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May 17, 2021

The Honorable Ron Wyden
Chair
Committee on Finance
United States Senate
Washington, DC 20510

The Honorable Mike Crapo
Ranking Member
Committee on Finance
United States Senate
Washington, DC 20510

Dear Senators Wyden and Crapo:

On behalf of the Patient Access Network (PAN) Foundation and the patients and families we support, we write to provide policy recommendations as the Finance Committee seeks to address the high out-of-pocket costs that are a significant barrier for too many Americans who cannot afford their critical prescription medications. We laud your leadership in authoring legislation in the 116th Congress to restructure Medicare Part D and decrease the cost for enrollees at the pharmacy counter.

Founded in 2004, PAN is a non-profit organization whose mission is to help underinsured people with life-threatening, chronic, and rare diseases get the medications and treatments their physicians prescribe for them by providing financial assistance for their out-of-pocket costs and by advocating for improved access and affordability. PAN provides patients with direct assistance through nearly 70 disease-specific programs and also collaborates with national patient advocacy organizations to provide patients with education and additional support. Since 2004, nearly one million underinsured patients have received financial assistance from the Foundation.

The Part D program and its beneficiaries have seen significant health spending growth over the last decade. Between 2007 and 2019, Part D spending increased at an average annual rate of 5.5 percent and from \$49 to \$85 billion.¹ Although extensive research demonstrates the favorable impact of Medicare Part D on access to prescription medications, the benefit design, along with other factors such as placement of certain drugs on specialty tiers, creates insurmountable barriers for Medicare beneficiaries and their ability to access needed treatments. Millions of Medicare beneficiaries struggle to afford their prescription medications, and in many cases, this is because of Part D's outdated benefit design.

Therefore, PAN urges the adoption of legislation to modernize the Medicare Part D benefit design to improve prescription medication access and reduce the financial burden on all beneficiaries. As you embark on the important work of marking-up and moving legislation to reduce out-of-pocket costs for prescription drugs, we respectfully urge your consideration of our recommendations and we stand ready to be a resource to you and your colleagues. Specifically, we ask your active support for:

Capping out-of-pocket costs for prescription medications by instituting monthly and/or annual limits for Medicare beneficiaries. Medicare beneficiaries are the only group of insured people in the U.S. that are not protected by a cap on annual out-of-pocket costs, forcing many to make difficult trade-offs or to forgo treatment altogether. When Medicare beneficiaries who are enrolled in Part D drug plans meet

¹ Medicare Payment Advisory Commission. Report to the Congress Fact Sheet. March 2020. Available at: http://www.medpac.gov/docs/default-source/fact-sheets/march_2020_medpac_fact_sheet_sec.pdf?sfvrsn=0.

their True Out-of-Pocket (TrOOP) threshold for the year—currently set at \$6,550 in OOP spending—they enter the “Catastrophic Coverage Phase,” and remain in this phase until the end of the calendar year. In this phase, beneficiaries pay 5 percent coinsurance (coinsurance is a percentage of the cost of a prescription medication) on their medications until the end of the year.

Although the 5 percent coinsurance that is imposed during the catastrophic phase may seem small, because it is a percentage of the cost of a beneficiary’s prescription medications, this amount can balloon to many thousands of dollars for some patients because there is no annual cap during this coverage phase. OOP drug costs during the catastrophic phase are especially challenging for certain groups of Medicare beneficiaries. These include beneficiaries who need high-cost specialty medicines, and economically vulnerable patients who are not eligible for the Low-Income Subsidy (LIS). The absence of an annual OOP cap for prescription medications means that these beneficiaries face great uncertainty about whether they can afford to buy the drugs that have been prescribed for them by their doctors.

PAN supports a cap at the lowest possible threshold to ensure access and affordability for the greatest number of Part D beneficiaries.

