



HFS

Illinois Department of
Healthcare and Family Services

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**Advisory Council on Financing and Access to Sickle Cell Disease Treatment and
Other High-Cost Drugs Meeting Minutes**

Date | Time: Tuesday, August 27, 2024, | 1:00 p.m. to 2:30 p.m.

Location: This meeting was held virtually via WebEx

Audience: Advisory Council on Financing and Access to Sickle Cell Disease Treatment and Other High-Cost Drugs

Council Members Present:

Chair (*)

Elizabeth (Lizzy) Whitehorn*, HFS, Director

Joan Ehrhardt, Illinois Department of Public Health, Newborn Screening Genetic Counselor

Adam Flores, Illinois Department of Insurance, Senior Insurance Advisor

Theodore (Ted) Tapas, Governor's Office of Management and Budget, Budget Analyst II

Beverly Chukwudozie, Sickle Cell Patient

Alexandra Carpenter, Parent of a Patient with Spinal Muscular Atrophy

Dr. James LaBelle, University of Chicago, Director Stem Cell & Gene Therapy Program

George Kitchens, Artia Solutions, Co-CEO

Susan Stuard, Oregon Health & Science University, State Technical Assistance at Center for Evidence-Based Policy

Nathan Schaefer, National Hemophilia Foundation, Senior Vice President

Brian Smolich, Health Alliance Medical Plans, Vice President of Quality and Managed Care Operations

Melissa Creary, University of Michigan, Associate Director Health Management and Policy

Rachel Sachs, Washington University School of Law, Law Professor

TaLana Hughes, Sickle Cell Disease Association of Illinois, Executive Director

Mark Trusheim, NEWDIGS, Tufts Medical Center, NEWDIGS Strategic Director

Anirban Basu, University of Chicago, Professor of Health Economics

Dr. Rena M. Conti, Boston University, Health Economist

Dr. Radhika Peddinti, The University of Chicago

Melissa Creary, University of Michigan, Associate Director Health Management and Policy

Anirban Basu, University of Chicago, Professor of Health Economics

Absences Recorded

Steve Sproat, Aetna Better Health, Pharmacy Director

Dr. Ruchika Goel, SIU School of Medicine

HFS Staff Present:

HFS Director (*)

Medicaid Administrator ()**

Director Lizzy Whitehorn*
Kelly Cunningham**
Jose Jimenez
Jennifer Dewitt

Laura Phelan
Melishia Bansa
Sheri Dolan
Dorian Manion
Michael Welton

- I. **Call to Order:** The meeting was called to order by Director Whitehorn, Chair of the Advisory Council on Financing and Access to Sickle Cell Disease Treatment and Other High-Cost Drugs, Tuesday, August 27, 2024, at **1:01 p.m. on the WebEx Platform**.
 - A. **Director Whitehorn**, the Council Chair, introduced herself to the council.
 - B. **General Meeting Operations and Communications:** This was provided by Melishia Bansa, Special Assistant to Director of HFS.
- II. **Roll Call of Council Members:** Ms. Melishia Bansa, Special Assistant to the Director of HFS, facilitated roll call of Committee Members. Quorum was confirmed.
- III. **Introduction of HFS Staff:** Ms. Bansa introduced HFS staff.
- IV. **Review and Approval of Meeting Minutes:** The minutes were moved for approval by Brian Smolich and seconded by Joan Erhardt. The motion was passed.
- V. **Review and Approval of Values and Priorities:** Director Whitehorn, Council Chair, provided an overview of the key objectives and guiding principles. The approval was moved by Brian Smolich and seconded by TaLana Hughes. The motion was passed.
- VI. **Recommendations Discussion on Financing Strategies Framework for Cell & Gene Therapy & Other High-Cost Drugs: Council Member Experience:** Director Whitehorn, Council Chair, began the discussion on financial strategies by seeking the council's recommendations for negotiating with drug manufacturers and invited questions and comments from members. This presentation can be referenced and reviewed on the HFS Website at the following link: [Advisory Council on Financing and Access to Sickle Cell Disease Treatment and Other High-Cost Drugs Meeting Presentation Decks | HFS \(illinois.gov\)](#).
 - A. Dr. Basu and Mark Trusheim offered additional comments on the scope of negotiation. Dr. Basu emphasized the need to develop a negotiation strategy for individual therapies before evaluating scalability. Mark Trusheim suggested negotiating multiple therapies together if several options are available, whereas for unique drugs, standard rebates might be preferable due to limited leverage.
 - B. George Kitchens provided additional comments on preparing for negotiation, noting that carving out inpatient drugs could prevent hospitals from feeling under-reimbursed and might make them eligible for supplemental rebates.
 - C. Joan Erhardt, Dr. Rena Conti, and Dr. Basu offered additional comments on negotiation strategies. Joan proposed collaborating with other states to enhance patient care and outcomes-based adjustments. Rena Conti and Dr. Basu discussed the benefits of a multi-state approach due to the high demand and need for increased provider capacity. Director Whitehorn noted the potential for federal models to negotiate on behalf of the state.
 - D. Dr. LaBelle and George offered additional comments on strategies for negotiation. Dr. LaBelle inquired about leveraging population size to negotiate better rates for high-

cost drugs. George discussed various value-based agreements, noting that different levels might be based on population size.

- E. Rena Conti and Mark Trusheim provided further comments regarding pricing strategies. Rena Conti expressed concerns about over-relying on a single manufacturer and emphasized considering both private and social demand in price calculations. She also raised the issue of whether to use supplemental rebates or 340B pricing strategies. The 340B program often benefits providers but can be complex regarding rebate distribution. Mark Trusheim proposed tender negotiations for drug classes and addressing gaps between clinical trial results and FDA labels.

- VII. **Next Steps:** Director Whitehorn, Council Chair, emphasized that the September meeting will continue the discussion on pricing strategies.
 - VIII. **Public Comment:** No public comments.
 - IX. **Additional Business:** Director Whitehorn, Council Chair, opened the floor for any new or additional business.
 - X. **Announcements:** Ms. Melishia Bansa reminded the council to complete mandatory ethics training and to visit the Boards and Commissions web page for meeting minutes and presentation materials.
 - XI. **Adjournment:** Meeting was adjourned at 2:30 p.m.
 - A. **Motion:** Director Whitehorn, Council Chair presented motion to adjourn meeting. Brian Smolich, Council member, seconded the motion. No oppositions. No abstentions. **Motion Carried.**
 - B. Next meeting is scheduled for September 2024.
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