



June 9, 2022

The Honorable Nancy Pelosi
Speaker, U.S. House of Representatives
1236 Longworth House Office Building
Washington, DC 20515

The Honorable Chuck Schumer
Majority Leader, U.S. Senate
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Kevin McCarthy
Minority Leader, U.S. House of Representatives
2468 Rayburn House Office Building
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader, U.S. Senate
317 Russell Senate Office Building
Washington, DC 20510

Dear Speaker Pelosi, Minority Leader McCarthy, Majority Leader Schumer, Minority Leader McConnell:

The undersigned patient groups, representing over 74 million patients across the United States living with arthritis, cancer, multiple sclerosis, cystic fibrosis, and epilepsy, urge you to ensure a \$2,000 annual cap in Medicare Part D out-of-pocket costs is included in the final reconciliation package currently under negotiation. We first wrote to you in September 2021 with this request, and now more than ever we want to reiterate the critical need to cap Part D costs in this Congress. High out-of-pocket costs result in devastating consequences for patients every day, and new data from Health Affairs corroborates this; a recent study found that beneficiaries with subsidies were nearly twice as likely to initiate therapy within 90 days than those without subsidies.¹ This simply adds further evidence to the abundance of data and patient stories our organizations have been collecting for years from patients who are desperate to remain on their medications and looking for solutions.

In our September letter we highlighted the fact that currently more than 1.5 million patients pay annual out-of-pocket costs so burdensome that they pass the Part D program's catastrophic threshold—up from 380,000 patients in 2010.² Taking a specialty drug is often an indication that a beneficiary will enter catastrophic coverage. "Beneficiaries taking a specialty drug are more likely to enter catastrophic coverage than those with multiple (3 or more) chronic conditions."³ The Part D plans for many of these patients require \$10,000 or more annually in out-of-pocket costs to access a single drug. For example, over 10% of people with cystic fibrosis enrolled in Medicare pay more than \$10,000 in annual out of pocket expenses, excluding deductibles and premiums.

¹ Health Affairs. (2022). Many Medicare Beneficiaries Do Not Fill High-Price Specialty Medications. Retrieved from <https://www.healthaffairs.org/doi/epdf/10.1377/hlthaff.2021.01742>.

² Medicare Payment Advisory Commission (MedPAC). (2021). Report to the Congress: Medicare Payment Policy. Page 438.

³ The Commonwealth Fund. (2020). Catastrophic Coverage in the Medicare Part D Drug Benefit: Which Beneficiaries Need It and How Much Are They Spending? Page 3. Retrieved from <https://www.commonwealthfund.org/publications/issue-briefs/2020/sep/catastrophic-coverage-medicare-part-d-drug-benefit>.

Below we would like to reiterate the examples from our previous letter of the ways our patients are burdened by high out-of-pocket costs:

- A 2019 Arthritis Foundation survey showed 40% of Part D enrollees could not access the drugs they needed to manage their disease, and 19% had to switch to a Part B drug due to out-of-pocket costs.
 - **What this looks like in real life:** A patient from CA entered Medicare Part D and realized she could no longer use her co-pay assistance to help pay for her drugs. She found herself unable to afford the cost-sharing for her biologic and had to abruptly switch to a Part B drug so she could get a supplemental benefit. This drug is not as effective for her, yet she has no choice but to stay on it for affordability reasons. Her health is worsening, and she is ultimately costing Medicare more money in unnecessary interventions. Worse, her quality of life has deteriorated and has had a ripple effect on her ability to complete daily tasks.
- In 2019, the cumulative annual out-of-pocket spending for Medicare beneficiaries with MS just for their MS disease modifying treatments (DMTs) was \$6,894- including an average of \$352 in out-of-pocket costs per month for those already in the catastrophic coverage phase. ⁴
 - **What this looks like in real life:** A woman with MS from Ohio stopped taking her DMT for the first three months of the year when she couldn't secure financial assistance from a foundation. People with MS typically enter catastrophic coverage within the first few months, putting a significant cost burden early in the year, every year. Each time a person with MS goes without their DMT, they risk disease and disability progression which cannot be reversed, and may ultimately place a larger financial burden on Medicare.
- At least 1.1 million people with epilepsy rely on Medicare, where they have experienced exponential growth in medication costs. Twenty-one percent of adults with epilepsy have reported not being able to afford prescription medications within the last year.⁵
 - **What this looks like in real life:** A Pennsylvania woman with epilepsy found her medication to be unaffordable after switching to Medicare from commercial insurance as she no longer had an out-of-pocket cap. A woman with epilepsy from New York paid \$6,800 in total Part D out-of-pocket costs in 2021. Delaying access to the anti-seizure medications puts a person with epilepsy at increased risk for breakthrough seizures and related consequences including injury, disability or even death. In addition to the human and quality of life toll, a review of studies has shown that direct, epilepsy-related medical costs associated with uncontrolled epilepsy are 2 to 10 times higher than costs associated with controlled epilepsy.⁶

⁴ Hartung DM, Johnston KA, Bourdette DN, Chen R, Tseng CW. Closing the Part D Coverage Gap and Out-of-Pocket Costs for Multiple Sclerosis Drugs. *Neurol Clin Pract.* 2021 Aug;11(4):298-303. doi: 10.1212/CPJ.0000000000000929. PMID:34484929; PMCID: PMC8382442.

⁵ Thurman, D.J., Kobau, R., Luo, Y., Helmers, S.L., & Zack, M.M. (2016). Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013. *Epilepsy & Behavior*, 55, 184-88. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5317396/>.

⁶ Begley, C.E. & Durgin, T.L. (2015). The direct cost of epilepsy to the United States: A systematic review of the estimates. *Epilepsia*, 56(9), 1376-87. Retrieved from <https://onlinelibrary.wiley.com/doi/full/10.1111/epi.13084>.

With these examples in mind, we urge you to prioritize a Part D cap of \$2,000 with a smoothing mechanism in the final reconciliation package. This bipartisan proposal has gained wide support over the last four years and would result in immediate and dramatic reductions to out-of-pocket costs for millions of seniors and people with disabilities.

Millions of patients need Congress to act now to lower their out-of-pocket costs and help make their medications more affordable. In this critical phase of negotiations, we urge you to consider the human faces behind each of the proposals under discussion, and to ensure inclusion of the bipartisan proposal outlined above as you move forward with reconciliation. We stand ready to support you in this effort and we encourage you to use us a resource. Please contact Anna Hyde at ahyde@arthritis.org with any questions or if we can be of assistance. Thank you for your consideration of our requests, and we look forward to working with you to protect patients.

Sincerely,

American Cancer Society-Cancer Action Network
Arthritis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation
Leukemia and Lymphoma Society
National Multiple Sclerosis Society