



October 5, 2021

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 critical patient protections specifically related to patient affordability in Medicare Part D are included in the final reconciliation package currently under negotiation. High out-of-pocket costs result in devastating consequences for patients every day. Some beneficiaries cannot afford their Part D drugs and stop taking medications. Other beneficiaries incur great medical debt. And some endure worsening health outcomes, leading to higher overall costs to Medicare.

Patients often get caught in the political tug-of-war between industries over how to lower drug prices, prolonging the status quo and leaving patients shouldering the burden. **We urge you to prioritize patients and include provisions to limit out-of-pocket costs in the final bill.** Policies to reduce cost-sharing will have a multiplying impact by helping ensure access and adherence to treatment while simultaneously lowering overall system costs in avoided adverse events. We urge you to include in the final package a redesign of the Medicare Part D benefit that includes an out-of-pocket cap and smoothing, as well as policies that ensure patients receive savings from rebates and discounts.

Chronic diseases like those we represent contribute to high costs in Medicare. The Congressional Budget Office estimates that Medicare will spend \$96 billion in Part D benefits in 2021, representing 13% of total Medicare spending. These are unsustainable costs to both Medicare and beneficiaries. 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.<sup>1</sup> Taking a specialty drug is often an indication that a beneficiary will enter catastrophic coverage. "Beneficiaries taking a specialty drug

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<sup>1</sup> Medicare Payment Advisory Commission (MedPAC). (2021). Report to the Congress: Medicare Payment Policy. Page 438.

are more likely to enter catastrophic coverage than those with multiple (3 or more) chronic conditions."<sup>2</sup> 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.

Some other specific examples of the ways our patients are burdened by high out-of-pocket costs now include:

- 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 treatment (DMT) was \$6,894- including an average of \$352 in out-of-pocket costs per month for those already in the catastrophic coverage phase.<sup>3</sup>
  - **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.<sup>4</sup>
  - **What this looks like in real life:** A Pennsylvania woman with epilepsy found her brand name medication to be unaffordable after switching to Medicare from commercial insurance as she no longer had an out-of-pocket cap. A man with epilepsy in Louisiana is struggling to afford his generic medication on Part D after the price increased 233% in

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<sup>2</sup> 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>.

<sup>3</sup> 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.

<sup>4</sup> 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/>.

a year. 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.<sup>5</sup>

With these examples in mind, we urge you to prioritize the following protections so patients can get the life changing medications they need:

- **Part D redesign.** While the Part D program has been a successful and needed lifeline for patients since 2006, it is overdue for changes that reflect the current realities of the drug market. In 2017, 45 percent of beneficiaries who entered the catastrophic benefit had cost-sharing over \$1,000 in one month, and nearly 20 percent faced costs of over \$2,500 in one month. We urge Congress to implement a cap on Part D out-of-pocket costs and a smoothing mechanism to allow patients to pay their cost-sharing over the plan year. These bipartisan ideas have 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.
- **Rebates.** Currently, there are no mechanisms that ensure patients benefit from rebates and discounts negotiated between manufacturers, pharmacy benefit managers, and payers. For example, patients often pay co-insurance based on the list price, rather than net price, of a drug. This means that patients miss out on discounts that are part of the healthcare system. With many drugs for complex conditions costing thousands of dollars a month, and co-insurance rates rising as high as 40%, cost-sharing becomes out of reach for most beneficiaries. Multiple policies have been proposed in recent years that would shift some of the rebate savings to patients, and we support efforts to ensure the downstream impact from rebates and discounts truly benefit patients.

**Millions of patients need Congress to act now to lower their out-of-pocket costs and help make their medications more affordable.** There are human faces behind each of the numbers being considered throughout these negotiations, and we urge you to support the bipartisan proposals outlined above as you move forward with reconciliation. This is a critical window of opportunity to make a meaningful difference for millions of patients who are struggling to access the medications they need to stay healthy. 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](mailto: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

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<sup>5</sup> 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>.