomes for individuals with sickle cell disease.

Amerigroup Community Care

Amerigroup offers both an Adult and Pediatric Sickle Cell Outreach Program that outreaches to the entire Sickle Cell Disease population and particularly to any new enrollee each month with Sickle Cell Disease who receive immediate outreach. This population has a dedicated Case Manager and Complex Adult and Pediatric Case Managers outreach to the higher acuity enrollees. The case managers have incorporated depression and anxiety screenings to link enrollees to a Behavioral Health specialist if needed. Integrated Case Management ensures the Behavioral and Physical Health needs of these enrollees are met. Amerigroup also has a Reconnection and Advocacy Program in which its ER Diversion team identifies enrollees with sickle cell disease with high ED utilization and performs outreach to this population. Social drivers of health (SDoH) data is used to stratify enrollee risk on a monthly basis providing further insight into enrollees who may appear to be at risk based on Amerigroup's proprietary predictive model but their multiple SDOH needs may raise their overall risk.

The Adult Sickle Cell Preferred Provider Program supports secondary and tertiary prevention interventions based on a comprehensive, multidisciplinary approach. Amerigroup collaborates with preferred providers to achieve program goals and objectives and links all enrollees to preferred providers or Sickle Cell Clinics. Beginning in 2019 with the pediatric sickle cell

population Amerigroup has formed partnerships with multiple providers in every region. With the expansion of the program to include Sickle Cell enrollees of all ages, the partnerships continue to grow and increase. Outreach including face to face visits with all Sickle Cell Disease Centers of Excellence and providers is a newly implemented intervention strengthening Amerigroup's collaborative efforts. Each region has a dedicated point of contact, a 24-hour nurse help line and a 24-hour a day referral process for providers or enrollee self-referrals.

Anthem Community Care Coordination (A3C) is a program addressing enrollee's social determinants of health needs through a face-to-face approach with Preferred Community Health Partners (PCHP). The A3C team provides in-person engagement with a Community Health Worker (CHW) or social worker to address social risk factors for enrollees with sickle cell disease. Field-based CHWs and social workers engage with the enrollees over a period of 30 to 90 days completing a comprehensive assessment identifying gaps and needs, schedule follow-up appointments, connect the enrollee with their primary care provider, support adherence to discharge orders, and link with appropriate community resources.

Collaborative efforts with United Healthcare and sickle centers in the West region have led to a pilot initiative that is underway to help address the barriers and concerns regarding transportation for the sickle cell population especially in rural areas.

BlueCare Tennessee

Population Health Care Management provided for BlueCare enrollees with sickle cell disease based upon the individual's level of risk where engagement strategies and interventions are matched to the enrollee's needs. Case Managers engage with enrollees and develop a personal care plan, bolster knowledge of the disease, facilitate successful self-management, and coordinate access to needed clinical services and social supports. Care plans are tailored based upon the enrollee's developmental life stage including pediatric, adolescent, and adult. A very specific approach is taken with adolescent and adult enrollees who become pregnant. All care plans address pain management, crisis management, resources and supports available, genetic counseling, and adherence to their treatment plan. Case Managers lead regional integrated care teams who support enrollees holistically with connections to their assigned primary care physician, sickle cell disease specialty providers, transportation, and other needed social supports. Behavioral Health Case Managers on the regional teams address pain management, behavioral health conditions, and potential substance use disorders with enrollees. All BlueCare care management staff are provided training on sickle cell disease including the disease process, complications, management and treatment, and opportunities for engagement.

BlueCare will continue to work with Sickle Cell specialty providers and will make personal visits to Sickle Cell specialty centers in 2023. BlueCare data will be shared regarding enrollees seen by these providers including medication use, other utilization patterns, and how we can better support them in coordinating optimal care for enrollees with sickle cell disease. Leaders from BlueCare, in collaboration with TennCare and the other two MCOs, will also seek to engage the

broader Sickle Cell community in supporting primary care providers statewide in improving care and social supports for enrollees with sickle cell disease.

UnitedHealthcare Community Plan of Tennessee

UnitedHealthcare Community and State Plan (UHCCSP) has sickle cell disease specific programs within its population health stratification to support individuals with sickle cell disease and their families ranging from wellness to the highest tier. These programs involve UHCCP case managers working with UHCCSP enrollees and their families to close wellness gaps in care, targeted sickle cell interventions, and addressing social determinants of health. Additionally, case managers assist enrollees navigating the healthcare system through life challenges including milestone changes, maternity, and pain management.

In 2023, UHCCSP introduced the Sickle Cell Disease Management Program (SCDMP), a vendor program that provides tech-enabled care extenders, including nurse care managers, to deliver 24/7 care coordination, psychosocial support, and skills training/mentoring to eligible enrollees with Sickle Cell Disease and their support person. The vendor starts by conducting risk stratification of enrollees based on an analysis of claims and other variables, prioritizing outreach to those with the greatest need as well as the greatest possible financial and quality of life impact from this intervention. After risk stratification the vendor conducts outreach to engage and enroll enrollees in SCDMP and assign each their own tech-enabled team of care extenders according to individualized needs identified through proprietary screens and measures. The vendor's 'Care at Hand' predictive analytics tool is utilized to identify enrollees with elevated risk for admissions/readmissions and potentially avoidable ED utilization. The vendor also utilizes its 'Mindoula Messenger' engagement app to maintain ongoing interaction with SCDMP-registered enrollees after establishing a trusted connection. The vendor collaborates with each enrollee to develop and implement a personalized pain management plan and to address both the medical and social aspects of sickle cell disease. SCDMP will augment UHCCSP's population health efforts of intense case management for sickle cell disease enrollees with the highest needs. SCDMP like programs have had great success in other markets with outreach, engagement, and overall program outcomes.

