

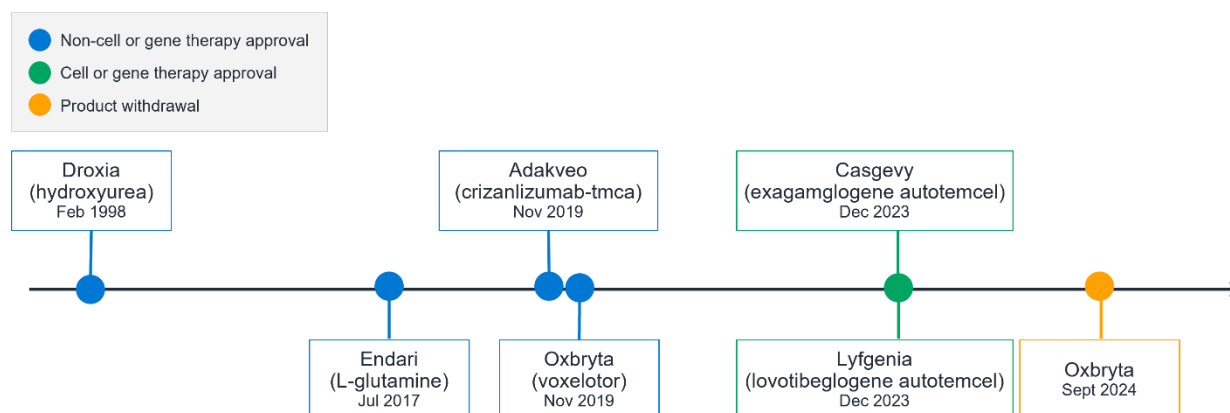
Understanding barriers to access for sickle cell disease therapies

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Introduction

Sickle cell disease (SCD), although rare, is a highly debilitating condition, impacting both patients and their families.¹ In the last few years, significant advancements were made in treating this condition. Prior to 2019, few therapies were approved specifically for SCD, and they were not fully successful in preventing and relieving associated occlusive crises that may arise.^{2,3} However, in the last six years, four new treatments were approved to treat SCD, and three are currently available, as shown in Figure 1.

FIGURE 1: TIMELINE OF THERAPY LAUNCHES AND WITHDRAWALS FOR SCD IN THE U.S.



Oxbryta was removed from the market in 2024 after risks were seen to outweigh clinical benefit, leaving five therapies remaining.^{4,5,6} Two of the therapies, Casgevy and Lyfgenia, are novel single-administration gene therapies that work to address the root cause of the condition by adjusting a patient's genes to remove or fix the sickling gene.⁷ These

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2. Ballas, S. K., Bauserman, R. L., McCarthy, W. F., Castro, O. L., Smith, W. R., Wacławski, M. A., & Investigators of the Multicenter Study of Hydroxyurea in Sickle Cell Anemia. (2010). Hydroxyurea and acute painful crises in sickle cell anemia: Effects on hospital length of stay and opioid utilization during hospitalization, outpatient acute care contacts, and at home. *Journal of Pain and Symptom Management*, 40(6), 870–882. <https://doi.org/10.1016/j.jpainsymman.2010.03.020>

3. Zaidi, A. U., Estep, J., Shah, N., Alkindi, S., Ezzat, H., Lam, H., & Minniti, C. P. (2021). A reanalysis of pain crises data from the pivotal L-glutamine in sickle cell disease trial. *Contemporary Clinical Trials*, 110. <https://doi.org/10.1016/j.cct.2021.106546>

4. U.S. Food and Drug Administration. (2024, March 18). Novel drug approvals for 2019. U.S. Department of Health and Human Services. Retrieved May 28, 2025, from <https://www.fda.gov/drugs/novel-drug-approvals-fda/novel-drug-approvals-2019>.

5. U.S. Food and Drug Administration. (2024, January 24). 2023 biological license application approvals. U.S. Department of Health and Human Services. Retrieved May 28, 2025, from <https://www.fda.gov/vaccines-blood-biologics/development-approval-process-cber/2023-biological-license-application-approvals>.

6. Pfizer Inc. (2024, September 25). Pfizer voluntarily withdraws all lots of sickle cell disease treatment OXBRYTA® (voxelotor) from worldwide markets [Press release]. Retrieved May 28, 2025, from <https://www.pfizer.com/news/press-release/press-release-detail/pfizer-voluntarily-withdraws-all-lots-sickle-cell-disease>.

