

**IN THE UNITED STATES DISTRICT COURT  
FOR THE DISTRICT OF MASSACHUSETTS**

STATE OF CALIFORNIA,  
COMMONWEALTH OF  
MASSACHUSETTS, STATE OF NEW  
JERSEY, STATE OF ARIZONA, STATE  
OF COLORADO, STATE OF  
CONNECTICUT, STATE OF DELAWARE,  
STATE OF ILLINOIS, STATE OF MAINE,  
STATE OF MARYLAND, STATE OF  
MICHIGAN, STATE OF MINNESOTA,  
STATE OF NEW MEXICO, STATE OF  
NEVADA, STATE OF NEW YORK,  
STATE OF OREGON, JOSH SHAPIRO, *in  
his official capacity as Governor of the  
Commonwealth of Pennsylvania*, STATE OF  
RHODE ISLAND, STATE OF VERMONT,  
STATE OF WASHINGTON, STATE OF  
WISCONSIN;

*Plaintiffs,*

v.

ROBERT F. KENNEDY JR., *in his official  
capacity as Secretary of Health and Human  
Services*, MEHMET OZ, *in his official  
capacity as Administrator for the Centers for  
Medicare and Medicaid Services*, U.S.  
DEPARTMENT OF HEALTH AND  
HUMAN SERVICES, U.S. CENTERS FOR  
MEDICARE AND MEDICAID SERVICES,

*Defendants.*

Civil Action No. 1:25-cv-12019

**BRIEF OF *AMICI CURIAE* NATIONAL HEALTH LAW PROGRAM, VICTORIA BAGGOT,  
JASON PIPERBERG, TIMOTHY REYBURN, BIANCA MAHMOOD, KENNY CAPPS,  
MARIAH ADEEKO, AMERICAN CANCER SOCIETY, AMERICAN CANCER SOCIETY  
CANCER ACTION NETWORK, THE LEUKEMIA & LYMPHOMA SOCIETY, LEGAL  
COUNCIL FOR HEALTH JUSTICE, AiARTHRITIS, AMERICAN LUNG ASSOCIATION,  
THE COALITION FOR HEMOPHILIA B, EPILEPSY FOUNDATION OF AMERICA,  
FAMILIES USA, MUSCULAR DYSTROPHY ASSOCIATION, AND NATIONAL MS  
SOCIETY IN SUPPORT OF PLAINTIFF STATES' MOTION  
FOR A PRELIMINARY INJUNCTION AND STAY  
(Leave to file granted 7/25/2025)**

## TABLE OF CONTENTS

TABLE OF AUTHORITIES .....	i
INTEREST OF AMICI CURIAE .....	1
ARGUMENT .....	1
I. CONGRESS PASSED THE AFFORDABLE CARE ACT TO ADDRESS SERIOUS BARRIERS TO PEOPLE’S ABILITY TO OBTAIN HEALTH CARE .....	1
A. Before the ACA .....	1
B. After the ACA .....	3
II. HEALTH INSURANCE SAVES LIVES, BUT THE FINAL RULE ERECTS BARRIERS TO COVERAGE AND, AS A RESULT, PEOPLE WILL BE HURT.....	5
A. Individual Amici .....	6
B. Organizational Amici .....	12
III. CONCLUSION.....	19

## TABLE OF AUTHORITIES

### CASES

<i>Nat’l Fed’n of Indep. Bus. (NFIB) v. Sebelius</i> , 567 U.S. 519 (2012) .....	3
--	---

### STATUTES

26 U.S.C. § 36B .....	3
42 U.S.C. § 300gg.....	3
42 U.S.C. § 300gg-1 .....	4
42 U.S.C. § 300gg-2 .....	4
42 U.S.C. § 300gg-3 .....	3
42 U.S.C. § 300gg-4 .....	3
42 U.S.C. § 300gg-6 .....	4

42 U.S.C. § 300gg-11 .....	3
42 U.S.C. 18022.....	4
42 U.S.C. § 18083.....	4
Inflation Reduction Act, Pub. L. No. 117-169, 136 Stat 1818 (2022).....	3

