Statement of David E. Mitchell

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before the

U.S. House of Representatives Subcommittee on Health
of the Energy and Commerce Committee

"Examining the Drug Supply Chain"

December 13, 2017

Chairman Burgess, Ranking Member Green, Members of the Subcommittee: I am honored to be here today.

Section 1. Background and Introduction

My name is David Mitchell. I am the Founder of Patients For Affordable Drugs. We are a bipartisan, national patient organization focused on policies to lower drug prices. We don't accept funding from any organizations that profit from the development or distribution of prescription drugs.

More importantly to today's hearing, I have an incurable blood cancer, and prescription drugs are keeping me alive. Several days ago, I received five hours of drug infusions that carry a price tag of more than $20,000 every time I get them. I've had them 22 times over the course of the year. So, $450,000 worth of drugs are keeping me upright.

I am very grateful to the science and research communities in our country for these drugs. And because my disease is incurable, I need innovation and new drugs if I am going to live as long as I hope to. This is not theoretical for me—it is life and death.

But my experience as a cancer patient has taught me one irrefutable fact: **Drugs don't work if people can't afford them.**

Section 2. Patients are crying out for help

Since our launch in February, we have built a community of almost 20,000 Americans across every state.

Dalia Hunter from Texas wrote, "I've got Rheumatoid Disease. My monthly drug cost, after insurance, is somewhere from $700-$1,800 a month. There is no way to afford this so I've gone without these meds. Who knows what kind of permanent damage has been done to my joints."

There are thousands of people like Dalia, who tell us devastating stories of skipping doses, cutting pills in half, and even declaring bankruptcy because of the prices of their drugs.

People are scared and angry, and they need help.

A September Harvard poll showed that 4 in 10 Americans want lowering prescription drug prices to be Congress' top priority.

Sixty four percent of Americans, including a majority of Democrats, Independents, and Republicans, listed lowering drug prices as their top health care priority, according to a Kaiser Health poll.

The message we hear from patients is simple. They understand that drug corporations have monopoly pricing power. Patients and taxpayers know the prescription drug pricing system in the U.S. is rigged against them. They want leaders in Washington to fight to lower the price of drugs and get something done.

This is a central health care issue that impacts millions of people every day. We agree with President Trump: "Drug companies frankly are getting away with murder." And drug companies are not the only ones who take advantage of patients' pocketbooks.

Section 3: The Supply Chain Is Part of the Problem

Prices set by drug corporations with government-granted monopolies are at the headwaters of the problem we face.

But the drug supply chain downstream is also part of the problem.

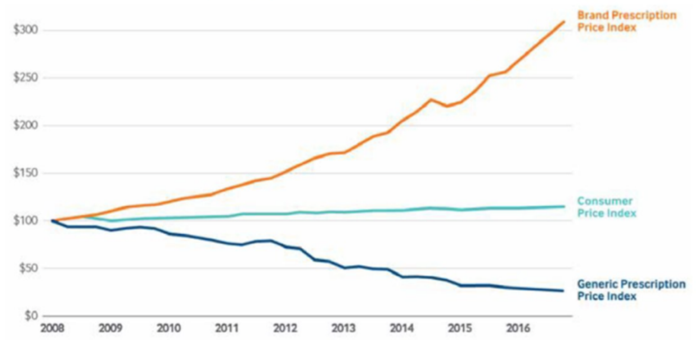
When retail prices set by drug corporations rise, all players in the system make more money – drug manufacturers, PBMs, doctors, and hospitals. The people hurt are patients, consumers, taxpayers, and employers who foot the bill.

There are steps we can take to help Americans struggling under high drug prices.

Here is a patient perspective on some of the important issues in the supply chain and what can be done about them:

- **Allow Medicare to negotiate lower costs for patients**. The government grants drug manufacturers a monopoly for up to 12 years. Medicare negotiations would help balance that monopoly pricing power. Below is a chart that demonstrates why we need negotiations – especially for brand drugs – the fastest growing sector of health spending.

Prices for Brand-Name Prescription Drugs Doubled Between 2008 and 2016



Source: Kaiser Family Foundation analysis of data from Express Scripts 2015 Prescription Price Index.