7. U.S. Food and Drug Administration. (2023, December 8). FDA approves first gene therapies to treat patients with sickle cell disease [Press release]. U.S. Department of Health and Human Services. Retrieved May 28, 2025, from <https://www.fda.gov/news-events/press-announcements/fda-approves-first-gene-therapies-treat-patients-sickle-cell-disease>.

therapies may be used in patients age 12 and older, and they bring a high treatment cost. Both are priced more than \$2 million (\$2.2 million for Casgevy and \$3.1 million for Lyfgenia), which does not account for any associated healthcare costs related to the administration process.^{8,9}

Although these therapies represent life-saving innovation, the high cost has sparked discussion about patient access and payer affordability for gene therapies. bluebird bio has estimated that 20,000 patients may be eligible for their therapy, Lyfgenia. As of March 2025, bluebird bio reported 32 patients started cell collection and revenue indicating approximately four patients had been treated by the end of 2024.¹⁰ Similarly, Vertex Pharmaceuticals reported 50 patient starts and revenue in 2024, reflecting approximately four patients treated that year.¹¹ Access to therapy includes many factors, such as financial and other barriers to patients gaining access to these life-altering medications.

This paper discusses various barriers within the cell and gene therapy (CGT) administration journey that may affect potential patients living in various locations across the United States.

Background

SCD is a genetic disease estimated to affect approximately 100,000 people in the United States. About one of every 365 Black or African American births and one of every 16,300 Hispanic births result in some form of SCD.¹²

Most individuals with SCD are covered under Medicaid (>50%) or Medicare (~10%).^{13,14} A 2023 study found the average life expectancy for these enrollees to be 52.6 years, which is approximately 20 years shorter than that of the average American.¹⁵ Some patients are living long enough to age into Medicare, but most Medicare coverage in the SCD patient population stems from chronic renal failure and dialysis needs related to SCD.¹⁶ The severe morbidity and decreased life expectancy associated with SCD contribute to the demand for a CGT alternative that could address the root cause of this condition.

Barriers to SCD CGT access

GEOGRAPHIC ACCESS

All CGTs are administered only at approved sites where providers have undergone specifically designated training from the manufacturer. These may be called authorized or qualified treatment centers (ATCs or QTCs). In addition to needing an ATC for drug administration, both Casgevy and Lyfgenia are therapies with a lengthy treatment process where the pre-administration and post-administration steps also occur at the ATC. Prior to receiving the active drugs,

8. U.S. Food and Drug Administration. (2023, December 8). FDA approves first gene therapies to treat patients with sickle cell disease [Press release]. U.S. Department of Health and Human Services. Retrieved May 28, 2025, from <https://www.fda.gov/news-events/press-announcements/fda-approves-first-gene-therapies-treat-patients-sickle-cell-disease>.

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11. Vertex Pharmaceuticals Inc. (2025, February 10). Vertex reports fourth quarter and full year 2024 financial results [Press release]. Retrieved May 28, 2025, from <https://investors.vrtx.com/news-releases/news-release-details/vertex-reports-fourth-quarter-and-full-year-2024-financial>.

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13. Scott, M. J., Valentine, A., Darlington, D., & Howell, B. (2023). 2023 Medicaid access and landscape review for sickle cell disease. Sick Cells. Retrieved May 28, 2025, from <https://sickcells.org/wp-content/uploads/2024/04/2023-Medicaid-Access-and-Landscape-Review-for-SCD.pdf>.

14. Wilson-Frederick, S. M., Hulihan, M., Blaz, J., & Young, B. M. (2019, June). Prevalence of sickle cell disease among Medicare fee-for-service beneficiaries, age 18-75 years, in 2016. Centers for Medicare & Medicaid Services. Retrieved May 28, 2025, from <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Data-Highlight-15-Sickle-Cell-Disease.pdf>.

15. Jiao, B., Johnson, K. M., Ramsey, S. D., Bender, M. A., Devine, B., & Basu, A. (2023). Long-term survival with sickle cell disease: A nationwide cohort study of Medicare & Medicaid beneficiaries. Blood Advances, 7(13), 3276–3283. <https://doi.org/10.1182/bloodadvances.2022009202>

16. Wilson-Frederick, S. M., Hulihan, M., Blaz, J., & Young, B. M. (2019, June). Prevalence of sickle cell disease among Medicare fee-for-service beneficiaries, age 18-75 years, in 2016. Centers for Medicare & Medicaid Services. Retrieved May 28, 2025, from <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Data-Highlight-15-Sickle-Cell-Disease.pdf>.

patients require red blood cell transfusions (pre-mobilization stage), receive medications to produce stem cells, and undergo stem cell collection (mobilization and apheresis). Apheresis may take multiple cycles before enough stem cells have been collected. Once the CGT is received, patients remain hospitalized for monitoring. Hospitalization depends on the therapy received and the patient's response to therapy. Thus, the proximity of the ATC to the patient's residence becomes important.

Given the complexity of the treatment administration, it is very possible that the closest treatment center is not in the metropolitan statistical area (MSA) where a patient resides. Using Milliman's Consolidated Health Cost Guidelines™ Sources Database (CHSD), we determined SCD prevalence rates per 100,000. We found that less than half of patients age 12 to 75 years with SCD have a treatment center within the MSA in which they live.