Allowing Medicare beneficiaries to spread out-of-pocket costs for prescription medications more evenly throughout the benefit year without a financial threshold to qualify. The structure of Medicare Part D prescription drug plans front loads OOP medication costs early in the benefit year. This can have a devastating impact on patients who face high cost sharing for their medications. Many patients cannot afford large out-of-pocket expenses all at once, but could afford the total expenditure if spread out over time. Modifying the structure of Medicare plans so that out-of-pocket costs for prescription medications are spread more evenly over the course of the year will improve access and help patients remain on the treatments they need.

PAN appreciates the bipartisan support to date for a smoothing option and urge that there be no trigger mechanism so that enrollees can opt in to smoothing at their first fill of the plan year. Waiting until an enrollee incurs a significant percentage of their OOP threshold would require patients to incur thousands in out-of-pocket expenses before an enrollee is eligible for smoothing.

In 2020, PAN supported research conducted by the University of Pennsylvania, highlighting the impact of certain policy solutions on Medicare beneficiaries’ medication costs. Research results were clear: as low a Part D cap as possible, combined with smoothing, will have the largest impact on lowering out-of-pocket costs and reducing prescription abandonment at the pharmacy counter. A summary of this research is attached to inform the Committee’s deliberations.

Modernizing the Medicare Part D Low-Income Subsidy (LIS) program to increase enrollment and provide continuity for enrolled individuals. PAN urges the Committee to modernize the LIS program to make eligibility easier to establish, increase the income requirements to 200% of the federal poverty level to help a larger population of beneficiaries in need, eliminate cost sharing for generic drugs, and include specific efforts to ensure all eligible beneficiaries are enrolled and taking advantage of the program.

Expanding Medicare to include dental, hearing, and vision benefits and minimize out-of-pocket spending for these services. The need for dental, hearing, and vision coverage among patients on

Medicare is significant. Almost two-thirds of Medicare beneficiaries—37 million people—do not have any dental coverage.² Only one in four Americans diagnosed with hearing issues uses a hearing aid, with the cost being a major barrier to obtaining them.³ And, 92 percent of Medicare beneficiaries require eyeglasses.⁴ For those that receive these services there is a high out-of-pocket burden with three-fourths of the costs of dental and hearing services and 60 percent of the costs of vision services paid out of pocket.⁵ Older adults who forgo or delay these services are at greater risk for emergency department visits and hospitalizations, dependence on family caregivers or skilled nursing facilities, and depression and dementia.⁶

Providing parity between Medicare Part B and D by eliminating vaccine co-pays in the Medicare Part D program. Older adult vaccination rates remain low. According to the Centers for Disease Control and Prevention, more than 50,000 adults die annually from vaccine-preventable diseases. Treatment for these preventable illnesses is estimated to have cost the Medicare program \$106 billion from 2016 to 2018.⁷ Although many Part D plans cover vaccines, they usually require co-pays. The higher the co-pays, the more likely it is that patients will forgo the vaccine.

The PAN Foundation appreciates your leadership in seeking solutions to increase access to and affordability of health care for more Americans. For Medicare beneficiaries, lowering out-of-pocket costs of prescription medications is an urgent need, and we hope Congress will pass legislation this year to provide them with the relief they need. If you would like further information or have questions, please contact Amy Niles, Executive Vice President at aniles@panfoundation.org.

Sincerely,



Dan Klein, MHS
President and Chief Executive Officer

Attachment

² Kramarow EA. Dental care among adults aged 65 and over, 2017. NCHS Data Brief, no 337. Hyattsville, MD: National Center for Health Statistics. 2019. Available at: <https://www.cdc.gov/nchs/products/databriefs/db337.htm>.

³ Hearing Health Foundation. Hearing Loss and Tinnitus Statistics. Available at: <https://hearinghealthfoundation.org/hearing-losstinnitus-statistics>.

