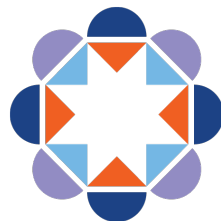


# Advisory Council

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

September 17, 2024



**HFS**

Illinois Department of  
Healthcare and Family Services



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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. Live Poll on Financing Strategies Framework for Cell & Gene Therapy & Other High-Cost Drugs
- VII. Financing Framework Wrap-Up Discussion
- VIII. Next Steps
- IX. Public Comments
- X. New Business
- XI. Announcements
- XII. Adjournment



II.

# Housekeeping

Presenter: Laura Phelan



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 turned on, however, if you call in & need materials, please email [Laura.Phelan@illinois.gov](mailto:Laura.Phelan@illinois.gov) cc. [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 via the Webex platform. Please email [Laura.Phelan@Illinois.gov](mailto:Laura.Phelan@Illinois.gov) cc. [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 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: Laura Phelan



# 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: Laura Phelan





V.

# Review and Approval of Meeting Minutes

Presenter: Laura Phelan





VII.

# Recommendations Discussion:

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

Presenter: Director Whitehorn



# Survey Responders

Advisory Council members will participate in the following discussion and survey responses.

- Alexandra Carpenter
- Joan Ehrhardt
- Adam Flores
- Beverly Chukwudozie
- Theodore (Ted) Tapas
- Dr. James LaBelle
- TaLana Hughes
- Nathan Schaefer
- Steve Sproat
- Brian Smolich
- George Kitchens
- Susan Stuard
- Dr. Anirban Basu
- Melissa Creary
- Dr. Radhika Peddinti
- Rachel Sachs
- Dr. Rena Conti
- Mark Trusheim
- Dr. Ruchika Goel

