

Statement of Therese Ball
before the
U.S. House of Representatives Subcommittee on Health
of the
House Committee on Energy and Commerce
for a hearing on
“Negotiating a Better Deal: Legislation to Lower the Cost of Prescription Drugs.”
May 4, 2021

Chairwoman Eshoo, Ranking Member Guthrie, and Members of the Committee, thank you for the opportunity to share my story.

Section I. Background and Introduction

My name is Therese Ball.

I am a proud grandmother and retired registered nurse from Ogden Dunes, Indiana. I am here as a multiple sclerosis patient, a Medicare beneficiary, and an advocate. I am also here because I am one of the millions of Americans who struggle to afford their medications.

My life’s work was caring for patients. I’ve lived all over the United States and cared for patients in four states. Because of my nursing training, I was able to provide medical care and alleviate suffering for thousands of people across the span of my career.

But what nursing school did not prepare me for was the suffering caused because patients could not afford treatment. When a patient had a promising clinical plan but left their prescriptions unfilled due to cost, I felt helpless and frustrated.

Every prescription left unfilled was pain left out of control, infections left untreated, or cancer left to devastate someone's health. Throughout my 20-year career, I had a front-row seat to the horrifying reality of our drug pricing system: Drugs don't work if people can't afford them.

I never thought I'd be one of these struggling patients until 2003, when I was diagnosed with multiple sclerosis and prescribed a medication called Copaxone.

Section II. Copaxone

Let me tell you about Copaxone. The drug was first marketed by Teva in 1997. At that time, a monthly supply of the 20 mg injection was priced at \$769.15. Today, that same monthly supply costs \$7,114 — almost 10 times the launch price.¹ Teva accomplished this outrageous price by hiking the price *27 times* over 20 years.

This pattern was not mirrored in other countries. By 2015, the price of Copaxone was, on average, five times higher in the United States than in other comparable nations.

This was no accident. Last year, a congressional investigation found that Teva targeted the United States because our country's drug market allows price hikes without penalty. Internal documents reveal that Teva identified legislation permitting Medicare to negotiate drug prices as the biggest threat to the company's revenue.

The reform that drug companies identify as a threat is the very thing that can make a difference between life and death for people like me.

Remarkably, this is not even Teva's most egregious abuse of our drug pricing system. In 2014, when the company faced losing their monopoly on the 20 mg injection, it introduced a new 40 mg injection. The drug was not more effective — in fact, there was *no* difference between the old product and new product — but the company devised a profit-driven scheme to market the drug as “more convenient” since it could be taken three times a week instead of daily.

¹ House Committee on Oversight and Reform. (2020). *Drug Pricing Investigation: Teva—Copaxone*. <https://oversight.house.gov/sites/democrats.oversight.house.gov/files/Teva%20Staff%20Report%202009-30-2020.pdf>

Through this scheme, the company aggressively marketed the product to physicians and patients in an attempt to move all Copaxone patients to the new version before the company faced a generic competitor.

Internal documents uncovered by a congressional investigation reveal that Teva executives pursued a clinical trial to rationalize this strategy despite the opposition of scientists who said they were against the study “since it has no scientific rationale/value.”¹ In a slideshow detailing “opportunities” and “threats” for the strategy, executives cited “barrier to generic entrance” as the number one opportunity, highlighting the company’s true motivation: to keep patients on their monopoly-protected drug even when a less expensive alternative became available.

The plan was successful; Teva was able to maintain its profits and continue dictating prices to patients and payers. Independent researchers have estimated that Teva’s scheme cost the U.S. health care system between \$4.3 billion and \$6.5 billion.

As I mentioned, my personal Copaxone story began in 2003, when the drug cost me \$1,800 a month. Within nine months, it completely wiped out my savings. It was devastating. I feel grateful that eventually, I found an independent charity that gave me a grant to cover my costs. But grants are never guaranteed, and I lived in fear of the day I might lose access.

My fear came true in 2017, when the foundation did not renew my grant. At that point, the drug had increased in price to \$6,000 a month. I was completely overwhelmed by the price tag, and no matter how many times I crunched the numbers, I couldn’t make it work.

So I made the terrifying decision to go without the drug. The health consequences were immediate and severe. I suffered from memory loss and lost my ability to concentrate. My disease progressed and my quality of life suffered tremendously. It affected my whole family’s life — my family began planning for my MS to get much worse, for a future when I would lose my mobility and could no longer walk. It was devastating to me. I have worked for decades to keep my MS under control and my brain sharp so I could remain independent. I know my kids and grandchildren will always be there for me, but they shouldn’t have to care for me early just because my prescription drug is too expensive.