⁴ Otte B, Woodward MA, Ehrlich JR, Stagg BC. Self-reported Eyeglass Use by US Medicare Beneficiaries Aged 65 Years or Older. JAMA Ophthalmol. 2018;136(9):1047–1050. Available at: <https://pubmed.ncbi.nlm.nih.gov/30003222/>.

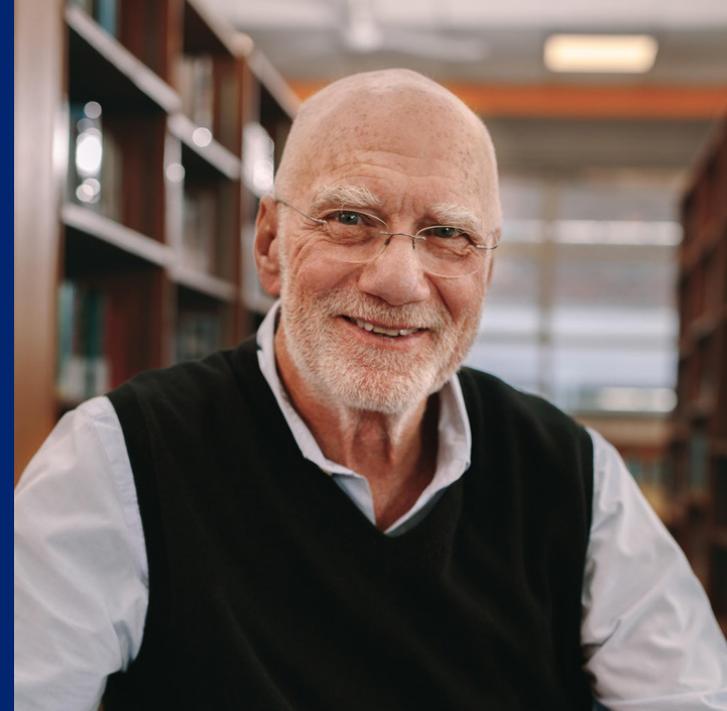
⁵ Willink A, Schoen C, Davis K. How Medicare Could Provide Dental, Vision, and Hearing Care for Beneficiaries. Commonwealth Fund. Jan 18, 2018. Available at: <https://www.commonwealthfund.org/publications/issue-briefs/2018/jan/how-medicare-could-provide-dental-vision-and-hearing-care>.

⁶ Ibid.

⁷ Liow C, Hughes R, Petrilla A, Kumar S, Trost A, Shaw M, Cole M, Kornfield T. Medicare Spent \$106B on Vaccine-Preventable Diseases Over 3 Years. Avalere. June 2, 2020. Available at: <https://avalere.com/insights/medicare-spent-106b-on-vaccine-preventable-diseases-over-3-years>.



Monthly Out-Of-Pocket Cost Caps are Needed Under Medicare Part D to Improve Access to Specialty Drugs



PATIENT CASE STUDY

John Doe, a 73-year-old retired Medicare beneficiary, has been diagnosed with chronic myeloid leukemia, a form of blood cancer. The life-saving cancer medication prescribed to him is an oral specialty drug to be taken daily with an annual list price of \$166,629. John's monthly income is barely enough to cover food, rent, and utilities. Unfortunately, his income is slightly above the qualifying threshold for the Medicare Part D Low-Income Subsidy program, and therefore he cannot benefit from lower out-of-pocket (OOP) costs.

With the current Medicare Part D "standard" benefit, John will pay thousands of dollars in out-of-pocket costs for his medication, starting with his deductible of \$435, followed by 25% of the drug costs until he reaches the catastrophic phase, where he will pay 5% of drug costs with no limit until the end of the calendar year.

