



HFS

Illinois Department of
Healthcare and Family Services

JB Pritzker, Governor

201 South Grand Avenue East, Springfield, Illinois 62763

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

Date | Time: Tuesday, June 25, 2024, | 2:00 p.m. to 3:30 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 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

Absences Recorded

Dr. Radhika Peddinti, The University of Chicago

Dr. Ruchika Goel, SIU School of Medicine

HFS Staff Present:

HFS Director (*)

Medicaid Administrator ()**

Director Lizzie Whitehorn*

Helena Lefkow

Jose Jimenez

Katy Hinshaw

Laura Phelan

Melishia Bansa

Kelly Cunningham**

Jennifer Dewitt

Sheri Dolan

- 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, June 25, 2024, at **2:01 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. **Presentation on Advisory Council on Financing and Access to Sickle Cell Disease Treatment and Other Parliamentary Meeting Procedures:** Bylaws were provided by Melishia Bansa, Special Assistant to Director of HFS.
- V. **Review and Approval of Bylaws:**
 - A. **Motion:** Director Whitehorn, Chair, presented motion for approval of Bylaws. Bylaws were approved with modifications to numbering. This motion was moved by Director Whitehorn. George Kitchens, Council Member, seconded the motion. No oppositions. No abstentions. **Motion Carried.**
- VI. **Review of Advisory Meeting Framework** was provided by Director Whitehorn, Council Chair.
- VII. **Financing and Access Challenges Overview:** Director Whitehorn, Council Chair, provided an overview of the current challenges and opportunities, highlighting the need for the advisory council.
- VIII. **Illinois Medicaid Overview:** Kelly Cunningham, Medicaid Administrator, reviewed the current role of the D&T Advisory Board and the drug review process. She also discussed ongoing efforts to exclude HCD from hospital DRG payments and the establishment of a managed care HCD pool effective in 2025, which aims to distribute HCD costs across MCOs and improve cost equity. 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 \(illinois.gov\).](#)
- IX. **Brainstorming Discussion:** Director Whitehorn, Council Chair, reviewed the definitions related to contracting strategies.
 - A. Additional comments were provided by George Kitchens regarding federal and supplemental rebates, and Brian Smolich also commented on supplemental rebates.
 - B. Additional comments were provided by Dr. Basu, Dr. LaBelle, and Dr. Conti regarding factors and challenges affecting the future state of the market.
 - C. Additional comments were provided by Melissa Creary, Rachel Sachs, and Susan Stuard on the actionable steps needed for decision-making.
- X. **Next Steps:** Director Whitehorn, Council Chair, emphasized sharing data from other states, and additional resources with the Department.
- XI. **Public Comment:** Public comments were not reviewed.

XII. Additional Business: Director Whitehorn, Council Chair, opened the floor for any new or additional business; none was noted by the council.

XIII. Adjournment: Meeting was adjourned at 3:27 p.m.

A. Motion: Director Whitehorn, Council Chair presented motion to adjourn meeting. George Kitchens, Council member, seconded the motion. No oppositions. No abstentions. **Motion Carried.**

B. Next Meeting July 2024.
