

Committee on Energy and Commerce
Opening Statement as Prepared for Delivery
of
Full Committee Ranking Member Frank Pallone, Jr.

Hearing on “Legislative Proposals to Support Patients with Rare Diseases”

February 29, 2024

For years, this Committee has worked to expand access to care and research and development of new treatments for rare diseases. I am pleased we are continuing this work today by considering bills like the Accelerating Kids’ Access to Care Act, the Innovation in Pediatric Drugs Act, and the RARE Act.

However, it is unfortunate that we are also considering a number of proposals that will undermine policies to lower prescription drug prices that Congressional Democrats and President Biden delivered for the American people as part of the Inflation Reduction Act.

I was proud to lead the effort on the drug pricing reform measures that were ultimately included in the Inflation Reduction Act. Thanks to that law, Medicare is finally going to be able to negotiate lower drug prices for America’s seniors. Just a few weeks ago, the Biden Administration sent the first offers in drug price negotiations to the ten drug manufacturers selected for negotiation during this first year. About nine million seniors take one or more of the drugs selected for negotiation, at a cost to these seniors in 2022 of \$3.4 billion. We can make a real difference by negotiating lower costs for these drugs.

Last year, thanks to the Inflation Reduction Act’s penalty on drug manufacturers who raise prices faster than the rate of inflation, seniors saved as much as \$618 per average dose on 47 drugs. And beginning next year, prescription drug costs will be capped for seniors at \$2,000 annually.

Despite the fact that this law is already making prescription drugs more affordable for our nation’s seniors, the pharmaceutical industry and Congressional Republicans are relentlessly attempting to undermine it through lawsuits and detrimental policy changes that will only delay lower costs for patients.

Republicans claim that we must choose between lower prices and greater innovation. They argue that if we want innovative therapies, it’s up to American families to pay for high-priced drugs that wipe out their life savings, cost more than the average household’s monthly rent or groceries, and are priced two-to-three times higher than in other countries.

I reject that premise. I refuse to believe that innovation and lower costs are a zero-sum game. After all, we know that patients need affordable access to new therapies, particularly those with a rare disease or condition.

That is why I am disappointed we are discussing legislation that allows potential blockbuster drugs to be exempt from negotiation and delays negotiating other drugs for years. These bills are contrary to the intent of the law, which was carefully drafted to protect innovation while also delivering savings.

Our intent in passing the Inflation Reduction Act was to ensure that those drugs that represent the greatest share of costs to the Medicare program are negotiated on behalf of the American people. We crafted a narrow exclusion for orphan drugs that treat one rare disease, but this was not intended to be an escape hatch for manufacturers to avoid negotiating fair prices and game the system. Patients with rare diseases can only access treatments if they can afford them, and the Republican plan laid out today will keep these products out of reach for too many families.

While I cannot support legislation that undermines the Inflation Reduction Act, I am pleased we are examining bills from Ranking Member Eshoo and Representative Matsui on how we can incentivize additional development of rare disease treatments and ensure regulatory certainty for developers.

However, it is important that we also consider whether existing programs are providing the incentives Congress intended. One of the bills before us today reauthorizes the Rare Pediatric Disease Priority Review Voucher program at the Food and Drug Administration. I am concerned about reports from the Government Accountability Office and others that suggest that vouchers fail to incentivize research and development, and instead use scarce public health resources to reward development that would have taken place even without this program. I look forward to hearing what our witnesses have to say about these proposals.

I understand and appreciate the unique needs of the rare disease community and the hope that innovation and treatments can bring, especially for small populations of patients without other therapy options. I hope we can reject efforts to undermine the Inflation Reduction Act, which will likely cost the federal government billions of dollars and increase prices for consumers.. Instead, we should focus our attention on finding consensus approaches to bring more cures to patients. And with that, I yield back the balance of my time.