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Figure 2 depicts the SCD prevalence rate per 100,000 insured members, the percentage of members with an ATC in their MSA, and the percentage who had a diagnosis of at least one social determinant of health (SDOH) by payer type. To be included, members had to have continuous enrollment for 2023 and be age 12 to 75 years. Figures 3 and 4 display the prevalence rates by geographic location along with the locations of facilities registered as ATCs for these two SCD therapies. Figures C and D in the Appendix provide the prevalence rates by state.

We compared our managed Medicaid prevalence rates to those previously published using the 2017 Centers for Medicare & Medicaid Services (CMS) Transformed Medicaid Statistical Information System (T-MSIS) data, which is a 100% sample. For states that had at least 2,000 continuously enrolled members where at least one individual was identified with SCD, our calculated prevalence was within $\pm 25\%$ of the T-MSIS value for half of those states.¹⁷ A comparison of prevalence rates by state can be found in Figure D within the Appendix.

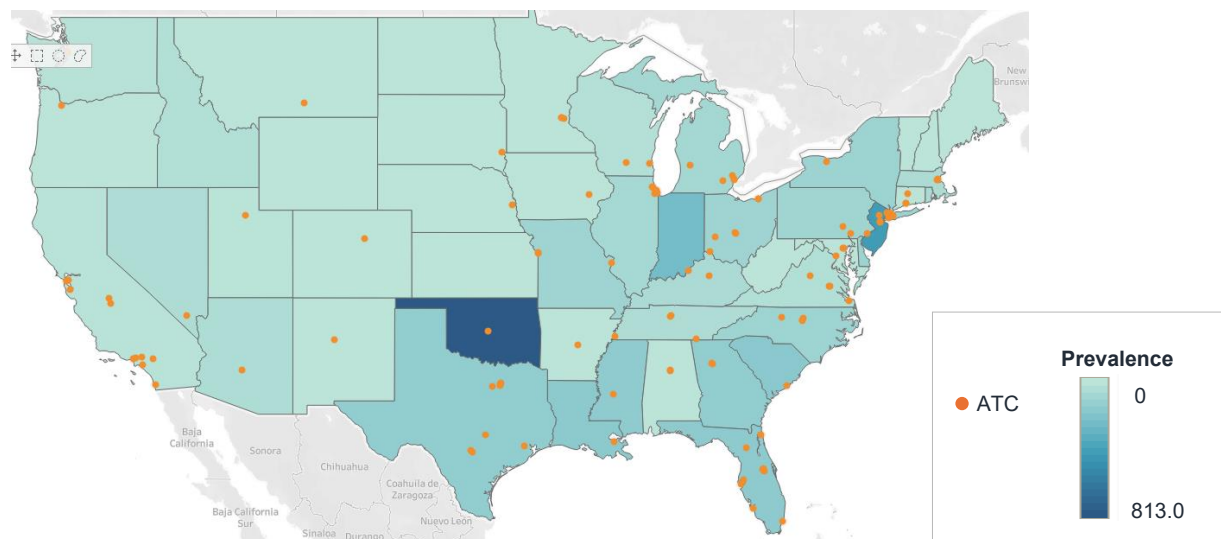
FIGURE 2: 2023 SCD PREVALENCE BY PAYER

PAYER	PREVALENCE RATE PER 100,000*	PERCENT WITH ATC	PERCENT WITH SDOH†
Employer-sponsored	11.27	44%	4%
Managed Medicaid	72.38	49%	14%

*Had at least two claims that included a SCD diagnosis code (D571, D572, or D574).

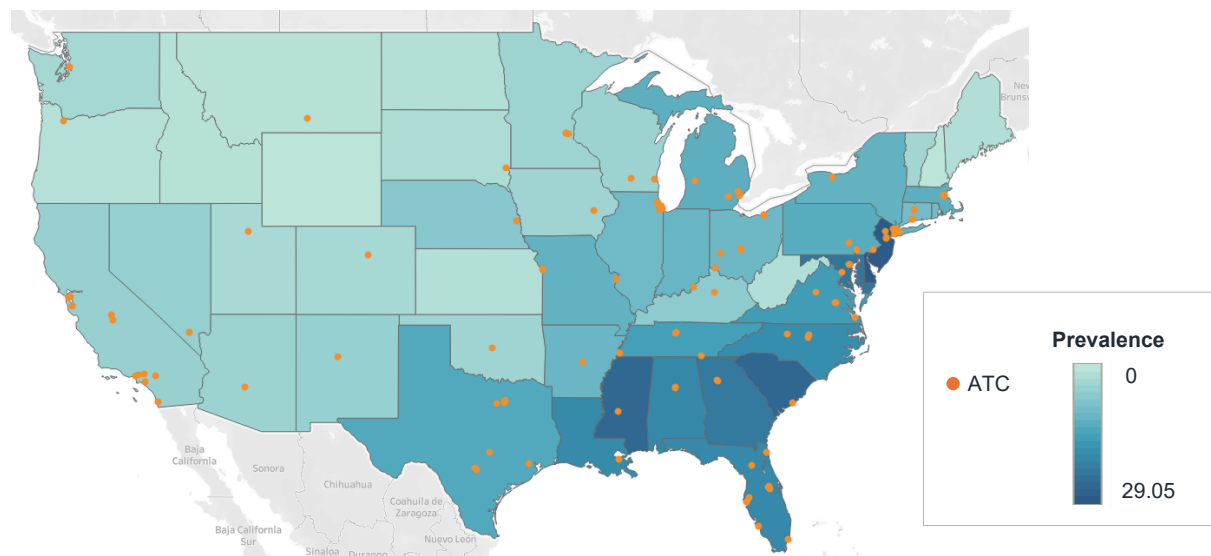
†Lack of SDOH diagnosis may be indicative of incomplete data rather than absence of diagnosis.

