



The Honorable Janet Yellen
Secretary
Department of the Treasury
1500 Pennsylvania Avenue, NW
Washington, DC 20220

The Honorable Xavier Becerra
Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: New York Section 1332 Waiver State Innovation Waiver: Amendment Application

Dear Secretary Yellen and Secretary Becerra:

On behalf of the nearly 1700 people living with cystic fibrosis (CF) in New York, the Cystic Fibrosis Foundation appreciates the opportunity to submit comments on the 1332 Waiver Amendment Request. Specifically, we support New York's request to implement cost sharing reduction (CSR) subsidies for consumers with incomes up to 400% of the federal poverty level (FPL) and for consumers in all metal tiers who receive diabetes-related services. Cost-sharing reduction payments are a critical tool for the health insurance Marketplace, keeping care affordable for many people with CF and other chronic diseases. Together, these proposals will reduce out-of-pocket costs and improve access to care for people living with CF in New York.

About Cystic Fibrosis and Cystic Fibrosis-Related Diabetes

Cystic fibrosis is a life-threatening genetic disease that affects nearly 40,000 children and adults living with cystic fibrosis in the United States, and CF can affect people of every racial and ethnic group. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. While great strides have been made in the treatment of the disease, the lives of young people with cystic fibrosis are still cut far too short. In 2022, half of those who died from CF were younger than 37.¹ CF requires an intensive daily treatment regimen to address its many manifestations and eighty-six percent of CF patients also have at least one health complication in addition to cystic fibrosis, including cystic fibrosis-related diabetes (CFRD), asthma, sinus disease, and others.

Cystic fibrosis-related diabetes is one of the most common complications experienced by people with CF, occurring in five percent of adolescents and nearly one in three adults living with CF.² Due to the disease's progressive nature, CF can cause scarring or "fibrosis" of the pancreas, which can lead to insulin deficiency and CFRD. Like type-1 and type-2 diabetes, treatment for CFRD relies on insulin and additional supplies such as continuous glucose monitors, test strips, insulin pens, syringes or needles, lancets, and alcohol swabs.

The Cystic Fibrosis Foundation is committed to ensuring that New York's healthcare programs provide quality and affordable healthcare coverage. We believe the state's proposal to enhance cost-sharing subsidies for Marketplace consumers will advance these objectives. Once implemented, New York's waiver

^{1,2} <https://www.cff.org/sites/default/files/2022-11/Patient-Registry-Annual-Data-Report.pdf>

should increase coverage affordability for tens of thousands Marketplace enrollees and improve health equity, while satisfying the federal guardrail protections governing waivers. We applaud the state's work to improve equitable access to care in New York and offers the following comments:

Reduction in Cost Sharing for Individuals Up to 400% of the FPL

New York's proposed cost-sharing subsidies will lower healthcare costs for individuals above 250% of the federal poverty level. For example, the waiver projects that 79,000 individuals will save an additional average of \$3,450 annually as a result of the cost-sharing subsidies. The state anticipates that a total of 118,000 enrollees will experience improved affordability of coverage as a result of this proposal. Research consistently shows that higher cost-sharing is associated with decreased use of preventive services and medical care among low-income populations.³ The amendment further estimates that this waiver will improve access to care in New York by increasing enrollment by approximately 3,000 people per year. The Cystic Fibrosis Foundation supports the proposed cost-sharing subsidies as a method to improve both affordability and accessibility of coverage in New York.

At the same time, the state's analysis demonstrates that the waiver satisfies four statutory guardrails. While affordability and enrollment will improve, the comprehensiveness of coverage will not be affected. The amendment also states that additional costs will be fully covered by the pass-through surplus from New York's existing 1332 waiver.

Reduction in Cost-Sharing for Diabetes Services

The Cystic Fibrosis Foundation also supports New York's request to create a cost-sharing wrap that reimburses insurers to reduce cost sharing for non-hospital-based diabetes-related services, supplies and prescription drugs, for all Marketplace consumers. As a result, consumers will have \$0 out-of-pocket costs for diabetes-related services while remaining in a plan of their choice. We appreciate that New York intends to use passthrough funding to reimburse insurers for cost sharing they would have received from consumers for diabetes-related care, offsetting potential premium increases for the Marketplace.

Reducing out-of-pocket costs for diabetes services will improve access to care for New Yorkers living with CFRD. Due to the high cost of insulin and other prescription drugs, many people with CF—even with the help of financial assistance—are forced to make difficult spending tradeoffs that can impact their health. According to a recent survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half of those surveyed reported delaying or forgoing care—including skipping medication doses, taking less medicine than prescribed, filling a prescription, or skipping a treatment altogether—due to cost concerns.⁴ Further, one in seven people with CF who use diabetes supplies reported having problems paying for them. Diabetic supplies are commonly classified as durable medical equipment and often do not have adequate coverage with commercial insurers, frequently leading to high out-of-pocket costs for people with CF. Those living with CFRD who do not have consistent access to insulin or accompanying supplies may be unable to properly manage their blood sugar levels, putting them at increased risk of irreversible damage, costly hospitalizations, and declining health outcomes.

