



# THE REAL AND RISING PRICE OF PRESCRIPTION DRUGS

Stories from Americans struggling to pay for what keeps them alive.



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# THE REAL AND RISING PRICE OF PRESCRIPTION DRUGS

## APRIL 2022 STORYBOOK

High prescription drug prices are forcing American families to make the impossible choice of paying for life-saving medications, or other essential expenses like rent and utilities. Prescription drug prices account for roughly 10 percent of total healthcare spending in the U.S., and more and more patients are concerned about how they can afford the medicine they need.

Prescription drugs should be affordable and accessible for hardworking families when they need them. No one deserves the stress that comes from an endless back-and-forth between you and your insurance company, just to get medicine that your doctor says you need. Drug prices should be transparent, and companies shouldn't be able to monopolize markets and drive up prices for families struggling to pay the bills. We need broad reform that allows companies to invest in innovative new drugs, without breaking the bank for working families.

In the U.S., pharmaceutical companies drive high prices, and we cannot depend on their goodwill to look out for the needs of families across our country. The stories in this book reflect the need for lowering the prices of prescription medications. Read more about the real decisions working people and families need to make in order to stay healthy.

The total price is more than just the out-of-pocket cost at the pharmacy.



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# Benjamin Conner

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Tempe, AZ

Like so many others, Ben lost his job during COVID. He worked for a healthcare company analyzing customer calls. But even working for a healthcare company in the middle of the pandemic didn't mean his livelihood was protected.

Ben has had chronic migraines for years, and while treatable, the prescription drugs his doctor prescribes are incredibly expensive. Out of pocket costs for these drugs would be more than \$20,000. As he searches for a new job, Ben finds himself first needing to ask for details on their health insurance plan, making sure his medication is covered. Otherwise, his salary almost doesn't matter.

Ben's migraines don't just affect his ability to work, they crush his quality of life. Ben absolutely wants to continue his career, and it pains him that anything he considers must be viewed through the lens of his medication costs.

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*Prescription drug price relief would make a massive, life-changing difference for me. I hope that we can use this election to work towards solutions on prescription costs that bring real relief to the thousands of Arizonans like me.*

*Benjamin*

# Brenda Dickason

Tucson, AZ

Brenda Dickason is a retired police department detective and middle school science teacher living in Tucson, Arizona. She lives with asthma and is allergic to bee stings and latex.

Brenda is 66 years old and recently switched to Medicare coverage. Upon switching, she couldn't believe how expensive her EpiPens were. She is supposed to carry an EpiPen with her at all times to avoid hospitalization for her severe allergies, but it has been difficult to do that with the \$250 out-of-pocket expense each and every time she needs to refill her prescription. There have been times Brenda has been unable to afford to refill her prescription and has ended up hospitalized with anaphylactic shock.

Brenda has worked hard her entire life, giving back to her community as a detective and teacher, and was looking forward to her retirement. She had no idea how crippling the costs of both her EpiPen and inhaler would be. She now relies on her small business - making and selling specialty soaps - in order to be able to afford the prescriptions she needs to live.



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*It is unfair that seniors like myself have to worry as much as I do to afford my prescriptions. I shouldn't have to spend my retirement praying that my small business sales go well so that I can finally purchase the EpiPen that could save my life. It isn't right. Something has to change. Drug prices must be lowered now.*

Brenda

# Sierra Tyson

Flagstaff, AZ

One in 10 Arizonans live with diabetes, Sierra Tyson is one of them. Sierra has lived with diabetes since she was 11 years old. The disease has imposed many difficulties on her life, but there has always been one constant: cost. Not long after her diagnoses, Sierra saw the struggle her parents endured to afford her medication. Soon enough, her parents' struggles became her own. Ever present in the back of her mind, she constantly had to make decisions that her friends don't even have to think about - decisions that save Sierra's life.

Between 2012 and 2016 the price of insulin nearly doubled to over \$300 per vial. That's thousands of dollars every year that most Arizonans can't afford. As a full-time college student, Sierra works tirelessly to afford her insulin. Saving money is incredibly difficult and she is forced to constantly evaluate what she can do to afford her insulin.

Sierra believes that we need to work to cap insulin costs, as that would save Arizonans like her thousands of dollars a year and make a massive difference in her quality of life.



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*We need to make a clear choice to elect candidates that understand both the financial and human costs of diseases like diabetes. One in ten Arizonans have diabetes and we need help. Insulin has become unaffordable.*

*Sierra*

# Amy Brady

Hollis, NH

Amy Brady is a working mom of two, and the wife of a combat veteran. Amy and her children all have life-threatening chronic medical conditions; she lives with an autoimmune disorder, her son has a congenital heart defect, and her daughter has Type 1 diabetes.

She describes the cost of prescription medications as “astronomical.” In addition to life-sustaining insulin, there is a long list of required medical equipment and secondary prescriptions necessary for keeping her daughter alive: insulin needles, insulin pens, emergency glucagon pens, alcohol, prep-pads, lancets, test strips, glucometers, insulin pump, adhesive removers, continuous glucose monitors, transmitters – the list goes on. Amy calculates the cost of managing her daughters’ diabetes, even before paying for insulin, is over \$8,290 every three months.

