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“Patient Relief from Collapsing Health Markets”

**United States House of Representatives
Committee on Energy and Commerce
Subcommittee on Health**

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Chairman Michael Burgess, Ranking Member Green, and other members of the Subcommittee:

I am Dr. Len Lichtenfeld, Deputy Chief Medical Office for the American Cancer Society. On behalf of the Society, thank you for the opportunity to testify today. ACS is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing the disease, saving lives, and diminishing suffering through research, education, advocacy, and service. The Society, operating through its national office and 11 geographic divisions throughout the United States throughout the United States, is the largest voluntary health organization in the United States.

In the United States there are more than 1.6 million Americans who will be diagnosed with cancer this year.¹ An additional 15.5 million Americans living today have a history of cancer.² For these Americans – many of your own constituents – access to affordable health insurance is 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

Yet for many years, a cancer diagnosis made it nearly impossible to get or keep insurance. Before the Affordable Care Act was passed into law, millions of cancer patients found themselves unable to purchase insurance because of their pre-existing condition. Even those who were able to obtain coverage often found that annual or lifetime limits severely curtailed their coverage leaving them vulnerable to enormous costs. Some people even found their insurance policies rescinded after being diagnosed with cancer.

One such example is that of Kathleen Watson, a now 61-year-old woman living in Lake City, Florida. Kathleen sought to purchase insurance on the individual market, but was denied because of a pre-existing diagnosis of leukocytosis, a condition of too many white blood cells that is often a sign of leukemia, but in and of itself is not a cancer diagnosis. She was denied coverage by several insurance carriers outright and as a result she could not afford treatment and delayed necessary medical care.

¹ American Cancer Society, *Cancer Facts & Figures 2017*, available at <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2017/cancer-facts-and-figures-2017.pdf>.

² *Id.*

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-with-cancer-care>.

Kathleen continued applying for coverage, and in 2008 a plan in the individual market finally accepted her application. In 2009, after having enrolled in the plan, Kathleen was diagnosed with chronic non-Hodgkin's lymphoma. However, as she began treatment the plan denied all her claims – the plan even denied the claim for testing her bone marrow to confirm her diagnosis. Later the Florida insurance commissioner determined the plan was not credible and Kathleen's insurance was cancelled. Kathleen says about this time, "The stress was overbearing. I couldn't sleep – always worried, didn't know what the next step would be. When everything is yanked out from underneath you, you don't know where to turn. I lost my 401k, savings, everything." She was left with \$250,000 in medical debt and no health insurance coverage. This medical debt continues to affect her credit today.

In the intervening years Kathleen—unable to get insurance on the individual market because of her pre-existing condition – was able to find work and get employer-sponsored coverage and cancer care. I am happy to report that she is now cancer-free.

However, four months ago Kathleen suffered a non-workplace injury that has left her unable to work and on short-term disability. Her inability to work means her employer coverage expired at the end of the December. Keenly aware of the need for health insurance with her history and health complications, Kathleen enrolled before the deadline in an individual plan through the state exchange. Fortunately, her disability income allows her to make just enough to qualify for subsidies in the exchange instead of falling into Florida's Medicaid expansion coverage gap. Her new exchange plan includes all of her doctors and financial assistance that makes accessing her recommended cancer follow-up and other necessary health care affordable.

She's gone from being uninsured and uninsurable in 2004, with a delayed diagnosis, and heaps of medical debt to finally being able to purchase a quality individual plan that is affordable in 2016.

Kathleen's story is just one example of the significant strides we have made in the quest to prevent cancer and central to this success is ensuring that all Americans can access and maintain affordable health insurance coverage. As Congress considers legislation to change the current health insurance market we urge you to consider how the policies will impact a person with cancer or other serious illness. Further, we believe any changes should be grounded in the following principles for ensuring that cancer patients have access to the care they need for their cancer treatment.

Protecting Patients – For cancer patients and survivors, getting and keeping insurance is paramount. The following patient protections contained in current law should be retained: prohibition on pre-existing condition exclusions; prohibition on annual and

lifetime limits; maximum out-of-pocket limits; and prohibition on insurance policy rescissions.

