

Statement of Samantha Reid, Crohn's Disease Patient

before the

U.S. House of Representatives Ways & Means Committee

Investing In The U.S. Health System By Lowering Drug Prices, Reducing Out-of-pocket Costs, And Improving Medicare Benefits

Thursday, October 17, 2019

Chairman Neal, Ranking Member Brady, and Members of the Committee, I am honored to be here today. Thank you for giving me the opportunity to share my story.

Section I. Background

My name is Samantha Reid, I am 27 years old, and I am here today as a patient and health care advocate.¹

I'd like to start by telling you a story about my 18th birthday. The thing that made that day remarkable was that I don't actually remember much about it at all. I don't remember if I had a cake, or where my family went to dinner. I don't remember what presents I got, or what I wore. Although knowing me, I had a special outfit planned.

For better or worse, all I remember about my 18th birthday is...Crohn's Disease.

I remember lying on my bedroom floor, in terrible pain. I remember hospital gowns and liquid diets.

And I remember this because it was just a few short days after I turned 18 that I officially got my Crohn's diagnosis and became someone who will be sick, forever.

Section II. Drug Prices Keep Rising

I've come a long way since the winter of 2010. With a formal diagnosis came treatments and ups-and-downs. And with those treatments came high priced drugs.

The main drug treating my Crohn's right now is called Entyvio. This one drug costs over \$6,000 per dose.² It's increased by \$1500 since I started taking it in 2016. If I live to be 80, that's \$4.34 million in health care costs over the course of my lifetime for that medication alone.

¹ I currently serve as the Digital Director for Patients For Affordable Drugs, a 501c3 nonprofit in Washington, DC.

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Another drug I take is called Xolair. It's one of the most expensive drugs in Medicare Part B. In 2017, this drug cost taxpayers over \$375 million in Medicare spending.³ The list price for each monthly treatment is over \$1,100.⁴ And the drug maker has raised the price every year, often multiple times a year, for the last 16 years — without once decreasing it.

Last month I was experiencing extreme abdominal pain and weight loss, so my doctors prescribed a steroid called Entocort to stabilize my symptoms. The catch? Entocort is over \$2,300 for a monthly supply, in spite of the fact that it's an old drug.⁵ It's not innovative. Because of the high price, my insurer wouldn't cover Entocort and I was forced to take an inferior drug with severe side effects called prednisone. The side effects included insomnia, depression, permanent bone damage, and much more. I was forced to take a drug that made me sicker in other ways, all because Entocort is priced far too high.

Section III. Innovation, My Future, and a Broken Market

I understand the importance of pharmaceutical innovation. Before Entyvio, I could barely get out of bed. Now I can work full-time, travel, and enjoy my favorite hobbies, like an occasional baseball game with my family (go White Sox). I'm not ungrateful.

But I will eventually build up antibodies to Entyvio and need new drugs. Without new medicine, I risk once again being in the same situation I was in on my 18th birthday: sick, incapacitated, struggling through life.

But the last ten years of treatment have taught me one fact: drugs don't work if people can't afford them.

Crohn's Disease is a chronic, incurable illness — meaning I will be paying these prices every month for the rest of my life. And expensive biologic drugs like Entyvio are, increasingly, the only truly effective option in treating autoimmune diseases like Crohn's.

The high prices that accompany these drugs mean I live in constant fear of an economically unstable future.

I make every career move not based on what's best for me professionally but based on which option provides the most stable insurance coverage.

I don't plan for parenthood or home ownership because, with my disease, I can barely stay above water paying for the basics like food and rent.

Drug companies try to scare patients by telling us that if we lower drug prices by even a nickel, innovation will come to a screeching halt. But that's just not true.

