



HFS

Illinois Department of
Healthcare and Family Services

JB Pritzker, Governor

Lizzy Whitehorn, Director

401 South Clinton, 7th Floor
Chicago, Illinois 60607

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

June 25, 2024

Article I - Name and Mandate

Section A

The Advisory Council on Financing and Access to Sickle Cell Disease Treatment and Other High-Cost Drugs and Treatment ("Advisory Council") is established under Executive Order 2024-01 for the purpose of advising the Illinois Department of Healthcare and Family Services ("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.

Section B

The Advisory Council shall:

- a. 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.
- b. 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.
- c. Evaluate the success and challenges of various value and outcome-based payment approaches implemented in other states.
- d. Make recommendations on financing approaches that could be adopted in Illinois and/or nationally with the support of the federal Centers for Medicare & Medicaid Services (CMS).
- e. Identify any state and federal policy, legal, regulatory, and resource changes necessary to successfully implement the Advisory Council's recommendations.
- f. Provide leadership for and collaborate with those working to make sickle cell disease treatments and other high-cost drugs and treatment accessible.



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g. 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.

h. 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.

Section C

Vision Statement: Forming an Advisory Council is an important and effective tool in expanding access to new sickle cell disease treatments and other high-cost drugs and treatment, bringing together State resources for this common goal, drawing from the deep knowledge and expertise of national, state, provider, and consumer advocates, and prioritizing patient voices and community partnerships in developing and implementing solutions.

Article II - Membership

Section A

The Advisory Council, to be appointed by the Governor, shall consist of:

- a. The Director of HFS, or their designee, who shall serve as chair.
- b. One member representing the Illinois Department of Public Health.
- c. One member representing the Illinois Department of Insurance.
- d. One member representing the Governor's Office of Management and Budget.
- e. One member with lived experience as a person with sickle cell disease.
- f. One member with lived experience as a person with a condition requiring access to new, innovative drugs or treatment.
- g. One member representing providers treating sickle cell disease patients.
- h. One member representing providers treating patients with another condition requiring access to new, innovative drugs or treatment.



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- i. Two members with expertise in prescription drug rebate negotiations and outcomes-based agreements.
- j. Two members with published research in financing new, innovative drugs and treatments within public health insurance programs.
- k. Two members with health economist or actuarial backgrounds.
- l. One member representing sickle cell disease advocacy organizations.
- m. One member representing advocacy organizations for a condition(s) requiring access to new, innovative drugs and treatment.
- n. Two members representing the health insurance industry.
- o. Two at-large members, who may or may not meet the qualification requirements for the other appointees.

Section B

Members of the Advisory Council shall serve at the will of the Governor. If there is a vacancy for any cause, the Governor shall make an appointment to become immediately effective.

The Advisory Council shall sunset on December 31, 2024.

Section C

Members of the Advisory Council shall serve without compensation, except that the two members with lived expertise may be provided an honorarium to reimburse them for their time, not to exceed \$250 per meeting.

Section D

If a member misses three consecutive regularly scheduled meetings or does not complete HFS mandatory trainings within three (3) months of written notice, said action will be considered a voluntary resignation, and their membership will be automatically terminated.



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Article III - Officers

Section A

The Director of HFS or their designee shall serve as the Chair of the Advisory Council indefinitely for the entire duration of the Advisory Council until its completion.

Section B

The Chair of the Advisory Council shall perform the duties ordinarily ascribed to such office and shall preside at all meetings of the Advisory Council.

Section C

In the event the Chair is absent or unable to complete their duties due to illness, disability, relocation outside of Illinois, resignation, or another similar circumstance the designee of the Director of HFS shall serve as Chair.

Article IV - Meeting

Section A

The Advisory Council shall meet at least four (4) times. Such meetings shall take place at locations, dates, and times specified by the Director of HFS. The Advisory Council meetings are subject to the Open Meetings Act (5 ILCS 120/2).

Advisory Council meetings will be held via electronic options (web-based, video conferencing, and/or telephonic) at the discretion of the Director of HFS.

It shall be the responsibility of HFS to give notice via the HFS website of the location, date, and time of said regular meetings to each member of the Advisory Council at least forty-eight (48) hours prior to each of the meetings.

Section B

A special meeting of the Advisory Council may be called to discuss and consider only a special item identified at the time in that notice, provided it complies with the Open Meetings Act, which requires at least forty-eight (48) -hours advance notice.

Section C

An agenda of business scheduled for deliberation shall be prepared and distributed to the members of the Advisory Council and posted on the HFS Website at least forty-eight (48) hours prior to a scheduled or special meeting of the Advisory Council.



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Section D

The Advisory Council shall strive to operate by consensus; however, so long as they each have a quorum, they may approve measures and make recommendations based on an affirmative vote of a majority of the members present.

A quorum shall be eleven (11) members.

Section E

The Chair of the Advisory Council may request Advisory Council members to limit their comments to conform to the posted agenda. The Chair of the Advisory Council has the right to limit public comments to fit the allotted time on the agenda. All deliberations of the Advisory Council shall be governed by Robert's Rules of Order to the extent not inconsistent with these Bylaws. All applicable Federal and State laws and Advisory Council Bylaws take precedence over Robert's Rules, in that order.

Section F

Under the New Business portion of an Advisory Council meeting, any Advisory Council member may add an item to the agenda of a future Advisory Council meeting for discussion and action with approval from a simple majority of Advisory Council members present.

Article V - Professional Staff

The Director of HFS and/or their designee shall serve as the Advisory Council official consultant. The Director of HFS may designate members of HFS Boards and Commissions staff to assist in such consultation.

Article VI - Communication Among Chair and Committee Members

Any communication related to committee business or surveys involving members and officers needs to be channeled through the HFS Boards and Commissions Lead Administrative staff, to prevent any violations of the Open Meetings Act.

Article VII - Amendment to the Bylaws

The Bylaws may be amended by a two-third ($2/3^{\text{rd}}$) majority vote of the members present at any regular or special meetings of the Advisory Council if the proposed amendment is distributed in writing at forty-eight (48) hours before said meeting.