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, September 17, 2024, | 1:00 p.m. to 2:00 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, Health Assessment and Screening Section Chief
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
Melissa Creary, University of Michigan, Associate Director Health Management and Policy

Absences Recorded

Dr. Ruchika Goel, SIU School of Medicine
Anirban Basu, University of Chicago, Professor of Health Economics
Dr. Rena M. Conti, Boston University, Health Economist
Dr. Radhika Peddinti, The University of Chicago

HFS Staff Present:
HFS Director (*)
Medicaid Administrator (**)

Director Lizzy Whitehorn*	**Laura Phelan**	**Sheri Dolan**
Kelly Cunningham**	**Melishia Bansa**	**Dorian Manion**
Emma Watter Reardon	**Jose Jimenez**	**Melissa Davis**
Michael Welton	**Jennifer Dewitt**	**Margaret Dunne**
		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, September 17, 2024, at **1:02 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 Laura Phelan, Deputy Director, New Initiatives at HFS.

II. **Roll Call of Council Members:** Laura Phelan, Deputy Director at HFS, facilitated roll call of Committee Members. Quorum was confirmed.

III. **Introduction of HFS Staff:** Laura Phelan introduced HFS staff.

IV. **Review and Approval of Meeting Minutes:** The minutes were moved for approval by Brian Smolich and seconded by James LaBelle. The motion was passed.

V. **Live Poll on Financing Strategies Framework for Cell & Gene Therapy & Other High-Cost Drugs:** Director Whitehorn, Council Chair, prefaced survey instructions, allowing only council members to participate in the poll. She then introduced Sheri Dolan, who offered expert insights on survey questions. 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. The results of the poll indicated that 93% of participants favored a dual approach, recommending that the state consider both value-based and supplemental rebate structures during negotiations. Brian Smolich provided further insights, highlighting that manufacturers frequently attempt to exclude claims by referencing issues such as missed doses or deviations from FDA trial protocols. This practice makes it difficult to effectively collect funds under these contracts.

B. The findings regarding when value-based rebates should be considered indicate strong support, with 69% in favor for high-cost drugs, 77% for rare drugs, and 85% for cell and gene therapies, while only 15% supported them in cases with low administrative burden. George Kitchens raised concerns about durability and the challenges of measuring long-term data, suggesting that effective measurement may require agreements of 3 to 5 years, although some therapies could demonstrate effectiveness within the first year.

C. The findings regarding what elements HFS should prioritize to drive down costs in rebate negotiations indicate that key factors include competition, patient volume, outcomes, access, and equity. Brian Smolich emphasized that understanding patient volume is crucial for effective negotiation and accurate forecasting of the treatment pool. Dr. LaBelle suggested leveraging state-funded support for centers of excellence to negotiate rebates for specific drugs.

D. The survey results indicate that 92% of participants support evaluating Purchasing

Pool Models as a tool. Mark Trusheim noted that federal models provide valuable benchmarks for negotiations, although not all states may participate. Susan highlighted Illinois's strong independent position due to its population size and the need to understand disease prevalence, recommending that CMS enhance transparency. George Kitchens added that Illinois can operate independently, and that manufacturers are more aggressive with pools.

E. Susan Stuard, Dr. LaBelle, and Mark Trusheim provided additional comments on how the state should investigate higher supplemental rebates until the manufacturer completes the post-marketing trial. Susan highlighted the limitations imposed by Medicaid requirements, while Mark proposed a proactive approach through value-based contracts (VBCs) to manage uncertainty.

F. Melissa Creary and George Kitchens provided additional comments on whether to use a third-party assessment, such as ICER, to inform our decision on a drug's value. Melissa expressed concerns about ICER's measurement and valuation methods, while George acknowledged its usefulness as a reference point, despite occasional inaccuracies.

VI. **Financing Framework Wrap-Up Discussion:** Director Whitehorn, Council chair, welcomed final comments on the discussion.

VII. **Next Steps:** Director Whitehorn, Council Chair, reminded the council about upcoming meetings. Laura informed the council they would be receiving a post-meeting survey.

VIII. **Public Comment:** No Public comments.

IX. **Additional Business:** Director Whitehorn, Council Chair, opened the floor for any new or additional business.

X. **Announcements:** Laura Phelan reminded the council to visit the Boards and Commissions webpage for meeting minutes, presentation materials, and the resource tab. She also reminded the council of the importance of completing the mandatory ethics training.

XI. **Adjournment:** Meeting was adjourned at 1:59 p.m.

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

B. Next meeting is scheduled for September 24, 2024.