UHCCSP recognizes that transportation continues to be an area of need in Tennessee. Due to the limits of NEMT driver availability UHCCSP is contracting with Lyft and UberHealth to support its enrollee's transportation needs through a single point of contact for any of the NEMT options.

TENNCARE COLLABORATIONS

Tennessee and TennCare has a complete network of committed sickle cell disease providers. This network participates in a CDC-funded surveillance program for sickle cell disease. Tennessee is one of only eleven states in the nation participating in the program (https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc-data.html). This program provides a

link between the CDC and the TN provider community coordinating the collection and sharing of data from multiple sources with a goal of reducing knowledge gaps about sickle cell disease care. TennCare is a supporter of this program and will continue to identify opportunities learned from the program to improve care for its enrollees.

TENNCARE OPPORTUNITIES

As described, TennCare provides comprehensive coverage for any enrollee with sickle cell disease. Enrollees can receive all clinically indicated medications, treatments, and services through their MCO or the pharmacy benefit. Additionally, through add-on services provided by TennCare's MCO population health teams, enrollees can access programs and services that further meet their needs due to sickle cell disease and optimize their clinical outcomes. Opportunities do still exist to improve the health outcomes and to better support cost-effective care for these enrollees.

Enrollees with sickle cell disease often have multiple chronic medical conditions that increase the clinical risk and complexity of their medical journey. Ongoing education efforts for enrollees and their families on how best to manage their sickle cell disease holistically across all of their chronic conditions can also support improved outcomes. TennCare and its MCOs have developed outreach systems, as outlined in the report, to educate enrollees with sickle cell disease about management of their disease. TennCare and our MCOs will continue to build on these opportunities for ongoing outreach to enrollees to further provide education, supports, and care coordination for their needs

From a medical utilization standpoint, emergency room visits and hospital admissions for vaso-occlusive crises remain an ongoing challenge for individuals with sickle cell disease and a costly site of care for TennCare. Having consistent utilization of preventive services and consistent connections between the enrollee and their primary care physicians and hematologists are critical to reducing these acute events. TennCare and its MCOs have made progress and will continue to increase connections between the MCO care coordination team and the provider community to ensure that enrollees can access all of the services and supports for which they are eligible. All of the MCOs have also identified workflows to help support primary care providers and hematologists treating enrollees to get necessary imaging, diagnostic testing, and other studies as needed. The MCOs have sought input on prior authorization processes and utilization management criteria to streamline where appropriate. TennCare's MCOs will play an ongoing role in encouraging improved communication and coordination between TennCare primary care physicians and specialists to help prevent some of these crises.

Continuing to focus on how TennCare, the MCOs, and the sickle cell provider community can continue strong partnerships to ensure enrollee's access to appropriate care will be an ongoing goal and opportunity. Increased communication and integration between TennCare MCO's clinical programs and the provider community will remain a focus. These efforts will include

coordination of mental health services, especially considering how significantly depression and anxiety can increase overall health care utilization.

Additionally, an important transition point occurs when as an enrollee gets older and progresses from childhood to adulthood. TennCare's MCOs are identifying opportunities to improve support of this transition as adult sickle cell disease enrollees begin to identify new adult primary care providers and specialists to continue their care. Supporting providers and specialists through warm handoffs and strong care coordination at these key inflection points is a focus and continued opportunity for the MCOs and their population health programs targeted at enrollees with sickle cell disease.

An additional area of focus will be on efforts to better address non-medical risk factors that can have an outsized impact on an enrollee's health and health outcomes. As described earlier in the report, food security, transportation needs, and health literacy can all impact the care of an enrollee and on an enrollee's utilization of care. Many innovative solutions to address non-medical risk factors have been deployed by TennCare and there is an important opportunity to leverage these solutions for enrollees with sickle cell disease.

Lastly, with the increasing and potentially promising clinical pipeline for therapeutic and curative treatments for sickle cell disease, TennCare will continue to leverage its pharmacy program to ensure thorough and efficient review of new medications. The TennCare pharmacy team will continue to ensure timely access to medically necessary medications and treatments and identify opportunities to continue learning from pharmaceutical and clinical leadership.

RECOMMENDATIONS TO THE LEGISLATURE

TennCare has solicited input from multiple stakeholders and incorporated their feedback into this report. TennCare also remains committed to receiving ongoing feedback from the legislature, providers, pharmacy industry, patient advocates, and enrollees specifically in reaction to this report or regarding any additional feedback related to sickle cell disease. At this time, TennCare does not recommend any specific legislation with respect to the needs of TennCare enrollees with sickle cell disease. Many of the opportunities highlighted in this report already have targeted initiatives underway or can continue to be accomplished through partnerships with the provider community. TennCare is eager to focus its continued efforts to address areas of improvement that have been identified by enrollees and sickle cell providers. The structure of the TennCare program will readily allow TennCare to continue to make significant strides to accomplish these efforts in partnership with its enrollees and providers. TennCare will continue to update this report on an annual basis and remains deeply committed to its mission to provide high-quality, cost-effective care for all Tennesseans, including those with sickle cell disease.