



FOR RARE INNOVATION, ONE SIZE DOES NOT FIT ALL

RAAP study shows potential 300 to 2400 percent cost increases for manufacturers, straining a fragile market for patients with few if any treatment options

Washington, D.C. (09-29-2021) - The Rare Access Action Project, (RAAP), released an updated study reflecting the impact to companies that develop treatments for Rare Diseases through proposed Congressional plans to change Medicare Part D. Rare Diseases are defined as conditions that impact fewer than 200,000 people and that often have no treatments of any kind.

The updated 2021 RAAP study found the costs to drug manufacturers could rise from 400 percent to 2,000 percent, a crushing blow to emerging companies that often have only a few orphan drugs in their repertoire. The one-size-fits-all approach potentially has a disproportionate impact on the fragile rare disease market.

The previous study, conducted by RAAP in 2020, showed potentially devastating increases in obligations (contributions to the government) for manufacturers that were projected to rise by at least 400 percent.

“As we found in our previous study, one size fits all simply is not a solution for rare innovation and ultimately for rare disease patients. While these policy solutions are intended to contain the costs of medicines in the United States, plans such as HR3 as well as other alternative proposals will impose massive cost increases,” said Mike Eging, Executive Director of RAAP.

The 2021 RAAP study analyzed 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)

“Treatments for rare diseases are an inherently different market than that of chronic diseases. There is a small set of patients for whom rare disease prescriptions are appropriate, compared

to the millions of Americans who may be taking medications for chronic conditions. And while this makes the market for these products more fragile, with limited potential growth year over year, they are often seen by manufacturers and patients as meeting a critical unmet need. This is a marketplace that needs to be nurtured, not decimated, by unintended consequences,” Eging concluded.

To read the entire report, <https://rareaccessactionproject.org/wp-content/uploads/2021/09/RAAP-Changes-in-Medicare-Part-D-Benefit-Design-2021.pdf>

For interviews, e-mail media@rareaccessactionproject.com

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RAAP, [the Rare Access Action Project](https://rareaccessactionproject.org), 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>