LEUKEMIA & LYMPHOMA SOCIETY®
fighting blood cancers

May 16, 2017

The Honorable Mitch McConnell
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Chuck Schumer
Democratic Leader
United States Senate
Washington, DC 20510

Subject: LLS Perspective on the American Health Care Act (H.R. 1628)

Dear Majority Leader McConnell & Democratic Leader Schumer:

On behalf of the Leukemia & Lymphoma Society (LLS) and the one million two hundred thousand Americans living with a blood cancer diagnosis, I am writing to express our significant concerns regarding the impact of the American Health Care Act (AHCA) on blood cancer patients, survivors, and their families. Until the Senate makes the significant changes necessary to address the concerns outlined below, LLS urges all senators to vote 'no' on the AHCA on the Senate floor.

LLS supports legislation that advances our four core principles for meaningful coverage: guarantee access, promote affordability, ensure quality, and encourage stability. Unfortunately, the House-passed version of the AHCA fails the test of advancing these principles and represents a step backward in improving the lives of American cancer patients. Based on analyses by the Congressional Budget Office (CBO), our own experts, and other cancer stakeholders, LLS believes the AHCA would put insurance coverage out of reach for many blood cancer patients and increase out-of-pocket costs for many others—threatening their access to life-saving treatments. At the same time, the legislation does not address the financial and bureaucratic barriers that most distress blood cancer patients. In this letter, we summarize the specific concerns we have regarding the negative impact this bill will have related to the ability of blood cancer patients to secure and maintain access to affordable, high-quality health coverage.

Guaranteeing Access

Since the enactment of the Affordable Care Act (ACA), one key patient protection has provided peace of mind for millions of cancer patients, survivors, and their families: An insurer offering health insurance to your healthy neighbor cannot deny you coverage or charge you more for the same coverage simply because you have been diagnosed with cancer. With the House's adoption of the MacArthur amendment, the AHCA would take away this vital guarantee enjoyed today by every cancer patient and survivor in America.[i]

In its place, the AHCA would establish a framework allowing insurance companies to charge higher premiums to patients with a cancer diagnosis or another pre-existing condition, which will leave many of those patients without access to affordable insurance coverage. The bill attempts to narrow the effect of eliminating the pre-existing condition affordability guarantee by including language intended to limit it only to those who have not maintained continuous insurance coverage. Nevertheless, the

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economic incentives established under the provision would mean that the elimination of this crucial guarantee will extend to anyone with a pre-existing condition, not just those who have experienced a lapse in their coverage.[2]

The AHCA attempts to mitigate the impact of these changes on Americans with pre-existing conditions by, first, providing funds to help states who waive this pre-existing conditions protection to help address this problem and, second, creating a backstop federal 'invisible high-risk pool' for costly patients in states who waive the protections without directing funds to this purpose. Unfortunately, these provisions and the funding allotted to them within the AHCA fall short of guaranteeing affordable access to coverage for cancer patients and create new risks and uncertainty for cancer patients and survivors. In fact, independent experts, as well as lawmakers on both sides of the aisle have admitted that the high-risk pool framework and the funding allotted to it under the AHCA would be insufficient to guarantee affordable access to insurance for Americans with a pre-existing conditions.[3][4][5] Put simply, the AHCA would remove a vital guarantee of equal access to coverage and replace it with an untested and underfunded framework that takes control away from consumers and patients and puts it back in the hands of insurers. The Senate should reject this approach.

It is important to note that the MacArthur amendment to the AHCA was released publicly less than 10 days prior to the House vote on the bill. Similarly, the text of the Upton-Long amendment was available only hours before the vote. As a result, the CBO did not have an opportunity to analyze and report on the full impact of the final bill on coverage and federal spending before members of the House of Representatives cast their votes. Once the CBO publishes its analysis of these provisions and their combined effects, LLS will provide you with additional comments.