Annual list price for specialty medication

\$166,629

Annual out-of-pocket cost

\$10,602

Current Medicare Part D Benefit and Alternative Policy Solutions

POLICY SCENARIO	ANNUAL PART D OUT-OF-POCKET COST CAP	OUT-OF-POCKET COST SMOOTHING	POLICY STATUS
● Scenario 1: Current 2020 Medicare Part D standard benefit design	None	None	Active
● Scenario 2: \$3,100 Annual OOP Cap, without smoothing ¹	\$3,100 ¹	None	Proposed to Congress
● Scenario 3: \$2,000 Annual OOP Cap, without smoothing ¹	\$2,000 ²	None	Proposed to Congress
● Scenario 4: \$3,100 Annual OOP Cap, with smoothing ²	\$3,100 ¹	Over 12 months ³	Concept introduced to Congress
● Scenario 5: \$2,000 Annual OOP Cap, with smoothing	\$2,000 ²	Over 12 months ³	Concept introduced to Congress
● Scenario 6: Income-based Annual OOP Cap with smoothing	\$500 for income 135%-200% FPL \$3,100 for income >200% FPL ⁴	Over 12 months ³	Not proposed to Congress

¹ Senate Finance Bill S. 2543 and House Republicans Bill H.R. 19 both proposed an annual Part D out-of-pocket cost cap of \$3,100

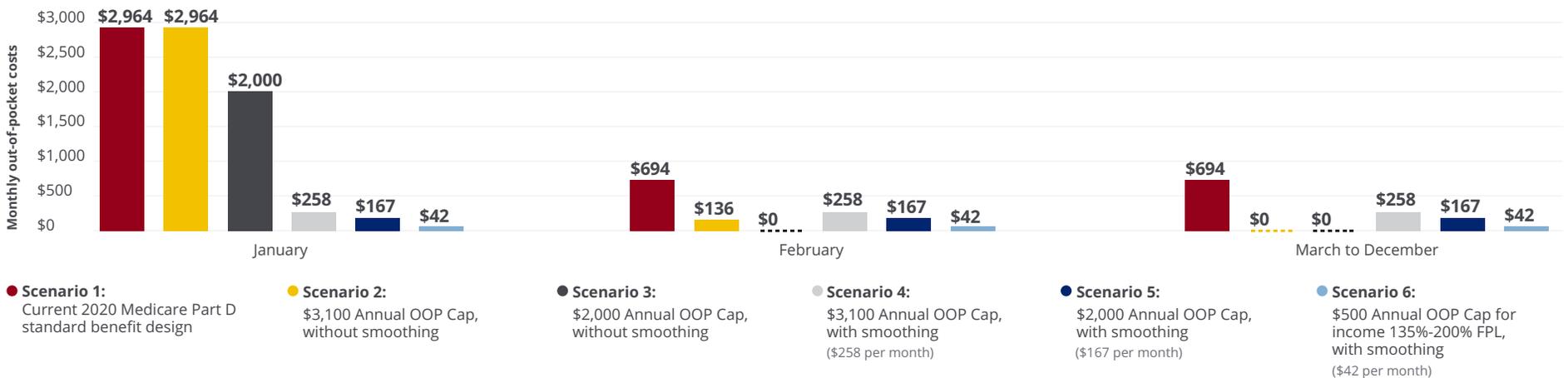
² House-passed Bill H.R. 3 proposed an annual Part D out-of-pocket cost cap of \$2,000

³ Presumes creation of monthly out-of-pocket costs caps via smoothing out of annual out-of-pocket cost cap evenly across 12 months as proposed in Doshi et al. "Reducing Out-of-Pocket Cost Barriers to Specialty Drug Use Under Medicare Part D: Addressing the Problem of 'Too Much Too Soon.'" Am J Manag Care 23(3 Suppl):S39-S45, 2017; and Doshi et al. "High Cost Sharing and Specialty Drug Initiation Under Medicare Part D: A Case Study in Patients with Newly Diagnosed Chronic Myeloid Leukemia." Am J Manag Care 22(4, Suppl): S78-S86, 2016.