³ CMS Medicare Part B Dashboard

⁴ Source: AnalySource® as reprinted with permission by First DataBank Inc. All rights reserved. © (2019)

⁵ Source: AnalySource® as reprinted with permission by First DataBank Inc. All rights reserved. © (2019)

The drug industry enjoys some of the highest profits in the world — roughly two to three times the average of the S&P 500 — and spends most of it on expenses outside of research and development.^{6,7} Drug company R&D budgets have not increased in step with profit. In fact, drug industry spending on research has remained relatively level.⁸ When drug companies do bring new drugs to market, they often just repurpose old blockbusters in order to preserve their monopoly sales.^{9,10}

So if the pharmaceutical industry is not investing in new inventions, what are they doing with all this profit? Well, 9 out of 10 big pharma companies spend more on marketing, advertising, and overhead than research.¹¹ They're also paying their top 20 CEOs an average salary of \$23.7 million a year.¹² There is plenty of room in those high prices to lower them and still have innovation.

Furthermore, U.S. taxpayers cover much of the bill to develop new drugs. The National Institutes of Health (NIH) is the single largest source of biomedical research in the world.¹³ Based on data from PhRMA, American taxpayers pay for one out of every three dollars spent on drug research.^{14,15}

And the pharmaceutical industry piggy-backs on taxpayer-funded research. For example, 100% of the drugs approved by the FDA between 2010-2016 were based on science funded by taxpayers through the NIH.¹⁶ That means that taxpayers like me are paying twice — once to develop the drug, and again to purchase it from our pharmacies.

In light of these facts, I refuse to buy into pharma's scare tactics.

Steve Ubl, the CEO of the drug lobby want us to believe that H.R. 3 will have a devastating effect on innovation.¹⁷ He's exaggerating at best and lying at worst. According to the Congressional Budget Office (CBO), at least 95% of all drugs anticipated to come to market under our current system will be brought

⁶ <https://www.yardeni.com/pub/sp500margin.pdf>

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https://www.washingtonpost.com/news/wnk/wp/2015/02/11/big-pharmaceutical-companies-are-spending-far-more-on-marketing-than-research/?utm_term=.dc7e820c4172

⁸ https://rooseveltinstitute.org/wp-content/uploads/2019/02/RI_Profit-Over-Patients_brief_021319-1.pdf

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<https://www.bloomberg.com/news/articles/2017-11-01/most-new-drug-patents-are-for-old-remedies-research-shows>

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https://www.washingtonpost.com/news/wnk/wp/2015/02/11/big-pharmaceutical-companies-are-spending-far-more-on-marketing-than-research/?utm_term=.dc7e820c4172

¹² <https://www.fiercepharma.com/special-report/top-20-highest-paid-biopharma-ceos>

¹³ <https://www.nih.gov/about-nih/what-we-do/impact-nih-research>

¹⁴ <https://www.sciencemag.org/news/2018/09/nih-gets-2-billion-boost-final-2019-spending-bill>

¹⁵ <https://www.phrma.org/advocacy/research-development>

¹⁶ <https://www.pnas.org/content/115/10/2329>

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<https://thehill.com/policy/healthcare/465257-phrma-ceo-warns-pelosi-bill-to-lower-drug-prices-would-be-devastating-for>

to market under H.R. 3. The only difference? We'll pay about 55% less for the most expensive drugs.¹⁸ And this small effect on innovation can be mitigated if we take some of the \$345 billion in savings and direct it to the NIH and publicly funded institutions that drive the most groundbreaking research.¹⁸

CBO also clearly states that H.R. 3's "lower prices would increase use of drugs and improve people's health." The report even cites savings that would come from a decrease in the use of medical services due to increased use of prescribed drugs.

So while drug corporations want to scare us into thinking this bill will lead to a "nuclear winter", please remember that millions of Americans are already experiencing catastrophic life circumstances due to the drug pricing crisis.^{19,20} Patients across the country are skipping meals, suffering due to rationed doses, falling behind on bills, and filing for bankruptcy — all due to the overwhelming burden of high drug costs.

Section IV. H.R. 3 Solutions

Here's how H.R. 3 would help me — and other young patients like me.