Promoting Affordability

The AHCA includes several policies that would increase costs for patients who are currently enrolled in commercial insurance plans purchased on the individual market or on Medicaid. These changes would have the most significant impact on Americans who are older and those with lower incomes—putting insurance coverage and the care provided under that coverage completely out of reach for millions of Americans.

LLS is particularly concerned that the AHCA's framework for waiving federal Essential Health Benefits (EHB) would allow plans to reinstate lifetime limits and eliminate the annual out-of-pocket maximum for vital cancer treatments. In fact, under the AHCA, an insurer could use one state's low standards for essential benefits to eliminate these protections for services like prescription drugs, which many blood cancer patients rely on to control their cancer. In such a case, an insurer operating in a state that does not require prescription drug coverage as an EHB could continue to cover prescription drugs for its enrollees—and even advertise drugs as a covered benefit—while simultaneously subjecting that coverage to a lifetime limit and exempting spending on drugs from the patient's annual out-of-pocket cap. As a result, once drug spending on behalf of a patient reached a certain threshold, the insurer could refuse to provide further coverage—eliminating the ability of that patient to access her cancer therapy. Similarly, the AHCA's framework would allow the same insurer to not apply cost-sharing on anti-cancer prescription drugs toward the patient's annual out-of-pocket maximum—putting patients on the hook for thousands more in out-of-pocket costs each year. These changes would impact patients who receive coverage through a large employer—even an employer operating in a state that has not waived the federal EHB standard—in addition to those who purchase small group coverage or individual insurance plans.

In the individual insurance market, the AHCA would shift more costs onto patients and their families—increasing premiums and lowering the percentage of expenses paid by insurers.[6] First, low- and middle-income patients benefiting from existing income- and cost-based financial assistance would receive significantly less financial support under the AHCA, both through reductions in their tax credits and the elimination of cost-sharing reduction subsidies intended to lower out-of-pocket requirements. Compounding the impact of these reductions, the AHCA expands "age rating" bands, allowing insurers to charge older patients five times as much as younger patients. In addition, the bill's tax credit design does not account for significant geographic variation in premiums, exposing patients in high-cost areas to an even higher financial burden.

As a result of these changes, patients who are older, have lower incomes, and live in states with higher-than-average healthcare costs could see dramatic increases in their out-of-pocket costs.[7] LLS appreciates that the AHCA attempts to address the significant problems created by the changes highlighted above by establishing the Patient and State Stability Fund to provide some ability for states—or the federal government if states neglect to act—to counteract the increase in premiums and out-of-pocket costs. Unfortunately, the funding provided for this purpose under the AHCA does not appear sufficient to address the sizable problems cited above.

Cancer patients enrolled in Medicaid are some of the most vulnerable Americans—facing significant health problems, low-incomes, and often disability. The AHCA would immediately freeze Medicaid enrollment for the ACA's Medicaid expansion population in expansion-participating states, begin refusing current Medicaid expansion enrollees who temporarily lose eligibility, and eventually eliminate the ACA's additional funding for the Medicaid expansion population altogether. In addition, the AHCA would transform Medicaid into a per-capita capped payment program, in which federal funds are not responsive to inevitable changes in per-beneficiary spending as populations change and new medical breakthroughs come to market. Even more concerning, the updated AHCA provisions released on March 21 would allow states to go further and turn Medicaid into a block granted program, in which federal funds are capped and completely divorced from real world fluctuations in Medicaid demand and healthcare costs.

CBO has noted that the underlying bill's Medicaid changes will drastically cut the funding dedicated to providing care for our most vulnerable patients and will lead to states eliminating coverage for millions of patients.[8] These consumers are unlikely to have the resources to purchase private, individual market coverage, especially given the smaller tax credits allowed under the AHCA. In addition to many losing coverage, LLS is also concerned that these new fiscal constraints will require states to make short-sighted, cost-focused decisions that could imperil access to quality cancer care for the patients who remain on Medicaid. The provisions discussed above are key to understanding the AHCA's impact on cancer patients, as policies designed to guarantee access to coverage are effectively false promises unless accompanied by the financial assistance necessary to allow a cancer patient to actually maintain and use that coverage.

