

Advisory Council

On Financing & Access to Sickle Cell
Disease Treatment & Other
High-Cost Drugs & Treatment

December 13, 2024



HFS

Illinois Department of
Healthcare and Family Services



HFS

Illinois Department of
Healthcare and Family Services

OUR VISION FOR THE FUTURE

We improve lives.

- ▶ We address social and structural determinants of health.
- ▶ We empower customers to maximize their health and well being.
- ▶ We provide consistent, responsive service to our colleagues and customers.
- ▶ We make equity the foundation of everything we do.

This is possible because:

- ▶ **We value our staff as our greatest asset.**

We do this by:

Fully staffing a diverse workforce whose skills and experiences strengthen HFS.

Ensuring all staff and systems work together.

Maintaining a positive workplace where strong teams contribute, grow and stay.

Providing exceptional training programs that develop and support all employees.

- ▶ **We are always improving.**

We do this by:

Having specific and measurable goals and using analytics to improve outcomes.

Using technology and interagency collaboration to maximize efficiency and impact.

Learning from successes and failures.

- ▶ **We inspire public confidence.**

We do this by:

Using research and analytics to drive policy and shape legislative initiatives.

Clearly communicating the impacts of our work.

Being responsible stewards of public resources.

Staying focused on our goals.



Agenda

Presenter: Director Whitehorn





Summary of Agenda

Presenter:

Lizzy Whitehorn, Director

- I. Call to Order
- II. General Meeting Operations and Communications
- III. Roll Call of Advisory Council Members
- IV. Introduction of HFS Staff
- V. Review and Approval of Meeting Minutes
- VI. Report Review
- VII. Advisory Council Vote on Report
- VIII. Public Comments
- IX. Additional Business
- X. Announcements
- XI. Adjournment



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II.

General Meeting Operations and Communications

Presenter: Melishia Bansa





**Comments or questions
during the meeting**

Housekeeping

- Please note, this meeting is being recorded.
- To ensure accurate records, please type your name and organization into the chat.
- If possible, members are asked to attend meetings with their camera turned on, however, if you call in & need materials, please email FlorLopez@illinois.gov and copy Melishia.Bansa@illinois.gov as soon as safely possible.
- Please be sure to mute your audio except when speaking.
- Please note that HFS staff may mute participants to minimize any type of disruptive noise or feedback.



Meeting Basics

Housekeeping

- If you are an Advisory Council member and wish to make a comment or ask a question during the meeting, please use the WebEx feature to raise your hand, contact the host/co-host, or unmute yourself during QA sections facilitated by chair.
- Please state your full name when asking a question or passing a motion.
- If you are a member of the general public and wish to make a comment, please register to make a public comment prior to the meeting. Instructions to make public comments have been provided for you in the public meeting posting located on the HFS Boards and Commissions website.
- If you have a question during the meeting, please utilize the Webex chat feature to send your question directly to the host or co-host.



Meeting Basics

Housekeeping

- HFS is committed to hosting meetings that are accessible and ADA compliant. Closed captioning will be provided via the Webex platform. Please email Melishia.Bansa@illinois.gov in advance to report any requests or accommodations you may require or use the chat to alert the host/co-host of challenges you may have encountered during the meeting.
- Patience, please – many meeting attendees may be new to these advisory council proceedings.
- After today's meeting, meeting minutes will be circulated to Council members in advance of the next meeting. Once approved, they will be posted to the website along with today's presentation deck.



III.

