TennCare Sickle Cell Disease Report
January 15, 2026

BACKGROUND OF TENNESSEE PUBLIC CHAPTER NO. 186 of 2021

PC 186 of 2021 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. Over the past few years, as described in previous TennCare Sickle Cell Disease Reports, TennCare and all three MCOs have continued to have regular meetings with Sickle Cell Providers through forums, onsite and virtual visits, and other avenues of continued feedback and conversation. This report outlines the information required by PC 186 of 2021.

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] This 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

[1] CDC Data and Statistics on Sickle Cell Disease

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 November 2025, TennCare provides healthcare coverage to approximately 1.39 million Tennesseans. All medical data provided in the report is based upon TennCare claims data from Calendar Year 2024 (CY2024).

TENNCARE SICKLE CELL DISEASE KEY POPULATION STATISTICS

Enrollee Demographics

Throughout 2024 TennCare provided healthcare coverage to over 1,400 enrollees diagnosed with sickle cell disease. 56% of enrollees were between 0-20 years of age and 44% were 21 years or older. The average enrollee age was 21 years old. In 2024, there were 183 TennCare enrollees whose primary residence was in the East grand region, 363 in the Middle grand region, 893 in the West grand region. Approximately 87% of the TennCare sickle cell disease population lives in urban areas and 11% in rural areas.[2]

Medical Services and Expenditures

In CY2024, TennCare expenditures for all medical services provided for enrollees with sickle cell disease totaled $22 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
2024	Medication Costs	$6,412,777
2024	Professional Outpatient Services	$4,615,626

[2] Data from TennCare medical claims for CY 2024.

2024	Inpatient Services	$6,841,524
2024	Emergency Department Services	$1,473,256
2024	Labs and Ancillary Services	$2,829,239
2024	TOTAL	$22,172,424

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.

TENNCARE PHARMACY BENEFIT FOR SICKLE CELL DISEASE (SCD)

TennCare covers all drugs approved by the FDA for the coverage of sickle cell disease. This includes an extensive formulary of medications linked here: TennCare Preferred Drug List (PDL).

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. TennCare references the most recent version of these guidelines, which are linked here:

ASH Clinical Practice Guidelines on Sickle Cell Disease

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. Furthermore, it is essential to understand the barriers of care from the patient perspective (e.g. transportation) to ensure adherence to care. Health providers should have access to the best scientific evidence that focuses on identification and treatment of complications that affect the heart, lungs, and kidneys, and should use this evidence to make shared decisions with patients. Progressive organ damage is one of the primary causes of early death in the sickle cell population. 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. Additionally, patients who experience acute vaso-occlusive crises (VOCs) 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) 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 both FDA-approved through an accelerated approval pathway for the treatment of sickle cell disease in November 2019. Adakveo is accessible for TennCare enrollees with sickle cell disease who meet the clinical coverage criteria for this treatment. Oxbryta was granted FDA-approved for the treatment of sickle cell disease for children ages 12 and older in 2019. The FDA expanded Oxbryta's indication to include patients 4 years of age and older in December 2021. Unfortunately, Oxbryta, was voluntarily withdrawn from the market by the manufacturer in September 2024. The decision to discontinue the agent was based on clinical data that demonstrated the overall benefit of Oxbryta no longer outweighed the risks (i.e. VOCs and fatal events) in the approved sickle cell population.

TennCare's pharmacy benefit focuses on providing effective and appropriate FDA-approved outpatient 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 TennCare through our pharmacy and/or medical benefit. Most agents have clinical criteria outlined to help support evidence-based pharmacy coverage. Other agents such as Adakveo are available via the medical benefit. TennCare continuously collaborates with its managed care partners to ensure seamless access through the medical benefit for members with SCD.

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 and Endari, require prior approval before a prescription can be dispensed. Endari (l-glutamine powder) is indicated to reduce the acute complications of sickle cell disease in adult and pediatric patients 5 years of age and older. In

February 2025, initial prior authorization criteria for Endari was modified to require only a diagnosis, use in combination with hydroxyurea or trial/failure, contraindication or intolerance of hydroxyurea, and weight-based dosing. Additionally, Siklos (hydroxyurea tablets) prior authorization criteria was modified with removal of renewal criteria. Thus, in an effort to reduce barriers to care and continue support of appropriate care, all Siklos requests require only a diagnosis of sickle cell anemia and either patient is unable to swallow hydroxyurea capsules or requires dosing that is not available with the preferred hydroxyurea agent.

The enrollee, physician, or an authorized agent of the healthcare provider can initiate routine utilization management processes such as prior approval and step therapy to ensure 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.

