

2022 SERIES

# PRESCRIPTION DRUG AFFORDABILITY COMMUNITY FORUMS: MARYLANDERS TELL THEIR STORIES



Public Forum

**MAKING HIGH-COST DRUGS  
MORE AFFORDABLE FOR  
MARYLANDERS**

**SEPTEMBER 28, 2022  
10:30 AM**

With special guests  
Frederick County Executive Jan Gardner  
Prescription Drug Affordability Board Executive Director Andrew York  
Maryland AARP Advocate Jim Gutman  
Maryland Health Care for All Coalition President Vincent DeMarco

FREDERICK COUNTY SENIOR SERVICES DIVISION  
AT THE FREDERICK SENIOR CENTER  
1440 TANEY AVENUE  
FREDERICK, MD 21702



SHARE YOUR STORY



**FORUMS HOSTED BY  
LOCAL LEADERS  
MARYLAND HEALTH CARE FOR ALL &  
AARP MARYLAND**

**IN PARTNERSHIP WITH THE MARYLAND  
PRESCRIPTION DRUG AFFORDABILITY BOARD**

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# THE ISSUE

**WE ARE ALL HURT BY THE SKYROCKETING COSTS OF PRESCRIPTION DRUGS, WHETHER IT IS AT THE PHARMACY COUNTER, IN OUR INSURANCE PREMIUMS, OR THROUGH OUR TAXPAYER DOLLARS.**

Recent polling by Altarum Health Care Value Hub shows that high-cost prescription drugs are a significant issue for Marylanders:

1  
2

NEARLY 50% OF SURVEYED MARYLANDERS REPORT BEING WORRIED ABOUT THE COST OF PRESCRIPTION DRUGS



NEARLY A QUARTER OF RESPONDENTS REPORTED SKIPPING A DOSE OR NOT FILLING A PRESCRIPTION DUE TO COST

Despite increased health and financial burdens as we enter the third year of the COVID-19 crisis, prescription drug manufacturers **continue to raise prices** of medications, often above the rate of inflation. This places undue stress on Marylanders, our counties' budgets, and our health care system at large.

ACCORDING TO PATIENTS FOR AFFORDABLE DRUGS  
IN 2022  
**DRUG CORPORATIONS HAVE HIKED PRICES ON**

**1,186**

**PRESCRIPTION DRUGS**

**DRUGS DON'T WORK IF PEOPLE CAN'T AFFORD THEM.**



[www.healthcareforall.com](http://www.healthcareforall.com)

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# PURPOSE OF THE FORUMS



## EDUCATE THE PUBLIC

Since our last series of community forums in 2020, considerable progress has been made. Our goal was to inform the public about landmark federal legislation with the **Inflation Reduction Act**, the **Board's great progress** towards addressing high-cost drugs for state and local governments, and **other important state-level prescription drug affordability measures** like the 2022 insulin co-pay cap.

## HEAR FROM MARYLANDERS

Patient input is critical to the Board's success, particularly to ensure that **equity and affordability for all Marylanders** are chief considerations in the decision-making process. These forums provided an opportunity for the public to **provide input, share stories, and learn about ways in which they can engage** with Maryland's Prescription Drug Affordability Board.



# 2022 FORUM SERIES

## COMMUNITY FORUMS WERE HELD IN:

ANNE ARUNDEL COUNTY

BALTIMORE CITY

CHARLES COUNTY

FREDERICK COUNTY

HOWARD COUNTY

MONTGOMERY/PRINCE GEORGE'S COUNTIES

& STATEWIDE WITH A VIRTUAL FORUM

Each of the seven forums featured representation from Maryland's Prescription Drug Affordability Board, AARP, Maryland Health Care for All, and local government leadership. For several of the forums we were happy to welcome state and federal lawmakers who discussed the new drug provisions in the Inflation Reduction Act.

## PROGRESS MADE



### INSULIN AFFORDABILITY

Since the 2020 forums, over 70 Marylanders have shared their experience with struggling to afford insulin, making it a top issue.

With the support of the Board, & under the leadership of Del. Joseline Peña-Melnyk, the MGA passed a law implementing a \$30 co-pay cap on insulin.



### STAKEHOLDER COUNCIL

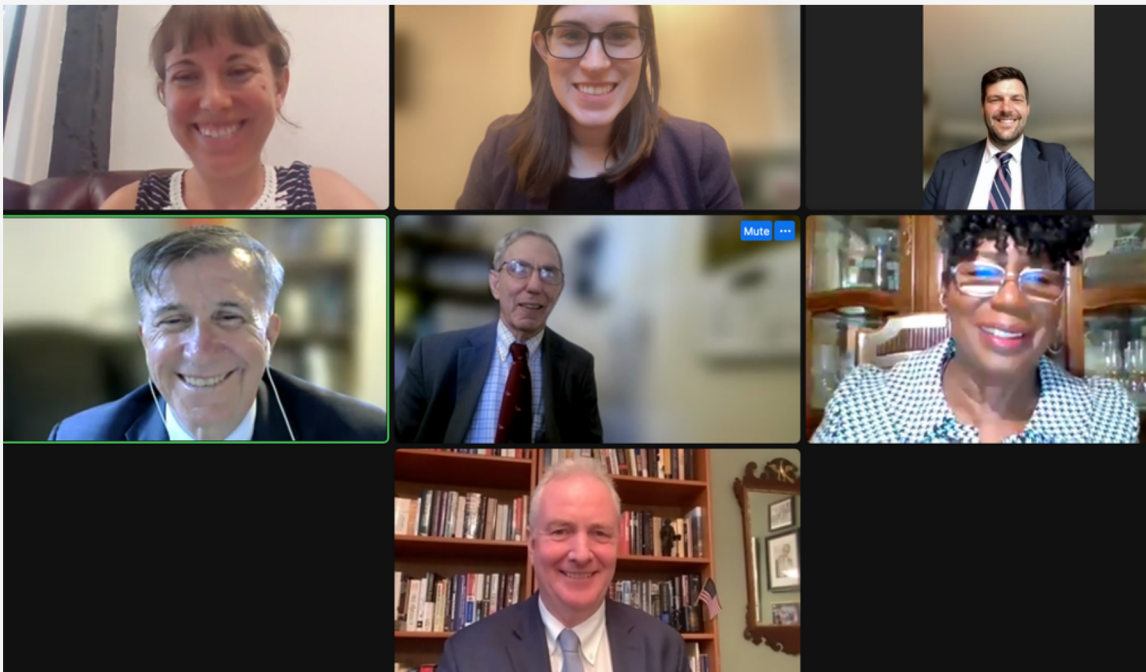
The Stakeholder Council is fully appointed and providing critical input to the Board.



### STATE & FEDERAL ACTION

The passage of the Inflation Reduction Act marks important progress for prescription drug affordability for Medicare recipients.

Forums featured discussion of the Board's work towards creating an Upper Payment Limit Action Plan.



# STATEWIDE VIRTUAL FORUM

SEPTEMBER 13

**Advocates were joined by US Senator Chris Van Hollen & PDAB Executive Director Andrew York to discuss the prescription drug provisions in the Inflation Reduction Act & the work of the Prescription Drug Affordability Board.**



## ANNE ARUNDEL COUNTY

SEPTEMBER 21

"In Anne Arundel County, we spend twice the amount of money on prescription drugs- just for our employees and retirees- twice as much than on our entire library system."

