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Before the

House Ways and Means Committee Hearing

on

Protecting Americans with Pre-Existing Conditions

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Good morning Chairman Neal, Ranking Member Brady and members of the Committee. I am Keysha Brooks-Coley, Vice President of Federal Advocacy for the American Cancer Society Cancer Action Network (ACS CAN). ACS CAN is the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society and supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN empowers advocates across the country to make their voices heard and influence evidence-based public policy change as well as legislative and regulatory solutions that will reduce the cancer burden.

I appreciate the opportunity to testify today on behalf of cancer patients, survivors and those at risk for cancer. In 2019 nearly 1.8 million Americans are expected to be diagnosed with cancer.[1] An additional 15.5 million Americans living today have a history of cancer.[2] For these Americans – many of whom are your own constituents – access to affordable health insurance

[1] American Cancer Society, Cancer Facts & Figures 2019, available at https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2019/cancer-facts-and-figures-2019.pdf.

[2] Id.

is truly a matter of life or death. Research from the American Cancer Society has shown that uninsured Americans are less likely to get screened for cancer and thus are more likely to have their cancer diagnosed at an advanced stage when survival is less likely and the cost of care more expensive.[3] ACS CAN appreciates the Committee holding today's hearing to examine how policymakers can ensure that cancer patients – and other Americans with serious illnesses – continue to have access to affordable health care and how policymakers can build on the critical patient protections included in the Affordable Care Act (ACA) and prevent further erosion of these important protections.

Cancer Patients Before the Affordable Care Act

For many years, a cancer diagnosis made it nearly impossible to get or keep insurance for Americans who relied on private health plans sold in the individual and small group markets. In most states, prior to enactment of the ACA, health insurers that sold in those markets could refuse to cover an individual with a pre-existing condition like cancer; could limit and/or refuse to cover care associated with a pre-existing condition; or could charge a higher premium based on pre-existing conditions. A survey conducted before passage of the current law found that 36 percent of those who tried to purchase health insurance directly from an insurance company in the individual insurance market were turned down, charged more, or had a specific health problem excluded from their coverage.[4]

Cancer patients fortunate enough to get health care coverage through an employer often found themselves locked into their jobs out of fear that they would be unable to get affordable coverage if they left. Individuals who lost their coverage or were unable to obtain coverage faced extraordinary costs that often led to financial hardships. According to one study,

[3] E Ward et al, "Association of Insurance with Cancer Care Utilization and Outcomes, *CA: A Cancer Journal for Clinicians* 58:1 (Jan./Feb. 2008), http://www.cancer.org/cancer/news/report-links-health-insurance-status-withcancer-care.

[4] Doty MM, Collins SR, Nicholson JL et al. *Failure to Protect: Why the Individual Insurance Market is not a Viable Option for Most US Families.* The Commonwealth Fund, July 2009.

enactment of the ACA was a major factor in the fifty percent reduction in bankruptcy filings between 2010 and 2016.[5]

Prior to the ACA, cancer patients and others with serious illnesses could not always rely on having insurance coverage to protect them when they needed it most. This had devastating effects on health outcomes, finances and quality of life.

How the ACA Improved the Lives of Cancer Patients

Passage of the Affordable Care Act, with its many patient protections, significantly changed the landscape for cancer patients – and all Americans. In 2018, approximately 10 million Americans – many of these are persons facing serious illness – were enrolled in health care plans through the private marketplaces[6] and 17 million through Medicaid expansion (as of 2017).[7]

Enactment of the ACA has allowed Americans with cancer and other serious conditions access to the care they need. Those with comprehensive insurance are now enjoying new protections that make health care coverage more reliable and more affordable. The approximately 102 million Americans with pre-existing conditions[8] like cancer no longer have to worry that their illness could preclude them from comprehensive coverage. Americans who purchase insurance can depend on their plan covering essential health care benefits. Those with expensive illnesses like cancer no longer have to fear that their insurer will impose annual or lifetime limits on their coverage. Critical preventive benefits like mammograms and colon cancer screening are now available without cost-sharing. Young people finishing school or starting