As a reminder, the 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.

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 disease 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 currently 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. 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. Additionally, following input from healthcare providers and sickle cell disease forums, TennCare submitted proposed changes to its opioid policies in 2024. These policy changes enable individuals with SCD who suffer from more frequent or severe pain crises to receive opioid based treatment exceptions tailored to their individual needs. TennCare received approval for modifications to the opioid policy in 2025.

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

TABLE 2 – Medication Use by TennCare Enrollees with Sickle Cell Disease in 2024[2]

Calendar Year	Number of Enrollees Receiving Prescriptions	Percentage of Enrollees Receiving Prescriptions	Average number of Prescriptions for Enrollees
2024	1,396	86.6%	23

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

TABLE 3 – Opioid Use by TennCare Enrollees with Sickle Cell Disease in 2024[2]

Calendar Year	Number of Enrollees Receiving Opioids	Percentage of Enrollees Receiving Opioids	Number of Opioids Prescribed	Total Cost
2024	740	45.9%	238,081	$269,781

Additionally, TennCare continues to follow the emerging clinical pipeline of 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. TennCare closely tracks the FDA approval processes of all emerging sickle cell treatments based on review of clinical trials. 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. On December 8, 2023, the FDA approved the first two cell-based gene therapies for SCD, exagamglogene autotemcel (Casgevy) and lovotibeglogene autotemcel (Lyfgenia). The cell-based gene therapies provide unique opportunities to develop innovative strategies to manage access and utilization while ensuring safety and efficacy. The upfront cost for cell-based gene therapy is high, but these transformative therapies have the potential to reduce health care spending over time by addressing the underlying causes of disease, reducing the severity of illness, and reducing health care utilization. Cell-based gene therapies (CGT) are currently accessible through the TennCare MCOs when medically indicated. Links are included below to additional information detailing the MCOs' CGT access and prior authorization criteria.

MCO links related to Cell-Based Gene Therapies for Sickle Cell Disease:

BlueCare Gene Therapy Clinical Guidelines:

- BlueCare CGT Specific Link: Casgevy
- BlueCare CGT Specific Link: Lyfgenia

UHC Gene Therapy Clinical Guidelines

Wellpoint Gene Therapy Clinical Guidelines

TENNCARE SICKLE CELL DISEASE POPULATION HEALTH AND CARE COORDINATION

TennCare provides a comprehensive Population Health program through its Managed Care Organizations for all enrollees, including 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 clinical support and care coordination for enrollees across the entire care continuum, offering health education and promoting healthy behaviors and disease self-management. Enrollees with identified needs can receive care coordination and thorough care management services through MCO care managers, who help them access a wide range of 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 cohorts ranging from minimal clinical risk to high clinical risk. Each cohort 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 in the risk stratification along with the entire population. Individuals with sickle cell disease may be stratified into low or high-risk cohorts, depending upon their underlying sickle cell disease characteristics and any accompanying chronic conditions. Many individuals with sickle cell disease fall into the high-risk category, including those with high inpatient or emergency department utilization and those receiving cell and gene therapy.

Care Coordination is impactful for enrollees with sickle cell disease as it assists with acute healthcare needs, health service needs (including the transition from pediatric to adult care), or risks needing immediate attention. The goal of Population Health and Care Coordination Services is to make sure enrollees receive the services they need to prevent or reduce adverse health outcomes. The care management team can also work with an enrollee's primary care provider, specialists, and other care providers to provide wraparound 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, Utilization Management and Enrollee Resource Coordinator. The member's primary care provider and/or specialist also serves as an integral part of the care team.

Enrollee Story

As part of a targeted outreach initiative for young adult members, an MCO case manager reached out to 18-year-old "Joseph" and his father to discuss his upcoming transition from pediatric to adult sickle cell care. Joseph had previously been receiving care at a Pediatric Center of Excellence. To ensure continuity and quality of care, the case manager collaborated with the enrollee and his father to initiate the transition to an Adult Center of Excellence for members with Sickle Cell Disease.

Further, to address immediate needs, the case manager assisted in locating a new dental provider and provided essential resources to the family, including contact information for the 24/7 nurse line, Member Services, and the Healthy Rewards program. Additionally, the case manager sent the family details on TennCare's transportation benefits via text message.

Recognizing the importance of addressing Social Determinants of Health (SDoH), the case manager referred the enrollee to an internal Community Engagement Navigator, who conducted a comprehensive SDoH assessment that identified needs for rental and financial assistance. The Navigator connected the family with key community partners, including the Delta Human Resource Agency, Metropolitan Inter-Faith Association (MIFA), Ground Game, Patient Assistance Fund, and the Sickle Cell Foundation.

