August 15, 2018

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Kentucky HEALTH - Application and CMS STCs

Dear Secretary Azar:

Hemophilia Federation of America (HFA) appreciates the opportunity to submit comments on the Kentucky HEALTH Section 1115(a) Demonstration Waiver and the Centers for Medicare and Medicaid Services (CMS) Special Terms and Conditions (STC). HFA is concerned that Kentucky's waiver would jeopardize access to quality and affordable health coverage for people with bleeding disorders, among many other Kentuckians. HFA urges CMS to reject the proposed waiver.

Background.
HFA is a community-based, grassroots advocacy organization that assists, educates, and advocates for people with bleeding disorders. Hemophilia and other bleeding disorders are genetic conditions that impair proper blood clotting. People with hemophilia, often the severest of these conditions, take prescription medications (clotting factor or other newer therapies) to treat or avoid painful bleeding episodes that can lead to advanced medical issues, such as joint and muscle damage, or even death. These medicines are highly effective and allow affected individuals to lead healthy and productive lives. However, hemophilia treatments are extremely expensive, costing anywhere from $250,000 to $1 million or more annually, depending on whether complications such as an inhibitor are present. Due to the high cost of treatments, good health coverage is essential for people with bleeding disorders.

Premiums and Cost-Sharing.
One of the key features of the Kentucky HEALTH program, as originally approved by CMS, is to charge premiums to both Medicaid expansion enrollees and extremely low-income parents and caregivers. Premiums will be set no lower than $1 and possibly as high as 4 percent of household income.[i] The waiver would allow Kentucky to increase premiums for enrollees who are on Medicaid for over a year. Kentucky only needs to give enrollees a 60-day notice of premium increase.

Prior experience in other states shows that premiums both increase the number of enrollees who lose Medicaid coverage and discourage eligible people from enrolling in the program.[ii] When Oregon implemented a premium in its Medicaid program, with a maximum premium of $20 per month, almost half of enrollees lost coverage.[iii] For individuals with bleeding disorders, maintaining access to comprehensive coverage is indispensable. People with bleeding disorders cannot preserve their health without access to their medications, and the medications are too expensive for anyone to pay for out-of-pocket.

A similar pattern emerged when Indiana implemented premiums requirements as part of a previous waiver demonstration. The evaluation report[iv] from the waiver demonstration found that over half of Medicaid enrollees failed to make at least one payment. The report also found that 29 percent of Medicaid eligible individuals either never enrolled because they did not make a payment or were disenrolled for failure to make payments. Coverage losses on this scale, especially for patients needing access to life-saving and life-sustaining treatment, would be dire. Individuals

with bleeding disorders cannot afford to cycle in and out of coverage; they need ongoing and reliable access to their medications and medical providers.

These and other premium-related changes proposed by Kentucky would create confusion and significant barriers for patients, jeopardizing their access to much-needed care.

Waiving Retroactive Eligibility.
Kentucky asked for and CMS approved the proposal to remove retroactive eligibility in Kentucky. Retroactive eligibility in Medicaid prevents gaps in coverage, by covering individuals for up to 90 days (or one quarter of the year) prior to the month of application, assuming the individual is eligible for Medicaid coverage during that time frame.

Medicaid paperwork can be burdensome and often-times confusing. A Medicaid enrollee may not have understood (or even received) a notice of Medicaid renewal, and may only discover their coverage lapse when picking up a prescription or going to see their doctor. Without retroactive eligibility, Medicaid enrollees could then face substantial costs at their doctor's office or pharmacy. For example, when Ohio was considering a similar provision in 2016, a consulting firm advised the state that hospitals could incur as much as $2.5 billion more in uncompensated care as a result of the waiver.[v] Patients should not be left to choose between massive medical bills and treating their illness.