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Am.’s Health Ins. Plans Ctr. for Pol’y & Rsch., <i>Individual Health Insurance 2009: A Comprehensive Survey of Premiums, Availability, and Benefits</i> (2009), <a href="https://www.kff.org/wp-content/uploads/sites/2/2011/08/2009individualmarketsurveyfinalreport.pdf">https://www.kff.org/wp-content/uploads/sites/2/2011/08/2009individualmarketsurveyfinalreport.pdf</a> .....	2
Assistant Sec’y for Plan. & Evaluation, Off. of Health Pol’y, <i>Healthcare Insurance Coverage, Affordability of Coverage, and Access to Care, 2021-2024</i> (2025), <a href="https://aspe.hhs.gov/sites/default/files/documents/9a943f1b8f8d3872fc3d82b02d0df466/coverage-access-2021-2024.pdf">https://aspe.hhs.gov/sites/default/files/documents/9a943f1b8f8d3872fc3d82b02d0df466/coverage-access-2021-2024.pdf</a> .....	4
Dania Palanker et al., <i>Eliminating Essential Health Benefits Will Shift Financial Risk Back to Consumers</i> , The Commonwealth Fund Blog (Mar. 24, 2017), <a href="https://www.commonwealthfund.org/blog/2017/eliminating-essential-health-benefits-will-shift-financial-risk-back-consumers">https://www.commonwealthfund.org/blog/2017/eliminating-essential-health-benefits-will-shift-financial-risk-back-consumers</a> .....	2
David U. Himmelstein et al., <i>Medical Bankruptcy in the United States, 2007: Results of a National Study</i> , 122 Am. J. Med. 741 (2009), <a href="https://pubmed.ncbi.nlm.nih.gov/19501347/">https://pubmed.ncbi.nlm.nih.gov/19501347/</a> .....	3
Families USA, <i>Dying for Coverage: The Deadly Consequences of Being Uninsured</i> (2012), <a href="https://familiesusa.org/wp-content/uploads/2019/09/Dying-for-Coverage.pdf">https://familiesusa.org/wp-content/uploads/2019/09/Dying-for-Coverage.pdf</a> .....	3
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Jennifer Tolbert et al., <i>KFF, A Look at ACA Coverage through the Marketplaces and Medicaid Expansion Ahead of Potential Policy Changes</i> (2025), <a href="https://www.kff.org/affordable-care-act/issue-brief/a-look-at-aca-coverage-through-the-marketplaces-and-medicaid-expansion-ahead-of-potential-policy-changes/">https://www.kff.org/affordable-care-act/issue-brief/a-look-at-aca-coverage-through-the-marketplaces-and-medicaid-expansion-ahead-of-potential-policy-changes/</a> .....	4
Jingxuan Zhao et al., <i>Health Insurance Status and Cancer Stage at Diagnosis and Survival in the United States</i> , 72 CA: Cancer J. Clinicians 542 (2022), <a href="https://doi.org/10.3322/caac.21732">https://doi.org/10.3322/caac.21732</a> .....	13
Jingxuan Zao et al., <i>Immune Checkpoint Inhibitors and Survival Disparities by Health Insurance Coverage Among Patients with Metastatic Cancer</i> , 8 JAMA Network Open e2519274 (July 7, 2025), <a href="https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2836042">https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2836042</a> .....	12
Kewei Sylvia Shi, <i>Association of Health Insurance Coverage Disruptions and Colorectal Cancer Screening</i> , 131 Cancer e35584 (Jan. 1, 2025), <a href="https://www.ovid.com/journals/canc/abstract/10.1002/cncr.35584~association-of-health-insurance-coverage-disruptions-and">https://www.ovid.com/journals/canc/abstract/10.1002/cncr.35584~association-of-health-insurance-coverage-disruptions-and</a> .....	13
Letter from Elizabeth G. Taylor, Exec. Dir., Nat'l Health Law Program, to Sec'y Robert F. Kennedy, Jr. (Apr. 10, 2025), <a href="https://www.regulations.gov/comment/CMS-2025-0020-19541">https://www.regulations.gov/comment/CMS-2025-0020-19541</a> .....	4
Patient Protection and Affordable Care Act; Marketplace Integrity and Affordability, 90 Fed. Reg. 27,074 (June 25, 2025) .....	1
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## INTEREST OF AMICI CURIAE

The *amici* are individuals enrolled in the ACA Marketplace—Victoria Baggot, Jason Piperberg, Timothy Reyburn, Bianca Mahmood, Kenny Capps, and Mariah Adeeko—and the following organizations: American Cancer Society, American Cancer Society Cancer Action Network, The Leukemia & Lymphoma Society, Legal Council for Health Justice, AiArthritis, American Lung Association, The Coalition for Hemophilia B, Epilepsy Foundation of America, Families USA, Muscular Dystrophy Association, National Health Law Program, and National MS Society.

Although each *amicus* has their own particular interests, the ability of people to obtain and maintain quality, affordable health care coverage through the Affordable Care Act (ACA) is essential to all of them. As such, *amici* have an interest in the Final Rule being challenged in this case, U.S. Department of Health and Human Services (HHS) Final Rule, Patient Protection and Affordable Care Act; Marketplace Integrity and Affordability, 90 Fed. Reg. 27,074 (June 25, 2025). The Final Rule will introduce significant barriers to coverage that, according to HHS’s own estimates, will cause up to 1.8 million people to lose their health insurance in 2026 alone.

*Amici* will provide background on the ACA and then provide the Court with examples of how the Final Rule is going to hurt individuals and families who rely on affordable Marketplace coverage.