17. Wilson-Frederick, S. M., Hulihan, M., Mangum, A., Khan, T., Geibel, M., Malsberger, S., Verghese, S., et al. (2021). Medicaid and CHIP sickle cell report, T-MSIS Analytic Files (TAF) 2017. Centers for Medicare & Medicaid Services. Retrieved May 28, 2025, from <https://www.medicaid.gov/sites/default/files/2021-01/scd-rpt-jan-2021.pdf>.

FIGURE 3: PREVALENCE OF SCD PER 100,000 MANAGED MEDICAID INSURED POPULATION ALONG WITH CASGEVY OR LYFGENIA ATCS

Source: Milliman CHSD 2023 Managed Medicaid Claims

In Alabama, Arkansas, Colorado, Connecticut, Iowa, Kansas, Maryland, Maine, Minnesota, Montana, North Dakota, Nebraska, New Hampshire, New Mexico, South Dakota, Vermont, West Virginia, and Wyoming, we identified no enrolled Managed Medicaid members with SCD in our data; however, this should not be interpreted as confirming the absence of SCD in these states.

FIGURE 4: PREVALENCE OF SCD PER 100,000 EMPLOYER-SPONSORED HEALTH INSURED POPULATION ALONG WITH CASGEVY OR LYFGENIA ATCS

Source: Milliman CHSD 2023 Commercial Claims

In New Hampshire and Wyoming, we identified no enrolled commercially-insured members with SCD in our data; however, this should not be interpreted as confirming the absence of SCD in these states.

Mapping the prevalence of SCD by state alongside the locations of ATCs reveals potential significant distances a patient may need to travel. While some treatment centers are situated in areas with high SCD prevalence, others are located in regions with lower demand. Maximizing ATCs in areas with greater SCD prevalence can optimize resource utilization and increase capacity within an ATC.

HOSPITAL AND MANUFACTURING CAPACITY

The infrastructure for gene therapy delivery is intricate, requiring a multidisciplinary team, coordination with specialized healthcare providers, and specialized reimbursement personnel to ensure billing and coding is completed accurately and there is good communication with the payer. Depending on the ATC, the treatment capacity for the SCD CGT may be only one to two patients a year.

The hub-and-spoke model that connects community healthcare practices with specialized clinical centers of excellence (COEs) is one approach to addressing some of these complexities. Patients and their caregivers may not have the capacity to travel to the nearest ATC for all the steps in the process. Implementing such networks can enhance patient access to expert facilities while providing relevant care locally when certain process steps can be conducted closer to home. Scaling this model requires standardized care frameworks, adequate COE availability, and assured reimbursement policies.¹⁸

Similarly, manufacturing gene therapies that use a patient's own cells involves complex processes that include stringent quality control and validation. Challenges, such as supply chain constraints, scalability issues, and maintaining product purity, can impede the availability of these therapies for use at ATCs. Ensuring that manufacturing capacity keeps up with demand and a consistent supply of high-quality product will be crucial for achieving broader treatment goals.^{19,20,21,22}

PATIENT JOURNEY THROUGH TREATMENT WITH A SCD CGT^{23,24}

As partially described above, the patient journey to receive one of these potentially life-altering therapies is long. Once a patient is deemed a candidate, they are referred to an ATC, where a comprehensive assessment is conducted to evaluate their physical health, behavioral health, and social support needs. Social support needs may include transportation and travel expenses. If a decision to move forward with the therapy is reached, the patient stops their current therapy and receives chronic transfusion therapy for two to three months (pre-mobilization). The mobilization and apheresis phase requires a hospital stay for approximately one week. Unfortunately, patients may need to complete the stem cell collection more than once, with a few weeks in between collection periods. This step can last anywhere from one to six months depending on the number of collections needed. The collected stem cells are then modified by the manufacturer, which may take up to six months. When Casgevy or Lyfgenia is ready, the