Even with employer-provided medical insurance, her family is forced to rely on community and state agencies for financial assistance to afford the cost of her daughters’ prescription drugs and required medical equipment. In addition, she often has to miss work – exhausting sick leave, using vacation time, or taking unpaid time off – to ensure that her daughter makes it to her numerous monthly doctor appointments and associated treatments.



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*Lowering the cost of prescription medication would be a huge relief. No family should have to choose between the costs of living and taking care of a child with chronic illness.*

*Amy*

# Tom Harris

Hollis, NH

When Tom's daughter experienced a sudden onset of severe diabetes, she found herself out of work for four months. During this period, she suffered from three separate episodes, each resulting in two to three days of hospitalization. Without a source of income, she was faced with steep hospital bills and insulin costs, on top of her regular expenses as a mother. Seeing his daughter in need, Tom started picking up her medical expenses.

Tom says he would regularly send checks for \$5,000 or more for his daughters' life-saving insulin. On top of that, Tom has recently been experiencing problems with his vision. Every five to seven weeks, Tom goes to the doctor to receive a needle injection in his eyeball. That one shot costs \$2,700 per visit. These egregiously high prices are eating away at Tom's retirement savings. He says that he feels lucky that he had savings to help his daughter, and that he has insurance for himself. But even with insurance, these prices are outrageously high, and unaffordable.

Tom says that his friends in Europe and Canada are horrified when they hear about how much Americans pay for prescription medications, especially given that most pharmaceuticals are developed with the financial support of the American taxpayer.



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*There has to be massive change in our electorate to say NO, these prices are not okay, and we are not going to do this anymore.*

Tom

# MK Kilcoyne

Dover, NH

Ever since MK Kilcoyne and their sister started getting their periods, their ovulation has been more irregular, stronger, and comes with more nausea, cramping, fatigue, and sickness than is normal or healthy, probably due to endometriosis, a condition which runs in their family. Since they were 14 years old, their mother sought to put them on birth control medication in order to mitigate these symptoms and limit the length of their periods.

While there are free or low-cost birth control options available through Planned Parenthood, MK has tried them all, including IUD and the patch, which resulted in worse sickness as well as a state of depression due to the side effects of those particular methods. In 2020, MK first received the Depo-Provera shot, which limits their periods to recurring only every 3 months, significantly improving their quality of life. But this medication needs a prescription, and can cost up to \$150 per month without insurance.

Because of their experience, MK believes that we should be doing everything we can to lower the cost of prescription medicine.



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*It's already hard to be struggling to find out what is wrong and go through multiple prescriptions to find the medication that works for you. Removing those cost barriers can be life-changing.*

MK



# Marcus LaCour

Cincinnati, OH

Marcus LaCour is a husband, father, and minister from Cincinnati, Ohio. In 2000, during his sophomore year of high school, he was diagnosed with type 1 diabetes. Since then, Marcus has relied on insulin each and every day to stay alive.

Struggling to afford insulin has become a pattern in Marcus' life. In college, he was constantly deciding between paying for his insulin or buying the materials he needed for school. His grades suffered and his health took a hit. While in between jobs, Marcus has been unable to afford his insulin altogether. He has been forced to rely on samples from his doctor, ration his supply, or simply go without. In some of his hardest times, Marcus was rationing his insulin while his wife skipped meals to help pay for it. No one should have to choose between food for their family and the medication they need to stay alive.

Marcus is in a much better place now and can afford his insulin thanks to good employer insurance. But not a day goes by where he doesn't worry about what would happen to his family if he lost his job or had to change insurance.



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*I'm thankful I have insulin to help keep me alive, but it is worthless if we cannot afford it. Right now millions of patients aren't able to afford their drugs, while drug companies celebrate annual profit margins higher than almost all other industries.*

Marcus

# Lester "Les" Lee

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Bensalem, PA

Lester "Les" Lee is a 75-year-old furniture store employee from Bensalem, PA. Fortunately, because he has insurance and only takes a few medications he can afford his and his wife's prescription drugs at this point in their lives. However, Les worries about what could happen if his situation changes because he knows other seniors who struggle to afford their medication.

Even with insurance, Les is frustrated that his prescription costs fluctuate every year when his deductible resets. He thinks it is a shame that people have to pay potentially hundreds of dollars out of pocket each year before their prescription costs are covered, especially for seniors who are living on a fixed income.

Les believes it is far beyond time for our legislators to end the gridlock and take action and lower the cost of prescription drugs. He has friends and family who cannot afford the prescription medicines they need to stay healthy and knows that he is one accident or illness away from being in a similar situation.

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*I am for lowering the cost of healthcare, period. There are so many people who cannot afford life-saving prescription medication and our legislators need to make a change.*

Les

# Ashley Suder

Morgantown, WV

Ashley Suder is a nursing student who lives in Morgantown, West Virginia. She also lives with lupus, an autoimmune disease where her immune system attacks her healthy tissue, resulting in painful inflammation that damages her skin, joints, blood vessels, and brain. Lupus is chronic and lifelong.