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[5] St. John A, How the Affordable Care Act Drove Down Personal Bankruptcy. Consumer Reports, May 2017. Available at https://www.consumerreports.org/personal-bankruptcy/how-the-aca-drove-down-personal-bankruptcy/

[6] Kaiser Family Found. Marketplace Effectuated Enrollment and Financial Assistance. https://www.kff.org/other/state-indicator/effectuated-marketplace-enrollment-and-financial-assistance/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

[7] Kaiser Family Found. Medicaid Expansion Enrollment. Available at https://www.kff.org/health-reform/state-indicator/medicaid-expansion-enrollment/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

[8] Mendelson D, Sloan C, Cole M, Repeal of ACA's Pre-Existing Condition Protections Could Affect Health Security of Over 100 Million People, Avalere, October 2018. Available at https://avalere.com/press-releases/repeal-of-acas-pre-existing-condition-protections-could-affect-health-security-of-over-100-million-people.

their careers are now able to stay on their parents' health insurance plans until the age of 26. In addition, more lower-income Americans now live in states that have expanded their Medicaid program thus expanding coverage options. The patient protections that are the cornerstone of the Affordable Care Act ensure that the insurance that Americans access provides the kind of critical coverage they need.

Policies That Could Damage ACA Patient Protections

Unfortunately, recent executive orders, legislative proposals and regulatory actions are putting some of these important protections at risk. As a result, the patient community is having to respond to policy changes that are chipping away many of the critical protections that were included in the law. Three specific proposals have been concerning to the broader patient advocacy community:

Short-term Limited-Duration Insurance: In August 2018, the administration issued a final rule to expand access to short-term, limited-duration health insurance.[9] Originally intended as temporary bridge or gap plans, these policies have lower premiums than other plans on the market because they are exempt from many of the key requirements that provide comprehensive coverage and protect consumers from high out-of-pocket costs. For instance, rather than maintaining the protection against discriminatory pre-existing condition exclusions that make it impossible for persons with cancer to obtain insurance, short term policies in most states are permitted to use these discriminatory practices. These plans are permitted to consider an individual's health status when issuing health insurance coverage. That means an insurer can choose to deny coverage, charge higher premiums, or not cover certain benefits for individuals based on their health history.

Unlike ACA-compliant plans, short-term plans also do not have to provide coverage for Essential Health Benefits (EHBs). Individuals with cancer and cancer survivors have unique health care needs and require access to a wide range of products and services, like oncology care,

[9] Department of Health and Human Services, Department of Labor, Department of the Treasury. Short-Ter, Limited-Duration Insurance. Final Rule. 83 Fed. Reg. 38212 (Aug. 3, 2018).

chemotherapy, radiation, prescription drugs, and hospital services. Consumers who enroll in health coverage expect their plan to cover these necessary products and services. If cancer patients do not have access to cancer treatment services through their health insurance coverage, they are forced to pay out-of-pocket for their treatment, which can often be prohibitively expensive. Individuals who have been diagnosed with cancer need access to specific treatments; delaying these treatments can lead to negative health outcomes.

Ironically, many short-term policies will not cover the services needed to prevent or detect cancer – including preventive services that receive an "A" or "B" rating from the U.S. Preventive Service Task Force. Coverage of cancer screenings helps to detect some forms of cancer at earlier stages when the individual has a higher likelihood of more treatment options and a better overall health outcome. Including preventive services as standard benefits in health insurance improves overall public health and saves lives.

