PAN Foundation

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May 3, 2021

The Honorable Frank Pallone, Jr.
Chair
House Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Anna Eshoo
Chair
House Subcommittee on Health
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member
House Committee on Energy and Commerce
2322-A Rayburn House Office Building
Washington, DC 20515

The Honorable Brett Guthrie
Ranking Member
House Subcommittee on Health
2322-A Rayburn House Office Building
Washington, DC 20515

RE: House Committee on Energy and Commerce Subcommittee on Health Hearing on Negotiating A Better Deal: Legislation to Lower the Cost of Prescription Drugs

Dear Chairs Pallone and Eshoo and Ranking Members McMorris Rodgers and Guthrie:

On behalf of the Patient Access Network (PAN) Foundation and the patients and families we support, we appreciate the opportunity to submit testimony for the record for the May 4 hearing and laud the House Energy and Commmerce Committee for holding this important hearing. PAN believes that Congress has an important opportunity at this time to address the high out-of-pocket costs that are a significant financial barrier for too many Americans who cannot afford their critical prescription medications.

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 Medicare population: economic insecurity and heavy disease burden

There are about 63 million people enrolled in Medicare today and that number will continue to grow over the next decade. Unfortunately, fewer than 25 percent are economically secure and Medicare beneficiaries remain the only insured population that isn't protected by an out-of-pocket cap. For many in the Medicare population—which includes 54 million older adults and 9 million people living with disabilities—healthcare costs are a source of major financial strain.

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About half of Medicare beneficiaries are living on less than $26,200 a year. And in 2017, they paid an average of $5,801 on healthcare costs—half on insurance premiums and half on out-of-pocket co-pays and services not covered.

Most Medicare beneficiaries today live with one or more chronic conditions, and many are prescribed expensive medications for their treatment. Unfortunately, these medications come with high out-of-pocket costs. The absence of an annual or monthly cap on what patients pay out of pocket directly contributes to their economic insecurity. High costs also have implications for overall patient health. High out-of-pocket costs contribute to prescription abandonment at the pharmacy counter, which ultimately negatively impacts health outcomes.

Policy Recommendations

PAN entirely supports the Committee's goal of improving access to and affordability of prescription drugs. That is a central part of PAN's mission, policy, and advocacy efforts. While legislative efforts to reduce the price of prescription drugs are important, changes to the Medicare Part D program are critically needed in order to reduce out-of-pocket costs for seniors and the disabled.

The Medicare Part D structure should be modernized to reflect the current prescription drug landscape.

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.

Recently, PAN partnered with Morning Consult to survey Medicare patients to gain a better understanding of the financial burden faced by seniors.[2] Three quarters (75%) of seniors on Medicare said they could not afford to pay over $200 for their prescription drugs each month. They reported making lifestyle changes and tradeoffs in order to afford their medications. For example, among seniors on Medicare with high out-of-pocket drug costs, (defined as costs greater than $200 in the first two months of the year), over half have reduced spending on non-

[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.

[2] Morning Consult Surveys for the PAN Foundation. Available at: https://www.panfoundation.org/app/uploads/2021/03/2102117-PAN-MC-powerpoint.pdf and https://www.panfoundation.org/app/uploads/2020/03/PAN-Foundation-Poll-on-Out-of-Pocket-Costs-Executive-Summary-2020.pdf.

essential activities, 49 percent have cut back on everyday purchases such as groceries and transportation, and 31 percent have accrued credit card debt to pay for prescription drugs.

In order to afford the out-of-pocket costs for their prescription drugs, nearly 30 percent of respondents reported taking less than their prescribed dose, 23 percent delayed starting treatment or stopped taking their treatment altogether, and 22 percent prioritized treatment or taking prescriptions drugs for one chronic condition over another.

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.

To reduce drug costs for Medicare beneficiaries, PAN urges Congress to adopt the following policy solutions:

Medicare Part D Cap and Smoothing

Support 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 their True Outof-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), a federal program that helps people with limited incomes pay for their prescription medications. 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.

In 2020, the Centers for Medicare and Medicaid Services (CMS) offered a new opportunity for Part D plans to lower out-of-pocket costs for beneficiaries through the Part D Payment Modernization Model, but only nine plans agreed to participate. Enacting a monthly or yearly

limit for out-of-pocket prescription drug costs for all Part D enrollees would facilitate access to needed treatments and help beneficiaries predict and plan for these costs throughout the year.

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

Spread out-of-pocket costs for prescription medications more evenly throughout the benefit year for Medicare beneficiaries.

The structure of Medicare Part D prescription drug plans front loads out-of-pocket 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.

While PAN appreciates that there are smoothing provisions in both H.R. 3 and H.R. 19, unfortunately, both require patients to incur thousands in out-of-pocket expenses before an enrollee is eligible for smoothing. PAN urges that there be no trigger mechanism and that enrollees can opt in to smoothing at their first fill of the plan year. Pharmacies should be held harmless and plans allowed appropropriate risk mitigation for losses incurred when an enrollee dies prior to the end of the plan year. In addition, enrollees should be notified if they've missed a monthly payment prior to termination from the smoothing option.

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.

<u>Other Important Medicare Reforms</u>

1. **Modernize the Medicare Part D Low-Income Subsidy (LIS) program to increase enrollment and provide continuity for enrolled individuals.**

   The Medicare Part D LIS program or Extra Help was established in the Medicare Modernization Act of 2003 to help low-income seniors and people with disabilities afford needed medicines. Despite outreach efforts, not all eligible beneficiaries have enrolled. Complex application processes and outdated eligibility thresholds have limited participation. In addition, many beneficiaries are required to change plans each year

because the premium for their current plan no longer falls below the low-income subsidy level.

