Dear Chairmen Neal and Pallone and Ranking Members Brady and Walden,

On behalf of the millions of current and future Medicare enrollees we represent, we urge you to continue to work together to lower out-of-pocket costs for patients who face enormous cost-sharing under the current Part D benefit design. Millions of Medicare enrollees rely on one or more specialty drugs as the standard of care in treating deadly or debilitating conditions like cancer, multiple sclerosis, lung disease including COPD, HIV, diabetes, viral hepatitis, arthritis, and psoriasis. Without reforms aimed specifically at lowering out-of-pocket costs on an annual and monthly basis, the number of enrollees struggling—and, too often, unable—to afford essential and life-saving therapies will continue to grow.

We are grateful for your bipartisan work to advance an out-of-pocket cap for Part D enrollees. A cap would make significant progress in addressing the burdensome out-of-pocket costs facing many Medicare enrollees who rely on a costly drug covered by their Part D plan. Medicare Part D is the only comprehensive insurance market in America that neither includes an out-of-pocket cap nor has associated supplemental coverage that provides a cap.1 As a result, more than one million patients each year pay out-of-pocket costs so burdensome that they pass the Part D program’s catastrophic threshold—up from 380,000 patients in 2010.2 For many of these patients, their Part D plans require $10,000 or more in out-of-pocket costs every year to access a single drug that they need to treat a serious condition.3 Under your draft proposal to cap cost-sharing in Part D, enrollees who rely on costly specialty drugs in Part D would see immediate and dramatic reductions to their out-of-pocket costs.

Although an annual cap on out-of-pocket costs is an essential reform for the patients we represent, a growing number of patients may not benefit from an annual cap without a provision to address the burdensome ‘first fill’ cost. Given the benefit design in Part D, hundreds of thousands of enrollees face thousands of dollars in cost-sharing in the first month of their prescription. For example, 370,000 Part D
enrollees exceeded the catastrophic threshold in 2017 by filling a single prescription—a 1000% increase from seven years earlier.⁴

When patients face costs this high, they often abandon their treatment. One study of cancer patients showed that 45% of Part D patients abandon their therapy when out-of-pocket costs are as high as Part D plans uniformly require.⁵ Another study found that Medicare patients across a series of disease diagnoses in 2018 were seven times more likely to abandon their first prescription at the pharmacy counter when facing high out-of-pocket costs.⁶ As a result, many Medicare enrollees with a chronic and life-threatening disease may never benefit from an annual cap unless it includes a provision that breaks down the financial barrier to filling their first prescription by spreading their annual out-of-pocket costs throughout the year.

The patients we represent are many of those hundreds of thousands of Medicare Part D patients currently unable to access the standard of care for their disease due to high out-of-pocket costs. These patients need Congress to act to address the burdensome ‘first fill’ costs that stand between patients and their therapies. We urge you to build on your proposal to establish an annual cap on Part D out-of-pocket costs by including a provision to spread burdensome upfront costs throughout the year. If you have any questions or need any additional information, please contact Brian Connell with The Leukemia & Lymphoma Society at brian.connell@lls.org. We would welcome any opportunity to work with you to ensure that Congress does not miss an opportunity to solve this important problem for Medicare enrollees.

Sincerely,
The AIDS Institute
American Cancer Society Cancer Action Network
American Diabetes Association
American Lung Association
Arthritis Foundation
Cystic Fibrosis Foundation
International Myeloma Foundation
The Leukemia & Lymphoma Society
National Multiple Sclerosis Society
National Psoriasis Foundation
Ovarian Cancer Research Alliance
Susan G Komen