18. Bhatia, S., Le Cam, Y., Carrion, J., Diamond, L., Fennessy, P., Gassman, S., Gutzwiller, F., et al. (2024). Strengthening health systems for access to gene therapy in rare genetic disorders. *Molecular Therapy: Methods & Clinical Development*, 32(2). <https://doi.org/10.1016/j.omtm.2024.101220>

19. Lee, N. K., & Chang, J. W. (2024). Manufacturing cell and gene therapies: Challenges in clinical translation. *Annals of Laboratory Medicine*, 44(4), 314–323. <https://doi.org/10.3343/alm.2023.0382>

20. Livshits, G. (2023). Uncovering manufacturing challenges behind cell and gene therapy. *GEN Biotechnology*, (2)3. <https://doi.org/10.1089/genbio.2023.29102.gli>

21. bluebird bio. (2024, December 8). bluebird bio presents positive long-term data on LYFGENIA™ (lovotobegligene autotemcel) gene therapy for sickle cell disease at 66th American Society of Hematology (ASH) Annual Meeting and Exposition [Press release]. Retrieved May 28, 2025, from <https://investor.bluebirdbio.com/news-releases/news-release-details/bluebird-bio-presents-positive-long-term-data-lyfgeniattm>.

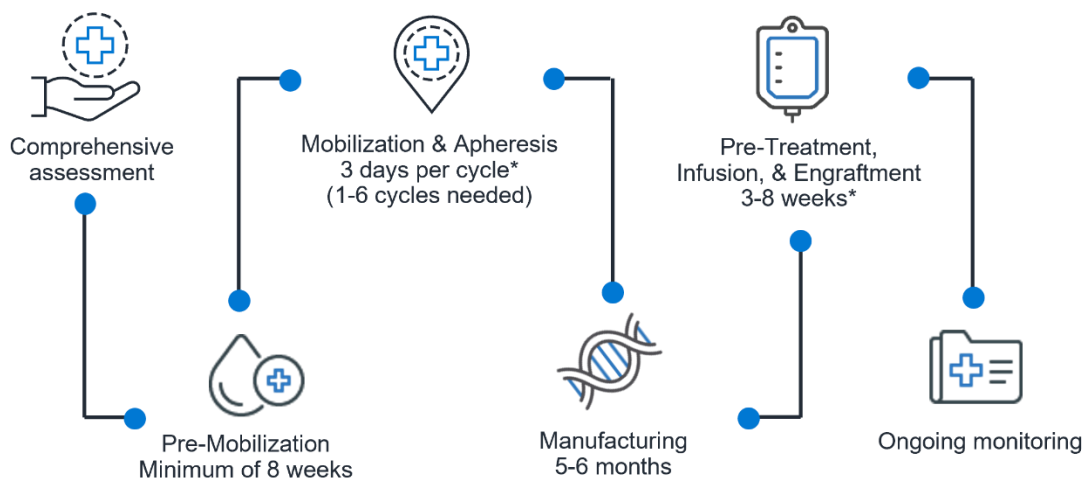
22. Vertex Pharmaceuticals Inc. (2025, January 12). Vertex provides pipeline and business updates in advance of upcoming investor meetings [Press release]. Retrieved May 28, 2025, from <https://investors.vrtx.com/news-releases/news-release-details/vertex-provides-pipeline-and-business-updates-advance-upcoming-0>.

23. bluebird bio. (2024, December 8). bluebird bio presents positive long-term data on LYFGENIA™ (lovotobegligene autotemcel) gene therapy for sickle cell disease at 66th American Society of Hematology (ASH) Annual Meeting and Exposition [Press release]. Retrieved May 28, 2025, from <https://investor.bluebirdbio.com/news-releases/news-release-details/bluebird-bio-presents-positive-long-term-data-lyfgeniattm>.

24. Vertex Pharmaceuticals Inc. (2025, January 12). Vertex provides pipeline and business updates in advance of upcoming investor meetings [Press release]. Retrieved May 28, 2025, from <https://investors.vrtx.com/news-releases/news-release-details/vertex-provides-pipeline-and-business-updates-advance-upcoming-0>.

patient returns to the ATC to receive the infusion. They need to remain hospitalized for an additional three to six weeks for monitoring (pre-treatment, infusion, and engraftment). Once the treatment is administered and the patient returns home, they are monitored by their hematologist weekly for six weeks, then monthly for the first year after treatment.²⁵ Figure 5 depicts the patient journey.