Ensuring Quality

The AHCA makes a number of changes that would erode current rules that provide cancer patients the peace of mind that all insurance options provide basic value to the consumer and coverage for necessary benefits. The bill would establish a framework for states to eliminate federal EHB standards,

allowing insurers to sell 'junk insurance'—collecting premiums but providing little to no coverage when a patient receives a diagnosis of a condition like blood cancer.[9]

Beyond the ability of individual states to waive this minimum benefit standard, the bill would allow insurers in every state to sell so-called "catastrophic plans" that provide very limited benefit and serve to remove currently healthy consumers from broader risk pools that spread high treatment costs for a small number of patients across the population. In addition, the bill repeals the consumer-friendly metal tier comparison options. When combined, these two changes increase the likelihood that consumers will purchase coverage that they think fits their needs, only to find out after a serious diagnosis that they must exhaust their savings to access their insurance benefits.

In addition to the commercial insurance changes above, the bill also eliminates EHB requirements for Medicaid coverage—opening the door to Medicaid benefit designs and eligibility rules that ration remaining Medicaid dollars and deprive the most vulnerable enrollees of necessary care.

Encouraging Stability

The AHCA creates significant instability for cancer patients on private, individual market insurance plans and on Medicaid. In particular, the bill's elimination of the existing individual and employer mandates could lead to dramatic changes in risk pools that could threaten the ability of plans to manage risks in 2017 and participate in the individual market in 2018. In contrast to the individual mandate's structure of penalizing consumers who remove themselves from the risk pool, the AHCA's continuous coverage penalty seems to exacerbate adverse selection problems by providing an additional incentive for currently healthy consumers who are uninsured to avoid coverage until they need insurance.

As a result of these changes and those in the sections above, initial CBO projections showed that the AHCA would lead to 14 million Americans losing their insurance coverage in just the first year of implementation, with an estimated 24 million total additional uninsured Americans after a decade of implementation. These policies have the potential to further skew the individual market risk pools and disincentivize insurers from participating in markets that have little competition under the ACA.

In addition to these concerns, the AHCA also includes a provision to provide bonus payments to states that create a Medicaid "work requirement." This policy threatens to take health insurance away from many low-income cancer patients who lose their jobs and are physically unable to work or search for employment while they are undergoing their cancer treatment. Cancer patients know all too well that a cancer diagnosis reverberates across a family's financial wellbeing, often causing the patient and even caregivers to lose their employment as they dedicate themselves to fighting the cancer. No government at any level should tell a cancer patient undergoing treatment that they are going to lose their health insurance because they also lost their job.

Summary

LLS shares Congress' goal of achieving higher quality care at a lower cost to American families. Unfortunately, in its current form, the AHCA aggravates existing problems by weakening key patient protections that cancer patients need to access life-saving treatment, increasing out-of-pocket costs for families, creating additional instability for vulnerable patients covered by Medicaid and individual market plans, and eliminating standards that hold insurers accountable for providing value to patients.

LLS and our patients are committed to working with Senate leaders to advance policies that address the many significant obstacles to care that remain today, even with the existing protections provided by the ACA. We sincerely hope that our concerns with the AHCA will help underline the need for a deliberate and thoughtful process as the Senate considers changes to improve the healthcare system. Improving this legislation will require an open and honest debate based on an updated CBO analysis of the budgetary and coverage impacts of the bill and any major amendments, as well as extensive engagement with patient organizations, provider associations, researchers, and health sector industries.

LLS is ready and willing to work with congressional leaders on both sides of the aisle to make the improvements necessary to advance a bill that works for all consumers, including cancer patients. As we committed to you in December, LLS stands ready to provide our perspective to ensure that no patient loses access to the treatment they need to win their battle with cancer.

Sincerely,

Dr. Louis J. DeGennaro, Ph.D.
President & Chief Executive Officer

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[2] Ibid.

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