## ARGUMENT

### **I. CONGRESS PASSED THE AFFORDABLE CARE ACT TO ADDRESS SERIOUS BARRIERS TO PEOPLE’S ABILITY TO OBTAIN HEALTH CARE.**

#### **A. Before the ACA**

Prior to the enactment of the ACA, over 50 million people in the United States (roughly

17 percent of the population) did not have health insurance. U.S. Dep't of Com., Census Bureau, *Income, Poverty, and Health Insurance Coverage in the United States: 2009*, at 23 (2010), <https://www2.census.gov/library/publications/2010/demo/p60-238/p60-238.pdf>. This was due in part to the fact that many lower-income Americans not eligible for Medicaid were unable to purchase insurance on the individual market, either because it was too expensive or unavailable to them. Rachel Garfield et al., KFF, *The Uninsured and the ACA: A Primer – Key Facts about Health Insurance and the Uninsured amidst Changes to the Affordable Care Act* (2019), <https://www.kff.org/report-section/the-uninsured-and-the-aca-a-primer-key-facts-about-health-insurance-and-the-uninsured-amidst-changes-to-the-affordable-care-act-how-have-health-insurance-coverage-options-and-availability-changed/>. Nearly 13 percent of people who applied for coverage in the individual market and went through the medical underwriting process were denied insurance due to pre-existing conditions. Am.'s Health Ins. Plans Ctr. for Pol'y & Rsch., *Individual Health Insurance 2009: A Comprehensive Survey of Premiums, Availability, and Benefits* 10 (2009), <https://www.kff.org/wp-content/uploads/sites/2/2011/08/2009individualmarketsurveyfinalreport.pdf>.

Even when people were able to purchase insurance, the coverage was often inadequate. It did not include important services such as prescription drugs, maternity care, and mental health care. See Dania Palanker et al., *Eliminating Essential Health Benefits Will Shift Financial Risk Back to Consumers*, The Commonwealth Fund Blog (Mar. 24, 2017), <https://www.commonwealthfund.org/blog/2017/eliminating-essential-health-benefits-will-shift-financial-risk-back-consumers>. And, plans capped lifetime and annual benefits. See Am. Cancer Soc'y, Cancer Action Network, *Bans on Lifetime and Annual Cost Caps Protect Cancer Patients* (2017),

<https://www.fightcancer.org/sites/default/files/Lifetime%20and%20Annual%20Caps%20Factsheet%2001-06-17.pdf> (noting that prior to 2014, more than 105 million Americans were enrolled in plans with a lifetime limit).

The lack of coverage and inadequate coverage had grave financial and health consequences. In 2007, more than 62 percent of all personal bankruptcies were related to medical costs. David U. Himmelstein et al., *Medical Bankruptcy in the United States, 2007: Results of a National Study*, 122 Am. J. Med. 741 (2009), <https://pubmed.ncbi.nlm.nih.gov/19501347/>. What is more, in 2010 alone, inadequate health coverage caused 26,100 premature deaths among individuals between the ages of 25 and 64. Families USA, *Dying for Coverage: The Deadly Consequences of Being Uninsured* 2 (2012), <https://familiesusa.org/wp-content/uploads/2019/09/Dying-for-Coverage.pdf>.

## **B. After the ACA**

With the enactment of the ACA in March 2010, Congress “aim[ed] to increase the number of Americans covered by health insurance and decrease the cost of health care.” *Nat’l Fed’n of Indep. Bus. v. Sebelius*, 567 U.S. 519, 538 (2012).

The ACA provides people with incomes between 100 and 400 percent of the Federal Poverty Level (FPL) with premium tax credits to help them purchase health insurance. 26 U.S.C. § 36B. (During the COVID pandemic, Congress increased premium tax credits and extended eligibility to people above 400 percent FPL until the end of 2025. Inflation Reduction Act, § 12001, Pub. L. No. 117-169, 136 Stat 1818, 1905 (2022)). In addition, the law prevents insurers from: charging higher premiums based on sex, health status, or medical condition, *see* 42 U.S.C. §§ 300gg, 300gg-4; imposing annual or lifetime dollar limits on benefits, *id.* § 300gg-11; and excluding coverage of benefits related to preexisting conditions, *id.* § 300gg-3. Perhaps most

critically, it provides for guaranteed availability and renewability of coverage. *Id.* §§ 300gg-1, 300gg-2.

To facilitate enrollment, the ACA establishes a single streamlined application process for multiple insurance programs, including the ACA Marketplaces, Medicaid, and the Children’s Health Insurance Program. 42 U.S.C. § 18083; *see* Letter from Elizabeth G. Taylor, Exec. Dir., Nat’l Health Law Program, to Sec’y Robert F. Kennedy, Jr., at 11 (Apr. 10, 2025), <https://www.regulations.gov/comment/CMS-2025-0020-19541> (comment noting that streamlined enrollment “procedures—including automatic re-enrollment—have become the standard to which people living in the United States who obtain their health care through the marketplaces are accustomed”). Finally, the ACA assures coverage of essential health benefits, such as maternity and newborn care, prescription drugs, mental health services, and preventive care. 42 U.S.C. §§ 300gg-6, 18022.

