Opening Statement: The Complex Web of Prescription Drug Prices, Part I: Patients Struggling with Rising Costs

Senator Susan M. Collins

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Good morning. Today the Senate Aging Committee is holding the first of three hearings focusing on the high cost of prescription drugs. These hearings build on the work we have done since 2015, which has produced new laws to encourage more competition from generic drugs and to prohibit "gag clauses" that prevented pharmacists from informing their patients about the least expensive way to purchase their medicines. But it is evident that much more work needs to be done.

We've heard the statistics.

- More than half of all Americans, including 90 percent of seniors, take prescription drugs regularly.
- One out of four Americans has a difficult time affording their medicine.

And, we've seen the headlines.

- Drugmakers Raise Prices on Hundreds of Medicines.
- Diabetes Patients at Risk from Rising Insulin Prices.

Behind these headlines and statistics, however, are real people: Average Americans trying to make ends meet – and at a loss to understand why the cost of a drug that they need to remain active, healthy, and in some cases, alive, continues to rise to the point where it is unaffordable.

Here are some of the stories of Mainers struggling to afford their prescription drugs:

Elizabeth, a 70-year-old from midcoast Maine, lives with a severe low blood pressure disease that makes daily activities, such as making her bed, difficult. Her neurologists have tried multiple treatments, and concluded that the medicine she needs is Northera. But with a price tag in the thousands, she simply cannot afford this treatment. Instead, she takes a different medicine that she says is "just barely keeping me able to function." She told us, "I'm just treading water."

Philip from Yarmouth, Maine, had his epilepsy under control for years since the 1990's. Every three months, he would drive to Canada to buy enough Onfi to last a quarter of the year at the price of \$120. Years later, he tells us, when this same drug got approved in the United

States, his monthly costs skyrocketed to \$1,200. So he stopped taking it. He is now taking an alternative drug for \$75 per month that does not work as well, and causes a host of unpleasant side effects, from balance to mood problems.

We've talked to Vereen from Lewiston, Maine, who describes the deteriorating condition of her 34-year-old son, Mark, who can't afford to treat his diabetes properly. And Renee from Portland, Maine, who one day found that the refill for her Multiple Sclerosis maintenance therapy would be \$12,000. She went without, risking her life until she was able to restore coverage.

When taken as prescribed, prescription drugs can work wonders keeping blood pressure in check and seizures under control; lowering cholesterol levels and triglycerides; combatting nausea and infection; and balancing hormones in the body and chemicals in the brain. For some conditions, prescription drugs represent a lifeline that allow individuals to live, breathe, eat, and sleep. But in the face of rising costs, these therapies are becoming increasingly out of reach for those who need them most. Prescription drugs don't work for those who cannot afford to take them.

On a national level, we are spending an enormous amount, while millions of Americans continue to be unable to afford the treatments they need. This year alone, Americans are expected to spend more than \$360 billion on prescription drugs. Of this amount, individuals will pay about \$49 billion out-of-pocket. The federal government will pick up another \$163 billion in payments through Medicare, Medicaid, and other programs.

Americans are going to great lengths to pay for their prescription drugs – cashing in retirement accounts, working three or four jobs at retirement age, and choosing medicine over food. These statistics don't capture the tribulations that Americans encounter every day because the drug they need carries a prohibitive price tag – causing them to stretch or skip doses, settle for an alternative that works poorly, or simply go without.

The entire drug supply chain is appallingly opaque. While family members and doctors are often doing everything they can to help, navigating the complex web of prescription drug prices is not easy, even for the experts. Renee summed up the problem well after getting back on her MS maintenance therapy. She said: "I'm lucky. As a community advocate, I knew who the players were and how the system worked. How does the average resident manage through all of this?"

The complexity in the current system seems designed to benefit everyone except the patient.

Of course, we want new medicines to reach consumers and for companies that invest in the research and take the risks necessary to develop these drugs to see a fair return on their investment. But we must do more to ensure these essential medicines are more affordable and their prices more transparent.

Addressing the rising costs of prescription drugs is a top priority for this Committee. Today, we will hear about the impact of high prescription drugs directly from patients. Tomorrow, we'll focus on potential policy solutions. At a third hearing later this spring, we will hear from Administration officials on their proposed solutions.

I am so grateful to each and every one of our witnesses for being willing to come here today and share their stories.

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