Follow-up confirmed that the enrollee was accepted into the Sickle Cell Foundation program, which provides financial assistance, social support, educational resources, and advocacy. The father also reported progress in transitioning his son to an adult physician at a Center of Excellence. This coordinated effort between case manager and family ultimately enhanced Joseph's quality of life and promoted continuity of care through a difficult time of transition.

Member Outreach and Engagement

TennCare utilizes a variety of methods to conduct outreach to enrollees. The MCOs outreach to individuals telephonically, digitally, by interactive voice response (IVR), secure enrollee portals, and by mail. MCOs conduct face-to-face interactions, teleconference calls, digital care management, 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, scheduling appointments, getting to urgent care centers or walk in clinics, or speaking directly with a doctor's office about health care needs.

At a minimum, enrollees in a low-risk category receive at least four communications each year, addressing self-management education and 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, self-efficacy and support, and the availability of community resources. MCOs also offer individual support for self-management if the enrollee desires it, including health coaching and a 24/7 Nurse Line. 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 that link the enrollee to 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

A 50 year old female, "Ella," was identified by her MCO for Complex Case Management following an authorization request for sickle cell gene therapy. Despite adherence to her prescribed treatment plan, Ella continued to experience severe pain and frequent emergency room visits as well as hospitalizations. Her disease was complicated by deep vein thromboses (DVTs), pulmonary emboli (PE), and joint necrosis.

After referral to a center offering gene therapy, Ella was identified as an excellent candidate for gene therapy. However, while hopeful, she experienced several barriers that threatened to delay her progress.

First, Ella was concerned about the cost of obtaining dental clearance, a required step in the gene therapy process. She was unaware that her TennCare benefits included dental coverage and had been paying out-of-pocket. Her MCO case manager provided education about her dental benefits, and Ella succeeded in scheduling a dental appointment with her insurance coverage.

Unfortunately, her dental office then closed without notice after completing only half of her dental work. Ella was left without medical records and in need of a new provider. Her MCO case manager provided a list of in-network dentists, and she was able to schedule another dental appointment with a new provider. Through advocacy by her dental benefit manager, she was also able to avoid new charges for repeat x-rays due to missing records.

Another challenge was the requirement to travel weekly to her new Center, 3 hours away, for care. Her MCO case manager coordinated care between her home Center and the gene therapy center to allow some aspects of her care to be performed locally, closer to home.

Ella remains on her journey toward gene therapy with support from her family and care team. Her case manager remains actively engaged through weekly outreach, providing guidance, advocacy, and resources.

Support for Health-Related Social Needs

Medical evidence continues to establish that up to 80% of an individual's health is directly influenced by health-related social needs, often referred to as the social determinants of health (SDOH). Needs like transportation, food security, and safe housing can all have a major impact on an individual's health. TennCare has been working to help identify and provide referrals and resources to individuals who may be able to benefit from these services through community organizations and other supports. TennCare MCOs work closely with enrollees to screen for social determinants of health during interactive contacts. When needs are identified, specific referrals and resources are provided to begin addressing these needs.

In 2024, TennCare began working with Findhelp to implement a social needs resource directory and closed loop referral system called Tennessee Community Compass. This social needs platform provides an online directory of social service organizations that can be accessed by MCO 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. Additionally, the platform allows TennCare MCOs and a growing network of providers to place referrals to social needs organizations and follow up on their status.

For transportation needs, non-emergency medical transportation (NEMT) is a covered benefit for TennCare enrollees attending an approved service. NEMT helps provide access to care when enrollees 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 MCO 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 and disease-specific programs to ensure appropriate access to care and improved health outcomes for individuals with sickle cell disease.

BlueCare Tennessee

Throughout 2025, a BlueCare interdisciplinary workgroup met monthly to collaborate on improvements to SCD member and provider interventions, review BlueCare member data, and operationalize processes for members authorized for new gene therapies. New and enhanced program interventions resulting from this collaboration included changes to the member identification process, updates to assessments and care plans, refinements to case management processes, and continuation of a Sickle Cell Clinical Advisory Panel.

BlueCare's Sickle Cell Clinical Advisory Panel (CAP) serves as a forum for ongoing collaboration with network providers and key stakeholders, including physicians, pharmacists, advocates, and state leaders across Tennessee. The Sickle Cell CAP was developed to collaborate on best practices to improve health outcomes and access to care, address barriers that significantly impact health outcomes, and strengthen outreach and engagement strategies for members living with sickle cell disease. Biannual meetings have included strong attendance from a wide variety of stakeholders and have covered topics such as BlueCare behavioral health resources, SSI/SSDI application resources including community health worker assistance with applications, and medication adherence data review.