Comprehensive Coverage – Insurance should cover the major health needs of cancer patients and survivors, including hospitalization, specialty cancer care, physician services, prescription drugs, rehabilitative care, and mental health services. Streamlined “basic” policies that do not include explicitly defined comprehensive benefits put cancer patients and survivors at risk of inadequate treatment, and could jeopardize access to necessary preventive care, treatment and follow-up care.

Affordable Coverage – Affordable premiums and cost-sharing (including deductibles, copays and coinsurance) should be retained to ensure that persons with cancer and survivors can buy and maintain insurance coverage.

Equitable Coverage – Changes to the insurance market should guarantee that people at all income levels have access to an affordable and consistent standard of coverage in every state. While 31 states and the District of Columbia have chosen to expand their Medicaid programs following the 2012 Supreme Court decision,⁴ unfortunately low-income individuals in 19 states lack access to comprehensive and affordable coverage options because their state decided not to expand their Medicaid program.

Preventive Care – A substantial number of all cancer deaths can be prevented and the substantial cost of the treatment of advanced disease could be reduced through the use of existing evidence-based prevention and early detection strategies.⁵ Research shows that required cost-sharing – including copays, coinsurance and deductibles – can be a significant barrier for patients who need preventive services.^{6,7} This is especially true for lower-income patients and patients on a fixed income, for whom these payments can represent a significant percentage of their income. Individuals need access to evidence-based preventive services.

We appreciate the invitation to testify today on four bills before the committee, which appear to work together to address concerns expressed by the insurance industry about the viability of the individual and small group markets. While we recognize the importance of strengthening the markets in order to keep the system working, we are concerned about how these bills, one

⁴ *National Federation of Independent Business (NFIB) vs. Sebelius*, 567 U.S. ____ (2012), 183 L. Ed. 2d 450, 132 S.Ct. 2556.

⁵ American Cancer Society. *Cancer Prevention & Early Detection Facts & Figures* 2015-2016.

Atlanta: American Cancer Society; 2015.

⁶ The Clinical Practice Guideline Treating Tobacco Use and Dependence 2008 Update Panel, Liaisons, and Staff. (2008). A Clinical Practice Guideline for Treating Tobacco Use and Dependence: 2008 Update: A U.S. Public Health Service Report. *American Journal of Preventive Medicine*, 35(2), 158–176.

<http://doi.org/10.1016/j.amepre.2008.04.009>

⁷ Han X, Robin Yabroff K, Guy GP, Zheng Z, Jemal A. Has recommended preventive service use increased after elimination of cost-sharing as part of the Affordable Care Act in the United States? *Prev Med*. 2015 Sep;78:85-91. doi: 10.1016/j.yjmed.2015.07.012.

of which is not completely written yet, might impact care and access to adequate and affordable coverage for individuals with cancer.

As the Subcommittee considers legislation to change health care markets, we want to share with you our thoughts on how some of the proposals currently under consideration would affect people with cancer and cancer survivors.

Continuous Coverage

Under current law, non-grandfathered health plans in the individual market are prohibited from taking into account an individual's pre-existing condition or health status when issuing health insurance coverage. The Kaiser Family Foundation estimates that 27 percent of adult Americans under the age of 65 have a pre-existing condition.⁸ Prior to January 1, 2014, health insurance issuers were permitted to refuse to cover an individual who had a pre-existing condition; could provide coverage but limit and/or refuse to cover care associated with the individual's pre-existing condition; or, could charge the individual a higher premium based on her pre-existing condition (thus making insurance unaffordable). A survey conducted before these exclusions were prohibited 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, were charged more, or had a specific health problem excluded from their coverage.⁹

In its current, admittedly incomplete draft, it appears that the continuous coverage legislation before the committee would exempt individuals from pre-existing condition exclusions only if they maintain continuous coverage (defined as having a gap in coverage of less than 63 days). Individuals who fail to maintain continuous coverage could be subject to medical underwriting. As currently discussed, this provision could actually restore the discriminatory practice of pre-existing condition exclusions insofar as individuals with pre-existing conditions could be charged higher premiums.