- County Executive Steuart Pittman



**Advocates and lawmakers, including Del. Heather Bagnall, spoke to attendees about the impact high-cost drugs have on Anne Arundel County residents. Following this, table discussions were held to collect stories and input from participants.**



## BALTIMORE CITY

OCTOBER 7

**Joined by US Representative John Sarbanes, Mayor Brandon M. Scott led discussion of the impact high-cost drugs have on the city's budgets, residents, and our health care system.**

Other speakers included Dr. Andrew York, Jim Campbell the Co-Chair of the Commission on Aging and Retirement Education Services, Baltimore City Health Department Deputy Commissioner Heang Tan, Maryland AARP Advocate Jim Gutman, and Baptist Ministers Night Conference of Baltimore & Vicinity President Rev. Sandra Conner.



## CHARLES COUNTY

SEPTEMBER 19

**Commissioner President Reuben B. Collins led a forum that featured Charles County Health Officer Dr. Abney and patient advocate/AARP representative Larry Zarzecki. Here, Charles County residents shared their experiences with high cost drugs.**

**One woman spoke on behalf of her mother, sharing her struggle to afford Eliquis. She raised concern with the state's Medicaid thresholds. She was able to connect with Stakeholder Council Co-Chair Lorraine Diana and find a way to help her mother access the medication she needs.**



## FREDERICK COUNTY SEPTEMBER 28

**Delegate Karen Lewis Young joined County Executive Jan Gardner and advocates to discuss the impact high cost drugs have on Frederick County residents and the actions the Maryland General Assembly continues to take to address this issue.**



Staff shared a story of a Frederick County employee whose medicine to treat her cancer costs **\$20,000/month**- she is grateful her insurance covers it, but she is unable to pay for the medicine if she retires.



## HOWARD COUNTY SEPTEMBER 14

**During the first forum in the series, County Executive Calvin Ball was joined by Board member Dr. Ebere Onukwugha to discuss Maryland's work to address high-cost drugs. Speakers and participants indicated a desire and need for continued communication between the Board, the Stakeholder Council, and the Marylanders most impacted by high-cost drugs.**



## MONTGOMERY & PRINCE GEORGE'S COUNTIES

OCTOBER 4

Hosted at Riderwood Senior Living, Montgomery County Executive Marc Elrich and Prince George's County Health Officer Dr. Ernest Carter both highlighted a need for continued action to address high-cost drugs.

Panelists were joined by Senator Brian Feldman and Delegate Bonnie Cullison, both of whom are leaders for prescription drug affordability in the Maryland General Assembly.



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## SUMMARY

These forums served as an important opportunity to share information about the PDAB's work and to inform the public about the prescription drug provisions in the Inflation Reduction Act.

Held primarily at senior centers, participants expressed gratitude for receiving information about the SHIP Program and other ways in which they may find assistance with affording their prescription drugs.



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# WHAT MARYLANDERS WANT YOU TO KNOW

There were several key takeaways from forum participants and survey respondents, which were largely similar to those expressed in the 2020 forum series. **Marylanders are eager to engage with the Board and appreciative of the work**, ultimately wanting the Board and Stakeholder Council to consider the following:

**When asked to define “affordability” for prescription drug costs, the most concise and direct responses indicated it means: anyone who needs a prescription is able to have it filled without sacrificing other necessities.**

**Participants voiced frustrations with confusing formularies, a lack of transparency, and discrepancies in drug costs.**

**Marylanders were excited to hear of upcoming actions that will be taken to address high-cost drugs for state and local governments & to learn of the relief that the Inflation Reduction Act will bring to Medicare recipients, but they would like more to be done to help those that will not benefit from these initial actions.**

Recent polling shows

**88%**

of Maryland respondents support a Prescription Drug Affordability Board that can examine expensive drugs and set acceptable costs.

## CONSUMER INPUT

Ruth Ann in Frederick County would like to see the **Board directly engage with the deaf community** to ensure their input is considered in decision-making.

Several Marylanders have suggested something like a **"Citizens' Advisory Council"** to further elevate patient perspectives.



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# QUESTIONS, COMMENTS, AND SUGGESTIONS

## FORUM ATTENDEES HAD THESE POINTS TO SHARE:

One of the main issues people brought up was inconsistency in prescription drug costs-- whether that is changes in formularies or finding different prices at different pharmacies or with various discount cards. **Patients want to know what they can expect their medications to cost so that they can plan accordingly.**



PARTICIPANTS WOULD LIKE TO SEE THE BOARD FIND A WAY TO ENGAGE/SHARE INFORMATION WITH INDIVIDUALS WHO MAY NOT COME OUT TO FORUMS AND/OR WHO CANNOT ACCESS TECHNOLOGY EASILY.

Attendees expressed confusion over the different prescription drug discount cards and services that are available. They would prefer to have one point of contact regarding their prescription drugs, rather than having to do extensive research to find the most affordable way of obtaining them.

"IT IS CONFUSING TO KNOW WHAT [PRESCRIPTION DRUG DISCOUNT CARD] WHEN"



"I CAN'T WAIT FIVE YEARS. I WANT IT TO GO FASTER"

While forum participants were excited to hear about the progress made, they expressed a desire to see more done to help Medicare recipients prior to the IRA's implementation and to see the Board address high-cost drugs for *all* Marylanders.



SEVERAL ATTENDEES EXPRESSED CONCERN WITH SCAMS INVOLVING PRESCRIPTION DRUG AFFORDABILITY ASSISTANCE



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# MARYLANDERS TELL THEIR STORIES

**THIS SECTION INCLUDES STORIES COLLECTED FROM FORUMS, ONLINE, THROUGH PHONE INTERVIEWS, IN TESTIMONY, AND BY OUR PARTNER, PATIENTS FOR AFFORDABLE DRUGS NOW**



Since 2017, we have been collecting stories from real Marylanders struggling to afford the prescription drugs they need. Many share their experiences with **having to choose between their medication and other necessities like rent and groceries.** Others have faced difficult decisions, like staying in a job to keep benefits, sacrificing retirement savings, or otherwise facing uncertainty about their financial and medical futures. Many of their stories are included in this report.

## PATIENTS FOR **AFFORDABLE DRUGS NOW**<sup>™</sup>

A leading voice for patients in DC and statehouses around the nation, Patients for Affordable Drugs Now has shared many of their stories featuring Marylanders.

Their work offers critical insight into Marylanders' experiences, including identifying some of the **drugs that most commonly cause affordability issues** for respondents, which include: **insulin, Eliquis, and cancer treatments.**



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# LARRY ZARZECKI

## EASTERN SHORE

Imagine going to countless doctors' appointments, knowing something is wrong with your body, but hearing at the end of each appointment "we can't find anything wrong." That was Larry's reality at every visit until 2009 when he was diagnosed with Parkinson's disease.

Larry was relieved to finally have an explanation for why his movements slowed; why his anxiety, fatigue and ability to walk with ease worsened; and why he had a resting tremor. Then came the next shock: in order to keep up with the demands of his disease, Larry would have to take seven different medications every day to get him through the day.