# Joining the Survey

Slido.com



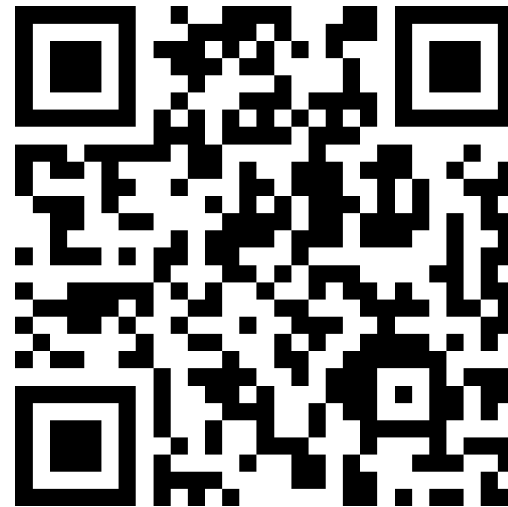
Join at

**Slido.com**

**#3760215**

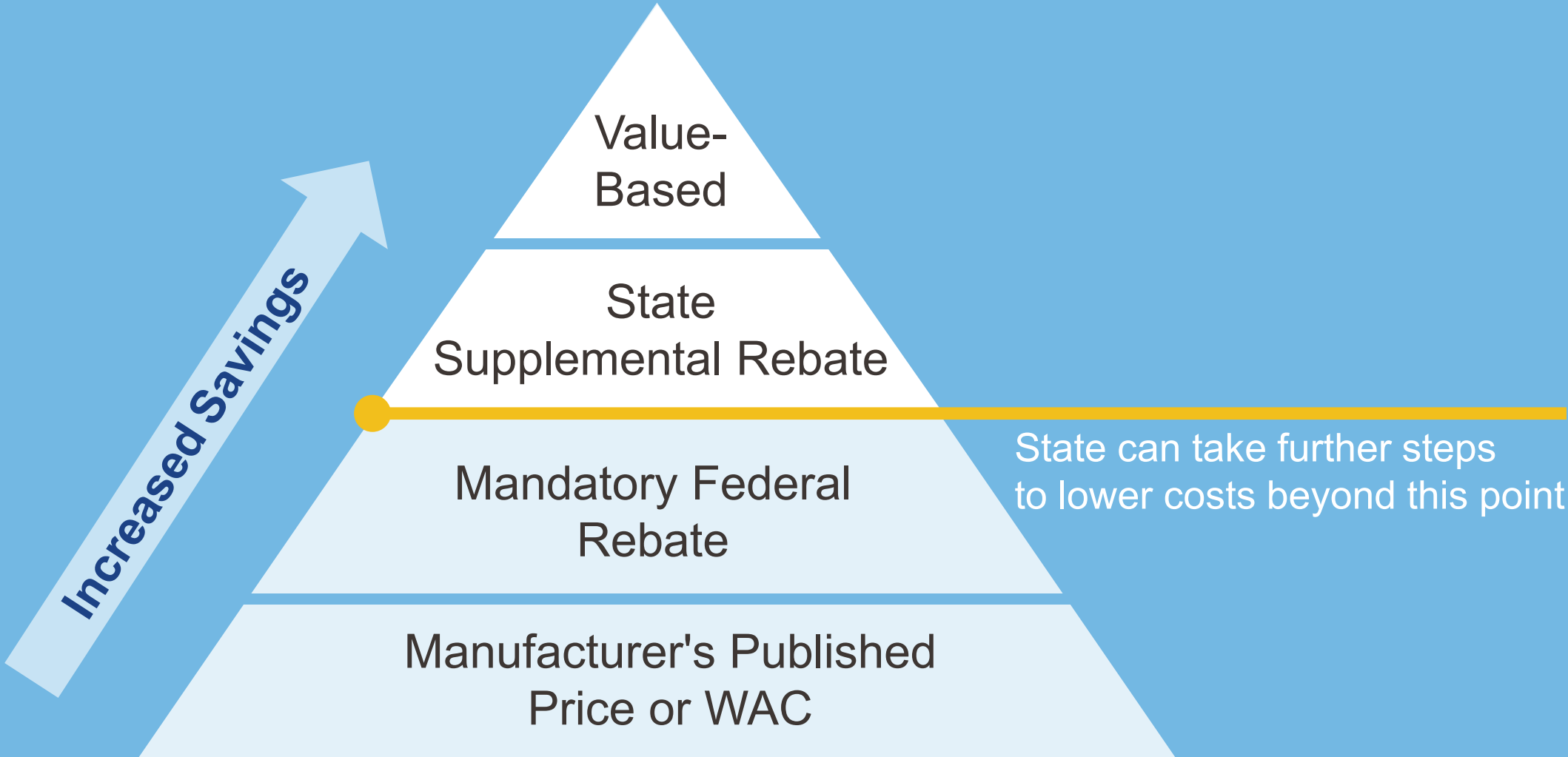
Enter passcode and full name

OR



If a Council Member does not have access to the passcode currently, please let us know in the WebEx chat. A team member will private message you the code in WebEx.

# Establishing a More Favorable Cost





# Which type of rebate structure do you recommend the state consider during negotiations?

- † Supplemental
- † Value-Based
- † Both



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# Under which circumstances should value-based rebate be considered?

- + For high-cost drugs,
- + For rare disease drugs,
- + For Cell and Gene Therapies
- + When administrative burden is determined to be low
- + Other: [explain in chat.]



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# Previously Discussed Tools During Rebate Negotiations



Examples Discussed by Council Members in Previous Meetings:

- + PDL status
- + Utilization management policies
- + Targeted closed formularies



We welcome additional examples

**What elements would you recommend HFS consider prioritizing for driving down cost in rebate negotiation?**



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# Pool Purchasing Power →

	Pros	Cons
<b>Multi-State Supplemental Rebate Consortium</b>	Pooled population numbers can result in increased purchasing power	Loss of autonomy and negotiating flexibility
<b>Federal Cell and Gene Therapy (CGT) Model</b>	Federal administrative burden vs state	<ul style="list-style-type: none"><li>— Highly dependent on other states</li><li>— Limited to sickle cell</li><li>— Decreases autonomy and flexibility</li></ul>

# Should Illinois evaluate Purchasing Pool Models as a tool?

- + Yes, the State should consider CGT Access model
- + Yes, the State should consider the Multi-State
- + Yes, the State should consider both options
- + No, Illinois should continue to negotiate independently



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# How should the state investigate higher supplemental rebates until the manufacturer completes the post-marketing trial?

- + Should investigate regulatory barriers
- + Should discuss with Federal CMS
- + Should not pursue
- + Other: [explain in chat.]



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# Should we use a third-party assessment, such as ICER, of the drug's value to inform our decision?

If yes, what are other reputable third-party groups we would want to consider looking into?



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# Open Discussion





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
- **Meet in Early December to Vote on Final Report**
- **Final Draft to HFS:** December 9
- **Report Submitted to Governor and Illinois General Assembly:** By December 31



# Post Meeting Survey

Qualtrics.com

- + A Post Meeting Survey will be distributed to Council Members.
- + Post Meeting Survey will contain the same questions covered in the Live Survey but have an additional option for free form responses.
- + Responses in the Post Meeting Survey do not have to match Council members responses in the Live Survey. The Post Meeting Survey responses will be treated as final responses.
- + The Post Meeting Survey will be distributed by email.
- + When starting the Post Meeting survey, you will be asked to enter your full name to ensure Post Meeting Survey results are properly tracked.



IX.

# Public Comments

Presenter: Laura Phelan



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# Public Comments- **No Public Comments**

Name	Title	Org	Comment
None Requested			



X.

# New Business

Presenter: Director Whitehorn





XI.

# Announcements

Presenter: Laura Phelan





# 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



<https://hfs.illinois.gov/about/boardsandcommissions.html>

## Advisory Council Meeting Resources:

[Boards and Commissions | HFS \(illinois.gov\)](#)

- + Executive Order
- + Members
- + Bylaws
- + Meeting Schedule
- + Meeting Presentation Deck
- + Meeting Notice: Public Meeting Postings & Agendas

[Resources Tab](#) 

<https://hfs.illinois.gov/about/boardsandcommissions/advcouncilofaatoscdaohcdt/sickle-cell-resources.html>





XII.

# Adjournment

Presenter: Director Whitehorn