As the Subcommittee moves forward with the legislation, we would welcome the opportunity to work with you to ensure policy changes do not impact a patient's uninterrupted access to health insurance coverage and necessary treatment. However, a one-size-fits-all approach that imposes penalties for any interruption in coverage fails to recognize the many legitimate reasons that patients have coverage gaps. For instance, many people may experience a gap in coverage when they lose their job and their employee coverage. Research suggests that

⁸ Claxton G, Cox C, Damico A, Levitt L, Pollitz K. Pre-existing Conditions and Medical Underwriting in the Individual Insurance Market Prior to the ACA. Kaiser Family Foundation. December 2016, available at <http://files.kff.org/attachment/Issue-Brief-Pre-existing-Conditions-and-Medical-Underwriting-in-the-Individual-Insurance-Market-Prior-to-the-ACA>.

⁹ 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.

between 40 and 85 percent of cancer patients stop working while receiving cancer treatment, with absences from work ranging from 45 days to 6 months depending on the treatment.¹⁰ Gaps in coverage also occur as a result of a divorce or death of a spouse when one spouse is no longer covered on the other's health plan. Moving from one state to another may result in a gap in coverage. All of these examples – and many others – are common reasons why a person may have an unexpected gap in coverage. Penalties imposed on people in these situations may adversely impact access to care, interrupt life-saving treatment and make insurance unaffordable when they attempt to regain coverage.

Gaps in coverage are detrimental to individuals in active cancer treatment who need regular access to care and services. When that access is disrupted, the effectiveness of the treatment could be jeopardized and the individual's chance of survival could be significantly reduced. Evidence-based protocols for chemotherapy and other cancer treatments often require treatment delivery on a prescribed timeline. Interruptions to this timeline because of coverage gaps can be detrimental. A gap in coverage can also cause a fatal delay in initiation of a treatment protocol. Recent research shows that delays in the initiation of chemotherapy for breast cancer patients resulted in adverse health outcomes.¹¹

Allowing health insurers to charge higher premiums to those with pre-existing conditions who experience a gap in coverage of more than 63 days is overly broad and would unfairly penalize those who lose their coverage unexpectedly. Individuals with cancer may lose their job because their cancer and/or cancer treatment makes them unable to work. This also includes cancer survivors who are more likely to report being unable to work because of their health or having employment disability, including more missed work days or additional days spent in bed due to poor health.¹²

Enacting a policy that penalizes individuals for losing their health insurance coverage – particularly at a time when they have also lost their employment – imposes an undue cost burden on individuals. Moreover, once an individual with a history of cancer is no longer

¹⁰ Scott Ramsey, et al, "Washington State Cancer Patients Found to be at Greater Risk for Bankruptcy than People Without a Cancer Diagnosis," *Health Affairs*, 32, no. 6, (2013): 1143-1152.

¹¹ Chavez-MacGregor M, Clarke CA, Lichtensztajn DY, Giordano SH. Delayed Initiation of Adjuvant Chemotherapy Among Patients With Breast Cancer. *JAMA Oncol*. 2016;2(3):322-329. doi:10.1001/jamaoncol.2015.3856.

¹² Yabroff KR, Dowling EC, Guy GP, et al. Financial Hardship Associated With Cancer in the United States: Findings From a Population-Based Sample of Adult Cancer Survivors. *Journal of Clinical Oncology*. 2016;34(3):259-267. doi:10.1200/JCO.2015.62.0468; GP Guy Jr, DU Ekwueme, KR Yabroff, et al: Economic burden of cancer survivorship among adults in the United States *J Clin Oncol* 31:3749–3757,2013; EA Finkelstein, FK Tangka, JG Trogdon, et al: The personal financial burden of cancer for the working-aged population *Am J Manag Care* 15:801–806,2009; KR Yabroff, WF Lawrence, S Clauser, et al: Burden of illness in cancer survivors: Findings from a population-based national sample *J Natl Cancer Inst* 96:1322–1330,2004.

protected from the pre-existing condition exclusion policy, it remains unlikely that he/she will be able to purchase health insurance coverage at all.