The overall total of all his medication sums up to about \$3,800 per month even with insurance coverage. And when Larry asked for the best medications for his condition, he learned they would cost many thousands of dollars more per month, making them completely unaffordable for him. As it is, there are times Larry has to go without his medication when he is informed at the pharmacy that his insurance no longer covers what was prescribed. When that happens, his doctors have to find alternatives because the original prescriptions are too expensive for Larry to purchase out-of-pocket.

The effects of not taking the medications are horrifying and often lead to bad withdrawals. The majority of the medications Larry takes are necessary for his daily function; without them he cannot perform the simplest of tasks. Adding to his financial burden, Larry is also helping a family member pay for their high-cost medication. Through this support, his own experience, and his work with individuals with movement disorders, Larry has come to find that the high-costs of prescription drugs impact so many Marylanders.

Since Larry first told his story and began working to help make prescription drugs more affordable, he has spent over \$90,000 on his medication, depleting his savings and retirement, and causing him to lose his home. You can find more about Larry's current situation as he continues to tell his story with [AARP](#).

**Pat**  
**Annapolis**

My granddaughter has three stage-four cancers. She has to keep working to keep her health insurance because without it, there's no way she could afford the full prices of her meds. She can't drive anymore, so her dad drives her to work. She can barely move without pain but she can't quit. Just one of her meds is \$1,200 and there are lots more. She cries from pain and frustration but she is stuck between a rock and a hard place and nowhere to go. She can't keep it up much longer then what does she do? This is not right or moral.

I am 65 years old and had to go off my diabetes medication because I cannot afford it. I have no additional insurance other than Medicare and \$400 for a box of insulin that might last me 2 weeks, maybe 3, is thoroughly ridiculous. How do you expect people to live?

**Therese**  
**Fort Washington**

My wife currently has lupus as well as degenerative disc disease. She is currently on various medications to combat these diseases. The price for these medications are putting an extreme financial burden on my family. We currently spend on my wife's medications alone approximately \$1,200 every three months. This does not include doctor's visits as well as my own medications that are approximately \$1,000 every three months. Because I am retired and I can't collect my pension or Medicare until I'm 65, I have had to return to work to qualify for benefits from my company.

**Kyle**  
**Baltimore**

I am a cancer patient and the cost of medication is outrageous. I currently owe over \$120,000 for treatment that is life saving. I am at the point where it is debatable if it is worth staying alive, and nobody should have to be in that position. Drug companies and other medical entities are forcing us patients to make decisions between crushing debt and agonizing death.

**Richard**  
**Columbia**

**John**  
**Baltimore**

I was diagnosed with Multiple Myeloma in 2020 and finished my bone marrow treatment in 2022. Since completing the treatment I've been placed on Revlimid, a drug whose origins go back to Thalidomide. The doctors told me that it was maintenance therapy, but I soon found that it was unsustainable. I now take 21 doses a month, and each pill costs \$990. Do the math. Insurance won't touch it, and given my particular brand of MM, I need it to keep the cancer under control. At present my only recourse is writing to the company manufacturing it and begging for them to give me a benefit. They call it generosity, but it is entirely on their terms. They can pull it anytime, at no obligation.

I am 82 years old and a couple of years ago I was diagnosed with very slight Hep C. My medication, Harvoni, costs \$1,200 a pill. It was a few dollars a pill before Big Pharma bought the rights and made it \$1,200 for one pill. The suggested dosage? One or two pills a day. Who can afford that?

**Marlene**  
**Adelphi**

**Margaret**  
**Ellicott City**

I was diagnosed with M.S. in 2003. At that time, I considered taking no medication as it was way too expensive. I moved to Maryland and a new neurologist highly recommended Copaxone for me in 2013. I remained on the injections until 2015 at which time I declined to continue. Their price was nearly \$2,000 every month. I had a cheering squad helping me afford the med, along with my Aetna insurance, otherwise I wouldn't have been able to afford it at 77 years of age.

I am 65 years old and had to go off my diabetes medication because I cannot afford it. I have no additional insurance other than Medicare and \$400 for a box of insulin that might last me 2 weeks, maybe 3, is thoroughly ridiculous. How do you expect people to live?

**Linda**  
**Montgomery Village**

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# ANIL

LAUREL

PATIENTS FOR **AFFORDABLE DRUGS NOW**  
**BLOG POST**

## HIGH DRUG PRICES MAKE LIFE UNBEARABLE

My name is Anil Kadam and I am a 64-year-old husband and father from Laurel, Maryland. I retired a few years ago, and I try to spend as much time as I can with my wife and my family, as well as on my hobbies, which include working with the HAM radio. I wish I could spend my retirement in a carefree manner, but even when I'm doing things I love, there is a constant, nagging fear at the back of my mind: the high cost of my medication.

I was diagnosed with congestive heart failure (CHF) and a host of other issues in 2012. I have a Cigna health insurance plan that has always taken care of my family's needs adequately. I have been able to cover the copays for most of my medications over the years, but I was recently presented with one that I couldn't pay for.

My doctor prescribed me Entresto, a blood pressure medicine manufactured by Novartis, that has proven to be effective in mitigating some of the difficulties associated with my disease. I was really happy with the results of the medication, but my happiness was quickly turned into fear when I found out how much it would cost me per month. As a retiree, I have a lot of health care and living expenses, and having to pay \$50 out of pocket for Entresto is simply out of my reach.

High drug prices make life unbearable. If Entresto had a generic, maybe I wouldn't be stretched so thin financially. Fifty dollars may not be much to some, but it is a ton more for me, especially when you add up all of the other healthcare related costs.

My wife, Joyce, lives with diabetes and requires an expensive drug called Jardiance that costs \$250 a month. I have to carefully consider what food I buy, what I spend my small income on, because of the high cost of my Entresto. We have cut back, for instance, by sharing a vehicle, but we cannot afford new tires we need due to the costs of our medications. Patients like me deserve better. I urge my lawmakers to fight for lower drug prices for all those who need them.

**Marilyn  
Frederick**

I am a 72 year old senior, who takes over 9 medications daily for cancer, heart and breathing problems, and other medical problems. I exist (note: not live) on Social Security and the cost of my medications is astronomical. Some months, we have to do without some food and we have to rob Peter to pay Paul with regard to our monthly bill responsibilities. If only I could receive some kind of help for our costs or with incontinence supplies and other medical aids, my life would be much improved.

I am a liver and kidney transplant patient. One of my drugs that I take is over \$13,000 monthly. But with a pharmacy coupon, I paid \$72. Even with those savings, this cost is too high for me along with the other meds that I have to take to keep the transplants from rejection. I am a retired person with limited income.

**Rhonda  
Bryans Road**

I have Stage IV (incurable) cancer. It is a genetic mutation cancer called ALK+. My treatment is a targeted therapy and, amazingly, because I take pills taken at home, not infusions in a cancer center, my treatment is not covered by Medicare or supplemental insurance. Even with a separate Part D policy for prescription drugs, our annual out-of-pocket drug costs to treat my cancer total about \$14k/year. That's in addition to our Medicare, supplemental, and Part D policy premiums which cost another \$15k/year. That's like buying a car with cash every year! It is especially frustrating as I have lived a healthy lifestyle and nothing I did caused my cancer yet the expensive drugs required to treat my cancer take a big bite out of our budget.