FIGURE 5: SCD CGT PATIENT JOURNEY



* Steps requiring hospitalization

REQUIRED SUPPLEMENTAL SERVICES

Patients undergoing treatment with these therapies may need supplemental and/or wraparound services related to the side effects or sequelae of the CGT. For example, fertility effects can occur with SCD gene therapy, and fertility preservation may be desired depending on the age of recipient. To improve access for Medicaid beneficiaries, CMS developed the Cell and Gene Therapy (CGT) Access Model. At this time, the model is specific to SCD gene therapies but is intended to expand into future CGTs. Under the model, CMS incorporates coverage of a defined scope of fertility preservation services and ancillary services, including travel expenses, case management, and behavioral health services for SCD gene therapies.²⁶ Patients who receive their health insurance through their employers may be offered access to additional benefits to support their patient journeys. However, due to provider network contracting, commercial carriers may limit access to treatment facilities where they do not have negotiated payment rates. This can be a particularly high barrier to these patients as there are so few facilities able to administer the CGT.

INSURANCE COVERAGE

Payers, including Medicaid and commercial insurers, play a critical role in facilitating access to these high-cost therapies while managing their financial impact.

Beinfeld, et al., found clinical restrictions in place for 53.5% and 68.3% of the 11 CGTs included in their research by commercial health plans and state Medicaid agencies, respectively.²⁷ The variation found in clinical requirements for those 11 therapies creates inconsistent access across the potentially eligible population.²⁸ It is important to note that Casgevy and Lyfgenia were not included in that analysis.

25. bluebird bio. (2024, December 8). bluebird bio presents positive long-term data on LYFGENIA™ (lovotobegligene autotemcel) gene therapy for sickle cell disease at 66th American Society of Hematology (ASH) Annual Meeting and Exposition [Press release]. Retrieved May 28, 2025, from <https://investor.bluebirdbio.com/news-releases/news-release-details/bluebird-bio-presents-positive-long-term-data-lyfgeniadm>.

26. Centers for Medicare & Medicaid Services. (n.d.). Cell and Gene Therapy (CGT) Access Model. Retrieved May 28, 2025, from <https://www.cms.gov/priorities/innovation/innovation-models/cgt>.

27. Beinfeld, M. T., Rucker, J. A., Jenkins, N. B., de Breed, L. A., & Chambers, J. D. (2023). Variation in Medicaid and commercial coverage of cell and gene therapies. *Health Policy Open*, 5. <https://doi.org/10.1016/j.hpopen.2023.100103>

28. Ibid.

Assessing whether ATCs are within a payer's network and if they are accessible to their covered populations may be beneficial to understanding potential costs. Data analysis, geographic distribution mapping, and identification of potential travel requirements will help payers anticipate costs and patient needs when patients seek SCD treatment.

In any CGT coverage policy, clarity around billing and reimbursement for each step should be included as well as addressing any associated support that may accompany the CGT from a clinical standpoint. This may include fertility preservation process for the SCD CGTs, travel expenses, and behavioral health services. The likelihood of treatment success may increase when the wraparound services are also covered for patients receiving CGT to allow the patient and their caregivers to focus on recovery.²⁹

Gene therapies such as Casgevy and Lyfgenia come with substantial up-front costs. Medicaid's Cell and Gene Therapy (CGT) Access Model aims to mitigate these costs through outcomes-based agreements (OBAs) that link payment to the therapy's effectiveness.³⁰ Payers and legislatures may also explore risk pools, multiyear payment agreements, warranties, and carve-out solutions to manage financial risk.³¹

Conclusion

The approvals of Casgevy and Lyfgenia represent a milestone advancement in the treatment of SCD. They highlight the many barriers to receiving CGT as well as the significant promise such treatments offer to afflicted individuals. Collaboration between manufacturers, payers, and healthcare systems is needed to overcome logistical, financial, and infrastructural challenges inherent to these CGTs.

As more CGTs come to market, new challenges will arise with respect to patient access. Ultimately, the integration of these novel gene therapies into the healthcare system will require a coordinated effort to ensure the needs of each stakeholder are met, including SCD patients and their caregivers.

Limitations

This study provided a list of potential barriers to patient access to SCD CGTs. These represent many but not necessarily all barriers that exist for SCD therapies. Also, these barriers may not be reflective of all CGT barriers to access, particularly those therapies indicated for other conditions. Each therapy retains its own unique set of barriers related to access to care.

This study relied on Milliman's proprietary CHSD version 2409 (as of September 2024). Although the files are reflective of members from a national perspective, data contributors may not be equally distributed across the U.S.; thus, state-level data may not be reflective of the national estimates. Actual prevalence of SCD in each state may differ from the sample when used to predict the SCD size in any state. Diagnoses for SDOH are not well populated, and it is likely that the percentage of members with SDOH is understated.

When creating the U.S. SCD ATC mapping, we relied on locations that were publicly known and activated as of December 2024. Additional ATCs were planned by the manufacturer and may continue to launch as time progresses.

29. Centers for Medicare & Medicaid Services. (n.d.) Cell and Gene Therapy (CGT) Access Model. Retrieved May 28, 2025, from <https://www.cms.gov/priorities/innovation/innovation-models/cgt>.