⁴ Doshi, Li, and Ladage (2020) propose the idea of income-based annual out-of-pocket cost caps with smoothing with an example of \$500 for income 135%-200% FPL and \$3,100 for income >200% FPL

Monthly Out-of-Pocket Costs under Alternative Policy Solutions compared to Current Benefit

Monthly out-of-pocket costs for the life-saving cancer medication needed by John Doe under alternative scenarios compared to current benefit.



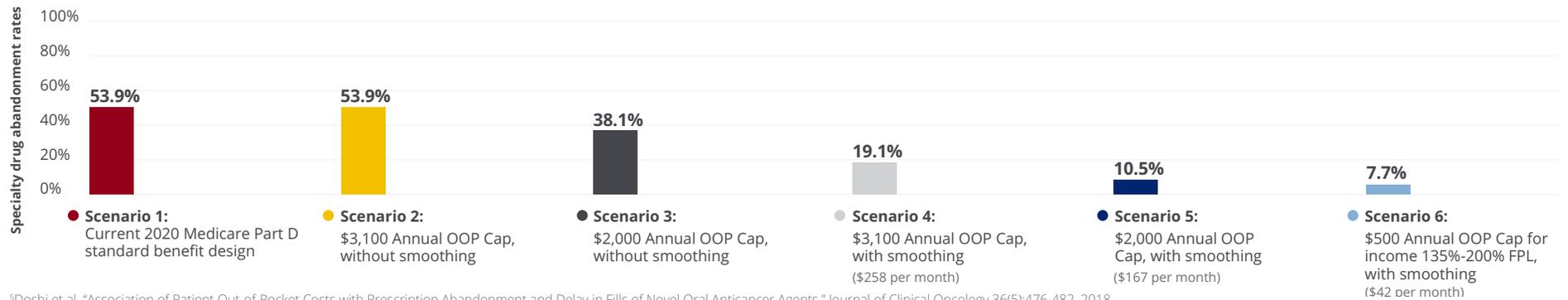
Medication Abandonment Rates under Alternative Policy Solutions compared to Current Benefit

With high out-of-pocket costs in January when deductibles reset, abandonment rates for the life-saving cancer medication under alternative scenarios are evaluated.⁵

JANUARY OOP COSTS UNDER ALTERNATIVE SCENARIOS



SPECIALITY DRUG ABANDONMENT RATES UNDER ALTERNATIVE POLICY SOLUTIONS COMPARED TO CURRENT BENEFIT



⁵Doshi et al. "Association of Patient Out-of-Pocket Costs with Prescription Abandonment and Delay in Fills of Novel Oral Anticancer Agents." *Journal of Clinical Oncology* 36(5):476-482, 2018.

Conclusions and Recommendations

- » **Under the existing 2020 Part D benefit, Medicare beneficiaries like John Doe face prohibitive annual out-of-pocket costs,** especially early on in the year, which likely leads to high rates of abandonment of critical specialty drugs.
- » **An annual out-of-pocket cost cap alone, whether \$2,000 or \$3,100, will not alleviate the high financial burden faced by patients early in the year,** nor reduce their likelihood of abandoning needed specialty drugs.
- » **Smoothing annual out-of-pocket costs uniformly across the year is a more effective solution than just having an annual cap.** Smoothing addresses the burden of high out-of-pocket costs early in the year and improves access to specialty drugs.
- » **The most effective and equitable option applies different annual cost caps based on income, and smooths these costs over 12 months.** This reduces the out-of-pocket cost burden while lowering abandonment rates for critical specialty drugs, especially for lower-income Medicare patients like John Doe who do not qualify for cost sharing subsidies under Part D.



Research was conducted by Jalpa A. Doshi, PhD; Pengxiang Li, PhD; and Vrushabh P. Ladage, MHCI at the University of Pennsylvania Perelman School of Medicine and Leonard Davis Institute of Health Economics. The research was made possible by a grant from the Patient Access Network (PAN) Foundation. September 2020.

Photography Credit: Smiling older man sitting in library with college materials by Jacob Lund from Noun Project