Improving the Public-Private Partnership; Rethinking Medicare Part D

RAAP study shows how out-of-pocket (OOP) cap in the Medicare prescription drug benefit, Part D will help millions of beneficiaries and create a path to improved access.

Washington, D.C. (06-9-2022) - The Rare Access Action Project, (RAAP), released a new study reflecting the impact of high out of pocket (OOP) liability to beneficiaries seeking treatment for Rare Diseases through Medicare Part D. These patients, afflicted with conditions that impact fewer than 200,000 people, remain disproportionately vulnerable as the catastrophic copayments for those treatments often creates an insurmountable barrier for those affected.

The 2022 RAAP study found that lowering patient cost-sharing through an OOP cap with a smoothing mechanism in Part D, similar to what exists in most Medicare Part B plans, is likely to improve rare disease prescription abandonment rates, help with more appropriate utilization, and enhance access to rare disease products.

The study notes that the idea that some patients may end up bankrupt because their Medicare prescription falls under Part D rather than the Part B outpatient benefit is maddening.

“By closing the catastrophic coverage in Medicare Part D, the savings for rare disease patients is significant,” said Mike Eging, Executive Director of RAAP. “Congressional efforts to close this hole in coverage can provide beneficiaries with immediate savings, as well as reduce patient abandonment of their rare therapies. For those with a fixed income, this means they will no longer have to walk away from their rare disease treatment because they cannot afford the copayment. We urge Congress to close the catastrophic copayment and provide immediate assistance to rare patients.”

The 2022 RAAP study analyzed the Medicare coverage provisions that are also included in the following Congressional proposals:

- The bipartisan Prescription Drug Pricing Reduction Act (PDPRA) (S-4199)
- The House Democrat-Driven Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3)
- The House Republican-Driven Lower Costs, More Cures Act. (H.R. 19)
- The Senate bi-partisan Seniors Prescription Drug Relief Act (S – 2327)
“We can close the Medicare Part D catastrophic copayment today, and provide immediate relief to rare patients. We urge Congress to focus on this critical reform to bring the program into the 21st century,” Eging concluded.


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RAAP, the Rare Access Action Project, is a non-profit founded by a coalition of emerging and pre-commercial rare disease companies and patient organizations working together to develop solutions to access challenges with Rare Disease therapies and care. Find us at https://rareaccessactionproject.org