Over time, the ACA has helped drive the uninsured rate down from over 14 percent in 2013 to just 7.6 percent in the second quarter of 2024. Assistant Sec’y for Plan. & Evaluation, Off. of Health Pol’y, *Healthcare Insurance Coverage, Affordability of Coverage, and Access to Care*, 2021-2024, at 3 (2025), <https://aspe.hhs.gov/sites/default/files/documents/9a943f1b8f8d3872fc3d82b02d0df466/coverage-access-2021-2024.pdf>; *see* Jason Furman & Matt Fiedler, *2014 Has Seen Largest Coverage Gains in Four Decades, Putting the Uninsured Rate at or Near Historic Lows*, the White House Blog (Dec. 18, 2014), <https://obamawhitehouse.archives.gov/blog/2014/12/18/2014-has-seen-largest-coverage-gains-four-decades-putting-uninsured-rate-or-near-his> (noting the drop in the uninsured rate in 2014 was the largest since the early 1970s). As of 2024, 44 million people in the United States were enrolled in health insurance because of the ACA. Jennifer Tolbert et al.,



*KFF, A Look at ACA Coverage through the Marketplaces and Medicaid Expansion Ahead of Potential Policy Changes* (2025), <https://www.kff.org/affordable-care-act/issue-brief/a-look-at-aca-coverage-through-the-marketplaces-and-medicaid-expansion-ahead-of-potential-policy-changes/> (finding 21.4 million enrolled in a Marketplace plan, 21.3 million in the Medicaid expansion, and 1.3 million in a Basic Health Plan).

## **II. HEALTH INSURANCE SAVES LIVES, BUT THE FINAL RULE ERECTS BARRIERS TO COVERAGE AND, AS A RESULT, PEOPLE WILL BE HURT.**

ACA Marketplace coverage saves lives. But without question, the Final Rule will create barriers to obtaining this coverage and take serious steps backwards. Among other things, the Final Rule will increase consumer premiums and out-of-pocket costs. The Final Rule's changes to the premium adjustment percentage methodology and actuarial value ranges will cause a consumer's share of premiums to rise, and allow bronze, silver, and gold plans to have higher deductibles, copayments, and coinsurance costs. Under the Final Rule, even people with low income such that they are entitled to Marketplace coverage with no premiums will now incur an arbitrary \$5 premium that they must pay or risk losing their coverage.

The Final Rule will shorten the open enrollment period. Enrollment in late December (in states that use the federal Marketplace, healthcare.gov) or January will no longer be permitted beginning with the 2027 plan year.

The Final Rule will harm people with fluctuating incomes and those with relatively low health literacy, as they will have difficulty meeting paperwork verification requirements for advance premium tax credits. These changes will be especially hard-hitting for the self-employed. From artists to hairdressers, ride-share drivers, consultants, and adjunct professors, their incomes are often sporadic with months of plenty and months with little work or income. Finding acceptable

proof of income can be difficult, and those who are unable to produce this evidence may be unable to enroll at all. The Final Rule also cuts in half the time permitted for people to file their taxes and reconcile their earned income with the amount they received in ACA premium assistance based on their projected income. Many low-income, self-employed adults are able to remain in the Marketplace specifically because they have had two years for reconciliation. The Final Rule's change to yearly reconciliation will lead to many self-employed individuals losing access to financial help and, with it, their only health coverage option, the Marketplace.

#### **A. Individual Amici**

The provisions of the Final Rule are going to hurt people, as illustrated by these individuals' stories:

**Victoria (Tori) Baggot** is a 34-year-old woman who lives in Pittsburgh, Pennsylvania. She considers herself to be a typical American. Tori is in the midst of launching her own small letterpress printing business, making greeting cards, prints and other paper goods.

When she was 13 years old, Tori began to have joint problems. She was eventually diagnosed with Hypermobility Spectrum Disorder (HSD), a chronic condition that is part of a spectrum of disorders that includes Ehlers-Danlos Syndrome. The condition has major effects on her joints and connective tissues. She experiences mobility problems and pain. The cause of HSD is not yet understood, so treatment focuses on controlling symptoms, which can appear and shift quickly. Tori requires regular specialist visits, testing, and medications.

Because of HSD, it is essential for Tori to have a health care plan that meets her needs. Tori is entering her second year of Marketplace coverage (called Pennie in Pennsylvania). Her husband's employer-based coverage would cost more than triple what she now pays—\$600 a month. Tori qualifies for premium tax credits through Pennie that allow her to save \$164 a month,

nearly \$2,000 a year.

Tori and her husband live frugally, but money is quite tight as she works to get the printing business off the ground. If the Final Rule's increases in premiums and cost sharing occur, she will likely have to choose less than the full coverage she needs to treat her HSD symptoms. The financial burden of having to pay more for health coverage would present a significant challenge to her ability to have the printing business and would certainly involve taking a second job.

