



Myths vs Facts



Medicine for a hemophiliac can range anywhere from \$500,000-\$1,000,000 annually.

Patients with rare diseases rely on Patient Assistance Programs offered by pharmaceutical companies and non-profits to meet their deductible requirements, which they often hit the first month or two of the year. These payments are not given to the patient, but directly to insurance. These are different than the coupons that you might use at a local pharmacy.

Recently, insurance companies have implemented Copay Accumulators on many health plans, and are NOT accepting this patient assistance to count toward patients' deductibles.

Think of it this way: You are a college student with a \$10,000 tuition bill and have a \$5000 scholarship. The University accepts the \$5000, but still makes you pay the full \$10,000 bill (thus receiving \$15,000 instead of \$10,000) because you personally didn't pay it. Is that fair?

This is happening to patients all over the US, including North Dakota. Health plans will tell you patients are driven to high cost name brand drugs. **Patients with bleeding disorders do not have a generic option.** They will tell you we have no skin in the game, no personal costs -we still pay our premiums, multiple doctor visits, lab work, and ancillary supply costs.

To date, 21 states and Puerto Rico have enacted copay accumulator legislation. Help us add North Dakota to the list!

[Scan this to see the full list -->](#)



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## 💧 Bleeding Disorders Awareness

### **Facts:**

- Hemophilia & von Willebrand Disease (VWD) are bleeding disorders caused by a protein deficiency required for blood to clot. Patients use products made from either human plasma or animal cells that replace proteins and control clotting.
- Many bleeding disorder patients were exposed to HIV and viral Hepatitis (B&C) prior to 1992 when all blood products were screened.
- It is estimated that 70% of all individuals with bleeding disorders who used factor products before 1987 may have been exposed to HIV and as many as 90% were exposed to Hepatitis C.
- About 20,000 people are affected by hemophilia in the U.S. and approximately 1% of the population is affected by VWD.
- Bleeding Disorders Alliance of North Dakota (BDAND) serves about 300 individuals and families who live with bleeding disorders in North Dakota and NW Minnesota.

### **Challenges:**

- Access to insurance, discrimination issues, access to medications, co-infections.
- High annual medication cost, many with costs that exceed \$500,000.
- Patients live with multiple chronic conditions and have unique care issues.

**For more information about bleeding disorders, or to arrange a meeting, please contact:**  
Bleeding Disorders Alliance of North Dakota, Emily Ouellette, Executive Director

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# Copay Accumulator Adjustors Clearing Up the Misconceptions

Copay Accumulator Adjustment Programs are affecting a tremendous number of patients with a diverse set of health conditions – most affected are those with chronic and/or rare disorders.

- Allowing Health Plans to utilize Copay Accumulator Adjuster programs leave a lot of patients vulnerable and unable to access their medication. Patients are choosing between paying their rent/mortgage, putting food on the table, or paying for their medication.
- Bleeding Disorder patients meet their OOP maximum the first month or two of the year. They depend on Copay Assistance Programs to help them meet their deductible.

The health plans will argue this is manufacturers “gaming” the system or trying to preserve market share to drive more business to higher cost drugs.

- In this version of the bill language, the medicine either doesn't have a generic available OR if it does, the plan still has control over whether the patient can access it through their internal utilization and appeals processes.
- Bottom line is that health plans should be designed to ensure that the most medically appropriate medicine that is covered by the plan is what is approved.
- And if this “gaming the system” argument is truly the case, why did health plans create these accumulator adjustment programs specifically in the specialty areas where there are no generic equivalents?

There is a misconception that copay coupons allow patients to circumvent the formulary.

- Health plans still determine:
  - What is on or off formulary and what is preferred and non-preferred.
  - The utilization processes that patients and their doctors must navigate to ask for any exceptions to a preferred drug or for something that not on the formulary.
- Patients should not be penalized for correctly working through the process their plan has laid out for them, whether that is the copay and out-of-pocket costs they have to pay OR the process to gain approval to get access to a medicine that is prescribed for their condition.
- Keep in mind that copay cards are just a patch for a broken system overall; Current health plans and drug prices make it difficult for patients to obtain their medication - manufacturers and some non-profits are providing copay assistance because patients can't afford their out-of-pockets on their medicines.