All BlueCare members with a diagnosis of sickle cell disease receive an educational Sickle Cell Guide that addresses healthy habits for living with sickle cell, annual PCP visits for children and adults, vaccinations, medications, transport, planning for pregnancy, planning for

appointments, treatment options, and BlueCare care team resources. A total of 665 guides were mailed to members in 2025. For members with complex needs, including members with high emergency department and inpatient utilization as well as those undergoing cell and gene therapy, BlueCare has adopted additional, proactive strategies to promote engagement. New strategies included text messaging, doubling the number of outreach attempts, and reducing the intervals between contacts. These enhancements drove improvements in engagement within the Complex Case Management cohort, with a 38% increase in participation as of October 2025 compared to year-end 2024.

During September, BlueCare observed Sickle Cell Awareness Month by hosting a training webinar presented by Vertex Pharmaceuticals and inviting participation from all MCOs. The session, which drew 90 attendees, focused on sickle cell gene therapy, shared educational resources, and explored opportunities to enhance clinical and operational strategies for addressing SCD. Throughout the year, BlueCare also engaged in additional learning opportunities, including ongoing participation in Methodist SCD Clinic Lunch and Learns and attendance at the "Sickle Cell Disease Comprehensive Management for Healthcare Providers" conference hosted by the UT Health Sciences Center. These expert-led trainings helped enhance BlueCare's outreach and care management efforts.

Finally, BlueCare continued its commitment to supporting community partners in serving and advocating for the Sickle Cell population. BlueCare again participated in the Methodist Comprehensive Sickle Cell Center's Community Health Fair, where health promotion activities included sickle cell trait testing and attendees received guidance from a BlueCare Social Worker and CHOICES Community Advocate on Sickle Cell management, along with resources and benefit information. BlueCare also again promoted the Breaking the Sickle Cell Cycle Foundation's "Merry Christmas Bash" to members in the Middle TN region through text messaging. This event, aimed at children, families and caregivers affected by sickle cell disease, provided food, gifts, and other essential items during the holidays.

UnitedHealthcare Community Plan of Tennessee

UnitedHealthcare continues to focus on advancing targeted interventions for members with sickle cell disease through detailed analysis of population demographics, SDOH needs, and service utilization trends. This approach reinforces a commitment to delivering the right care at the right time for every member.

In late 2024, UnitedHealthcare Community and State Plan (UHCCSP) enhanced its outreach model to improve engagement with adolescents and young adults living with sickle cell disease. This enhancement was driven by engagement and population data, which revealed an opportunity to expand reach beyond the highest-risk members and engage a broader

population, particularly those preparing for the critical transition from pediatric to adult care. Changes in the outreach model delivered measurable improvements in engagement among this population.

Additionally, UHCCP actively worked to identify members with high utilization, including those with recurrent inpatient or emergency department visits, who may benefit from enhanced collaboration and support. These members were reviewed during interdisciplinary rounds to address transition-of-care needs, social determinants of health (SDOH), and opportunities for case management referrals or team interventions for those already engaged. The team also assessed member engagement with essential provider services such as primary care, specialty care, and behavioral health to ensure comprehensive coordination across all aspects of care.

UnitedHealthcare also strengthened its presence in community-based initiatives to support individuals living with sickle cell disease. These efforts included a strong partnership with the Sickle Cell Foundation of Tennessee, in which UnitedHealthcare actively participated in member clinical discussions, provided panelists for educational events, and volunteered at the annual Sickle Cell Walk.

Wellpoint

Wellpoint remains committed to delivering comprehensive and empathetic care for its members with sickle cell disease (SCD). Over the past year, Wellpoint received monthly enrollment reports for newly enrolled members with sickle cell disease and conducted outreach to confirm specialist connections and medication access. A dedicated case manager served this population exclusively. Additionally, Wellpoint received quarterly behavioral health reports identifying members with SCD who have high emergency department utilization. Outreach was conducted to these members with recommendations for care navigation.

Recognizing the challenges associated with transitioning from pediatric to adult care, especially given the ongoing management needs of members with SCD, Wellpoint also continued to focus outreach efforts on members aged 18-21. This initiative facilitated several successful transitions into adulthood, where members receive coordinated support services tailored to their evolving healthcare needs.

