



Build Back Better Will Crush Rare Disease Innovation

Washington, D.C. (11.29.2021) - This morning, the Rare Access Action Project (RAAP) released a study entitled, ***Build Back Better Act (BBBA) may not build a future of innovation.***¹ The study explores the Medicare Part D provisions of the House passed BBBA to understand the impact on rare disease products and ultimately on rare disease patients.

The study found that under the BBBA, rare products would face an increase in Medicare Part D costs of between 519% - 1423%. Such increases would be devastating, particularly for smaller, emerging rare disease companies without resources to absorb those new costs, which will lead to the decline of innovation in rare disease therapies.

According to the study, “a 20% manufacturer liability in the catastrophic phase would likely change the path of innovation. The incentives to develop drugs for rare or ultra-rare conditions will likely be affected because, unlike the current baseline, there is no cap to the manufacturer liability. Rare and ultra-rare disease drugs are inherently more expensive because they reach fewer beneficiaries. But these drugs address critical unmet needs and should be encouraged, not decimated, by legislation.”

Michael Eging, Executive Director of the Rare Access Action Project, noted, “The rare disease marketplace is very diverse. From family foundations to investors who take a leap of faith, to emerging and global companies, innovation keeps hope alive for the over 25 million Americans living with rare diseases. While the Build Back Better Act works to cap patient out of pocket costs, it does so at the expense of rare disease patients who desperately need research, development and the innovation of new therapies and medications. Congress must take a balanced approach that keeps hope alive for millions of rare patients and their families.”

To read the entire report, <https://rareaccessactionproject.org/wp-content/uploads/2021/11/RAAP-BBBA-Nov-2021.pdf>

For interviews, e-mail media@rareaccessactionproject.com

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¹ Study completed by Xcenda on behalf of the Rare Access Action Project.

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>