Tori and her husband hope to start a family soon. Knowing that prenatal care and family planning care would be covered through Pennie is a huge relief; however, Tori is concerned that significant increases in the cost of coverage will mean that she cannot afford to have children.

**Jason Piperberg** is 35 years old. He lives in Philadelphia, Pennsylvania and works as a freelance illustrator, earning roughly \$30,000 a year. He has used the ACA Marketplace to enroll in health insurance since 2017.

During a routine check-up in October 2022, Jason asked his primary care provider about a lump in his neck. After a series of tests, he was diagnosed with thyroid cancer, which had spread to the surrounding lymph nodes. He underwent a total of three surgeries (removing his entire thyroid and dozens of lymph nodes) and one round of radioactive iodine therapy. With his silver-tier Marketplace plan, Jason was able to receive care from some of the best doctors in the country. The treatment was successful, and although the cancer is not officially in remission, all of his current scans and test results are in a good place.

Despite being enrolled in a silver-tier plan, Jason still incurred several thousand dollars out-of-pocket for the treatment. Those out-of-pocket expenses were on top of his monthly premiums, which are currently approximately \$114 per month. Jason eventually qualified for

financial aid through the hospital, and that helped to relieve some of the financial stress of the situation.

Jason needs ongoing monitoring, including regular checkups, ultrasounds, and blood work to make sure his condition remains stable. In addition, he will have to take thyroid hormone daily for the rest of his life to remain healthy. If his premiums increase under the Final Rule, he will have to switch to a lower-tier plan with higher out-of-pocket costs and potentially a different network of doctors. He has good relationships with his doctors and does not want to lose access to them. He is even more concerned that a significant increase in premiums and cost sharing requirements under the Final Rule will put coverage and care out of reach for him, which would be catastrophic for his health.

**Timothy Reyburn** is 64 years old and lives in Laurel, Maryland with his wife, Angelika. He is an entrepreneur who has owned and operated a specialized scientific services company since he founded it in 1994 when Angelika was diagnosed with muscular dystrophy. As a new business owner and with his wife's new health needs, Timothy needed to obtain health insurance. He enrolled in coverage, but premiums rose—sometimes doubling—as he was forced to pay more for health insurance or choose plans with less coverage.

When Marketplace coverage became available in 2014, new protections were introduced: preexisting conditions could not be excluded from coverage, and plans covered preventive care without cost sharing. The Reyburns immediately enrolled in platinum-level coverage. Their premium costs dropped significantly and coverage improved. Timothy was able to breathe a sigh of relief due to the reduced risk of bankruptcy from exposure to large medical bills.

The Reyburns have been enrolled in Marketplace coverage ever since. They rely on the ACA because it provides: affordable care, 100% comprehensive preventive care, and makes care

readily available for Angelika on a wide range of health needs. This year, Timothy and Angelika's gold-tier Marketplace plan covered a full physical, vaccinations, colonoscopy, a knee MRI, cataracts surgery, and an ENT for Timothy's temporary loss of hearing and balance. As of July 2025, the Reyburns had already reached their plan's annual out-of-pocket maximum and deductible for this year. They will face similar or related health needs again in 2026. Under the Final Rule, Timothy's premiums and cost sharing requirements are expected to increase, making preventive care and ongoing necessary treatments less accessible and less affordable to him and his wife.

**Bianca Mahmood**, 41 years old, lives in Los Angeles, California. She is enrolled in the ACA Marketplace, called Covered California, for health coverage. Bianca enrolled in Covered California when she lost employer-sponsored insurance three years ago.

Covered California has given Bianca access to high-quality plans at a fraction of the cost of buying directly from the insurance companies. The ability to purchase affordable and adequate health insurance independent of an employer is critical to allowing her to remain self-employed while pursuing her goals: Bianca completed a certificate in Data Analytics in June 2025 and is preparing to attend graduate school part-time while continuing to work for herself.

Covered California gives Bianca the security of knowing that she will have the opportunity to enroll in plans vetted by individuals who understand both the state health infrastructure and the health care needs of Californians. Although Bianca is an avid researcher and educated consumer, she finds navigating the notoriously opaque and confusing health insurance landscape as an individual purchaser overwhelming. Covered California has provided her with a centralized, transparent, and easy-to-navigate platform for obtaining resources to meet her health care needs.

Bianca is in good health—she primarily uses her health insurance for preventive care like annual checkups and vaccinations—but her Covered California insurance gives her the peace of mind of knowing she will be able to get additional care as health challenges arise. When she injured her knee last year, her plan covered the necessary imaging, treatment, and physical therapy. Bianca is concerned that the premium and cost sharing increases contained in the Final Rule will make it financially burdensome for her to pay for high-quality, comprehensive health insurance and that her coverage and health care access will suffer as a result.

