Advisory Council

Advance Financing & Access to Sickle Cell Disease Treatment & Other High-Cost Drugs & Treatment in Illinois

July 23, 2024

HFS

Illinois Department of Healthcare and Family Services

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.
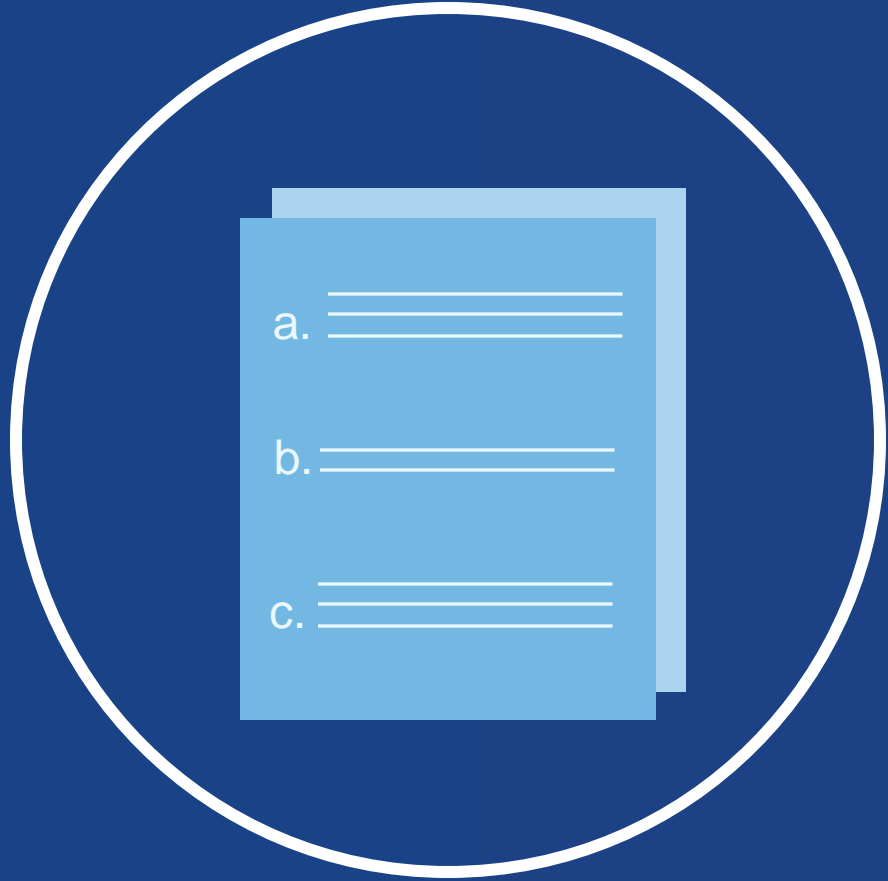
▸ We inspire public confidence.

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.

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Summary of Agenda

Presenter:
Lizzy Whitehorn, Director

I. Call to Order

II. House Keeping

III. Roll Call of Advisory Council Members

IV. Mission, Vision, Values, and Priorities

V. Access to High-Cost Drugs and Treatments: Council Member Experience

VI. Advisory Council Access Discussion

VII. Next Steps

VIII. Public Comments

IX. New Business

X. Announcements

XI. Adjournment

II.

House Keeping

Presenter: Melishia Bansa

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Comments or questions during the meeting

House Keeping

- 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 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

House Keeping

- 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

House Keeping

- HFS is committed to hosting meetings that are accessible and ADA compliant. Closed captioning will be provided. Please email 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
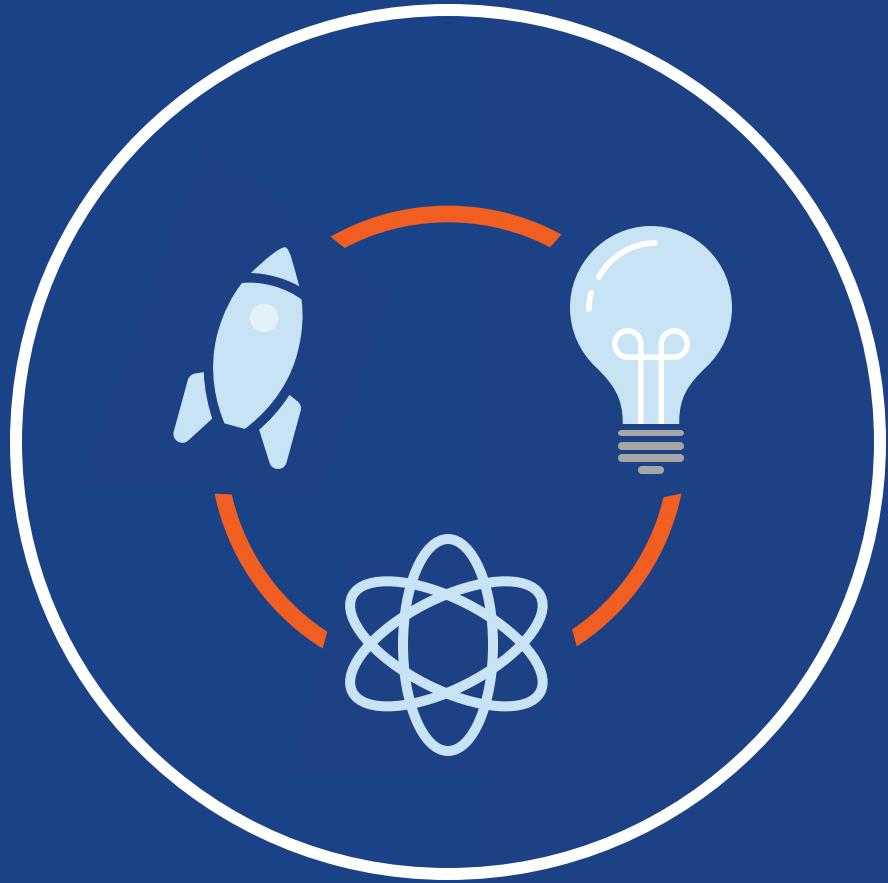
IV.