Work and Community Engagement Requirements.
Kentucky's waiver was the first waiver CMS approved that conditioned Medicaid coverage on hours worked. The STC detail that individuals between the ages of 19 and 64 will be required to either demonstrate that they work at least 80 hours per month or meet exemptions. One major consequence of this proposal will be to increase the administrative burden on all patients. Individuals will need to attest that they meet certain exemptions, or that they have worked the required number of hours, on a monthly basis. Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. For example, after Washington state changed its renewal process from every twelve months to every six months and instituted new documentation requirements in 2003, approximately 35,000 fewer children were enrolled in the program by the end of 2004.[vi] Patients and caregivers should not have to battle administrative red tape in order to keep health coverage.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with serious, acute and chronic diseases, including bleeding disorders. After an initial three-month period, if Kentucky finds that individuals have failed to comply with the new requirements for one month, those individuals will be locked out of coverage until they complete a health or financial literacy class, make up the missing hours in the next month, or complete the required 80 hours of work in the next month. People with bleeding disorders cannot afford sudden gaps in care as they depend on regular access to their health care providers and rely on ongoing medication regimens to manage their chronic conditions.

HFA is also concerned that the current exemption criteria may not capture all individuals with, or at risk of, serious and chronic health conditions that prevent them from meeting the work and community engagement requirements. No exemption criteria can circumvent this problem and the serious risk to the coverage and health of the people we represent.

Administering these requirements will be expensive. Kentucky and other states including Tennessee and Virginia have estimated that setting up the administrative systems to track and verify exemptions and work activities will cost tens of millions of dollars.[vii] These costs would divert resources from Medicaid's core goal – providing health coverage to those without access to care.

These requirements do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care. Most people on Medicaid who can work already do so.[viii] A recent study, published in JAMA Internal Medicine, looked at the employment status and characteristics of Michigan's Medicaid enrollees.[ix] The study found only about a quarter were unemployed (27.6 percent). Of this 27.6 percent of enrollees, two thirds reported having a chronic physical condition and a quarter reported having a mental or physical condition that interfered with their ability to work.

Ultimately, the Kentucky HEALTH program will harm people with bleeding disorders and other Kentuckians. Leading public health and health policy deans and professors estimated that implementation of the waiver would result in a coverage loss of 175,000 to 300,000 people in the state.[x] This would be devastating for Kentucky and for its small but vulnerable population of individuals with bleeding disorders.

HFA believes healthcare should be affordable, accessible, and adequate. The Kentucky HEALTH program does not meet that standard, and HFA therefore urges CMS not to re-approve the waiver. Thank you for the opportunity to provide comments.

Sincerely,

Miriam Goldstein

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Hemophilia Federation of America

CC: Demetrios L. Kouzoukas
Principal Deputy Administrator
Centers for Medicare and Medicaid Services

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[i] Centers for Medicare and Medicaid Services. KY HEALTH Section 1115 Demonstration. January 12, 2018. Accessed at: https://kentuckyhealth.ky.gov/SiteCollectionDocuments/Kentucky%20HEALTH%20Demonstration%20Approval.pdf

[ii] Artiga, Samantha, Petry Ubri and Julia Zur. The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings. Kaiser Family Foundation. June 1, 2017. Accessed at: https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/

[iii] Artiga, Samantha, Petry Ubri and Julia Zur. The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings. Kaiser Family Foundation. June 1, 2017. Accessed at: https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/

[iv] The Lewin Group, Health Indiana Plan 2.0: POWER Account Contribution Assessment (March 31, 2017). Accessed at: https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-POWER-acct-cont-assesmnt-03312017.pdf

[v] Virgil Dickson, "Ohio Medicaid waiver could cost hospitals $2.5 billion", Modern Healthcare, April 22, 2016. (http://www.modernhealthcare.com/article/20160422/NEWS/160429965)

[vi] Tricia Brooks, "Data Reporting to Assess Enrollment and Retention in Medicaid and SCHIP," Georgetown University Health Policy Institute Center for Children and Families, January 2009.

[vii] Misty Williams, "Medicaid Changes Require Tens of Millions in Upfront Costs," Roll Call, February 26, 2018, https://www.rollcall.com/news/politics/medicaid-kentucky.
[viii] Rachel Garfield, Robin Rudowitz, and Anthony Damico, "Understanding the Intersection of Medicaid and Work," Kaiser Family Foundation, February 2017, http://kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/.
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[x]Stewart et al v. Azar, Brief for Deans, Chairs, and Scholars as Amici Curiae in Support of Plaintiffs, United States District Court for the District of
Columbia, April 10, 2018. Available at:
https://publichealth.gwu.edu/sites/default/files/downloads/HPM/Kentucky%20Medicaid%20Proposed%20Amici%20Curiae%20Brief.pdf