**Deborah  
Bethesda**

Until I reach my \$3,000 deductible, I pay \$1,200 out-of-pocket for 5 vials of insulin for my Type 1 diabetic daughter. I am a single mother who works as an administrative assistant at a medical practice. I bring home less than \$1,700 a month. Also the cost of test strips, lancets, pump supplies, etc. all adds up on top of the insulin costs. Why is insulin virtually free in the UK and so incredibly expensive in the US? If this doesn't change, it will bankrupt me.

**Ebby  
Cockeysville**



**Darrell**  
**Catonsville**

I am retired and on Medicare. I was diagnosed with multiple myeloma in early 2015 and started on the standard treatment of Revlimid plus the steroid dexamethasone in June. The regimen was one Revlimid capsule per day for 21 days followed by 7 days off. I recall the retail price was about \$600 per capsule in June 2015, but by Jan. 2017 it was \$826 per 15 mg capsule. My Part D insurance and a grant from the Cancer Co-pay Assistance Foundation fortunately covered these exorbitant costs. I went into remission in mid-2017 and was off these meds until mid-2019 when I had to start them again. The retail price of Revlimid was then \$996 per capsule! Again, I'm fortunate to have a grant from the Leukemia and Lymphoma Society to cover this. Even with Part D coverage, I could not afford this medication without a grant. I think it shameful that the manufacturer, Celgene, can get away with this; Revlimid is a slight molecular variation of the infamous thalidomide which has been around since the 1950's. Truly outrageous!

I found out I have cystic fibrosis at age 69. I was first put on Pulmozyme, which carried a copay of \$700 per month. The pharmacist at Johns Hopkins Hospital got me a grant to help cover that cost. I am also now take two pills a day of another CF drug called Kalydeco. The cost of this drug is \$293,000 per year. Thankfully, I got another grant from JHH, or I don't know how I would afford that. Who can afford that kind of price?

**Sara**  
**Kennedyville**

**Mary**  
**Mount Airy**

I am in one of the most at risk groups for COVID as I have diabetes and asthma. I get asthmatic bronchitis quite easily. The nebulizer medicine I was prescribed to have on hand was too expensive causing me not to get it. I do have expired neb meds but it causes my heart to feel like it is beating out of my chest. My cardiologist said to not take it. She said to get medication without the albuterol. I am in the situation that if I get the virus or another round of bronchitis, I don't have the appropriate meds I need.

My fiancé was a renal dialysis patient. One of the many times he was in the hospital and was given several prescriptions, I dropped them off at the drug store and when I went to pick up the medication (about 5-7 of them), the woman said the cost was \$3,000. I was in complete shock. That was just one month's supply. Needless to say, I left those prescriptions right there. On another occasion, he had stopped taking some of the medication because we couldn't afford it and he ended up back in the hospital as a result.

**Claudette**  
**Gwynn Oak**



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# NATASHA

## PRINCE GEORGE'S COUNTY

Envision being the caregiver for your parent and having to tell them you can't afford their medication.

When Natasha took care of her mother before she passed away, she experienced this multiple times. One time Natasha's mother was prescribed a medication for her lungs. When Natasha went to the pharmacy to pick it up, she was shocked to learn it was \$900.

Another time, Natasha went to pick up a medication she filled every month for less than \$50 and was suddenly told that from now on she would have to pay \$200 out of pocket. In both cases there was no way Natasha and her mother could afford these medications at such high prices.

Natasha would like her legislators to know, "It's a hassle and ridiculous. There is no way people, especially those on a fixed income, can afford that." Natasha wants something to be done so that hard working people are able to afford life-saving medication for their loved ones.

**Carl**  
**Silver Spring**

I was diagnosed with Hepatitis B in 2001. My doctor put me on a medicine called Vieread. It is the only thing that works. I will be on it the rest of my life. It costs me \$450 a month. I cannot afford that so the doctor cut the dose in half and the meds still work for me, so I save a little money. I am also a diabetic, and my insulin costs me \$92 a month. Each month, it goes up in price until I have to pay the full price of almost \$200. If I were in Beirut, Lebanon, my insulin would be \$92 for a 90 day supply. Here, \$92 gets me a 30 day supply. I am lucky I have insurance, but I still pay out \$5,647 per year for my meds. I take a total of 9 different prescriptions.

Both my husband and I have problems with high prescription prices. I have asthma and need to use two different inhalers. My husband has diabetes and uses insulin five times a day. We spend over \$100 a month just on his insulin. He also has additional medication that goes with it. All of our medication is much cheaper in Mexico and Canada. Many people go to foreign countries for their meds, but we can't afford to do that! We deserve to afford our meds here in the U.S.

**Mary Lou**  
**Bishopville**

I have liver cancer. I got a transplant and my insurance company did not want to pay for it. I was supposed to start medicine right after surgery but the insurance company said medicine was too much to cover, \$3000.00 for three months. I didn't get the medicine until I returned back to hospital for infection four months later. So when I started the new medicine my body rejected it. It is just so hard trying to figure out if I should pay bills or buy meds.

**Carolyn**  
**Columbia**

I have an 11 year old son who suffers from atypical Hemolytic Uremic Syndrome. He is currently on Soliris (ecluzimab). This drug is one of the most expensive on the market (\$500,000 - 600,000 a year) and because of this so many patients are not able to afford this life-saving treatment. Fortunately, my son was able to get the medicine covered by our private insurance, but this isn't the case for so many people affected by this life-threatening disease. Also, it is currently the only drug available to treat this ultra-rare condition. How is it possible that there is only one drug available at \$500,000 a year?! I simply don't understand how this is allowed to happen.

**Jennifer**  
**Silver Spring**

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# ALLISON

GAITHERSBURG

PATIENTS FOR **AFFORDABLE DRUGS NOW**  
**BLOG POST**

## WE SHOULDN'T HAVE TO CROWDSOURCE THE MEDICATION THAT'S KEEPING US ALIVE.

My name is Allison and I am a resident of Gaithersburg, Maryland. My journey with high drug prices began when I was diagnosed with type 1 diabetes 15 years ago at just 8 years old.

I have always been fortunate enough to have a strong support system within the diabetes community. My childhood best friend was diagnosed just a year before I was. My high school had seven other people who lived with diabetes. When I went away to college at UC Davis, there were over 50 other people with type 1 diabetes. We supported and cared for one another. Living with type 1 diabetes is incredibly mentally draining, and I have always been thankful to have these folks to lean on.

The first time I realized that the drug pricing system in our country needed to change was in college. The other 50+ diabetics and I made a spreadsheet where we would share what supplies/medications we used. It was then that I learned: It was for when people ran out of insulin and needed to ask for help.

There was more than one occasion where I have donated my extra insulin to people who were on their last vial. I could not believe that there would be any circumstance where anyone would have to reach out to their friends for help getting insulin. We shouldn't have to crowdsource the medication that's keeping us alive.

Right now I am fortunate enough to still be on my parents' insurance, where my insulin is very affordable. I continue to give extra insulin that I have to people in the diabetes community who need it. However, I am fearful as to what will happen when I turn 26 and age off of my parents' insurance. That fear stems from stories about people who had resorted to rationing, like Alec Smith, and ended up passing away. Will I soon be the person asking people in the diabetes community to send me spare insulin so that I can stay alive?