Section III. We can have innovation and lower prices

No one understands the value of innovation more than patients like me. There is no cure for MS and the disease is progressive, meaning I will continue to need more medications. My life is dependent on continued innovation and development of new medicines.

Since 2017, I've taken a drug called Tysabri. Tysabri is a biologic drug that is priced at \$7,463 for just one infusion. Since I require infusions every month, a year's supply is almost \$90,000.

Biologic medications have the potential to change the lives of thousands of people whose illnesses previously had no treatment. They are innovative, and I am grateful for that. But the average price of a biologic is \$10,000 to \$30,000 a year.² For people who receive a diagnosis early in life, spending on biologic drugs can reach over \$1 dollars in a lifetime. Many patients have to make the same choice I had to — going without the drugs we need, leaving our disease untreated, or settling for a less effective alternative. What good is innovation to patients if it's left out of reach?

Drug companies want you to believe that their high prices are required to fund research and development. If we act to curb their prices, the industry tells patients that innovation will dry up.

Drug companies want us to choose: Let the industry have unilateral pricing power, or say farewell to future cures.

But that's a false choice. Countless experts — on both sides of the aisle — have shown that there is plenty of revenue in the system to make room for lower prices. Pharma's profit margins are almost three times the average of the S&P 500. Brand-name drug companies could lose \$1 trillion in sales over 10 years and still be the most profitable industry in the world.³ The industry also spends \$26 billion a year marketing to consumers and prescribers.⁴

² Chen, B. K., Yang, Y. T., & Bennett, C. L. (2018). Why Biologics and Biosimilars Remain So Expensive: Despite Two Wins for Biosimilars, the Supreme Court's Recent Rulings do not Solve Fundamental Barriers to Competition. *Drugs*. 78, 1777–1781.

<https://pubmed.ncbi.nlm.nih.gov/30446980/#:~:text=They%20are%20highly%20targeted%2C%20efficacious.for%20the%20most%20expensive%20biologics>

³ West Health. (2019, November 14). *New Analysis Finds Large Drugmakers Could Lose \$1 Trillion in Sales and Still Be the Most Profitable Industry*.

<https://www.westhealth.org/press-release/new-analysis-finds-large-drug-makers-could-lose-1-trillion-in-sales-and-still-be-the-most-profitable-industry/>

⁴ Schwartz, L. M., & Woloshin, S. (2019). Medical Marketing in the United States, 1997-2016. *JAMA*. 321(1), 80-96. <https://doi.org/10.1001/jama.2018.19320>

To put it a different way: Drug companies are making so much profit — and spending that profit on so many activities that *aren't* R&D, that they can more than afford to cut prices and bring relief to patients.⁵

Consider the congressional investigation into Copaxone. Internal documents illustrated that the drug company was more focused on preserving a monopoly, even spending critical R&D dollars on clinical trials to rationalize recycling an old drug, than on investing in new drug discovery.

The truth is that taxpayers are responsible for enormous amounts of drug development. In fact, the National Institutes of Health contributed funding to research associated with all 356 new drugs approved by the FDA from 2010 to 2019.⁶ Even in the midst of the COVID-19 pandemic, the federal government contributed more than \$18 billion to help facilitate the development of COVID-19 vaccines.⁷ The technology that Pfizer and Moderna used to bring the mRNA vaccines to market was funded by the NIH and U.S. Department of Defense.⁸

Drug companies have shown us who they are, so I know not to believe the threats. We don't have to settle for a false choice; we can have more affordable drugs and meaningful innovation at the same time.

Section IV. Medicare negotiation would help patients like me

Medicare has been banned from negotiating directly with drug companies since 2003, the same year I was first diagnosed with MS. For almost two decades, Medicare beneficiaries have struggled to cover steep prices while the government left discounts on the table.

I am one of those beneficiaries. Since I went on Medicare in 2008, my family has been forced to make tough choices in order for me to obtain treatment. Instead of enjoying my retirement with my kids and grandkids, I've spent countless hours staring at my bills, trying to find a miraculous way to make a fixed income cover impossibly high drug prices.