Roll Call of Advisory Council Members

Presenter: Melishia Bansa





Advisory Council Representation

Lizzy Whitehorn

Illinois Department of Healthcare and Family Services (state Medicaid agency)

Joan Ehrhardt

Illinois Department of Public Health

Adam Flores

Illinois Department of Insurance

Theodore (Ted) Tapas

Governor’s Office of Management and Budget

Beverly Chukwudozie

Persons with lived experience as a person with sickle cell disease

Alexandra Carpenter

Persons with lived experience as a person with a condition requiring access to new, innovative drugs or treatment

Dr. James LaBelle

Providers treating sickle cell disease patients

TaLana Hughes

Sickle cell disease advocacy organization

Nathan Schaefer

Advocacy organization for a condition(s) requiring access to new, innovative drugs and treatment

**Steve Sproat,
Brian Smolich**

Health insurance industry

**George Kitchens,
Susan Stuard**

Experts in prescription drug rebate negotiations and outcomes-based agreements

**Melissa Creary,
Rachel Sachs**

Experts with published research in financing new, innovative drugs and treatments within public health insurance programs

**Anirban Basu,
Rena Conti**

Experts with health economist or actuarial backgrounds

**Dr. Radhika Peddinti,
Mark Trusheim**

Members who may or may not meet the qualification requirements for the other appointees.

Dr. Ruchika Goel

Providers treating patients with another condition requiring access to new, innovative drugs or treatment



IV.

Introduction of HFS Staff

Presenter: Melishia Bansa





V.

Review and Approval of Meeting Minutes

Presenter: Melishia Bansa





VI.

Report Review: Financing Strategies Framework for Cell & Gene Therapy & Other High-Cost Drugs

Presenter: Director Whitehorn



Previous Council Meetings

Scope of Discussions

June 25, 2024

The first meeting included an overview by HFS introducing the issue and a discussion of the council's vision statement and guiding principles. The council engaged in an open brainstorming session on payment and financing models available to HFS.

July 23, 2024

Councilmembers heard directly from patients and caregivers with lived experience, followed by an open brainstorming session on access and equity challenges.

August 27, 2024

Councilmembers discussed proposed guidelines and recommendations on payment and financing models for high-cost therapies.

Previous Council Meetings

Scope of Discussions

September 17, 2024

Further refinement of the proposed guidelines and recommendations on payment and financing models for high-cost therapies.

September 24, 2024

Councilmembers discussed proposed guidelines and recommendations to ensure equitable access to high-cost therapies.

Report Recommendation Review



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Report Recommendations One to Six

- 1 Ensure CGT and other high-cost drugs are considered “covered outpatient drugs” to entitle the state to rebates and discounts on their use.
- 2 Consider ways to estimate manufacturer production supply capacity and use HFS data and analysis to estimate eligible patient populations and their treatment adoption rates to inform drug negotiation strategies and budget impact analysis.
- 3 Consider using a third-party assessment to benchmark drug value.
- 4 Evaluate the federal CGT access model and determine whether participation would provide cost and access benefits.
- 5 Consider strategies to secure higher, volume-based rebates or discounts.
- 6 Continue to use the uniform PDL as leverage in negotiating prices and, where feasible, leverage the presence of alternative therapies in price negotiations.



Report Recommendations Seven to Ten

- 7** Explore all available discounting and rebating strategies on a case-by-case basis for each CGT or high-cost drug. Supplemental discounts and rebates are likely to be easier to implement, but other strategies, including Value-Based Agreements (VBAs), might be appropriate in certain specific circumstances.
- 8** Consider establishing uniform utilization management (UM) criteria across MCOs to ensure equitable access to CGTs and high-cost therapies for all Medicaid customers.
- 9** Consider developing UM criteria that ensure access encompasses not just the CGT or high-cost drug itself but also the full continuum of pre- and post-therapy services, such as preparation, follow-up monitoring, and long-term patient care, which are essential for delivery and patient outcomes.
- 10** Collaborate with expert clinicians to create initial UM guidelines for CGTs and high-cost drugs that distinguish between populations for whom FDA approval was granted and those included in clinical trials, ensuring clinical inclusion criteria are aligned with evidence and include provider assessments and shared decision-making with patients.