In the midst of a global pandemic, the call for change in drug prices is even more critical. For type one diabetics alone, our access to lifesaving drugs is under attack with drug companies attempting to block plans like the Alec Smith Emergency Insulin Act. It is time for the prescription drug pricing system in our country to make some monumental changes -- so no one ever has to worry about if they will be able to afford to live.



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# REVEREND JONES\*

## WORCESTER COUNTY

At age 73, all Pastor Jones wants to do is provide his congregation with prayer and support in their time of need. Unfortunately, the cost of his medication has skyrocketed, leaving him without enough money to pay for gasoline so that he can drive to visit his congregants. Rev. Jones is frustrated that he is now limited in his ability to fulfil his call to serve others.

Even when making this and other sacrifices, Rev. Jones cannot always afford his prescription medications. Rev. Jones and his wife live on a fixed income. After taking Clomipramine for over 40 years to treat his depression, the price suddenly surged to \$300/month with insurance. As a result, Rev. Jones sometimes has to go without his depression medication, causing his symptoms of depression and suicidal thoughts to resurface. He also has to go without his cholesterol medication and worries about the possible health consequences.

Rev. Jones says “The higher prices really changed our budgeting dynamic. I either have a choice of do without the medication or do without something else.” If drug costs do not become more affordable, Rev. Jones is worried that he and his wife may have to sell their home.

Rev. Jones would like his legislators to know “A drug that I need and that might save my life is prohibitively expensive. I just hope that the legislators are sympathetic and will do anything in their power.”

\*Name was changed to protect privacy.

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# ALLISON, A PROVIDER'S PERSPECTIVE

As a social worker at a hospital-based outpatient clinic, Allison works to make sure that her patients have the resources they need after discharge to stay healthy and avoid readmission. “One of my biggest frustrations,” she says, “is when people are admitted for illness that could have been prevented had they been able to afford their prescription medication.”

Allison frequently has patients that cannot obtain their prescriptions because they are too expensive. Even with insurance, many can't afford their medications for chronic diseases such as DM (diabetes mellitus), COPD (chronic obstructive pulmonary disease) and CHF (congestive heart failure). Insulin pens (e.g., Lantus, NovoLog), inhalers (e.g., Breo, Advair) and anticoagulants (e.g., Eliquis, Xarelto) are among the most common medications Allison's patients have difficulty getting. Without these medications, patients are at risk for serious complications that could put them right back into the hospital. “If they can't afford their medications, that is a barrier to patients successfully managing their chronic disease. That's something that continues to bring them back into the hospital.”


Allison recalls working with a 75-year old man with diabetes who was having difficulty regularly obtaining his insulin pens. The patient's wife had entered the donut hole and they were spending much of their fixed income on her medications. The team considered prescribing vials of insulin, which are more affordable. However, the patient lacked the dexterity to accurately draw up his medicine. Insulin vials were not a safe option. To get the patient through the year, Allison and the team decided to switch the patient to an oral medication that can be obtained for free from a local pharmacy. “We brought him back within a week to check on him. He would do better on insulin, but it was either that or nothing.” Allison worries about the long-term effects for this patient without insulin, noting he continues to be at high-risk for emergency hospitalization.

Allison would like legislators to know “I don't understand why some medications cost so much. The cost of a hospitalization is much greater than the cost of many of these medications. We are smart enough to make these medications and we are smart enough to make them accessible.”

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# DON

## POTOMAC



Don suffers from a bone marrow disorder on the same spectrum as cancer, and will have this disease for the rest of his life. His life-saving medication, Jakafi, would cost over \$13,000 each month without health coverage. Thankfully Don has insurance, but even so, at the beginning of each year he still has to pay around \$2000 in Catastrophic Care for his medication and then around \$690 per month thereafter. Without insurance and savings, Don would not be able to afford this medication at all and would ultimately suffer the worst consequences. “You don’t have a choice when you have an illness but to seek treatment,” Don said. Without a generic version or an alternative treatment there doesn’t seem to be a limit to the drug manufacturer’s ability to raise prices. In the 4 years Don has been taking Jakafi, the price has risen from \$8738/month to \$13,058/month.

Don is thankful he can take his medication but knows many are less fortunate. He is continuously frustrated that drug manufacturers get away with setting high prices and extending the patents that make creating generics impossible. “Instead of coming up with new ways to cure diseases, they are coming up with new ways to make profits.”

Don considers this medical condition a critical factor that has to be taken into account when making life decisions. He is glad to hear that Maryland’s lawmakers are tackling the high cost of prescription drugs. “The problem is bigger than my out of pocket cost. Why should the Incyte Corp have the unrestrained right to charge what they wish for this medication when I have no choice but to take it? This price goes well beyond the cost of manufacturing including the research and development.” Don supports strong regulation of pharmaceutical costs and urges all legislators to support the Prescription Drug Affordability Board.

# I LIVE AT THE MERCY OF DRUG PRICES.

I'm Kami Guiden, from Silver Spring, Maryland, and I'm 33 years old. For just over 20 years I've lived with Crohn's disease, an incurable and chronic and inflammatory illness of the gastrointestinal tract. I also live with celiac disease.

Affording my medications to manage my conditions is always on my mind. I absolutely have to maintain a job with sufficient coverage to pay for my expensive drugs. But the drugs I need are so costly; job to job, I live at the mercy of drug prices and worry about if and how I will be able to afford my next infusion or refill. I've had to wait for my paycheck to deposit before getting refills, ration my prescriptions, and stop taking my drugs altogether because of the prices. At one point I owed \$1,500 for the anti-inflammatory drug Mesalamine, a generic version of Pentasa, to treat a flare-up, and I just couldn't afford it. After I lost a job, I had to stop taking an important and expensive Crohn's treatment, Remicade. When I got a new job and wanted to re-start the medication, I was terrified not only of the drug's price but to ask for the time I needed for infusions. During the pandemic, people are fearful about endangering their employment with any special requests. It's a lot to deal with on top of worrying about drug prices for a person already managing multiple chronic conditions. Just thinking about any of it is so incredibly stressful.

For now, I'm not taking any of my medications. I'm waiting. Waiting because I'm afraid of catching COVID-19 at my regular checkups, because I'm afraid to ask my employer for the time I need to take care of myself, and because of worry that I won't be able to afford my drugs at all.

People like me don't have more time to wait for our lawmakers to make the reforms we need to lower drug prices. We shouldn't have to.



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# SARAH DIANE

## BALTIMORE COUNTY

"I was passing out. I was on an all-liquid diet. I barely had the ability to get out of bed every morning. I was in constant pain. I was always either freezing or had a fever," says Sarah Diane.

This was Sarah Diane's life before her doctor finally figured out that she had an autoimmune disorder called Auto-immune Autonomic Ganglionopathy (AAG). It affects her breathing, swallowing, digestion, pain, temperature control, blood pressure and more. Before she received her diagnosis, she was worried she wouldn't be able to continue to work.

After diagnosing Sarah Diane, her doctor prescribed the drug Gamunex. After starting treatment, the difference in her life was incredible. Sarah Diane says that without her medication "I would probably now be on disability. Instead I am able to be active in my community. I'm not bed-ridden. I can work and pay my taxes and be what's considered a 'good citizen.'"