Short-term plans can also impose lifetime and annual limits on coverage which will directly impact cancer patients. Cancer is one of the most expensive health conditions[10] and as a result cancer patients and survivors can exceed an annual or lifetime cap on covered services. According to one study, prior to the enactment of the ACA, one in ten cancer patients responding to the survey reached the limit of what their insurance plan would pay for their cancer treatment.[11] Short term plans are also not subject to limits on the amount of out-of-pocket costs and deductibles they can impose on enrollees for covered in-network services. One analysis of the best-selling short term plan in Georgia showed these plans had a 3-month out-of-pocket limit of $10,000, which did not include the deductible of $10,000, making the effective 3-month out-of-pocket maximum $20,000.[12] Another analysis found caps on coverage for short-term plans in

[10] U.S. Dep't of Health & Human Servs., Research in Action, Issue #19: The High Concentration of U.S. Health Care Expenditures (June 2006).
[11] USA Today, Kaiser Family Foundation, Harvard School of Public Health. National Survey of Households Affected by Cancer. Kaiser Family Foundation, November 2006. Available at https://www.kff.org/health-costs/poll-finding/usa-todaykaiser-family-foundationharvard-school-of-public-2/.
[12] Palanker, D, Lucia, K, and Curran, E. New Executive Order: Expanding Access to Short-Term Health Plans Is Bad for Consumers and the Individual Market. *To the Point*, The Commonwealth Fund, October 2017. Available at https://ccf.georgetown.edu/2017/10/13/new-executive-order-expanding-access-to-short-term-health-plans-is-bad-for-consumers-and-the-individual-market/.

Phoenix, AZ to be as low as $250,000.[13] ACS CAN's Costs of Cancer report showed that it is not unusual for a cancer patient who has just been diagnosed to incur expenses exceeding these amounts – meaning in the Georgia plan a cancer patient would have to pay $20,000 out-of-pocket, and in an Arizona plan a cancer patient would have to pay the full cost of her treatments after she reached the $250,000 cap.[14] Thus, for an individual in active cancer treatment the low caps and high out-of-pocket requirements essentially render coverage meaningless, particularly given that nearly half of all American adults report being unable to cover an emergency medical expense costing $400 without having to borrow or sell something to do so.[15]

Finally, short-term plans in most states are permitted to charge older enrollees significantly higher premiums and can even choose not to provide coverage to an individual based on age alone. While cancer can be diagnosed at any age, the incidence of cancer increases with age. According to the American Cancer Society, 85 percent of all cancers in the United States are diagnosed in people 50 years of age and older.[16] Prior to the enactment of the current age rating band restrictions for ACA-compliant plans, older adults faced significant problems accessing health insurance coverage, in large part because of age rating bands (compounded by the ability of issuers to use health status when setting premiums).[17]

Expansion of short term plans is not in the interest of consumers. These plans were originally designed as temporary bridge policies. Unfortunately, there is a real possibility that many people – attracted by lower premiums and expanded availability – will find themselves with seriously inadequate coverage and greater out of pocket costs. For people with serious conditions like cancer the lack of access to necessary treatment options and the potentially

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[13] Pollitz, K. Understanding Short-Term Limited Duration Health Insurance. Kaiser Family Foundation, February 2018. Available at https://www.kff.org/health-reform/issue-brief/understanding-short-term-limited-duration-health-insurance/.

[14] American Cancer Society Cancer Action Network. The Costs of Cancer: Addressing Patient Costs. April 11, 2017. Available at https://www.acscan.org/policy-resources/costs-cancer.

[15] Board of Governors of the Federal Reserve. Report on the Economic Well-Being of U.S. Households in 2015. May 2016. Available at https://www.federalreserve.gov/2015-report-economic-well-being-us-households-201605.pdf.

[16] American Cancer Society. *Cancer Facts & Figures 2018.* Atlanta: American Cancer Society; 2018.

[17] Smolka, G, Purvis, L, & Figueiredo, C. Health Care Reform: What's at Stake for 50- to 64-Year-Olds, AARP Public Policy Institute [Insight on the Issues #124], March 2009. Available at https://assets.aarp.org/rgcenter/health/i24_hcr.pdf.

high out of-pocket costs could be devastating. We urge Congress to enact legislation to limit and/or prohibit the availability of these products. At the very least, Congress should require that short term plans meet the same requirements as other plans in the marketplace.