**Kenny Capps** is 53 years old and a father of three. He lives in Black Mountain, North Carolina. Nearly ten years ago, Kenny was busy running a small marketing and printing business, taking care of his family, and training for ultra-marathons, when he began to experience extreme fatigue. He went to see his primary care provider. A few months later, in January 2015, he was diagnosed with multiple myeloma, a cancer that affects bone marrow. Kenny had lesions on bones throughout his body, including his skull, spine, hips, and ribs. He had two compression fractures in his back.

Shortly after he was diagnosed, Kenny was able to purchase health insurance through the ACA Marketplace, which allowed him to begin treatment. He underwent chemotherapy followed by a bone marrow transplant in August 2015. Without health insurance, the various statements of benefits showed that his first year of cancer treatment would have cost almost \$700,000. That amount would have been completely unaffordable for Kenny.

Since 2015, Kenny has maintained his enrollment in a Marketplace plan. The coverage has enabled him to receive ongoing monitoring, testing, and treatment for his condition. Because multiple myeloma currently has no cure, he will likely need to continue treatment for the rest of his life. Even with his health insurance, Kenny has significant out-of-pocket health costs, including

cost sharing for appointments, lab work, and medications. These expenses put a strain on his family budget. Kenny is now the director of a small non-profit, and he coaches runners. If his premiums or cost-sharing increase substantially, he is going to struggle to afford the care that he needs to be present for his children, work, and give back to his community. He is worried that he and his family will be forced to make an impossible choice—pay their mortgage and other basic expenses, or pay for the medical care that keeps him alive.

**Mariah Adeeko** is 21 years old and lives in Houston, Texas. Mariah is enrolled in family Marketplace coverage alongside their parents and sister. Thanks to the Affordable Care Act, Mariah can continue to be covered as a dependent until they turn 26 and will obtain their own health insurance. Mariah's family has long relied on Marketplace coverage as an affordable option, turning to the Marketplace when employer-sponsored insurance has not been available or affordable.

As a long-time Marketplace enrollee, Mariah knows that plan-specific coverage details—from provider networks to cost-sharing levels—can make a big difference in the care they are able to receive and the amount they must pay for that care. In some years, Mariah's Marketplace coverage included high-quality clinical networks that helped them manage their health needs and very low cost sharing for prescription drugs. In other years, Mariah faced higher out-of-pocket costs for the same care, and their health insurance covered less care than they expected. These plan design details matter because Mariah has a condition that requires regular care from a specialist, lab tests, and prescription drugs. Under the Final Rule, health insurers will have more flexibility to erode the actuarial value of Marketplace coverage, forcing Mariah to dive even deeper to understand new benefits and limitations for 2026. These and other changes under the Final Rule will also lead to higher premiums and cost-sharing for Mariah and their family.

Informed by these experiences navigating health insurance and care, Mariah's work includes offering training and consumer education to help other young adults understand their coverage options, improve their health insurance literacy, and use their coverage. Marian is deeply concerned that the Final Rule's burdensome new administrative requirements, such as new special enrollment period and income eligibility verification requirements, will deter young adults from enrolling in Marketplace coverage by making it even harder for them to navigate complex coverage decisions—often without the help they need to fully understand their options.

## **B. Organizational Amici**

The **American Cancer Society** mission is to improve the lives of people with cancer and their families through advocacy, research, and patient support, to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer. For over a decade, ACS research has demonstrated that access to comprehensive, affordable health insurance saves lives. The **American Cancer Society Cancer Action Network** (ACS CAN) is the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society. ACS CAN advocates for evidence-based public policies to reduce the cancer burden for everyone. Health insurance is crucial for advanced stage cancer patients to gain access to the newest lifesaving treatments and makes it more likely that people will survive. Jingxuan Zao et al., *Immune Checkpoint Inhibitors and Survival Disparities by Health Insurance Coverage Among Patients with Metastatic Cancer*, 8 JAMA Network Open e2519274 (July 7, 2025), <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2836042>. Research from the American Cancer Society has shown that uninsured Americans are less likely to be screened for cancer and thus more likely to have their cancers diagnosed at an advanced stage when survival is less likely and the cost of care, more expensive. Jingxuan Zhao et al., *Health Insurance Status and Cancer Stage at Diagnosis and Survival in the United States*. 72 CA: Cancer J. Clinicians 542



(2022), <https://doi.org/10.3322/caac.21732>. Moreover, disruptions in health insurance coverage—even if the individual re-gains coverage eventually—are associated with missed cancer screenings. Kewei Sylvia Shi, *Association of Health Insurance Coverage Disruptions and Colorectal Cancer Screening*, 131 *Cancer* e35584 (Jan. 1, 2025), <https://www.ovid.com/journals/canc/abstract/10.1002/cncr.35584~association-of-health-insurance-coverage-disruptions-and>. A.M.’s story illustrates the essential role of ACA Marketplace coverage for cancer patients.