The catch? Without insurance, Gamunex would cost more than \$160,000 per year. Sarah Diane's doctor cautioned that she could expect to face a battle with the insurance company to cover the drug, based on his experiences with other patients. But instead of drawn out negotiations, Sarah Diane and her doctor were pleasantly surprised to find that her insurance immediately paid for it, which Sarah Diane attributes to her employer offering very good health coverage.

Despite her coverage, the high cost of Gamunex still worries her. Before getting her current health coverage through her employer, there was a time that Sarah Diane struggled to pay for her asthma medication, Xopanex. She had to make sacrifices in other parts of her life, buying less healthy food and paying off her student loans more slowly in order to afford the medications she needed.

Even today, with great health coverage, Sarah Diane says "I know I'm expensive medically. I'm very aware of that. I'm afraid to ever leave my employer's insurance. I'm not saving as much for retirement because I need a medical emergency fund. Whenever I think about having a family, I think about how the medical costs will affect their lives. It affects everything from daily life to planning for the future."

Sarah Diane would like her legislators to know, "The rising prescription drug prices are taking advantage of very vulnerable people who we should be helping rather than helping someone else make a lot more money. It sends the message that the health of people is less important than making money."

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# TESTIMONY

## BELOW IS A SELECTION OF PATIENT TESTIMONY FROM LEGISLATIVE HEARINGS IN 2018 & 2019

Testimony of Ms. Anne Rowe  
IN SUPPORT OF SB0759/HB0768  
March 6th, 2019

Hyattsville MD  
20784

Good Afternoon Madam Chair and Members of the Committee. My name is Anne Rowe. I am a constituent of District 47a and I am speaking today in support of SB0759/HB0768, the Prescription Drug Affordability Board.

In 2001, I was diagnosed with a bleeding disorder called von Willebrands Disease. This means it takes longer for my body to form and strengthen clots. Von Willebrands is closely linked with another bleeding disorder called Hemophilia. People diagnosed with hemophilia don't make enough clotting factor, or any at all.

Fortunately, there is a medication available to us. The medication is clotting factor, derived from actual blood. It cannot be created synthetically, and there are no biosimilars, which makes it a Tier 4 medication.

It allows us to live a normal life, however, it comes at a cost. One person with hemophilia or severe von Willebrands could spend up to \$288,000 annually without insurance or emergencies. People with severe von Willebrands and Hemophilia take their medication to treat prophylactically, the same way someone with high blood pressure would.

It is difficult to explain to insurance companies, that even though our prophylactic care is expensive, it costs less than having an emergency, requiring additional medication and possible ambulance transport and treatment in an emergency room facility.

I fear the day that I am no longer eligible for my parents coverage. I come with a pre-existing condition and very expensive medication. The board that this bill will establish, would take one fear off my mind. I will not have the fear of choosing healthcare over food. Which is a reality to many. A reality that this board would reverse.

I am also a Paramedic. I have seen many patients who cannot afford their prescriptions. A common example are patient's with seizure disorders, when they cannot afford their anti-seizure medications, they seize. If its in public, someone will call 911 for them. They are then transported to the emergency room to receive treatment. Now, not only do they have to worry about paying their prescriptions, they now have to add an ambulance transport bill and emergency room bill.

If these patient's could afford their prescriptions in the first place, they would not have to worry about ambulance transport and emergency room bills. This board would vastly improve hundreds of lives. The board would provide better quality of life to people. It would improve their capability to work and care for their community and themselves.

I understand that the board is not the answer to all of the problems related to health care. This would be one step in the right direction. Let us make health care about people again. I want to thank Senator Klausmeier and Delegate Pena-Melnyk for introducing this bill. This will help to ensure that life saving medications can still save the lives of your constituents.

Thank you for your time.

**TESTIMONY OF JESSICA GORSKI**  
**Maryland WISE Women, Healthcare Huddle Co-Facilitator**  
**IN SUPPORT OF SB 1023,**  
**THE DRUG COST COMMISSION**  
**BEFORE THE SENATE FINANCE COMMITTEE**  
**February 28, 2017**

Mr. Chairman and Members of the Senate Finance Committee, thank you for this opportunity to testify in support of the SB 1023, for the creation of a Drug Cost Commission. My name is Jessica Gorski, and I am a member of Maryland WISE Women, an organization composed of over 600 women in Anne Arundel County. We advocate for representation consistent with our mission from our politicians and commit ourselves to modeling the values of inclusion, tolerance and fairness that we seek as we support each other to make our voices heard. I am the co-facilitator of the Health Care Huddle, a group dedicated to ensuring Marylanders' have access to quality, affordable care. Recognizing that the rising prices of prescription drugs are a major factor in soaring premiums and increasing health care costs, we have made SB 1023 one of our legislative priorities.

The high costs of prescription drugs have made it increasingly difficult for Marylanders to access the medications that they need. Prescription drugs account for about 17 percent of all health care spending in the United States; that's more than \$370 billion per year, exceeding all other countries. This total is the result of not only the high number of prescriptions written but also the high rates of the drugs prescribed. The creation of a Drug Cost Commission is an important step in addressing this issue. This legislation will help make drug pricing more transparent, and would ensure fair rates for very expensive prescription drugs. Not only are the costs of prescription drugs a burden to the state and consumers, they are an issue that has touched my family personally.

My eldest daughter Mary, a thriving sophomore in the South River High School STEM program, has a spontaneous genetic mutation of Neurofibromatosis 1. In addition my husband, Billy, suffered the loss of his right eye due to an acanthamoeba and underwent six surgeries in

order to try to save it before the final seventh surgery for enucleation in 2009, during which he received an orbital implant and subsequent ocular prosthesis.

Since then it was discovered in 2012, Billy suffered further from third degree heart block, due unfortunately to a terminal diagnosis of advanced cardiac sarcoidosis. He underwent 3 heart surgeries in three years; implanting a pacemaker, then a dual pacemaker ICD and finally a three lead ICD dual function pacemaker. Our medical bills are extensive every year for continued care, testing and prescription drugs. The cost of the eye drops for Billy during one 9 week period in 2009 exceeded \$10,000 that we had to pay out of pocket, as they were not covered with our insurance. That was just a small portion of the costs incurred during just that one illness. In addition, I need an EPI pen for severe allergies that cause anaphylaxis reactions and will result in my death without immediate intervention. As you know the price of EPI pens were soaring until it hit the radar of elected officials. Some Marylanders had to make the decision between replacing their EPI pen when it expired, or paying for their groceries and utility bills that month. I am thankful for oversight---this oversight allowed me to refill my EPI pen prescription when it expired this fall, for only my co-pay cost of \$10. This oversight continues to help save my life.

My life, my daughter's life, and my husband's life - all lives - are important and I welcome and applaud all medical innovation and research. It is recent innovations that led to providing a viable way for my daughter to have children of her own one day, after us being told when she was 4 years old she would never be able to. It is that continued drive to find lifesaving solutions I pray will, someday in the very near future, lead to a discovery that will save my husband's life. However even with my desire for continued progress and advancement, no one's access to affordable lifesaving prescriptions should be considered as possible infringement in the heavily profit driven pharmaceutical arena. A low cost/high utilization model stands to make pharmaceutical companies as much money as a high cost/low utilization model, since more people will be able to afford medications and will purchase their products. Industry image will also be improved, and big pharma stands to benefit from an improved public image.