Association Health Plans: In June 2018, the administration finalized a regulation that would expand access to Association Health Plans (AHPs).[18] The regulation makes it easier for AHPs to be exempt from the ACA's consumer protection standards including essential health benefit requirements and restrictions against requiring very high deductibles and coinsurance. Premiums for AHP products would likely be lower than for ACA-compliant plans, not because of any AHP administrative efficiencies, but because of the ability of these plans to offer more limited benefit packages. As a result, consumers who enroll in AHPs and who are then diagnosed with a serious illness like cancer will likely find they have inadequate coverage. Younger and healthier individuals attracted to AHPs because of the lower premiums will leave older, sicker, and costlier individuals in the individual and small group products that are subject to the ACA's stricter consumer protection and other market requirements. The adverse selection spiral generated by those non-AHPs could lead other plans in the individual and small group markets to charge increasingly higher premiums, making them unsustainable. It is for these reasons that the National Association of Insurance Commissioners,[19] the National Governors Association,[20] and the American Academy of Actuaries[21] have also been historically opposed to AHPs.

We are also concerned about AHPs' disturbing history of fraud and financial instability. For a long time, these products were not traditionally subject to the same state insurance solvency

[18] Department of Labor. Definition of "Employer" Under Section 3(5) of ERISA – Association Health Plans. Final Rule. 83 Fed. Reg. 28912 (June 21, 2018).
[19] National Association of Insurance Commissioners, Consumer Alert: Association Health Plans are Bad for Consumers, available at http://www.naic.org/documents/consumer_alert_ahps.pdf.
[20] National Governors Association, Governors Oppose Association Health Plans, May 2004, available at https://www.nga.org/cms/home/news-room/news-releases/page_2004/col2-content/main-content-list/governors-oppose-association-hea.html.
[21] American Academy of Actuaries Letter to John Boehner, Chairman, House Committee on Education and the Workforce, April 28, 2003, available at http://www.actuary.org/pdf/health/ahp_042803.pdf.

and licensing requirements that allowed regulators to maintain necessary oversight.[22] If an AHP lacked the financial resources to pay claims, then enrollees were left with no coverage and high out-of-pocket costs. Even in cases of well-meaning AHP sponsors, insolvencies led to millions of dollars in unpaid claims.[23] ACS CAN urges the Congress to act to limit the expansion of AHPs.

Navigator and Enrollment Education Funding: Up until this year, health insurance enrollment has steadily increased. Unfortunately, recent action by the administration is jeopardizing enrollment. In 2017 HHS shortened the enrollment period for marketplace plans from 90 days to 45 days leaving consumers less time to study options and select the plan that is best for them. In addition, funding for both navigators and marketplace education and enrollment activities has been significantly reduced. Spending on outreach and marketing have shrunk to $10 million – a 90 percent cut since 2016 – and funding for navigator programs has been cut 80 percent.[24] The administration is also requiring navigators to inform consumers about the new AHP and STLD coverage options – options that provide less comprehensive coverage. For individuals with a serious illness like cancer choosing the right health insurance plan is important. Navigators help cancer patients and others by providing answers to their questions. Shortened enrollment periods, fewer resources for outreach and education and less funding for consumer navigators not only creates confusion for consumers but directly impacts the number of individuals who enroll in Marketplace coverage. We urge Congress to restore full funding for navigators and for ACA enrollment and outreach activities. We also urge Congress to enact legislation that directs navigators to refrain from discussing short-term and AHP plan options with consumers if these are not appropriate options for the consumer.

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[22] Kofman M, Bangit E, Lucia K, MEWAs: The Threat of Plan Insolvency and Other Challenges, Commonwealth Fund, May 2004, available at http://www.commonwealthfund.org/usr_doc/kofman_mewas.pdf.
[23] Id.
[24] Straw T, Lueck S, Gonzales S, Cloud H, Strong Demand Expected for Marketplace Open Enrollment, Despite Administration Actions, Center on Budget and Policy Priorities, October 2018, available at https://www.cbpp.org/research/health/strong-demand-expected-for-marketplace-open-enrollment-despite-administration.

