



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, July 23, 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
Steve Sproat, Aetna Better Health, Pharmacy Director
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
Dr. Ruchika Goel, SIU School of Medicine

Absences Recorded

Melissa Creary, University of Michigan, Associate Director Health Management and Policy
Anirban Basu, University of Chicago, Professor of Health Economics

HFS Staff Present:

HFS Director (*)

Medicaid Administrator ()**

Director Lizzy Whitehorn*
Kelly Cunningham**

Laura Phelan
Melishia Bansa

Sheri Dolan
Dorian Manion

Dana Kelly

Jose Jimenez
Jennifer Dewitt

Angela Clark

- 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, July 23, 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 of Mission, Vision, Values, and Priorities:** Director Whitehorn, Council Chair, provided an overview of the key objectives and guiding principles.
- V. **Access to High-Cost Drugs and Treatments: Council Member Experience:** Melishia Bansa, Special Assistant to Director of HFS, introduced council members who shared their personal testimonies about the challenges of accessing high-cost therapies and drugs. Alexandra Carpenter, Beverly Chukwudozie, Dr. James LaBelle, Dr. Radhika Peddinti, TaLana Hughes, and Nathan Schaefer shared their experiences.
- VI. **Advisory Council Access Discussion:** Director Whitehorn, Chair, opened the discussion to council members for questions and comments. This complete 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. Conti offered additional comments on two key concerns for the council: out-of-pocket costs and access to centers of care deemed models of excellence. Director Whitehorn, Chair, clarified that the Illinois Medicaid program does not require premiums or cost-sharing.
 - B. Mark Trusheim provided additional comments on factors and challenges affecting the future state of the market. Brian Smolich offered further insights on patient advocacy.
- VII. **Next Steps:** Director Whitehorn, Council Chair, emphasized that the August meeting will begin the discussion on financing options.
- VIII. **Public Comment:** No Public comments.
- IX. **Additional Business:** Director Whitehorn, Council Chair, opened the floor for any new or additional business. Ms. Melishia Bansa reminded the council to visit the Boards and Commissions web page for meeting minutes and presentation materials.
- X. **Adjournment:** Meeting was adjourned at 2:32 p.m.
 - A. **Motion:** Director Whitehorn, Council Chair presented motion to adjourn meeting. Mark Trusheim, Council member, seconded the motion. No oppositions. No abstentions. **Motion Carried.**

B. Next meeting is scheduled for August 27, 2024.