Finally, in 2025, Wellpoint strengthened collaboration with Sickle Cell Centers of Excellence and key providers statewide through face-to-face meetings, calls, and email introductions. These included Quality of Life Cancer & Hematology Center, UT Hematology, East TN Children's Hospital, Erlanger Children's Hospital, St. Jude SCD Unit, Methodist Hospital SCD Center, and Regional One-Diggs-Krause Sickle Cell Center.

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 (CDC Sickle Cell Data Collection Program). 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, TennCare's MCO population health teams enable enrollees to access care management 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. Some enrollees also face behavioral health challenges alongside medical challenges. TennCare's MCOs are continuing efforts to improve methods of engagement for members with medical complexity. As highlighted above, the MCOs are utilizing a variety of outreach methods to connect with members, build trust, and provide the supports needed to manage multiple diagnoses and specialty needs. MCO engagement strategies continue to evolve and improve year by year. The MCOs are also continuing to partner directly with Sickle Cell Centers across the state to identify areas in which increased supports are needed for enrollees. TennCare and the MCOs will continue prioritizing efforts to strengthen outreach and engagement efforts so that all members with medical complexity who desire support have the opportunity to participate in MCO educational and case management services.

Unmet health-related social needs such as transportation, food, and housing continue to impact TennCare members, including those with sickle cell disease. Since 2021, through its Health Starts initiative, TennCare has been working to build new systems that better address members' social needs. The Health Starts initiative supports providers across the state who are implementing social needs screenings into workflows and designing systems to connect members to community resources when needs are identified. Health Starts is also supporting

pilots of community health workers within provider practices statewide and implementation of a social needs resource directory and closed loop referral system (Tennessee Community Compass, or TNCC) to better support addressing members' social needs. In the coming year, new provider partnerships will increase identification of social needs and access to critical community resources for TennCare members, including those with sickle cell disease. Additional community-based organizations will be added to the TNCC platform, expanding its impact statewide for all users. Additional agencies employing community health workers will apply for CHW Program Accreditation, reflecting their fidelity to high-quality, evidence-based CHW practices. As these program expansions occur, TennCare will continue to monitor outcomes and evaluate impact of the Health Starts pilot and investments.

Federal and state partnerships also offer new opportunities in the coming year. TennCare is currently participating in a federal opportunity, the Cell and Gene Therapy (CGT) Access Model, led by the Centers for Medicare & Medicaid Services' Innovation Center (CMMI). The Model aims to improve access to cell and gene therapies as well as health outcomes for Medicaid members while reducing healthcare utilization and expenditures. In 2024, sickle cell disease was identified as the first focus of the Cell and Gene Therapy Access Model. The Model negotiated with CGT manufacturers on behalf of states in order to lower prices and improve states' abilities to pay for CGT while also aligning payments to health outcomes. The CGT Access Model will further assist TennCare in streamlining coverage pathways and developing operational infrastructure to ensure medically appropriate access as these new therapeutic agents become more widely utilized. In 2025, TennCare regularly convened MCO clinical and pharmacy leadership to prepare for implementation of the Model. TennCare provided guidance to the MCOs regarding billing, coding, and process requirements set forth by CMMI. Tennessee met all necessary requirements and is actively implementing the model for all approved therapeutics to begin in 2026. TennCare will continue to monitor implementation and evaluate the model's ability to improve access and outcomes for Tennesseans.

Finally, the transition from adolescence to young adulthood and from pediatrics to adult medicine continues to represent an area of ongoing opportunity for TennCare. As young people navigate emerging independence, those with chronic diseases also face transitions in primary care providers and specialists and new responsibility for their own appointments and medication adherence. Without support through these transitions and strong coordination of care, critical aspects of care may fall through the cracks. Over the past year, the MCOs have continued to prioritize efforts to support age-based transitions of care through digital and electronic outreach focusing on holistic member assessment. Facilitating smooth and well-coordinated transitions of care for this population remains a continued and relevant area of opportunity for the MCOs moving forward.

RECOMMENDATIONS TO THE LEGISLATURE

TennCare has solicited input from multiple stakeholders and incorporated their feedback into this report. Throughout 2025, TennCare continued to meet with multiple different stakeholders including industry, sickle cell provider groups, researchers, legislators, patient advocates, and enrollees who all provided valuable feedback. TennCare remains committed to receiving ongoing feedback related to better supporting enrollees with sickle cell disease or as feedback to this report.

Many of the additional opportunities highlighted in this report already have targeted initiatives underway through partnerships with the provider community. No further specific legislation at this time is recommended as TennCare is actively working to address areas of improvement that can continue to be accomplished through existing partnerships and pathways available to TennCare. The structure of the TennCare program readily allows 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.