Other Improvements

There are other ways in which Congress can continue to improve the protection provided by the ACA, that we are hopeful this Committee and Congress will consider this year. Three policy changes that we would like to highlight include:

Fixing the Family Glitch: Under the ACA an individual is eligible for premium subsidies in the private market if the amount he/she would have to pay for their individual employer-sponsored coverage is more than 9.86 percent of their household income. The problem occurs when other family members are factored into the equation. Even if the employee is paying a family premium, only the amount of the individual employee's coverage is considered for purposes of calculating eligibility for subsidies. As a result, families who are paying insurance premiums in excess of 9.86 percent of their household income are ineligible for subsidies. Congress should consider fixing this family glitch so that more Americans could afford health insurance.

Prevent Changes to Essential Health Benefit Benchmarks: Section 2711 of the Public Health Services Act prohibits plans from having annual dollar limits on Essential Health Benefit (EHB) services. This prohibition applies to group health plans that do not have to comply with other EHB coverage requirements. In a proposed rule that would expand access to Health Reimbursement Arrangements,[25] the Tri-Agencies (Department of Health and Human Services, the Department of Labor, and the Department of the Treasury) recommended allowing employers to choose a benchmark selected by a state based on the new process adopted by HHS.[26] Under the guise of giving states more "flexibility," this policy change would allow states to choose a less generous benchmark – one that potentially does not represent a real plan sold in that state.

[25] Department of the Treasury, Department of Labor, and Department of Health and Human Services. Health Reimbursement Arrangements and other account-based group health plans. Proposed rule. Oct. 29, 2018. 83 Fed. Reg. 54420.

[26] Department of Health and Human Services. Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2019. Final Rule. Apr. 17, 2018. 83 Fed. Reg. 16930.

Allowing employers these new options for EHB standards could have serious implications for out-of-pocket spending for employees with serious and chronic illnesses like cancer. It could allow employers to choose weaker, more limited EHB standards. As a result, patients will find more services will be excluded from essential health benefits and thus plans could impose annual and lifetime limits for those services. In addition, patients could also face higher out-of-pocket costs as the annual cap on out-of-pocket expenses only applies to EHB services. Congress should consider enacting legislation to clarify that the EHB standards are meant to be robust enough to provide protections to individuals with pre-existing conditions.

Prevent the Subsidy Cliff: People who buy health insurance on the individual market may be eligible for premium subsidies. The maximum eligibility limit for subsidies is 400 percent of the federal poverty level (FPL). For an individual whose yearly income is only slightly higher than 400 percent FPL, purchasing insurance with no subsidy could be prohibitively expensive. This is a particular concern for individuals who received subsidies believing that their yearly income will be under the 400 percent FPL threshold, but find their annual income slightly above the 400 percent FPL threshold. These individuals no longer qualify for subsidies and must repay some or all of the subsidies when they file their yearly income tax.

Congress could consider eliminating the cliff and creating partial subsidies for individuals with incomes above 400 percent FPL. This would ensure that more Americans can afford their health insurance coverage.

Building on the ACA's Promise of Affordable Health Care

It is very rare that Congress enacts a major piece of legislation that doesn't require subsequent revisions and improvements. A case in point is the Medicare program. Enacted in 1965, Medicare – which enjoys overwhelming public support – continues to be fine-tuned today to ensure it meets the needs of beneficiaries. The same principle should be true for the Affordable Care Act. Rather than undoing the key consumer protections that are the cornerstone of the law we should be building on these protections.

We urge the Committee – and the Congress – to find bipartisan solutions that benefit patients. Such a process must ensure that individuals with pre-existing conditions are protected from discrimination, that essential health benefits are maintained, and that coverage is made affordable for individuals. We look forward to working with you to build upon the foundation of the ACA and strengthen health care coverage.