The drug Ashley takes, Benlysta, works well to manage her conditions, but it is outrageously expensive. Its list price set by Big Pharma is more than \$35,000 every year. Ashley currently works as a nursing assistant and at times almost her entire paycheck goes towards paying for her medicines. She constantly relies on samples from her doctors to treat her condition because it is just so expensive. It is no way to live, but she has no choice.

Benlysta's price is so high, Ashley knows she may not always have access to this drug. Going without it would negatively impact her entire life. Without Benlysta, she wouldn't be able to continue working, she wouldn't be able to go to school, and she wouldn't be able to fulfill her lifelong dream of becoming a nurse. Drug prices have to come down.



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*If I were left without my prescriptions, I wouldn't be able to continue working, wouldn't be able to go to school, and wouldn't be able to become a nurse. Drug prices have got to come down. It's wrong that I live paycheck to paycheck and in constant fear of losing my medications while Big Pharma rakes in profits.*

*Ashley*

# Saskia Hale

West Allis, WI

For the past 18 years, Saskia has been a Type I Diabetic, and relies on taking two types of insulin every single day to stay alive. One vial of each type of insulin costs over \$200, and Saskia uses upwards of four vials of each type of insulin every month. Recently, one of the types of insulin she takes increased by over \$100 per vial, and now a month's supply of that medication alone is nearly \$1,500.

Fortunately, through her employer, Saskia is able to have health insurance. Unfortunately, her insurance does not cover the full cost of her medications, so a large portion of her paycheck goes to covering the medications she needs to stay healthy. For the rest of the month, Saskia says she has to closely monitor her other essential living expenses.

Saskia believes we need to work towards having a cap on prescription drug costs, beginning with electing representatives who will fight for their constituents, and against pharmaceutical company greed.



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*There is no logical reason why diabetics in this country should have to pay thousands of dollars every single month for the medication that keeps them alive. This is the direct result of pharmaceutical company greed.*

Saskia

# Emily Mantel

Appleton, WI

Emily takes multiple medications for various reasons, but the ones that have affected her the most, financially and physically, are for a chronic illness related to neuropathy.

For the past two years, Emily has taken three different medications that work together to alleviate her symptoms, and if she does not have all three, her symptoms worsen. Last year, when she switched jobs, and subsequently switched her insurance, the cost of her medications increased unexpectedly. Emily went from paying about \$20 to \$150 per month.

Emily says that the price of her medications makes it more difficult to pay for other essentials. Additionally, Emily is still in search of a definitive diagnosis, so check ups and a variety of medical tests over the years adds up significantly.

Emily's financial situation would be significantly more comfortable if the monthly cost of her medications was lower. She says she could focus on solving her medical questions rather than treating them with no answer.



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*Regardless of the price of my medications, I do not have a choice in taking them or not; if I do not take my medications, I can't walk. If the cost of those medicines came down, it would positively change my life as I currently know it.*

*Emily*

# Anna Ringstad

Ladysmith, WI

For many years, Anna worked as a customer service representative at various call centers in Eau Claire, and one of those jobs was working for a healthcare system. But even though she was working for a healthcare system that provided its employees with insurance, Anna still experienced the high cost of prescription medications.

One morning, Anna woke up and her face was swollen, and although she was not experiencing any difficulty breathing, she was very uncomfortable as her lips were 10 times the size they are normally. After being rushed to the hospital and given antihistamines to reduce the swelling, it was determined that in case this were to happen again, Anna should carry an EpiPen.

Even with the insurance through her employer, the out-of-pocket cost of a single pen was \$400. At this time, Anna was barely able to make rent, and could not afford this additional expense, no matter how life-saving it would be.

While it is now expired, Anna has an EpiPen, and she is hoping it works in a pinch.



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*No one should have to hope that an expired medication will keep them alive in an emergency. Working families deserve access to affordable, prescription drugs to stay alive and healthy.*

Anna

# ABOUT US

## **Campaign for a Family Friendly Economy**

The Campaign for a Family Friendly Economy is dedicated to improving the lives of working families. At the ballot box and in the halls of power, we build grassroots support for solutions that would transform the lives of American families, like lower cost prescription drugs, paid family and medical leave and affordable elder and childcare. The Campaign for a Family Friendly Economy currently has active campaigns led by state teams in Wisconsin, Arizona, Pennsylvania, New Hampshire and Virginia.

## **Main Street Alliance of Wisconsin**

Main Street Alliance of Wisconsin is a state chapter of the Main Street Alliance, a national organization founded by small business leaders in 2008. MSA organizes small businesses around issues that matter most for businesses, their employees, and the community they serve. MSA aims to build a powerful, self-funded, multi-racial, small business membership organization that can shift our economic narrative, wield political power, and win policy reform for small business owners, employees, and communities.

## **Patients for Affordable Drugs Now**

Patients For Affordable Drugs Now is a bipartisan national patient organization focused exclusively on achieving policy changes to lower the price of prescription drugs. The organization amplifies the voices of Americans struggling under crushing drug prices to make policymakers and elected officials see the heavy toll of high-priced drugs. P4AD does not accept contributions from any organizations that profit from the development or distribution of prescription drugs.



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