I would like to thank Senator Conway for introducing this lifesaving legislation, and I am glad to be able to join the broad and diverse coalition of groups who wish to see this bill enacted. As a representative of Maryland WISE Women and someone who needs this legislation, I urge a favorable report of SB 1023.

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Testimony in Support of HB 1194  
March 6, 2018  
Elyse Lash, District 17 Constituent

3 years ago I was visiting my dad in Florida for his 80th birthday. No sooner did I arrive that I received a phone call no one ever wants to receive -- you need to come home immediately, your daughter is in the ICU. And so began our journey with type 1 diabetes. My daughter, Rachel, was in her junior year in college and looking forward to graduating, getting a job and living on her own. She was able to accomplish the first two, but living on her own has proven difficult given the costs of managing her diabetes.

Rachel has had to overcome a lot these past three years. First, she had to learn about the disease and understand that it was not her fault that she got diabetes. Then she had to learn what insulin was, how to administer and most critically, how much and when she needed to take it. She initially tried to use insulin pens. But she found this to be very disruptive to her life style as she was constantly excusing herself to administer her dosage. Her levels were also fluctuating too much each day. She then moved to the pump and also got a CGI. These devices alone cost over \$4,000 and have a short shelf life. And if all of this wasn't enough, she had to schedule many doctor visits as now she has to monitor her eyesight and her foot care, in addition to her glucose levels. This is all more than any person should have to deal with.

Rachel graduated this year and should be celebrating her success in finding a job working with special needs children. But instead of enjoying her entry into the workforce, she is stressing about the cost of her insulin. With the switch this year to a high deductive health plan, it means we are paying full price for her prescriptions. A few weeks ago, Rachel called our mail order company to place an order for her insulin. Of course as a millennial, she was doing this late at night. She came running into my room to wake me up. She was just told her 90 day supply of insulin would cost over \$1200 and didn't know what to do. It was almost a rhetorical question. She had no choice but to order the insulin. Without it, she would die. She doesn't have the choice on what to cut back on or to take something else instead. She needs insulin to live.

The cost of insulin has more than tripled over the past decade. For a drug that was developed in 1923, this is insane. People are dying from complications from diabetes and sometimes it's related to the people modifying their insulin levels because of the cost of the drug. No one should have to worry that they will die because they can't afford a drug that has been around for almost 100 years. This is a health imperative!

People like my daughter should be able to live independent lives without the constant worry about how they will pay for their medication.

Please help us change this narrative -- help us keep these drugs affordable to all.  
Please support HB 1194.

TESTIMONY IN FAVOR OF SENATE BILL 1023  
BEFORE THE SENATE FINANCE COMMITTEE  
By Barbara Gruber  
February 28 , 2018

Mr. Chairman and Members of the Senate Finance Committee, I greatly appreciate the opportunity to express my support for Senate Bill 1023. My name is Barbara Gruber. I am an artist, an adjunct professor at local colleges and universities, and an instructor in local schools and arts institutions.

I have asthma, an endocrine disorder and coronary artery disease-all require life-saving daily medication.

The ACA saved my life. For the first time EVER in my adult life I had health care and insurance that was effective and affordable without being in a good employer group. My coverage through the Maryland Health Connection for those three years, while premiums increased incrementally, was affordable and included doctor visits, prescriptions and medical tests.

Since President Trump has assumed office, my premium costs have risen 50%. The plan I was on was discontinued and, for the first time I am fighting Carefirst and CVS right now so they will continue to cover the rescue inhaler and endocrine medicine I need. They also refuse to cover other prescriptions. Those medicines would improve the quality of my life, but my life does not depend on them. I am fighting for the prescriptions needed for mere survival.

These are not new drugs. The endocrine medicine I take has been around since the 1930,'s, the rescue inhaler has been around since 1986. The drug costs, once affordable even without insurance, have tripled, and in the case of the inhaler they have almost quadrupled in the last few years, remaining at a steady 200% increase this past year and the year before. In previous years, insurance would refuse to cover the inhaler initially, but would cover it immediately after receiving my doctor's preauthorization. Insurance would cover the endocrine medicine, but at a greater cost. It was however, still affordable.

This year, however, they have refused to cover the costs of both these medicines. My doctor has submitted three appeals. In the case of the inhaler, Carefirst/CVS will cover the drug-but they will not cover the delivery method that works. The covered mechanism clogs, rendering the medication undeliverable. It is like getting a lifesaving prescription in a bottle that I cannot open.

Senate Bill 1023 would create a commission that would review these cases and make sure that unreasonable prices could not be charged for medication, especially medicine that has been on the market for a long time.  
I hope you will vote for Senate Bill 1023, so that medicine Marylanders need will be affordable and keep us healthy, productive and alive.

Thank you.

TESTIMONY IN SUPPORT OF HB 1194: DRUG COST COMMISSION BILL  
BEFORE THE HOUSE HEALTH AND GOVERNMENT OPERATIONS COMMITTEE  
PAUL AND JANET BOGNASKI  
MARCH 6, 2018

I am living with Parkinson's disease, and my wife Janet is my caregiver. The last thing we want to worry about is whether or not we are getting a fair price for the medications I need. Why would one drug cost \$300 at CVS but only \$80 from mail order Care Mart? Even if it is the wholesalers and retailers causing the confusion, this bill will remove the mystery from the system and create much needed transparency and accountability. I take 33 pills every single day to maintain my mobility and quality of life. We have Federal Blue Cross and Blue Shield, Medicare, and assistance from manufacturers based on our income. Last year my medications still cost us \$2,000. We have to find that money, sort through inconsistent pricing, and file for assistance from manufacturers. Even after all that, prices go up every year. We cannot continue the way we are going. My wife and I are retired. We worked our whole lives, and now I am living with Parkinson's. Why is there no protection for us? Why is there no transparency or consistency? We urge you to support HB 1194 so that no one else in Maryland has to go through what we are struggling to afford. Thank you.

TESTIMONY IN SUPPORT OF HB 1194: DRUG COST COMMISSION BILL  
BEFORE THE HOUSE HEALTH AND GOVERNMENT OPERATIONS COMMITTEE  
MARIE DEANGELIS  
MARCH 6, 2018

Thank you for allowing me the opportunity to support HB 1194, which would help so many people be able to afford their prescription medications. I have had Parkinson's disease for four years, and I know all too well just how much of a burden the cost of these medications can be. I take ten pills every day. I have heard that pharmaceutical companies say that their prices actually decrease over time. I have only seen my prices increase. I would love to see more generic alternatives, but big businesses block lower cost drugs from making it to the market. Marylanders should not be choosing between eating and taking their medicine. I hope you will support HB 1194. Thank you.

TESTIMONY IN SUPPORT OF HB 1194: DRUG COST COMMISSION BILL  
BEFORE THE HOUSE HEALTH AND GOVERNMENT OPERATIONS COMMITTEE  
TED WILSON  
MARCH 6, 2018

I have been a Physician's Assistant for forty years. Over the years, many medications move from behind the counter to over the counter. This is a problem for people because insurance often does not cover over the counter medications even if the person needs them. Examples are stomach medications and gastric reflux medications. I have known people over the years to send their patients to Canada to buy drugs because they are absolutely unaffordable in the U.S. There needs to be a fair, transparent process by which drug companies have what they need to manufacture new drugs but older people are not paying the price dearly. Pharmaceutical corporations always seem to cite the need for money to fund research and development, but we already support that with NIH tax dollars. What good is innovative medication if no one can afford to take it? Please support HB 1194, thank you.