⁵ Patients For Affordable Drugs. (2021, February 3). *Big Pharma's Big Lie: The Truth About Innovation And Drug Prices*. <https://patientsforaffordabledrugs.org/2021/02/03/innovation-report/>

⁶Ledley, F., Cleary, E., & Jackson, M. (2020, September 2). *US Tax Dollars Funded Every New Pharmaceutical in the Last Decade*. Institute for New Economic Thinking. <https://www.ineteconomics.org/perspectives/blog/us-tax-dollars-funded-every-new-pharmaceutical-in-the-last-decade>

⁷ Congressional Research Service. (2021, March 1). *Operation Warp Speed Contracts for COVID-19 Vaccines and Ancillary Vaccination Materials*. <https://crsreports.congress.gov/product/pdf/IN/IN11560>

⁸ LaFraniere, S., Thomas, K., Weiland, N., Gelles, D., Stolberg, S. G., & Grady, D. (2020, November 30). Politics, Science and the Remarkable Race for a Coronavirus Vaccine. *The New York Times*. <https://www.nytimes.com/2020/11/21/us/politics/coronavirus-vaccine.html>

Members of the Committee, you have a chance to change this. H.R. 3 would finally overturn the decades-long ban on Medicare negotiation and allow the program to rein in spending on the costliest drugs. Negotiations would take into consideration how innovative and valuable a drug is, while pegging the maximum allowable price to what people pay in other wealthy nations. Instead of facing unlimited out-of-pocket costs every single year, the amount that Medicare beneficiaries pay for drugs would finally have a limit. According to the Congressional Budget Office (CBO), H.R. 3's provisions would lead to significant savings for seniors; another study found that Medicare negotiation is expected to save the lives of 94,000 Americans each year.^{9, 10}

And relief would not be limited to Medicare beneficiaries like me. The steep discounts achieved through Medicare negotiation would be available to people on every type of insurance, bringing relief that would be life-changing for many of my friends on commercial insurance.

For Copaxone alone, Teva itself estimates that taxpayers could have saved \$1.4 billion over a three-year period if Medicare negotiated like the Department of Veterans Affairs and Department of Defense.¹ As the largest purchaser of prescription drugs in the world, the federal government shouldn't be paying prices that are nearly four times those in other developed countries for brand-name drugs.^{11, 12} Negotiation is common sense for patients *and* taxpayers.

In addition to H.R. 3, this Committee is considering several other pieces of legislation that would close loopholes that the drug industry has long used to thwart competition, preserve monopoly profits, and price drugs out of reach for patients. Together, these bills can help refocus our drug pricing system on patients, not profits.

⁹ Congressional Budget Office. (2019, October 11). *Effects of Drug Price Negotiation Stemming From Title 1 of H.R. 3, the Lower Drug Costs Now Act of 2019, on Spending and Revenues Related to Part D of Medicare*. <https://www.cbo.gov/system/files/2019-10/hr3ltr.pdf>

¹⁰ West Health. (2020, November 19). *New Study Predicts More Than 1.1 Million Deaths Among Medicare Recipients Due to the Inability to Afford Their Medications*. <https://www.westhealth.org/press-release/study-predicts-1-million-deaths-due-to-high-cost-prescription-drugs/>

¹¹ Congressional Budget Office. (n.d.). *Prescription Drugs*. Retrieved April 30, 2021 from <https://www.cbo.gov/topics/health-care/prescription-drugs>

¹² House Committee on Ways and Means. (2019). *A Painful Pill to Swallow: U.S. vs. International Prescription Drug Prices*. https://waysandmeans.house.gov/sites/democrats.waysandmeans.house.gov/files/documents/U.S.%20vs.%20International%20Prescription%20Drug%20Prices_0.pdf

Section V. Conclusion

Members of the Committee, drug pricing is personal for me and so many Americans.

There are millions of us suffering from unaffordable prescription prices. We have to go without the medications we need and choose between paying rent or utilities or picking up groceries. We need relief, and we have been waiting for too long.

The COVID-19 pandemic has only made the drug pricing crisis worse. I know this because last year, I had COVID-19. The infection was so destructive to my lung tissue that I now have to take an expensive inhaler called Breo — adding to my already steep monthly drug costs.

When you are considering H.R. 3 and the other legislation in front of you, please remember my story. Think about my kids and grandkids who deserve to live unburdened by my high drug prices. You have the chance to stand with millions of Americans and deliver us real and lasting relief.

On behalf of my former patients and my family, I urge you to vote in support of H.R. 3. We're counting on you to deliver on your promise to lower drug prices.

Thank you.