A.M. is a 47-year-old resident of Illinois. For more than 20 years, A.M. cared for others as a nurse, mother of two, and grandmother to her 5-year-old and 10-month-old granddaughters (with two more on the way). In the fall of 2021, she began having seizures and had to stop driving and working. She lost her health insurance. A.M. continued to have health problems, including suffering a stroke. After months of medical testing, she was diagnosed with leukemia. A.M. struggled to pay for health care. She sold her car, lost her house, and moved in with her brother and sister-in-law. She eventually applied for Medicaid and disability benefits. She first qualified for Medicaid but, when her application for disability benefits was approved in January 2024, her income exceeded Medicaid’s limits, and she lost that coverage. A.M. signed up for health insurance through the Marketplace in May 2024. She qualified for premium tax credits under the ACA, making the cost of her Marketplace plan \$132 per month as of January 2025.

A.M. currently lives alone. A Certified Nursing Assistant (CNA) visits her twice a week to help with bathing and personal hygiene, household chores, and shopping. As her condition deteriorates, she will need additional CNA help. She also started receiving hospice services in October 2024. A.M. is having great difficulty navigating the health care and social service systems, but it helps that she is receiving care from health care providers whom she knows and trusts.

Having affordable and comprehensive health insurance is key to A.M.'s treatment and ongoing care. Changes brought about by the Final Rule will mean that A.M. will be required to pay much higher premium contributions for the most basic Marketplace health plan, as well as higher out-of-pocket health care costs. This will require difficult choices, given her fixed disability income. She may also be forced to jump through more administrative hoops to do so. Changing to a cheaper or different plan will also mean that A.M. will have to start from scratch with new doctors, new referrals, and a different hospice provider.

The **Leukemia & Lymphoma Society** (LLS) is the world's largest voluntary health agency dedicated to fighting blood cancer and ensuring that the more than 1.6 million blood cancer patients and survivors in the United States have access to the care they need. LLS's mission is to cure blood cancer and to improve the quality of life of patients and their families. LLS advances that mission by advocating for blood cancer patients to have sustainable access to quality, affordable, coordinated health care, regardless of the source of their coverage. In addition to research and policy & advocacy, LLS provides one-on-one patient support to guide people with blood cancer and their families through treatment and financial and social challenges, including navigating insurance coverage and medical debt. The Final Rule would create barriers to LLS's mission and, most importantly, for the patients and survivors LLS works for, as the following examples illustrate:

**K.F-S.** is 51 years old and lives in Maine. For the past 15 years, she and her husband have been the primary caregivers for her father, who has chronic lymphocytic leukemia and is now in hospice care. In 2017, while running a fundraising race for the LLS, K.F-S. became ill. She lost vision in her right eye and mobility on the right side of her body. She was diagnosed with multiple

sclerosis—specifically, multiple demyelinating lesions in the brain and dangerously elevated brain pressure. K.F-S. had to stop working at the University of Southern Maine.

K.F-S. is able to obtain the health care she needs because she is insured through the ACA Marketplace. Her annual household income is about \$40,000, which qualifies her for a significant ACA subsidy and reduced out-of-pocket deductible. K.F-S. needs consistent, complex care: regular neurologist visits, twice-yearly MRIs and spinal taps, and consultations with eye specialists. She takes medication to reduce pressure in her brain. With her ACA plan, she pays \$10 a month. Without it, the medication would cost \$64 a month. K.F-S. has a medication regimen to support her care that costs \$230 with insurance. That regimen, while supportive, causes leeching of essential vitamins and minerals—necessitating routine supplements and quarterly IV treatments. Without insurance, a single spinal tap would cost K.F-S \$2,300; an MRI, \$4,800.

If the level of support she receives from the Marketplace decreases, K.F-S. will face difficult choices, including whether and when to delay or forgo health care. Without health care, K.F-S. would lose vision, mobility, and independence and live in constant pain. She would not be able to care for her family or her father in his final days.

*N.S. and B.S.* live in Dubuque, Iowa with their two sons, S.S. and L.S. In 2022, S.S. was diagnosed with a rare cancer, rhabdomyosarcoma, at just three and a half years old. S.S. underwent 66 weeks of cancer therapy. The treatment included many rounds of chemotherapy in Iowa City (a two-hour drive from home), dozens of radiation treatments, some of which S.S. needed to receive in Rochester, Minnesota (a more than three-hour drive from home), and nearly 20 prescriptions. This care saved his life. His doctors say his body now has no evidence of disease.

When S.S.'s treatment began, the family had health insurance through N.S.'s employer. But N.S. was forced to leave her job to care for S.S. B.S. was self-employed, so he did not have

access to employer-sponsored coverage. A hospital social worker helped enroll the two boys in Medicaid, allowing B.S. and N.S. to breathe easier knowing their children had access to essential health care.