Report Recommendations Ten to Fifteen

- 11 Use a combination of policy levers—including the model MCO contract, standardized single-case agreements, and HFS policies and procedures—to implement and adapt these UM criteria effectively. Collaborate with state-based experts who have specific expertise in the state's insured population and their multidimensional needs.
- 12 Consider stratifying managed care customers with SCD and other rare diseases as high-risk early in diagnosis to enable timely access to specialized care coordination.
- 13 Consider expanding tailored care management services for rare disease patients.
- 14 Consider developing and implementing disease-specific performance metrics to monitor and enhance the quality of MCO care coordination for rare disease patients, ensuring timely access, high-quality care, and comprehensive support.
- 15 Consider expanding Section 1115 waiver health-related social needs services to cover more patients with rare diseases and a broader range of wrap-around services for Medicaid customers undergoing CGTs and other high-cost therapies, including essential supports like temporary housing near a qualified treatment center, long-distance transportation, parking reimbursement, and childcare, to ensure equitable access to advanced therapies for patients with rare diseases.



Report Recommendations Sixteen to Eighteen

- 16 Consider ensuring that both in-state and out-of-state health centers in contiguous states administering CGTs and other high-cost drugs are included in Medicaid networks to ensure equitable patient access throughout Illinois. Also consider, incentivizing a robust network of specialized providers, including hematologists, across the state and ensuring that provider networks are accurate.
- 17 Explore the use of financial and nonfinancial incentives and supports to encourage specialist availability and patient access for rural populations. Explore the use of financial and nonfinancial incentives and supports to encourage specialist availability and patient access for rural populations.

Consider balancing access to CGTs and other high-cost drugs with support for comprehensive care for all patients with SCD and other rare diseases, ensuring that
- 18 resources are allocated to maintain high-quality preventive and routine services for those who may not qualify for or require these high-cost therapies.



Report Recommendations Nineteen to Twenty-Two

- 19 Consider expanding staff to include clinical and pharmaceutical experts and seek consulting support to implement the above recommendations, including to support enhanced tracking, reporting, and negotiations for CGTs and other high-cost drugs.
- 20 Strive to promote improved access to care at the provider-level for patients with rare diseases seeking complex therapies by supporting the expansion of complex care coordination and health IT infrastructure. Strive to promote improved access to care at the provider-level for patients with rare diseases seeking complex therapies by supporting the expansion of complex care coordination and health IT infrastructure.
- 21 Consider evaluating available financial risk mitigation strategies, such as reinsurance, annuity models, and multi-payer risk pools, and monitor the implementation of financial risk mitigation strategies in other state Medicaid programs.
- 22 Consider reviewing state regulatory options and advocating for federal regulatory changes to ensure access to CGTs and other high-cost drugs in ACA and employer-sponsored plans.



Report Recommendations Twenty-Two to Twenty-Four

- 23 Consider advocating for federal policies that advance equitable access to advanced therapies, deter other payers from shifting patients to Medicaid, and enhance state Medicaid agencies' capacity to pay for CGTs and other high-cost drugs.





VII.

Advisory Council Vote on Report

Presenter: Melishia Bansa





IX.

Public Comments

Presenter: Melishia Bansa





Public Comments- **No Public Comments**

Name	Title	Org	Comment
None Requested			





X.

New Business

Presenter: Director Whitehorn





XI.

Announcements

Presenter: Melishia Bansa





Advisory Council:
**Looking
Ahead**



Report Review & Submission

**Report Submitted to Governor and Illinois
General Assembly**

By December 31



Mandatory Ethics Trainings Reminder Email

All appointees must complete the following trainings on OneNet:

- 1 Security Awareness Training 2024
- 2 Diversity, Equity, Inclusion and Accessibility Training 2024
- 3 LGBTQIA+ Equity and Inclusion 2024
- 4 Ethics Training Program for State Employees and Appointees 2024
- 5 Harassment and Discrimination Prevention Training 2024
- 6 HIPAA & Privacy Training 2024

You can access the trainings at the following link: <http://onenet.illinois.gov/mytraining>

Please see attached memo for additional details. Please complete the trainings through OneNet no later than December 23, 2024. If anyone has any issues logging into OneNet, please email HFS.BureauofTraining@Illinois.gov





XII.

Adjournment

Presenter: Director Whitehorn

