RAAP
RARE ACCESS ACTION PROJECT

Providing Extra Help to Part D Patients with Orphan Diseases

The Rare Access Action Partnership (RAAP) advocates adding a new component to the Medicare Part D coverage gap discount program to help Part D patients with orphan diseases. Under our proposal, drug manufacturers would bear the cost-sharing burden for Part D patients with orphan diseases who have spent so much they have gotten through the Part D coverage "gap" and entered catastrophic coverage—the fourth and final phase of the Part D benefit.

This is an important protection because patients with orphan diseases face high cost-sharing, and any patient who enters catastrophic coverage must already have spent roughly $3,700 out-of-pocket on drugs covered under Part D. In this phase, patients now receive no manufacturer discount, and Part D plans usually impose high coinsurance on drugs for orphan diseases. Patients with the very rare diseases are especially vulnerable to high cost sharing, as the therapies they rely on are particularly expensive due to the small size of the patient population.

We would amend an existing law (the coverage gap discount program statute) to require that manufacturers cover all patient cost sharing for rare disease medicines in Part D catastrophic coverage. Patient cost-sharing in catastrophic coverage is generally about 5%.

Key Features:

- Manufacturers that sign coverage gap discount agreements (already required for Part D participation) must pay all patient cost-sharing in catastrophic coverage on any orphan indicated Part D drug they market. This would eliminate patients' out-of-pocket costs so they would not have to stop treatment or skip doses for financial reasons. This reform could improve health and quality of life for people with very rare diseases and reduce healthcare costs that can result from patients going without treatment.

- The existing coverage gap discount program already provides a mechanism for passing 100% of manufacturer discounts along to the patient. Using this existing mechanism will streamline implementation.

- Within 5 years, the National Academy of Medicine would report on the results of this reform—including its effects on patients' health and ability to stay on a treatment, drug costs, and overall Medicare costs.

About RAAP

The Rare Access Action Project (RAAP) began in 2017 as an ad hoc coalition of life sciences and patient stakeholders with interests in advocating for solutions to issues that limit patient access to health care. Many rare disease patients, upon a diagnosis, believe that because they have coverage (commercial, Medicaid or Medicare) that they will be able to utilize the medicine or technology that was developed for their disease. However, this is not always the case.

RAAP is a issue oriented coalition with a focus in finding solutions to reimbursement and access issues that impact patient continuity of care.

For more information, please conact us at rareaccessproject@gmail.com. And you can find us at www.rareaccessactionproject.org.