The cost of insulin and supplies places additional financial strain on patients who may already struggle to afford their care. In the aforementioned survey, people with CF reported having the most difficulty paying for prescription drugs compared to any other component of their health care. Further, more than 70 percent of people with CF said paying for health care has caused financial problems such as being contacted by a collection agency, filing for bankruptcy, experiencing difficulty paying for basic living expenses like rent and utilities, or taking a second job to make ends meet. Eliminating copayments for

³ https://hsrsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs

⁴ <https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings>

insulin and diabetes supplies will help mitigate some of the financial burden that accompanies managing cystic fibrosis and CFRD.

The Cystic Fibrosis Foundation supports the proposals in this waiver request as a method to improve affordability of healthcare for lower income individuals in New York, as well as equitable access to care, while complying with the 1332 waiver statutory guardrails.

Thank you for the opportunity to provide comments.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a large initial "M" and "D".

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President of Policy & Advocacy
Cystic Fibrosis Foundation



American Heart Association.



EPILEPSY FOUNDATION



LEUKEMIA & LYMPHOMA SOCIETY®



Arthritis Foundation®



Asthma and Allergy Foundation of America



Help Us Solve The Cruel Mystery LUPUS® FOUNDATION OF AMERICA



NATIONAL BLEEDING DISORDERS FOUNDATION Formerly NHF



NORD® National Organization for Rare Disorders



THE AIDS INSTITUTE

August 23, 2024

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200 Independence Avenue, SW
Washington, DC 20201

Re: New York Section 1332 State Innovation Waiver: Amendment Application

Dear Secretary Yellen and Secretary Becerra:

Thank you for the opportunity to provide feedback on the New York 1332 State Innovation Waiver Amendment Application.

The undersigned organizations represent millions of individuals facing serious, acute and chronic health conditions. We have a unique perspective on what individuals and families need to prevent disease, cure illness and manage chronic health conditions. The diversity of our organizations and the populations we serve enable us to draw upon a wealth of knowledge and expertise that is an invaluable resource regarding any decisions affecting the Affordable Care Act and the people that it serves. We urge the Department of the Treasury and the Department of Health and Human Services (the Departments) to make the best use of the recommendations, knowledge and experience our organizations offer here.

Our organizations are committed to ensuring that New York’s healthcare programs provide quality and affordable healthcare coverage. We believe the state’s proposal to enhance cost-sharing subsidies for Marketplace consumers will advance these objectives and we urge the Departments to approve this proposal. Once implemented, New York’s waiver should increase coverage affordability for tens of thousands Marketplace enrollees and improve health equity while satisfying the federal guardrail protections governing waivers. Our organizations applaud the state’s work to improve equitable access to care in New York and offer the following comments:

New York’s proposed cost-sharing subsidies will lower healthcare costs for individuals above 250% of the federal poverty level. For example, the waiver projects that 79,000 individuals will save an additional average of \$3,450 annually as a result of the cost-sharing subsidies. The state anticipates that a total of 118,000 enrollees will experience improved affordability of coverage as a result of this proposal. Research consistently

shows that higher cost-sharing is associated with decreased use of preventive services and medical care among low-income populations.¹ For patients with chronic disease, delaying or deferring necessary medications and treatments due to cost can lead to worse health outcomes. The amendment further estimates that this waiver will improve access to care in New York by producing an enrollment increase of approximately 3,000 consumers per year. Our organizations support the proposed cost-sharing subsidies as a method to improve both affordability and accessibility of coverage in New York.

At the same time, the state's analysis demonstrates that the waiver satisfies four statutory guardrails. While affordability and enrollment will improve, the comprehensiveness of coverage will not be affected. The amendment also states that additional costs will be fully covered by the pass-through surplus from New York's existing 1332 waiver.

Finally, our organizations support the positive effect that this waiver is expected to have on health equity in New York. Adult Black and Hispanic New Yorkers experience lower levels of health insurance coverage and higher incidences of preventable hospitalizations.² Increased affordability of coverage and enrollment can help to address these disparities.

Our organizations support this proposal as a method to improve affordability of healthcare for lower income individuals in New York, as well as equitable access to care, while complying with the 1332 waiver statutory guardrails. We urge the Departments to approve this amendment application.

Thank you for the opportunity to provide comments.

Sincerely,

Alpha-1 Foundation
American Cancer Society Cancer Action Network
American Heart Association
American Lung Association
Arthritis Foundation
Asthma and Allergy Foundation of America
CancerCare
Child Neurology Foundation
Epilepsy Foundation
Hemophilia Federation of America
Lupus Foundation of America
National Bleeding Disorders Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Patient Advocate Foundation
The AIDS Institute
The Leukemia & Lymphoma Society

¹Samantha Artiga, 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 2017. Available at: <https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/>.

² Department of Health, New York State. New York State Prevention Agenda Dashboard-State Level, 2023. Available at: https://webbi1.health.ny.gov/SASStoredProcess/guest?_program=/EBI/PHIG/apps/dashboard/pa_dashboard&p=sh