30. Ibid.

31. Grossi, G. (2024, July 21). Understanding coverage, financing, and future trends of gene therapy in employer health plans [News article]. American Journal of Managed Care. Retrieved May 28, 2025, from <https://www.ajmc.com/view/understanding-coverage-financing-and-future-trends-of-gene-therapy-in-employer-health-plans>.

Methodology

Using the Milliman CHSD, we identified continuously enrolled members age 12 to 75 with at least two claims bearing SCD diagnosis codes (D571, D572, or D574) for calendar year 2023. The prevalence rate of SCD per 100,000 members was calculated by dividing the number of members with SCD by the total number of enrolled members and multiplying by 100,000. The prevalence methodology reflects that used in the January 2021 Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017 report.³²

ATCs for Casgevy and Lyfgenia were obtained from their respective websites in December 2024 and were mapped to MSAs. Members with SCD were counted by MSA to assess the proximity of these facilities to the members' residences. Lastly, we identified members with SDOH based on relevant ICD-10 diagnosis codes, which can be found in Figure B in the Appendix.

Acknowledgment of qualification

Donna Wix, Michelle Robb, and Barbara Collier are actuaries for Milliman. They are members of the American Academy of Actuaries and meet the Qualification Standards of the American Academy of Actuaries to render the actuarial analysis contained herein.

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Appendix

FIGURE A: ICD-10 DIAGNOSIS CODES ASSOCIATED WITH SCD

ICD-10 DIAGNOSIS CODE	DESCRIPTION
D571	Sickle-cell disease without crisis
D5720	Sickle-cell/Hb-C disease without crisis
D57211	Sickle-cell/Hb-C disease with acute chest syndrome
D57212	Sickle-cell/Hb-C disease with splenic sequestration
D57213	Sickle-cell/Hb-C disease with cerebral vascular involvement
D57214	Sickle-cell/Hb-C disease with dactylitis
D57218	Sickle-cell/Hb-C disease with crisis with other specified complication
D57219	Sickle-cell/Hb-C disease with crisis, unspecified
D5740	Sickle-cell thalassemia without crisis
D57411	Sickle-cell thalassemia, unspecified, with acute chest syndrome
D57412	Sickle-cell thalassemia, unspecified, with splenic sequestration
D57413	Sickle-cell thalassemia, unspecified, with cerebral vascular involvement
D57414	Sickle-cell thalassemia, unspecified, with dactylitis
D57418	Sickle-cell thalassemia, unspecified, with crisis with other specified complication
D57419	Sickle-cell thalassemia, unspecified, with crisis
D5742	Sickle-cell thalassemia beta zero without crisis
D57431	Sickle-cell thalassemia beta zero with acute chest syndrome
D57432	Sickle-cell thalassemia beta zero with splenic sequestration
D57433	Sickle-cell thalassemia beta zero with cerebral vascular involvement
D57434	Sickle-cell thalassemia beta zero with dactylitis
D57438	Sickle-cell thalassemia beta zero with crisis with other specified complication
D57439	Sickle-cell thalassemia beta zero with crisis, unspecified
D5744	Sickle-cell thalassemia beta plus without crisis
D57451	Sickle-cell thalassemia beta plus with acute chest syndrome
D57452	Sickle-cell thalassemia beta plus with splenic sequestration
D57453	Sickle-cell thalassemia beta plus with cerebral vascular involvement
D57454	Sickle-cell thalassemia beta plus with dactylitis
D57458	Sickle-cell thalassemia beta plus with crisis with other specified complication
D57459	Sickle-cell thalassemia beta plus with crisis, unspecified

FIGURE B: ICD-10 DIAGNOSIS CODES ASSOCIATED WITH SDOH^{33,34}

Z55 – Problems related to education and literacy
Z56 – Problems related to employment and unemployment
Z57 – Occupational exposure to risk factors
Z58 – Problems related to physical environment
Z59 – Problems related to housing and economic circumstances
Z60 – Problems related to social environment
Z62 – Problems related to upbringing
Z63 – Other problems related to primary support group, including family circumstances
Z64 – Problems related to certain psychosocial circumstance
Z65 – Problems related to other psychosocial circumstances
Z75 – Problems related to medical facilities and other health care

FIGURE C: COMMERCIALLY INSURED SCD PREVALENCE RATES BY STATE

STATE	CONTINUOUSLY ENROLLED MEMBERS	MEMBERS WITH SCD	PREVALENCE RATE PER 100,000
AK	64,972	0	-
AL	1,095,813	215	20
AR	390,079	40	10
AZ	544,470	21	4
CA	1,266,451	55	4
CO	319,690	8	3
CT	157,772	14	9
DE	158,330	46	29
FL	1,474,875	286	19
GA	285,444	64	22
HI	231,121	2	1
IA	714,036	25	4
ID	401,990	3	1
IL	2,377,546	228	10
IN	378,385	40	11
KS	339,155	4	1
KY	230,071	13	6
LA	616,490	118	19
MA	1,251,038	148	12
MD	576,438	134	23
ME	75,696	1	1

33. Centers for Medicare & Medicaid Services. (n.d.). Improving the collection of social determinants of health (SDOH) data with ICD-10-CM Z Codes. Retrieved May 28, 2025, from <https://www.cms.gov/files/document/cms-2023-omh-z-code-resource.pdf>.

