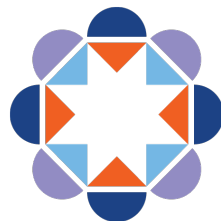


# Advisory Council

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

August 27, 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. Housekeeping
- III. Roll Call of Advisory Council Members
- IV. Introduction of HFS Staff
- V. Review and Approval of Meeting Minutes
- VI. Review and Approval of Values and Priorities
- VII. Recommendations Discussion: Financing Strategies Framework for Cell & Gene Therapy & Other High-Cost Drugs
- VIII. Next Steps
- IX. Public Comments
- X. New Business
- XI. Announcements
- XII. Adjournment





II.

# Housekeeping

Presenter: Melishia Bansa



Comments or questions  
during the meeting

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# 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's turned on, however, if you call in & need materials, please email [Melishia.Bansa@Illinois.gov](mailto: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. Please email [Melishia.Bansa@Illinois.gov](mailto:Melishia.Bansa@Illinois.gov) in advance to report any requests or accommodations you may require or use the chat to alert me 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 Committee 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

**Dr. 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.

# Review and Approval of Values and Priorities

Presenter: Director Whitehorn



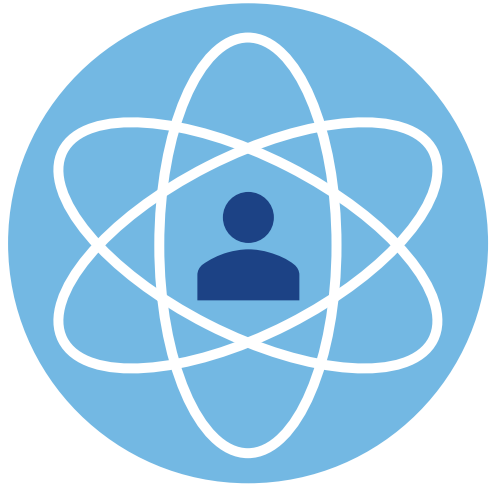


# Vision

## Vision Statement

Provide access to emerging and transformative cell and gene therapies and other high-cost drugs and treatments to all Medicaid customers who need them.





## Proposed Guiding Principles

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- † Ensuring patient access to evidence-based care and therapies
- † Improving health outcomes for populations receiving care
- † Prioritizing equity in distribution and dissemination of care as a means to decrease disparities for impacted populations
- † Maximizing the use of public resources in a financially responsible and ethically-driven manner
- † Developing appropriate reimbursement models
- † Considering a public health perspective which leverages the state's purchasing power





VII.

# Recommendations Discussion:

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

Presenter: Director Whitehorn





# Recommending a Financing Strategy Framework



**Cell and Gene Therapies**



**Other High-Cost Drugs**





# Negotiating with Manufacturers

- I. Scope of negotiation
- II. Negotiation preparation
- III. Strategies for negotiating down CGT drug prices and under which circumstances to use each one (developing a framework)
- IV. Pricing Strategies



# Scope of Negotiations

## ➔ Recommended framework for approaching the scope of negotiations with drug manufacturers:

- When to negotiate on a single therapy
- When to negotiate on the manufacturer's relevant product portfolio

## Estimating the value of Cell and Gene Therapy (CGT) drugs and other high-cost specialty drugs.

- + Factors to consider when deciding a starting point for negotiation
- + Health care outcomes, including drug efficacy/durability
- + Quality of life improvements
- + Cost savings
- + Estimating the demand for therapy
- + Estimating provider capacity to provide therapy
- + Negotiating support for patients and caregivers



# Preparing for Negotiations



# Strategies for Negotiating

- + Leverage during negotiations
  - + Speeding up the PA review process by the D&T, leveraging utilization management policies, and utilizing targeted closed formularies
- + Pooling purchasing power
  - + Illinois Medicaid + State Employee Health Plan
  - + Participating in multi-state supplemental rebate negotiating consortium
- + Participating in CGT Access model
  - + State evaluation of the CGT Access Model in terms of rebate, terms, TA support, and funding support, and determine participation
  - + Workload considerations

# IV.

## Pricing Strategies

### 1 Supplemental Rebates/Outright Discounts

- Carving drugs out of DRG/bundled payment (required for CGT Access Model participation and supplemental rebates)
- Carve out 340B Program from managed care
- Higher rebates until manufacturer completes post-marketing trial

# IV.

## Pricing Strategies

### 2 Outcome-Based Rebates

- Annuity model v. subscription model
- Deciding which outcomes to base the rebate on
- Deciding when to use an outcomes-based agreement, supplemental rebate, annuity/subscription model, or a combination of strategies

# IV.

## Pricing Strategies

### 3 Payment Based on Third Party Assessment

- └ Payment based on third-party assessment of the drug's value



# State Implementation Resources

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- State resources needed to implement recommendations
- Specific staff positions or skillsets, including staff or partnerships for modeling
- Successful staffing structures in other state Medicaid departments



# Federal Recommendations

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- New national drug benefit: coverage outside of the MDRP
- Increased FMAP for a specific set of high-cost therapies
- Building on CGT Access model



VIII.

# Next Steps

Presenter: Director Whitehorn





# Advisory Council: Looking Ahead →

## September Meeting

- Will discuss access recommendations.
- Can send HFS ideas in advance for inclusion in meeting four slide deck.

## Report Review & Submission

- **Outline for Report:** October 4
- **First Draft of Report:** November 13
- **Final Draft to HFS:** December 9
- **Report Submitted Officially:** December 31





IX.

# Public Comments

Presenter: Melishia Bansa



HFS

Illinois Department of  
Healthcare and Family Services

# Public Comments- **No Public Comments**

Name	Title	Org	Comment



X.

# New Business

Presenter: Director Whitehorn





XI.

# Announcements

Presenter: Melishia Bansa





# 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 13, 2024. If anyone has any issues logging into OneNet, please email [HFS.BureauofTraining@Illinois.gov](mailto:HFS.BureauofTraining@Illinois.gov)





# Advisory Council Operational Reminders

▶ Advisory Council Meeting Resources: [Boards and Commissions | HFS \(illinois.gov\)](https://www.illinois.gov)

Executive Order

Members

Bylaws

Meeting Schedule

Meeting Presentation Deck

Meeting Notice: Public Meeting Postings & Agendas





XII.

# Adjournment

Presenter: Director Whitehorn



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