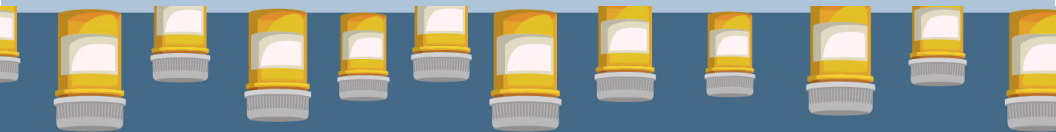




Rx Price Relief Now

**Stories of Struggle:
Granite Staters
feeling the impact of
high drug prices**



Drug Price Relief Bills

New Hampshire needs Senate Bills 685 and 687 (now included in **HB 1280**) to help ensure that Granite Staters can afford needed medications. Together, these bills will improve affordability, transparency, and accessibility of prescription drugs.

**RX Price
Relief
Now!**

- **SB 685 Affordability:** This bill would authorize NH to import certain high cost drugs from Canada, allowing the state to provide them at a much lower cost. Canada is able to negotiate lower drug prices than pharmacy benefit managers and insurers have been able to do in the US.
- **SB 687 Transparency:** This bill would require pharmaceutical companies to provide information about drug price increases over 20%. Additionally, this legislation seeks to establish a drug affordability board that will evaluate prices and set limits on how much certain payers, including state agencies, will pay for high cost drugs.

Skyrocketing Prices Must End

In the past five years, prescription drug prices have climbed at alarming rates. Since 2014, the price for all drugs, brand name and generic increased by 32% while inflation rose only 9.69% over that same time.

Skyrocketing and unpredictable prices are forcing many to ration their medications or to forgo their prescriptions altogether. In 2017, 22% of NH residents stopped taking their medications as prescribed due to cost, according to a survey by AARP. These cost-cutting measures are dangerous and put the health and well-being of our friends, neighbors and loved ones at risk. These price hikes are only making us sicker. Comprehensive change is necessary.

Granite Staters Speak Up

In this book, you'll find stories of Granite Staters who need relief from skyrocketing prescription drug prices. Passing SB 685 and 687 (now included in HB 1280) are important steps forward. With this comprehensive package of bills, lawmakers have the opportunity to support the health and financial well-beings of New Hampshire residents.

Brittany

Chichester, NH

Brittany O'Donnell has been a Type 1 diabetic for 29 of her 30 years of life. She was fortunate growing up -- her family didn't have to worry about how they would pay for her diabetes supplies and other basic necessities. She never thought about how much the supplies cost until she turned 26 and went to fill her insulin for the first time on her new insurance plan. The pharmacist rang her insulin up; over \$350 for a month's supply.



Both the pharmacist and later her insurance company explained that Brittany would have to pay full price for a name-brand prescription until her deductible was met. In the meantime, insurance would cover generic formulas. But, unfortunately, there wasn't one.

Facing these exorbitant costs, Brittany did what so many patients are forced to do: she rationed her insulin. She used every last expensive drop in the vial, and if she found an expired vial, she used that too. She watched her blood sugar rise to near dangerous levels before she corrected it, waiting to see if it might adjust on its own. For four months, Brittany walked the line of life and death. She never spoke a word to anyone. She felt ashamed that she was failing adulthood.

Since getting married several years ago, Brittany has been on her husband's insurance, and has not had to ration her insulin. Now she uses her voice to speak up for others whose voices can't be heard because they lost their lives to rationing.

Senate Bills 685 and SB 687 (now included in HB 1280) would help thousands of Granite Staters like Brittany to access and afford needed medications, ensure health and improve their quality of life.

Déodonné

Concord, NH



Déodonné Dustin Bhattarai was born and raised in Contoocook. Her family now owns a home in Concord and are raising their children here.

Just after his first birthday, in the spring of 2015, Déodonné's son was diagnosed with Spinal Muscular Atrophy (SMA - Type II), a degenerative neuromuscular disorder that causes his muscles to be very weak. The family was told they would have a couple "good years" with him before SMA robbed him of his ability to sit, eat, laugh, and eventually breathe.

However, shortly after diagnosis, their son was enrolled in a clinical trial and began receiving what is now known as Spinraza (Biogen). He will turn six this May and is thriving because of his access to Spinraza. In December 2018, Spinraza was approved by the FDA -- the first ever treatment for SMA. But it comes at a great cost: \$750,000 for the first year of Spinraza, and \$350,000-\$400,000 every year after.