Special Enrollment Periods

Special enrollment periods (SEPs) allow individuals with qualifying life changes – like divorce, marriage, birth, a permanent move, or loss of employer-sponsored health insurance – to enroll in a plan that best meets their needs. These SEPs are vital for individuals with cancer who may often experience a job loss (and subsequent loss of employer-sponsored health insurance) if their cancer and/or cancer treatment makes them unable to work. In addition, some individuals with cancer may have to move to a different location in order to be closer to family members who can provide necessary caregiving and/or to be closer to specialized treatment facilities to treat their specific form of cancer.

The legislation under consideration by the Subcommittee would require an individual seeking to enroll in health insurance coverage through an SEP to submit evidence of eligibility for the SEP before being permitted to enroll. We are concerned that the result of this seemingly minor change in policy could be cancer patients failing to access health coverage and treatment in a timely way.

Restricting SEPs and requiring enrollees to document their eligibility prior to coverage will lead to gaps in coverage, which can be detrimental to an individual who needs access to cancer treatment immediately. If the Subcommittee were to consider such legislation, the policy should provide a review process by which an individual could obtain expedited coverage when medically necessary.

We also note that it may be challenging for individuals to obtain the required documentation necessary to qualify for an SEP. For example, employers are not required to automatically provide former employees with documentation of loss of minimum essential coverage (MEC). This makes documentation for qualification under a loss of MEC difficult – particularly if the individual’s loss of employment was not a planned event, such as retirement.

According to the Urban Institute, fewer than 15 percent of eligible people elect to use an SEP to enroll in a health plan.¹³ While an industry-funded report indicates that individuals who enroll in health plans through an SEP have higher health care costs compared to individuals who enroll during an open enrollment period, the report does not provide data on *why* they are

¹³ Buettgens M, Dom S, Recht H, “More than 10 Million Uninsured Could Obtain Marketplace Coverage through Special Enrollment Periods,” Washington: Robert Wood Johnson Found. & Urban Institute, Nov. 2015 available at <http://www.urban.org/sites/default/files/alfresco/publication-pdfs/2000522-More-than-10-Million-Uninsured-Could-Obtain-Marketplace-Coverage-through-Special-Enrollment-Periods.pdf>.

seeking enrollment during an SEP.¹⁴ The individual may be a cancer patient seeking enrollment following the loss of employment due to illness. This SEP-qualifying individual will generate new costs, but it does not mean he is intentionally abusing the SEP system.

In addition, we are concerned that under the proposed legislation, the individual may not enroll in a health plan via an SEP until the Exchange verifies that the individual is qualified. But there is no requirement for the Exchange to act. For example, if the individual with a prior cancer diagnosis submits documentation for SEP eligibility within 63 days of losing creditable coverage, but the Exchange fails to act in a timely manner, the individual may not be able to enroll in a health plan within the 63-day time period. Thus lacking “continuous coverage,” the pre-existing condition exclusion provision would be triggered, allowing the health insurer to medically underwrite the policy. Absent additional legislative clarity, health insurers could use the combination of the SEP and restrictive continuous coverage provisions as a back-door way of denying coverage to potentially high-cost individuals. We strongly urge Congress to ensure that such highly discriminatory actions would not be permitted.

We share the Subcommittee’s concern about policies that could result in individuals “gaming” the SEP system. But people in cancer treatment or those who have a pre-existing cancer condition have no incentive to drop coverage. Many lose coverage when they lose their job because they are sick. Policy changes should not inadvertently prevent persons with cancer from having access to coverage. We are committed to working with the Subcommittee to advance this goal.

Age Rating

Under current law, health insurance issuers in the individual market are prohibited from charging older adults more than three times the premium charged to younger adults for the same coverage (e.g., 3:1 age rating). The legislation under consideration by the Subcommittee would relax these requirements and permit health insurance issuers to charge older adults five times that charged to younger individuals (e.g., a 5:1 age rating). The legislation also would allow states to impose a different ratio – either a higher or a lower ratio.

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.¹⁵ Thus, increasing the age rating bands would mean that older individuals (those more at risk of developing cancer) would face significantly higher health care premiums or be priced out of the market completely. This problem would

¹⁴ Carlson C, Giesa K, “Special Enrollment Periods and the Non-Group, ACA-Compliance Market,” Washington: Oliver Wyman, Feb 2016, available at <https://www.ahip.org/Wyman-SEP-Enrollment/>.