34. ICD10Data.com. (n.d.). ICD-10-CM Codes: Z00-Z99: Z69-Z76: Problems related to medical facilities and other health care Z75. Retrieved May 28, 2025, from <https://www.icd10data.com/ICD10CM/Codes/Z00-Z99/Z69-Z76/Z75->.

STATE	CONTINUOUSLY ENROLLED MEMBERS	MEMBERS WITH SCD	PREVALENCE RATE PER 100,000
MI	2,014,389	239	12
MN	622,659	23	4
MO	884,487	100	11
MS	177,695	46	26
MT	147,066	1	1
NC	1,103,765	203	18
ND	84,614	1	1
NE	340,507	22	6
NH	131,144	0	-
NJ	407,265	117	29
NM	221,815	10	5
NV	105,556	5	5
NY	1,572,518	177	11
OH	1,076,215	106	10
OK	492,372	17	3
OR	386,308	4	1
PA	2,570,258	322	13
PR	2,611	0	-
RI	331,389	31	9
SC	954,773	250	26
SD	213,838	4	2
TN	1,185,211	178	15
TX	3,462,492	454	13
UT	806,487	19	2
VA	350,983	55	16
VT	98,987	3	3
WA	1,200,673	33	3
WI	522,902	20	4
WV	155,176	2	1
WY	82,362	0	-

FIGURE D: MANAGED MEDICAID SCD PREVALENCE BY STATE AND REFERENCE TO 2017 CDC PREVALENCE³⁵

STATE	CONTINUOUSLY ENROLLED MEMBERS	MEMBERS WITH SCD	PREVALENCE RATE PER 100,000	PREVALENCE FROM 2017 CDC REPORT
AK	21	0	-	DS
AL	133	0	-	202.4
AR	148	0	-	79.8
AZ	25,907	12	46	24.4
CA	679,738	83	12	25.3
CO	220	0	-	17.3
CT	328	0	-	77.5
DE	39,106	41	105	136.8
FL	93,843	146	156	145.2
GA	9,876	14	142	219.0
HI	41	0	-	DS
IA	137	0	-	31.7
ID	8,869	3	34	DS
IL	173,836	126	72	79.9
IN	405	1	247	61.5
KS	37	0	-	45.7
KY	179,514	100	56	25.1
LA	125,901	203	161	167.2
MA	57,050	29	51	69.0
MD	369	0	-	DQ
ME	93	0	-	11.8
MI	429,878	332	77	74.3
MN	846	0	-	41.8
MO	55,927	55	98	88.3
MS	26,694	40	150	227.7
MT	31	0	-	DS
NC	163,540	164	100	129.7
ND	31	0	-	DS
NE	45	0	-	51.1
NH	17,863	0	-	DS
NJ	228	1	439	84.3
NM	74	0	-	3.9
NV	58,261	26	45	64.0
NY	285,289	297	104	93.3
OH	174,231	171	98	80.1

35. Wilson-Frederick, S. M., Hulihan, M., Mangum, A., Khan, T., Geibel, M., Malsberger, S., Verghese, S., et al. (2021). Medicaid and CHIP sickle cell report, T-MSIS Analytic Files (TAF) 2017. Centers for Medicare & Medicaid Services. Retrieved May 28, 2025, from <https://www.medicaid.gov/sites/default/files/2021-01/scd-rpt-jan-2021.pdf>.

STATE	CONTINUOUSLY ENROLLED MEMBERS	MEMBERS WITH SCD	PREVALENCE RATE PER 100,000	PREVALENCE FROM 2017 CDC REPORT
OK	123	1	813	47.7
OR	101,007	3	3	10.7
PA	825,867	783	95	78.3
PR	98	0	-	13.3
RI	138,809	78	56	49.1
SC	250,308	417	167	192.0
SD	33	0	-	DS
TN	4,616	2	43	91.4
TX	121,953	175	143	82.1
UT	84,887	5	6	11.8
VA	64,792	23	35	132.4
VT	41	0	-	11.1
WA	422,359	65	15	16.1
WI	94,085	23	24	80.3
WV	6,185	0	-	9.2
WY	23	0	-	DS

DQ = Not reported due to concerns about data quality in the 2017 v4 TAF.

DS = Data suppressed because data cannot be displayed per CMS' cell-size suppression policy, which prohibits the direct reporting of data for beneficiary and record counts of 1 to 10 and values from which users can derive values of 1 to 10.

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