This past year, a second treatment, Zolgensma, was approved for SMA. At \$2.5 million, it has the unlucky distinction of being the most expensive drug in the world.

Those living in the world of rare disorders are faced with many challenges -- the cost of life-saving prescription drugs should not top the list. Please support this suite of bills -- SB 685 and SB 687(now included in HB 1280) -- to help increase access to affordable prescription drugs. Lives depend on it.

Rachel

Keene, NH

Rachel Huckins was diagnosed with Type 1 diabetes when she was 7 years old. As a child, she had Medicaid, so she never really knew the “cost” of insulin. Her family lived in poverty, which, sadly, made her a really lucky diabetic. All of her medical costs and prescriptions were free.

When she was 11, Rachel's father died and her mother had to start working even more hours just to keep them afloat. With the longer work hours, her mother's annual income increased, meaning the family no longer qualified for Medicaid.

That's when financial reality hit. Rachel moved in and out of insurance coverage over the coming years, leaving her exposed at times to insulin costs as high as \$1,400 per month. She started rationing her supplies. She wouldn't check her blood sugar and tried to use as little insulin as possible.

Thankfully, Rachel has insurance now, but her co-pays for insulin and blood sugar test strips remain high -- \$211 per prescription, or more.

Rachel was admitted to the ICU last year because she ran out of insulin. Her blood sugar skyrocketed and she went into diabetic keto acidosis. High prices of my medical necessities have nearly killed her. Something needs to change.



Tim and Reid

Merrimack, NH

Tim Guidish lives in Merrimack, NH, and is a father to a 10-year-old boy with Cystic Fibrosis. CF is a genetic disease that causes the body to produce thick, sticky mucus, clogging vital organs throughout the body. His son, Reid, takes many medications and endures multiple lung therapy treatments every day.



They feel lucky, in that many new medications and therapies have been developed to treat the symptoms of this disease. These innovations come at a cost. Several medications that Reid takes have high price tags and high deductibles. These all pale in comparison to the recently approved drug Trikafta, developed through a joint effort between the CF Foundation and Vertex Pharmaceuticals. Trikafta is a revolutionary drug that treats the underlying cause of CF, and will drastically improve and prolong the lives of 90% of those afflicted with the disease. It, however, comes with a \$311,000 per year price tag. They are thrilled at the prospect of their son having a longer, healthier life, but they live with a feeling of guilt as they know the burden this drug must put on the system.

This drug is already saving lives. CF patients are being removed from lung transplant waiting lists as their lung function is improving so dramatically, they no longer need the procedure. It could arguably be referred to as a miracle drug, but a high price tag raises the concern that some patients who could greatly benefit from Trikafta, will not have access to it. They're not asking for a handout. They're just asking for reasonably priced drugs.

Bill

Hillsborough, NH

Bill, 62, was diagnosed with lung cancer two years ago. At the time, he was an employed construction worker who loved his job.

After undergoing surgery, chemotherapy and radiation, it looked as if Bill was in remission. However, his recovery took longer than anticipated, and Bill's COBRA health insurance lapsed while he was out of work. This left both Bill and his daughter uninsured for some time, forcing him to pay privately -- out of his retirement fund -- for his prescription drugs, including his cancer medication, Keytruda, which cost about \$12,500 per month. In Canada, the same medication cost about two-thirds of that amount, but facing costs of nearly \$150,000 per year, Bill's retirement savings ran out, and he was forced to miss the last three months of his cancer treatment.

Bill will never know what effect this interruption had, but what he does know is that he is now experiencing a full-blown reoccurrence of his disease and is terminally ill. He has chosen to stop all treatment and is receiving palliative care in home-based hospice.

Bill spends a lot of time thinking about what his life would be like if he had not had to stop taking his medication for those three months. He wonders if he would still be in remission and would have more time. It is devastating to think that the duration of Bill's life was possibly impacted by the high cost of the prescription drugs that may have extended his life.



Dan and Grace

Concord Area, NH

Dan and Grace are both 62 years old. Dan is newly retired and Grace worked a part-time job until she was diagnosed with colorectal cancer. While Grace was undergoing chemotherapy and receiving radiation treatments, her and Dan's 32-year-old Michael was diagnosed with leukemia. This posed even more challenges for a family that was already struggling.

Michael, a musician, had recently accepted a job teaching music when he was diagnosed, and was significantly under-insured. In addition to other medications, Michael's chemotherapy drug, Vincristine, costs roughly \$15,000 per month. Unfortunately, his insurance pays very little of this exorbitant expense.

