



December 12, 2019

Attn: David Buono
1326 Strawberry Square
Harrisburg, PA 17120

Re: Pennsylvania Section 1332 State Innovation Waiver

Dear Mr. Buono:

The Eastern Pennsylvania Hemophilia Foundation (EPHF), Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF), Hemophilia Federation of America (HFA), and The National Hemophilia Foundation (NHF) appreciate the opportunity to submit comments on Pennsylvania's Section 1332 State Innovation Waiver.

EPHF is a non-profit organization that is located in Springfield and WPCNHF is a non-profit located in Cranberry Township. Both are dedicated to enriching the lives of those living with bleeding disorders in the state of Pennsylvania. HFA and NHF are national non-profit organizations that represent individuals affected by bleeding disorders across the United States. Our missions are to ensure that individuals affected by hemophilia and other inherited bleeding disorders have timely access to quality medical care, therapies, and services, regardless of financial circumstances or place of residence.

About Bleeding Disorders

Hemophilia is a rare, genetic bleeding disorder that impairs the ability of blood to clot properly. It affects about 20,000 Americans, including more than 1000 males in Pennsylvania.¹ Without treatment, people with hemophilia bleed internally, sometimes due to trauma, but other times simply as a result of everyday activities. This bleeding can lead to severe joint damage and permanent disability, or even – with respect to bleeds in the head, throat, or abdomen – death. Related conditions include von Willebrand disease (VWD), another inherited bleeding disorder, which is estimated to affect more than three million Americans.

Patients with bleeding disorders have complex, lifelong medical needs. They depend on prescription medications (clotting factor or other new therapies) to treat or avoid painful bleeding episodes that can lead to advanced medical issues. Current treatment and care are highly effective and allow individuals to lead healthy and productive lives. However, treatment is also extremely expensive, costing anywhere from \$250,000 to \$1 million or more annually, depending on the severity of the disorder and whether complications such as an inhibitor are present. Access to treatment, care, and coverage are all critical needs for people living with bleeding disorders. For low income individuals, Medicaid is a critical path to obtaining necessary coverage.

EPHF, WPCNHF, HFA, and NHF believe everyone should have quality and affordable healthcare coverage. A strong, robust marketplace is essential for people with bleeding disorders to access the coverage that they need. EPHF, WPCNHF, HFA, and NHF support Pennsylvania's efforts to strengthen its marketplace by submitting this 1332 State Innovation Waiver to implement a reinsurance program.

Reinsurance is an important tool to help stabilize health insurance markets. Reinsurance programs help insurance companies cover the claims of very high cost enrollees, which in turn keeps premiums affordable for other individuals buying insurance on the individual market. Reinsurance programs have been used to stabilize premiums in several healthcare programs, such as Medicare Part D. A temporary reinsurance fund for the individual market was also



established under the Affordable Care Act and reduced premiums by an estimated 10 to 14 percent in its first year.ⁱⁱ A recent analysis by Avalere of the seven states that have already created their own reinsurance programs through Section 1332 waivers found that these states reduced individual market premiums by an average of 19.9 percent in their first year.ⁱⁱⁱ

Pennsylvania's proposal will create a reinsurance program starting for the 2021 plan year and continuing for 5 years. This program is projected to reduce premiums on average, between 4.9% and 7.5%, for the 2021 plan year and increase the number of individuals obtaining health insurance through the individual market between 0.5% and 1.0%. This would help patients with pre-existing conditions, including patients with bleeding disorders, obtain affordable, comprehensive coverage.

EPHF, WPCNHF, HFA, and NHF believe the 1332 State Innovation Waiver will help stabilize the individual market in Pennsylvania and protect patients and consumers. Thank you for the opportunity to provide comments. Should you have any questions or comments please do not hesitate to reach out to either Miriam Goldstein, HFA Director of Policy (m.goldstein@hemophiliafed.org), or Nathan Schaefer, NHF Vice President of Public Policy (nschaefer@hemophilia.org).

Sincerely,

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ⁱ U.S. Centers for Disease Control and Prevention, Geographic Distribution of males with hemophilia A or B attending federally funded integrated-care Hemophilia Treatment Centers by state of residence 1/2012 – 9/2018. Available at: <https://www.cdc.gov/ncbddd/hemophilia/communitycounts/data-reports/2018-9/hemo-map.html>.

ⁱⁱ American Academy of Actuaries, Individual and Small Group Markets Committee. *An Evaluation of the Individual Health Insurance Market and Implications of Potential Changes*. January 2017. Retrieved from https://www.actuary.org/files/publications/Acad_eval_indiv_mkt_011817.pdf.

ⁱⁱⁱ Avalere. *State-Run Reinsurance Programs Reduce ACA Premiums by 19.9% on Average*. March 2019. Retrieved from <https://avalere.com/press-releases/state-run-reinsurance-programs-reduce-aca-premiums-by-19-9-on-average>.