PAN urges Congress 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.

2. Expand Medicare to include dental, hearing, and vision benefits.

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.[3] Only one in four Americans diagnosed with hearing issues uses a hearing aid, with the cost being a major barrier to obtaining them.[4] And, 92 percent of Medicare beneficiaries require eyeglasses.[5] 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.[6]

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.[7] Congress should expand Medicare to include and ensure adequate dental, hearing, and vision coverage and minimize out-of-pocket spending for these services.

3. Vaccine co-pays should be eliminated under Medicare Part D

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. [8, 9]

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[3] 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.

[4] Hearing Health Foundation. Hearing Loss and Tinnitus Statistics. Available at: https://hearinghealthfoundation.org/hearing-losstinnitus-statistics.

[5] 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/.

[6] 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.

[7] Ibid.

[8] National Foundation for Infectious Diseases. 10 Reasons to Get Vaccinated. November 2019. Available at: https://www.nfid.org/%20immunization/10-reasons-to-get-vaccinated/.

[9] CDC. Vaccine Preventable Diseases. Available at: https://www.cdc.gov/vaccines/adults/vpd.html.

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Treatment for these preventable illnesses is estimated to have cost the Medicare program $106 billion from 2016 to 2018.[10] 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.

Congress should provide parity between Medicare Part B and D by eliminating vaccine co-pays in the Medicare Part D program in order to make them accessible to all beneficiaries.

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

[10] 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

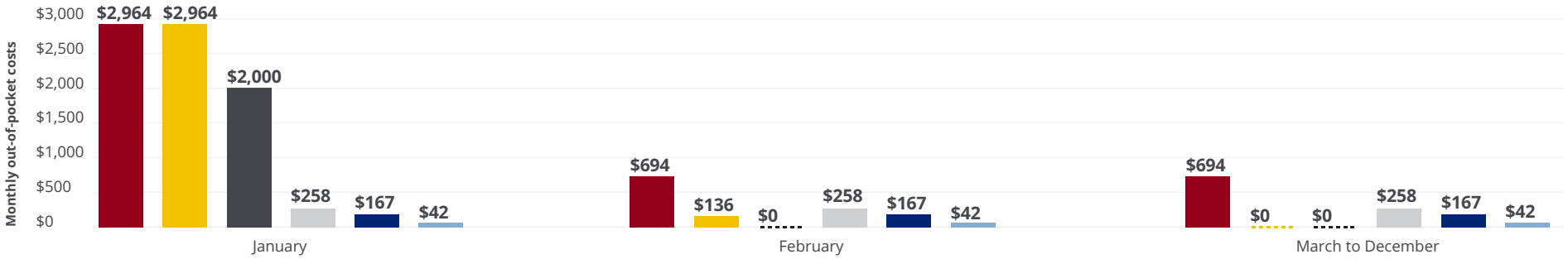
[2] House-passed Bill H.R. 3 proposed an annual Part D out-of-pocket cost cap of $2,000

[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.



Scenario 1: Current 2020 Medicare Part D standard benefit design

Scenario 2: $3,100 Annual OOP Cap, without smoothing

Scenario 3: $2,000 Annual OOP Cap, without smoothing

Scenario 4: $3,100 Annual OOP Cap, with smoothing ($258 per month)

Scenario 5: $2,000 Annual OOP Cap, with smoothing ($167 per month)

Scenario 6: $500 Annual OOP Cap for income 135%-200% FPL, with smoothing ($42 per month)

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

$2,964
Scenario 1:
Current 2020 Medicare Part D standard benefit design

$2,964
Scenario 2:
$3,100 Annual OOP Cap, without smoothing

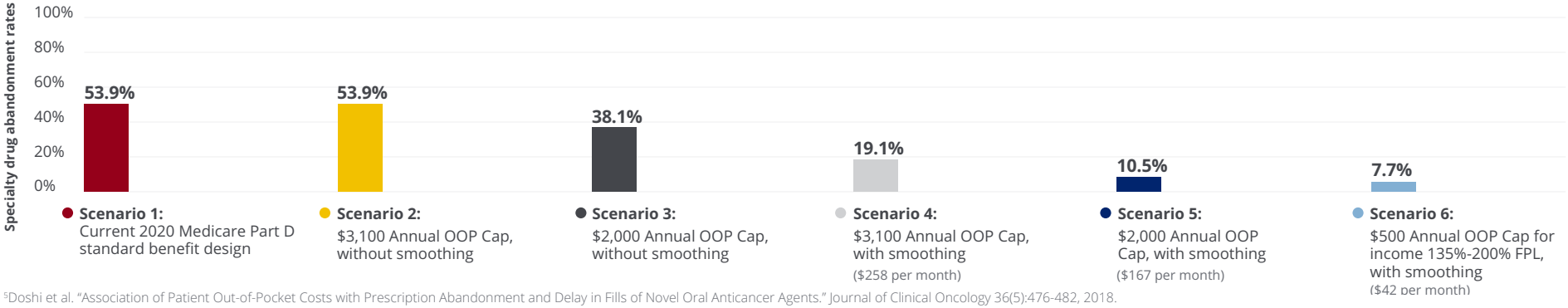
$2,000
Scenario 3:
$2,000 Annual OOP Cap, without smoothing

$258
Scenario 4:
$3,100 Annual OOP Cap, with smoothing

$167
Scenario 5:
$2,000 Annual OOP Cap, with smoothing

$42
Scenario 6:
$500 Annual OOP Cap for income 135%-200% FPL, with smoothing

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



[5]Doshi 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.

Penn
University of Pennsylvania

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