To cover Michael's prescription drugs and other related costs, Dan and Grace were forced to take out a second mortgage on their home. Michael is now fully insured, and the drug company has absorbed some of his treatment costs. Still, the family now faces a five-figure debt while they struggle to beat back these devastating diseases.

Drug price relief may not cure cancer, but it would provide couples like Dan and Grace with important financial security at a time when they desperately need it.

Mary and Jerry

Mary, 62, is experiencing a recurrence of lung cancer. She has never smoked and always takes care of herself. Mary and her husband, Jerry, both still work, and Mary has full health insurance coverage through Jerry's employer. But, Mary is out on an extended leave of absence while she receives treatment.

Suffering significant nausea as a result of her treatment, Mary was prescribed an expensive, generic anti-nausea medication. However, when her husband went to pick up the prescription from the pharmacy, they learned that their insurance denied coverage because a less expensive alternative was available. This has left Mary facing out-of-pocket costs as high as \$1,000 for each chemotherapy treatment.

Francine

North Conway, NH

As Nutrition Director at the Gibson Center for Senior Services in North Conway, Francine has listened for 35 years to the needs and challenges facing our elders.

Several years ago, Francine helped a 90-year-old volunteer send a prescription to Canada for Restasis, a popular and frequently advertised drug for dry eyes caused by an autoimmune syndrome. The dry-eyed senior couldn't afford the drug and there was no affordable, generic option available in the United States. So Francine helped fax the prescription to the Canadian pharmacy.

Soon after, Francine found herself diagnosed with the same condition by the same ophthalmologist. She filled the prescription locally using my employee health insurance supplement plan. At first it was affordable, though not inexpensive. However as the years progressed, the prices were increasing at an excessive rate.

Francine checked all the local pharmacies in the area and decided to try the Canadian pharmacy. There, a year's supply was about half the price, even considering shipping charges. Francine now gets her eyes checked yearly, and thankfully, has had no problems with her generic, imported eye drops. She is grateful that she was able to access other countries' cheaper medications.



Margi



Margi lives with Multiple Sclerosis, a painful and expensive disorder. To stabilize her symptoms, she uses multiple medications, one of which costs about \$10,000 every three months. Margi's insurance coverage helps her to afford her medications, but she fears this will not always be the case. In the past, her insurance has abruptly denied her coverage for physician-recommended medications. Changes or gaps in her coverage threaten her health and hard-won stability. Without this medication, she is likely to relapse and could permanently lose control of her symptoms. For Margi, this is a terrifying notion -- she does not want to lose more -- physically or emotionally -- to MS than she already has.

In addition to her own battle with MS, Margi's son has been diagnosed with several mental health conditions. He is supposed to be taking a blood thinner for deep vein thrombosis and pulmonary embolisms. But, Warfarin -- the medication that has been prescribed -- requires blood to be drawn regularly, which psychologically is too difficult for him. Physicians switched Margi's son to Eliquis, but unfortunately their insurance will not cover it, and they cannot afford to pay out of pocket. Margi is worried this could cost her son his life.

Margi often wonders why we, Granite Staters, are forced to choose between our health and our financial well-being. SB 685 and SB 687 (now included in HB 1280) would improve Margi and her son's lives, and they would mean that Margi and her son wouldn't have to make these impossible decisions. She asks lawmakers to please make medication in NH affordable to everyone.

Leah

Litchfield, NH

Like many New Hampshire residents, Leah's life has been severely impacted by high prescription drug costs. As a 23-year-old, she lives with multiple debilitating chronic conditions, and managing her complex healthcare needs is a financial burden for Leah and her family. Much of that burden is due to high prescription drug costs, which often add up to several hundred dollars each month in copayments and other charges.

There are many medications that Leah wishes to take to address her conditions, but she simply cannot afford them. In the past, her specialists have prescribed drugs that they believed were the best options for her and could help to improve her quality of life, but the high costs of these drugs put them out of reach. Last year, Leah was told that one of these medications would cost more than \$500 per month.

Leah is fortunate to have family support in covering her medical expenses. But, like any 23-year-old, she wants to be independent; Leah just wants to be in less pain; to work more hours each week, and to spend more time with her family and friends.

For Leah, the high cost of prescription drugs is a quality of life issue, but she recognizes that for many others, it's a matter of life and death.





Yes on HB 1280!

*Yes to prescription drug
price relief
for the health and
financial
well-being of the
Granite State!*