Susan Olsen

Cambridge, MD 21613

March 6, 2019

*Testimony in Support of HB768, Drug Affordability Board*

To: Hon. Shane Pendergrass and members of the House Health and Government Operations Committee

From: Susan Olsen

Madam Chair and members of the committee, thank you for the opportunity to testify in support of HB768 which will create a prescription drug affordability board. I am a 50% disabled Navy veteran. I was medically discharged from the Navy in 1985 for a debilitating chronic pain condition. Despite this unrelenting pain, I became an English teacher and was able to work for sixteen more years until I was forced to medically retire from the state of Maryland in 2003.

I would like to thank Delegate Joseline Pena-Melnyk and Senator Katherine Klausmeier for introducing this bill to create a Prescription Drug Affordability Board. House Bill 768 will help people like me to manage their medical conditions. I ask for a favorable report on this bill. Thank you for your consideration.

I regularly take more than fifteen medications to deal with my medical problems. I am more fortunate than most people in our state because the VA covers most of my prescription drugs. However, you may not realize that many of the more expensive drugs are not on the VA formulary. When that happens, veterans often must purchase these drugs on their own. I have been in that position with several medications.

Most important, I have found significant pain relief from duragesic patches containing a low dose of pain medication. This makes it possible for me to live a more normal life including being able to sleep through the night without having to pop pain pills every four hours. Unfortunately, this medication is very expensive, and the VA only prescribes it for the most serious medical conditions.

Because I was able to work for the state after my medical discharge, I have SilverScript pharmacy coverage; however, I just received a notice telling me that SilverScript will no longer cover this medication. I will have no choice but to pay for it on my own. This is hard for me

because I had to retire early due to my medical problems and do not have much in the way of financial resources.

It is frightening to me that even people like me who have excellent prescription drug coverage are more frequently having to pay for their medications because the price has gone up prohibitively. I have been battling medical problems created through no fault of my own when I served in the military. This has limited my ability to work; therefore, my financial resources are less and more unstable than my peers.

I hope you will consider that the pharmaceutical companies who are arbitrarily raising prices on medications are making those life-saving drugs unavailable even to those of us who have good medical insurance. I fear that the VA and Medicare as well as private insurance companies will no longer be able to provide many medications for those who require them.

Therefore, I am humbly requesting that you support HB768.

Sincerely yours,

Susan Olsen



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Testimony of Andrew Chalk  
IN SUPPORT OF HOUSE BILL 768  
Prescription Drug Affordability Board  
Before the House Health and Government Operations Committee  
March 6, 2019

Madam Chair, Madam Vice-Chair, and Members of the Committee, thank you for this opportunity to testify in support of House Bill 768. I am Andrew Chalk, and I'm a resident of Baltimore County.

The increasingly high costs of prescription drugs have made it difficult for many Marylanders, including me, to access the medications they need. Insulin is nearly a century old, and yet the prices have increased astronomically. When patients with diabetes cannot afford their medications, there can be devastating consequences – rationing of medications, health complications, financial hardship, and even death. House Bill 768 is a positive step towards ensuring all Marylanders like me have access to affordable prescription drugs they need to survive.

When I was 11 years old, I fell into a diabetic coma from ketoacidosis, which is caused by having extremely high blood sugar levels. This is how my family and I found out that I have type 1 diabetes. I am lucky to be alive. In order to maintain my health, it is essential that I take insulin shots 3 to 5 times daily. This health regimen cost me \$50 per month five years ago, and now costs me over \$200 per month.

Now that I'm 26 years old, I'm required to pay for my own health insurance, which is not provided by my employer. I joined the Maryland Health Exchange. Between the cost of my health insurance, medications, school loans, car payment, car insurance, groceries and rent, I am barely surviving. For the past two months, I have had to ask for an extension on my rent, because I have had to pay more than expected for my insulin. In January, my insulin was more expensive than anticipated, because I did not realize that Toujeo, the long-acting insulin that has done the best job of helping me maintain blood sugar control, was not on Kaiser Permanente's formulary list. This is why I now pay over \$200 per month for my diabetes medications.

Last summer, I ran out of insulin while on vacation. My doctor called in a prescription for 1 insulin pen to get me through the week. It cost me \$150 because it was "too soon" to fill my prescription. It should never be "too soon" for a person with type 1 diabetes to get insulin. I could tell you many horror stories about my own ordeals in doing the best I can to pay for my life-saving drugs. One of my biggest fears is that I'll miss a health insurance payment and won't have coverage anymore. My drugs without insurance would cost me over \$900 per month.

Pharmaceutical companies are out of control. In January alone, Eli Lilly spent 17.5 million dollars on advertising for a single drug. That is enough money to cover over 85,000 vials of their insulin, Humalog[1], which is one of the drugs I take. The patent for insulin was sold for \$1 in 1923 so that it would be available to people with diabetes for free. The pharmacy industry took advantage of that goodwill.

I would like to thank Delegate Joseline Peña-Melnyk and Senator Katherine Klausmeier for introducing this important legislation. House Bill 768 can help ensure that prescription drugs remain in reach of all Marylanders, because drugs don't work if people can't afford them. I ask that you support this lifesaving bill. Thank you for your consideration.

TESTIMONY IN SUPPORT OF HB 1194: DRUG COST COMMISSION BILL  
BEFORE THE HOUSE HEALTH AND GOVERNMENT OPERATIONS COMMITTEE  
MIKE MCQUAID  
MARCH 6, 2018

I live in Howard County Maryland, and I am the pastor of Living Grace Lutheran Church. I am also living with Parkinson's disease. Thank you for the opportunity to testify in support of HB 1194 to lower the cost burden of prescription drugs for people in our state.

My wife and I carefully plan every year in order to make our money stretch as far as it can for our medical care and prescription drugs. The inconsistency of prices between different retailers is confusing and difficult to manage. This bill may seem too myopic at first, but it will create the transparency we need to lower costs throughout this broken system. At Target, our medications cost significantly more than if we get mail order Express Scripts. You must have the tenacity and wherewithal to shop for the lowest prices. Many people do not have that capability. For only the four medications that I am prescribed, my insurance plan has already paid \$2,782.81 in 2018. If I did not have insurance, my drugs would have cost me \$7,632.10 in 2017. Drug prices may seem like a relatively small piece of health care spending, but is huge for us and continues to grow exponentially. Plus, bigger drug companies make it impossible for lower cost drugs to make it to the market. Even with our insurance, which is Aetna PPO, we spent both of our flex spending accounts in 2017, plus an additional \$600 out of pocket. That's a total of \$4,200. Drug corporations use coupons and copay assistance as an excuse to drive up costs, but we do not qualify for that assistance. We lose both ways.

These numbers are too high, and Maryland has the power to change that. This bill is a much needed compromise between pharmaceutical companies, pharmacies, and consumers. We need protection from unnecessary price hikes and the labor of hunting for the best prices. All prices should be fair. For these reasons, I urge you to support HB 1194. Thank you.



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