¹⁵ American Cancer Society, Cancer Facts & Figures 2017.

be exacerbated in states that choose to go beyond the 5:1 age rating provided in the legislation. Prior to the enactment of the ACA's age rating band restrictions, older adults faced significant problems accessing health insurance coverage, in large part because of age rating restrictions (compounded by the ability of issuers to use health status when setting premiums).¹⁶

Research suggests that relaxing the age rating bands would result in a slight reduction in premiums charged to younger cohorts relative to the significant increase in premiums charged to older cohorts. One study estimated that increasing the age bands to 5:1 would result in premiums for a 64-year-old to increase from \$8,500 to \$10,600 per year (a \$2,100 increase), while premiums for a 21-year-old would decrease from \$2,800 to \$2,100 (a reduction of only \$700).¹⁷ In addition, the policy would actually result in higher federal expenditures of an estimated \$9.3 billion due to the advance premium tax credits.¹⁸

Grace Periods

Under current law, individuals who have failed to pay premiums have a three-month "grace period" in which to repay overdue premiums before the issuer is permitted to terminate the individual's health insurance coverage. This policy is designed to ensure that individuals who are temporarily unable to afford a few monthly premium payments are permitted the opportunity to catch up before their plan terminates coverage. If an individual fails to pay her premium outside this grace period, coverage is terminated retroactive to the end of the first month of the grace period and the individual is responsible for the entire cost of any medical expenses incurred in the second and third months of the grace period.

The legislation under consideration by the Subcommittee would retain the three-month grace period for plan years beginning before January 1, 2018, but would eliminate this patient protection for subsequent plan years. States would have the authority to set the appropriate grace period. If a state chooses not to do so, the default period would be one month.

We are concerned that limiting the grace period would pose an undue burden on individuals who experience sudden or unexpected personal financial changes – such as coping with having to pay large deductibles and out-of-pocket costs associated with a serious disease like cancer. The out-of-pocket costs of a newly diagnosed cancer patient can be beyond the means of many Americans. When an individual is diagnosed and initially undergoes cancer treatment she usually incurs a significant portion in out-of-pocket costs between the deductible, and frequent

¹⁶ Gerry Smolka, Leigh Purvis, and Carols Figueiredo, "Health Care Reform: What's at Stake for 50- to 64-Year-Olds," AARP Public Policy Institute, Insight on the Issues #124, March 2009.

¹⁷ C. Eibner and E. Saltzman, "Charing Order Adults Higher Premiums Could Cost Taxpayers," [The Commonwealth Fund Blog](#), Sept. 15, 2015.

¹⁸ [Id.](#)

copayments and coinsurance associated with services and/or medications. Nearly half of all American adults report being unable to cover an emergency expense costing \$400 without having to borrow or sell something to do so.¹⁹ Yet many standard plans offer deductibles of \$2,500 or more. Individuals often need additional time in order to try to obtain funds to cover these unexpected medical costs. Enacting legislation that would reduce the grace period would curtail the ability of individuals to retain their health insurance coverage at a time when they need it most (e.g., while they are undergoing treatment for a serious disease or illness).

Moreover, we are deeply concerned that the legislation fails to provide a minimum protection – a state could conceivably limit the grace period to only a few days. While we would expect few states to take such draconian action, we nevertheless urge the Subcommittee to consider providing a federal floor of patient protections.

Finally, we urge the Subcommittee to consider how this provision will be impacted if the other legislative proposals discussed above were implemented. For example, if an individual failed to pay her health insurance premiums for more than 30 days and her coverage was terminated, she would be uninsured and thus potentially face medical underwriting if she lacked coverage for a period of time provided under the legislation.

Conclusion

Thank you for the opportunity to testify before you today. As the Subcommittee considers changes to the health insurance market, we urge you to give serious consideration as to how these four bills would interact with each other in restricting patient access to adequate and affordable insurance coverage, particularly if there is a break in continuous coverage.

As you continue consideration of legislation to strengthen the market, we hope that you will consider how this will work for people with cancer. We look forward to working with you to ensure stability in the market and a health care system that meets the needs of individuals with cancer.

¹⁹ 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>.