- **Increase transparency throughout the drug supply chain**. Three pharmacy benefit managers control about 75 percent of the drug market. PBMs negotiate deals in secret, leaving consumers and policymakers in the dark. Americans can't tell if these corporations provide value in the form of rebates for patients or if they keep rebates to increase profits. We do know the combined operating profit of the three largest PBMs was $10.1 billion in 2015, up 30% from 2013.

  Increased transparency would help consumers better understand drug prices. As recommended by the National Academies of Sciences, Engineering, and Medicine, Congress should require PBMs to disclose drug discounts and rebates, so we can ensure reductions in prices reach patients. The recommendation avoids specific disclosures that PBMs claim would inhibit their negotiating success. Instead, the report recommends that PBMs make quarterly disclosures at the national drug code level. We support this change.

- **Follow the Trump Administration's lead** to allow Part D Medicare beneficiaries to pay out-of-pocket costs based on rebated – not retail – drug prices. Right now, Medicare Part D beneficiaries pay out-of-pocket costs based on retail prices of drugs. Everyone else in the system – employers, insurers, the government – pays based on rebated prices. The Trump Administration requested feedback on changes so patients get the benefit of the rebate price. We encourage Congress to support such a change. Congress should also cap patient out-of-pocket costs at the catastrophic level. With drugs costing $20,000 per month, the catastrophic costs can be crushing.

- **Ensure patients with insurance don't pay more than they would if they paid cash.** Supply chain contracts often forbid pharmacists from telling insured consumers that they could pay less if they paid cash rather than use insurance cards. These gag clauses are wrong and should be outlawed.

- **Use caution around outcomes-based pricing arrangements**. First, it is important to distinguish between value-pricing and outcomes-pricing. Value-pricing is conducted by organizations like the Institute for Clinical and Economic Review, the American Society of Clinical Oncology, and the National Comprehensive Cancer Network. They examine the value of a new drug to patients and serve as one input for negotiations by private parties and the Veterans Administration. Value-pricing can be a useful tool.

Outcomes-based pricing is different. It ties reimbursement of a drug to its effectiveness. While this sounds attractive, it’s a disaster for patients. Outcomes-pricing in general stipulates that if a drug fails, the drug company will provide a refund. But that system contains a major flaw. It does not lower drug prices; it allows drug companies to keep prices high. Drug companies have the clinical data that tell them how many patients react positively to a drug and how many will fail. Rather than lower prices, drug companies will simply raise the price of a drug to compensate for failures. Furthermore, it is not clear any refunds will make their way to patients. It is also not clear how to use such a process for drugs like insulin where patients react differently as individuals and drug companies may want to claim user error if the patient doesn’t do everything right to manage their disease.

- **Work for lower prices instead of making patients rely on assistance programs and copay coupons.** Copay coupons and patient assistant programs are phony charities designed to do one thing: keep prices high. One MS patient called them band-aids—dirty, infected band-aids. They are not charity—they are marketing. According to Citi Research, for every $1 million spent on charitable donations, drug corporations reap as much as $21 million in return. We should lower drug prices and make copay coupons unnecessary.

- **Investigate the insulin market.** Three insulin manufacturers command 80 percent of the market for this lifesaving drug. Together, the companies raised prices more than 300 percent in the past ten years – for a drug invented in 1923 and for which the patents were sold for $3. The prices move in lockstep and people with diabetes suffer at the hands of what can only be called an insulin cartel. Democratic and Republican members in the House are already looking into the insulin market. We encourage Congress to look into anti-competitive behavior and possible price-fixing by Eli Lilly, Novo Nordisk, and Sanofi.

Section 4: Bipartisan action to restore balance is possible

In conclusion, our health care system should maximize affordability and accessibility of drugs while ensuring a robust R&D pipeline and fair profits for companies all along the supply chain. That balance has been lost. The system encourages high prices that benefit big players.

Consider this story from Jon Pavlus of Worland, Wyoming: "I've had diabetes for 52 years and in the last 6 years I've watched my insulin prices go from $6.75 a vial to $375 a vial. I can't afford this. I need help!"

We hope to work with Congress to lower drug prices and let Americans focus on living healthy and productive lives rather than struggling with the rising cost of medicines they depend on.

I am extremely encouraged that members on both sides of the aisle are focused on these issues. In my experience, the most enduring legislative successes in our country have come with bipartisan action.