N.S. and B.S. were able to find a high-quality plan for themselves on the ACA Marketplace. They were able to afford the coverage due to the ACA's premium tax credits. Maintaining coverage is especially important for B.S., who has a lifelong chronic illness. To keep his condition under control, he needs regular imaging and specialty medication that comes with its own high out-of-pocket costs.

The family is still facing the devastating economic consequences of illness and disease. Throughout S.S.'s care, N.S. and B.S. pursued grants from charities that paid for hospital parking, gas, and some out-of-pocket fees for medications. They negotiated with hospitals, found deals on hotel rooms, and got prescriptions from lower-cost pharmacies. Yet, they fell \$20,000 in debt. B.S. continues to work full-time, and N.S. helps with his business and works part-time at the children's school. Their income fluctuates. If their premiums increase, N.S. and B.S. are worried that they will not be able to afford their own health insurance, pay off their medical bills, and create a more stable and secure financial future for their family.

For over 30 years, **Legal Council for Health Justice** (Legal Council) has served individuals, children, and families impacted by chronic, disabling, and stigmatizing health conditions through medical-legal partnership programs. Legal Council is based in Chicago, Illinois. Legal Council has assisted thousands of Illinoisans in obtaining, maintaining, and re-establishing eligibility for health insurance, including coverage through the Marketplace. Legal Council's Marketplace clients tend to be people living with chronic medical conditions, including AIDS; people who were terminated from Medicaid for being just over income; and people who

work a variety of jobs, often more than one, but whose employers do not offer affordable health benefits or any health benefits at all. As illustrated by the examples of people whom Legal Council has helped, the Final Rule will create significant barriers to healthcare:

**A.A.** is a 38-year-old working parent of three whose Medicaid eligibility properly ended due to an increase in income. A.A. signed up for a Marketplace plan on their own. Their key medical providers were not in-network, and A.A. had not understood that the Marketplace offers health plan options. A.A. contacted Legal Council on December 17, 2024. Legal Council was able to help A.A. switch to a plan with their key providers in-network, thus enabling affordable access to continuous care with trusted doctors. Without the flexibility to enroll in late December, A.A. would have faced potential disruption in care as a result of loss of access to trusted providers for an entire year.

**B.B.**, a 55-year-old single adult, worked full-time at a small employer that did not offer health benefits. After being diagnosed with cancer, B.B. was able to obtain treatment under a hospital's financial assistance program. That program did not provide access to all the treatment that B.B. needed. With Legal Council's support, B.B. signed up for a health plan on January 14, 2025, with coverage effective as of February 1, 2025. Lack of access to employer-based insurance in spite of full-time work, the timing of the cancer diagnosis, and the critical need for access to medically necessary specialty care all led to B.B.'s need for enrollment during the extended open enrollment period. Had B.B. been forced to wait another year for access to cancer treatment, a positive health outcome would likely have been jeopardized.

**C.C.** is a 61-one-year-old single adult who lost Medicare eligibility due to improved health and disability cessation. Although the health improvement and new job were positives, C.C.'s employer did not offer health benefits. C.C. did not know that Marketplace coverage was

an option and, as a result, did not enroll during open enrollment. Because C.C.'s income was below 150 percent of the FPL, Legal Council helped C.C. apply for Marketplace coverage outside of open enrollment. The chosen plan covered needed medications and medical care. Losing access to health care until open enrollment would have put C.C.'s ability to remain healthy enough to be employed at risk.

**D.D.**, 25 years old, is a single, part-time worker who became over income for Medicaid. While the pay increase brought welcome stability, D.D.'s employer did not provide health benefits. Unfortunately, D.D. was hospitalized with an AIDS diagnosis more than 60 days after losing access to Medicaid. Legal Council helped D.D. enroll in Marketplace coverage, which began on February 1, 2025. This gave D.D. access to necessary follow-up care and health stability adequate to keep working.

**E.E.** is a transgender man whom Legal Council assisted during open enrollment. His main goal was to be able to obtain gender-affirming care. E.E. enrolled in a plan that covered gender-affirming services and was able to obtain surgery while also accessing appropriate specialty care. For E.E., the care was life-saving.

**F.F.**, 43 years old moved to Illinois from another state and was not aware of the health benefits available in Illinois. More than six months after arriving in Illinois, F.F. learned about Marketplace coverage. Legal Council worked with F.F. on January 10, 2025 to sign up for a health plan. Waiting a year for access to health coverage and healthcare could have been disastrous. Shortly after F.F.'s benefits were active, a dermatologist diagnosed F.F. with skin cancer. Because of Marketplace coverage, F.F. could afford to get the skin lesions removed.

### CONCLUSION

The Final Rule is going to harm Americans and their families. This Court should grant Plaintiff States' Motion for a Preliminary Injunction and Stay.

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Respectfully submitted,

/s/ Jane Perkins

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### CERTIFICATE OF SERVICE

I hereby certify that this motion and its accompanying certification will be served on all registered parties through this Court's CM/ECF system.

/s/ Jane Perkins

Jane Perkins