First, it allows Medicare to negotiate the price of the costliest drugs on the market. All three of the drugs I've mentioned today, Xolair, Entocort, and Entyvio, are within Medicare's top 250 drugs in terms of total spending.²¹ In 2017 alone, these three drugs cost Medicare over \$700 million.²²

Second, the bill ensures that Americans — regardless of insurance type — have access to lower-priced drugs. This critical provision would extend negotiated prices to the roughly 170 million Americans like me who rely on private insurance or coverage offered by their employer.²³ According to HHS Secretary Alex Azar, 47% of Americans under age 65 are on high deductible health plans and pay for prescription drugs based on list price.²⁴

By extending negotiated prices to the commercial markets, H.R. 3 will limit out-of-pocket costs for the millions of patients whose costs are traced back to the negotiated price.

¹⁸ <https://www.cbo.gov/system/files/2019-10/hr3ltr.pdf>

¹⁹ <http://www.cq.com/doc/news-5743009?3&srcpage=news&srcsec=cqn>

²⁰

<https://www.kare11.com/article/news/family-says-21-year-old-son-died-rationing-insulin/89-d451a01b-9170-4341-9010-155cb87edccc>

²¹

<https://insidehealthpolicy.com/inside-drug-pricing-short-takes/mcdermott-lists-drugs-likely-subject-price-negotiation-pelosi's-bill>

²² CMS Part D and Part B Spending Dashboards

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<https://www.kff.org/other/state-indicator/total-population/?dataView=1¤tTimeframe=0&selectedDistribution=employer--non-group&sortModel=%7B%22collId%22:%22Location%22,%22sort%22:%22asc%22%7D>

²⁴

<https://www.hhs.gov/about/leadership/secretary/speeches/2019-speeches/remarks-to-the-bipartisan-policy-center.html>

Finally, H.R. 3 would penalize price gouging by drug companies. Pharma companies pad their profit margins by increasing prices every year, especially while they have market exclusivity that protects them from competition. Under H.R. 3, companies would be fined if their price increases outpaced the rate of inflation. And the bill will bring U.S. drug prices more in line with what other wealthy nations pay. Without H.R. 3, Americans pay 200-300% more than what other wealthy nations pay for the exact same drugs. According to CBO, Americans will only pay on average 14% more than other nations for the most expensive drugs.¹⁸ We will still be the largest market in the world, paying the highest prices in the world, the same dynamic we have now — which brings companies to apply for approval and market their drugs here first.

Section V. Conclusion

Through my advocacy I've spent a lot of time volunteering with kids as young as eight years old who have been diagnosed with Crohn's, and it breaks my heart to hear them talk about the ramifications of this illness. Not only the physical and mental, but the financial. They see their parents sacrificing to pay the bills. They know, even at their young ages, the financial burden their illness is placing on their families. They should get to be a kid without worries, but instead, they are already planning for a future dependent on devastatingly expensive drugs and medical care.

Many of those kids depend on the blockbuster drug Humira — a drug that costs \$6,000 a dose.²⁵ While patients and their families are pinching pennies to make that work, AbbVie is raking in millions. AbbVie makes more money on Humira alone than every NFL team makes in revenue, combined.^{26,27} I'm not here to litigate how much money drug companies should make from a drug. But I do think we can all acknowledge that the balance is off.

I'm not naive. I know Congress can't cure my Crohn's or help the many kids I know who live with this crippling disease manage their symptoms.

But you can help us create a more stable future. Because good health isn't a moral virtue, and bad health isn't a moral failing. We're all one diagnosis away from a lifetime of reliance on expensive medications that threaten us with bankruptcy.

Medications must be affordable. And millions of patients like me are counting on you to enact fundamental reforms to help us all. Thank you for your attention.

²⁵ Source: AnalySource® as reprinted with permission by First DataBank Inc. All rights reserved. © (2019)

²⁶ <https://www.sec.gov/Archives/edgar/data/1551152/000155115219000004/abbv-20181231xexhibit991.htm>

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<https://www.bloomberg.com/news/features/2018-09-13/nfl-makes-more-money-than-ever-and-things-have-never-be-en-worse>