# Introduction of Staff

Presenter: Melishia Bansa

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IV.

Mission, Vision, Values, and Priorities

Presenter: Director Whitehorn

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"My goal is to make emerging and transformative gene and cell therapy treatments affordable and available to all Illinoisans who need them. If we can narrow the affordability gap, those who are suffering from these diseases won't have to wait a generation before they can access these groundbreaking cures." – Governor JB Pritzker
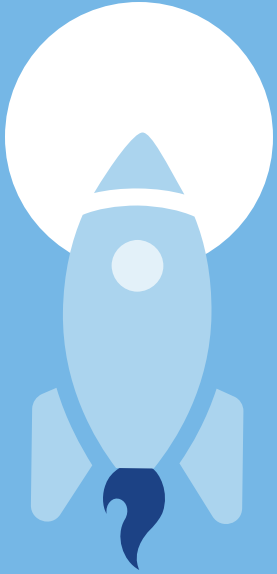
Mission

(Advisory Council Charge)

This Advisory Council shall advise HFS in the development of payment models and financing structures for sickle cell disease treatment and other high-cost drugs and treatment that support equitable access and contribute to national efforts to formulate solutions.

Executive Order Excerpt ➡
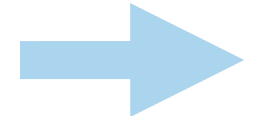
EO cont.

The Advisory Council shall meet at least four times and shall:

- Engage in a robust effort that considers the input of subject matter experts, providers, insurers, drug manufacturers, and Medicaid customers living with sickle cell disease or other conditions requiring access to high-cost drugs and treatment.

- Review innovative approaches establishing sustainable payment models and financing structures for high-cost drugs and treatment, with a focus on value and outcome-based models.

- Evaluate the success and challenges of various value and outcome-based payment approaches implemented in other states.

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EO cont.

- Make recommendations on financing approaches that could be adopted in Illinois and/or nationally with the support of CMS.

- Identify any state and federal policy, legal, regulatory, and resource changes necessary to successfully implement the Advisory Council's recommendations.

- Provide leadership for and collaborate with those working to make sickle cell disease treatments and other high-cost drugs and treatment accessible.

- Promote effective interagency collaboration and consider related efforts federally and in other states when drafting policy options related to financing, with a focus on ensuring equitable access to sickle cell disease treatment and other high-cost drugs and treatment in the Illinois Medicaid program.

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EO cont.

The Advisory Council shall develop a report to be delivered to the Governor and the General Assembly by December 31, 2024.

The report shall evaluate options for financing new cell and gene therapies and other high-cost drugs and treatment and monitoring patient outcomes within the Medicaid program and shall recommend strategies to equitably provide access to new treatments within the program.
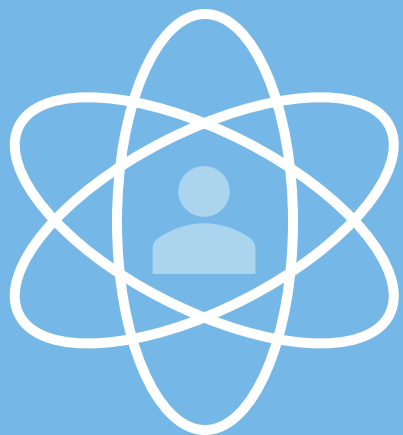
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Vision

Vision Statement

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

Values and Priorities

Proposed guiding principles:

- Ensuring patient access to high quality care and therapies
- Improving health outcomes
- Decreasing disparities
- Centering equity
- Stewarding public resources responsibly
- Developing appropriate reimbursement models
- Considering a public health perspective which leverages the state's purchasing power

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V.

Access to High-Cost Drugs and Treatments:
Council Member Experiences

Presenter: Melishia Bansa

Alexandra Carpenter
Experience

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Beverly Chukwudozie
Experience

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Dr. James LaBelle
Experience

Dr. Radhika Peddinti
Experience

TaLana Hughes
Experience

VI.

Advisory Council Access Discussion

Presenter: Director Whitehorn

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Potential Access Challenges

- Clinical infrastructure to take care of patients comprehensively

- Patient education

- Prior Authorization

- Long wait times for appointments

- Need to travel long distances to limited providers

- Lodging

- Childcare

- Transportation, including timeliness

- Young patients: dependence on caregivers for appointments

- Ability to be at appointments instead of work, school, childcare, or other obligations

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VII.

Next Steps

Presenter: Director Whitehorn

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Advisory Council: Looking Ahead →

For Future Meetings:

- Research or examples from other states to share?
  - HFS can compile submissions and share with Advisory Council.
- Any data we should pursue?
- Additional information about Illinois needed?

● Report Review

Outline for Report: October 4

First Draft of Report: November 13

Final Draft to HFS: December 9

Report Submitted Officially: December 31

August Meeting

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

September Meeting

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

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VIII.

Public Comments

Presenter: Melishia Bansa

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Public Comments- No Public Comments

Name	Title	Org	Comment

IX.

New Business

Presenter: Director Whitehorn

X.

Announcements

Presenter: Melishia Bansa

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