November 27, 2017

Ms. Seema Verma
Administrator
Centers for Medicare and Medicaid Services
Hubert Humphrey Building
Constitution Avenue, NW
Washington, DC 20510

Re: CMS-9930-P: *Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2019*

Dear Ms. Verma:

Hemophilia Federation of America (HFA) is the largest community-based, grassroots advocacy organization that assists, educates, and advocates for people with bleeding disorders. We are submitting comments in response to the HHS/CMS Request for Information published in the Federal Register on November 2, 2017, entitled *Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2019.*

Hemophilia and other bleeding disorders are genetic conditions that impair the body's ability to clot properly. People with hemophilia, often the most severe of these conditions, administer prescription medications (clotting factor or other newer therapies) to avoid painful or potentially life-threatening bleeding episodes that can lead to advanced medical issues such as joint and muscle damage, and even death. These medicines are highly effective and allow affected individuals to lead healthy productive lives. However, hemophilia treatments are extremely expensive, costing anywhere from $250,000 to $1 million annually, depending on the severity of the disorder and whether complications such as an inhibitor are present.

As an organization that represents individuals with a rare and chronic disease, HFA is concerned that CMS's proposed rule will allow states to create insurance packages that offer weakened essential health benefits (EHBs). This would harm patients with rare and chronic diseases, like hemophilia, who need access to quality health insurance.

The proposed rule outlines four new options that states may use in developing their EHB-benchmark plans. While we understand that CMS's goal is to enhance state flexibility, we believe the proposed rule gives states too much leeway to "race to the bottom" in plan design and does too little to protect consumers who need access to meaningful health insurance.

CMS proposes to allow states to adopt other states' EHB-benchmark plans, or to pick and choose from among one or more EHB categories from another state's plan. Using one of these options would allow a state to drop or weaken benefits needed by its most vulnerable populations, including people with chronic disorders like hemophilia, creating dangerous gaps in coverage.

Furthermore, both options would impact out-of-pocket protections for enrollees in Marketplace and group plans, since consumer protections such as yearly out-of-pocket maximums and the ban on lifetime and annual benefit caps apply only to EHB.[1] Eroding protections against ruinous out-of-pocket spending, and allowing for the return of annual and lifetime caps, would have a devastating effect on people with bleeding disorders and other chronic health conditions.

CMS's third option would allow states to start from scratch and build their own menu of EHBs. This, too, creates serious risks for individuals with hemophilia and other chronic disorders. While a state choosing this option must continue including all the required ten EHBs, "it could significantly scale back coverage within EHB categories, dropping or severely limiting some items and services within the category." [2] States would have to demonstrate that "the scope of benefits" are equivalent with the "typical employer plan" in the large or small group market with more than 5,000 enrollees. However, the rule's definition of "typical employer plan" would allow states to choose a plan used by only one company, providing very thin coverage, that is not in fact "typical" at all.[3]

An employer plan, for example, might cover only a limited number of hospital visits or doctor visits, or might only cover generic medications and not brand-name drugs. This year, a handful of patients have reported to HFA that some employer plans have severely limited their access to clotting factor. If such a plan were to become the basis for a new state benchmark standard, it would greatly reduce the overall value of the ACA benefit package and would create an overwhelming gap in coverage for people with bleeding disorders.[4]

Another problem with CMS's third option lies in the limits that apply to states that create new benchmark plans from scratch. A state that uses this option must ensure that the new plan it creates is less generous than existing comparison plans; otherwise the state will have to bear the costs of the additional benefits. This limitation will discourage states from offering comprehensive coverage and will be a disincentive to cover meaningful advances in care.

Many health experts caution that CMS's proposed rule will create a process for the states to weaken the package of EHBs for individual plans and will lead to skimpier health plans in the individual and small group insurance markets.[5] If individuals with rare and chronic diseases do not have access to quality affordable health care, then these individuals will not be able to maintain a healthy life. Therefore, we respectfully ask that HHS maintain the current process for states to select their essential health benefits packages.

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[1] Shelby Livingston, *CMS proposed rule open door to skimpier health plans, higher patient costs,* Modern Healthcare, Oct. 30, 2017, http://www.modernhealthcare.com/article/20171030/NEWS/171039987.
[2] Sarah Lueck, *Administration's Proposed Changes to Essential Health Benefits Seriously Threaten Comprehensive Coverage,* Center on Budget and Policy Priorities, Nov. 7, 2017, https://www.cbpp.org/research/health/administrations-proposed-changes-to-essential-health-benefits-seriously-threaten.
[3] Id.
[4] Id.
[5] Livingston, *supra* note 1.

Despite our concerns with the four new proposed options for states to select an EHB benchmark plan, we strongly appreciate that the proposed rule states that if a plan covers additional drugs (beyond those covered by the benchmark plans), those drugs are considered EHBs and must count towards the annual maximums on out-of-pocket spending.

However, we oppose the development of a "federal default definition of essential health benefits," which could include a "national benchmark plan standard for prescription drugs." We ask that HHS provide more information regarding the reasoning of implementing a federal default definition. We are concerned that a federal default definition of EHBs would then lead to limiting beneficiary benefits and increased patient cost-sharing. Additionally, a "national benchmark plan standard for prescription drugs" would limit the access of care to only a select list of drugs to many individuals with chronic and rare diseases who are already stable on specific drugs that are crucial for them to manage their conditions.

As we commented earlier this year to HHS/CMS, the continuation of patient protections is critical and health plans must meet the needs of all consumers, including the most vulnerable patients living with rare and chronic diseases. Even under current law, patients still contend with skimpy and discriminatory plans that lack meaningful formulary coverage for prescription drugs, impose burdensome prior authorization and step therapy requirements, and entail high out-of-pocket spending. Therefore, we urge HHS/CMS to continue to enforce and strengthen patient protections and continue to stabilize the health insurance market and enhance affordability.

We thank you for the opportunity to comment. If you have any additional comments, or need any additional information, please contact Katie Verb at 202-675-6984 or k.verb@hemophliafed.org.

Sincerely,

Kimberly Haugstad
President & CEO
Hemophilia Federation of America