

December 15, 2016

The Honorable Paul Ryan
Speaker
U.S. House of Representatives

The Honorable Mitch McConnell
Majority Leader
U.S. Senate

The Honorable Nancy Pelosi
Democratic Leader
U.S. House of Representatives

The Honorable Charles Schumer
Democratic Leader
U.S. Senate

Dear Speaker Ryan, Majority Leader McConnell, and Democratic Leaders Pelosi and Schumer:

On behalf of the Leukemia & Lymphoma Society (LLS) and the over one million two hundred thousand Americans living with a blood cancer diagnosis, I am writing to share our perspective on legislative efforts regarding the Affordable Care Act in the 115th Congress.

Since our founding, we have invested more than one billion dollars in medical research aimed at finding cures for the blood cancers. Over the past 15 years, that investment has led to exciting breakthroughs that have helped turn many cancers from a death sentence to a chronic disease, often requiring strict adherence to sometimes costly treatment regimens. Without meaningful insurance coverage, patients cannot access the treatments they need to win their battle with cancer.

Patients' lives quite literally depend on their access to affordable, high-quality coverage, and they understand that such coverage has not always been a guarantee. Not long ago, cancer patients willing to purchase coverage were often denied by insurance companies—even years after a diagnosis. Meanwhile, those able to purchase coverage were often subject to lifetime caps that eliminated benefits in the middle of their treatment regimen and out of pocket costs that could total tens of thousands of dollars in a single year.

The stakes could not be higher for cancer patients whenever Congress considers changes to the protections they need and the coverage they rely on to access their care. As the voice of these patients and their families, LLS strongly urges Congress to ensure that any changes to existing law meets these four principles:

- Guarantee Access – Cancer patients rely on insurance to help cover the often costly treatments that can mean the difference between life and death. Cancer patients must continue to have the right to purchase quality, affordable health insurance to help them access the care they need.
- Ensure Quality – While the existing rules governing the quality of coverage need improving, cancer patients currently have the peace of mind that every insurance plan option will cover minimum benefits and sufficient providers to access cancer treatments and drugs. Policymakers

must continue to provide minimum quality standards that protects patients from being locked out of necessary treatment due to barebones coverage.

- Promote Affordability – Cancer patients often face financial burdens due to loss of income during treatment, making it difficult to afford coverage. This is particularly problematic for patients without employer-based coverage or with very low incomes. Guaranteed access to coverage is a false promise without premium assistance and cost-sharing limits that allow a cancer patient to use that coverage.
- Provide Stability – For many cancer patients, even a short interruption in their coverage can have dire consequences for their treatment and their outcomes. Policymakers must provide cancer patients with the peace of mind that every patient will have access to affordable, quality coverage, even if existing or future policymakers do not act. Given the recent history of political gridlock, cancer patients cannot afford for chaos to be the default if elected officials cannot come to an agreement.

As the House and Senate consider legislation in the next Congress regarding the Affordable Care Act, LLS and the patients we serve will partner with policymakers to ensure that any new proposals meet these principles. We stand ready to provide our perspective to ensure that no patient is denied access to the treatment they need to win their battle with cancer.

Sincerely,



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