Costs rise when patients don't have access to their specialty medication.

- Patients experience complications and disease progression, sending them to the Emergency Room, needing avoidable surgeries, and additional treatment they would not have needed had they had access to the medication in the first place. They often miss school and/or work. • A patient's mental health also suffers when they have to deal with complications of their disease, and navigate health plans.

Health Plans say patients have 'no skin in the game' if they rely on Copay Assistance Programs

- Patients still pay the cost of multiple doctor visits, lab work, and ancillary supplies for their infusions. Many patients also pay for physical therapy and other services to treat their bleeding disorder.

For more information, please contact:



**BDAND**

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NATIONAL  
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Please Support HB 1216 in North Dakota!



## Patients for Prescription Access



# Copay Assistance Helps Patients

## Copay Accumulators Hurt Patients

Copay assistance provided by pharmaceutical manufacturers and nonprofit organizations provide a financial lifeline for many people living with chronic conditions who need lifesaving medications.

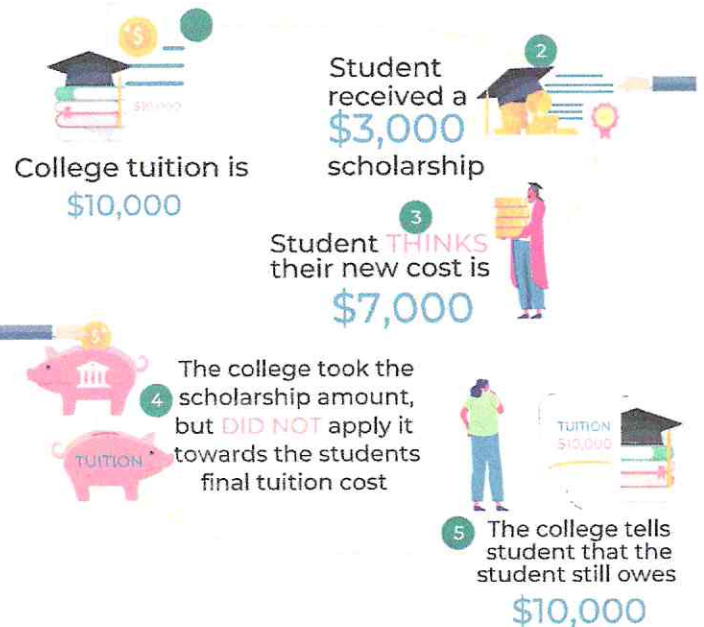
Insurers have raised deductibles, increased use of coinsurance, and added new prescription drug formulary tiers.

### Insurers Double Dip While Patients are Denied Life-Essential Medications:

Many Insurers and PBMs are now utilizing copay accumulators that stop copay assistance from counting towards a patient's deductible and maximum out of pocket spending. These practices are creating significant financial and health issues for patients.

- All of the money paid through the copay assistance, which was intended to help the patient, goes directly to the health insurance company.
- Copay accumulators allow the insurance company to double dip and get paid TWICE - once from the copay assistance and then again by patients' deductibles
- This jeopardizes the health of patients and can ultimately result in the use of more expensive health care services, disability, unemployment and loss of independence.

### Imagine if this same practice was applied to college tuition...



\*The college receives \$13,000, when the bill was only \$10,000.

## Call to Action

Lawmakers must pass legislation to prevent harmful and unfair copay accumulator policies, an emerging change in insurance plans.

As of Jan 2025, 21 states (and Puerto Rico) have enacted laws banning payer and PBM use of copay accumulator programs: AR, AZ, CO, CT, DE, GA, IL, KY, LA, ME, NC, NM, NY, OK, OR, TN, TX, VA, VT, WA, WV) DC, and Puerto Rico



We must "Stop the Double Dip"

Assumes law impacted premiums the year after it was passed.

Key:

Blue cells = States with copay accumulator adjustment bans passed between 2019 and 2022;

Orange font = Year law impacted premiums

Marketplace Average Benchmark Premiums by State Copay Assistance  
Accumulator Bans in Place by 2023

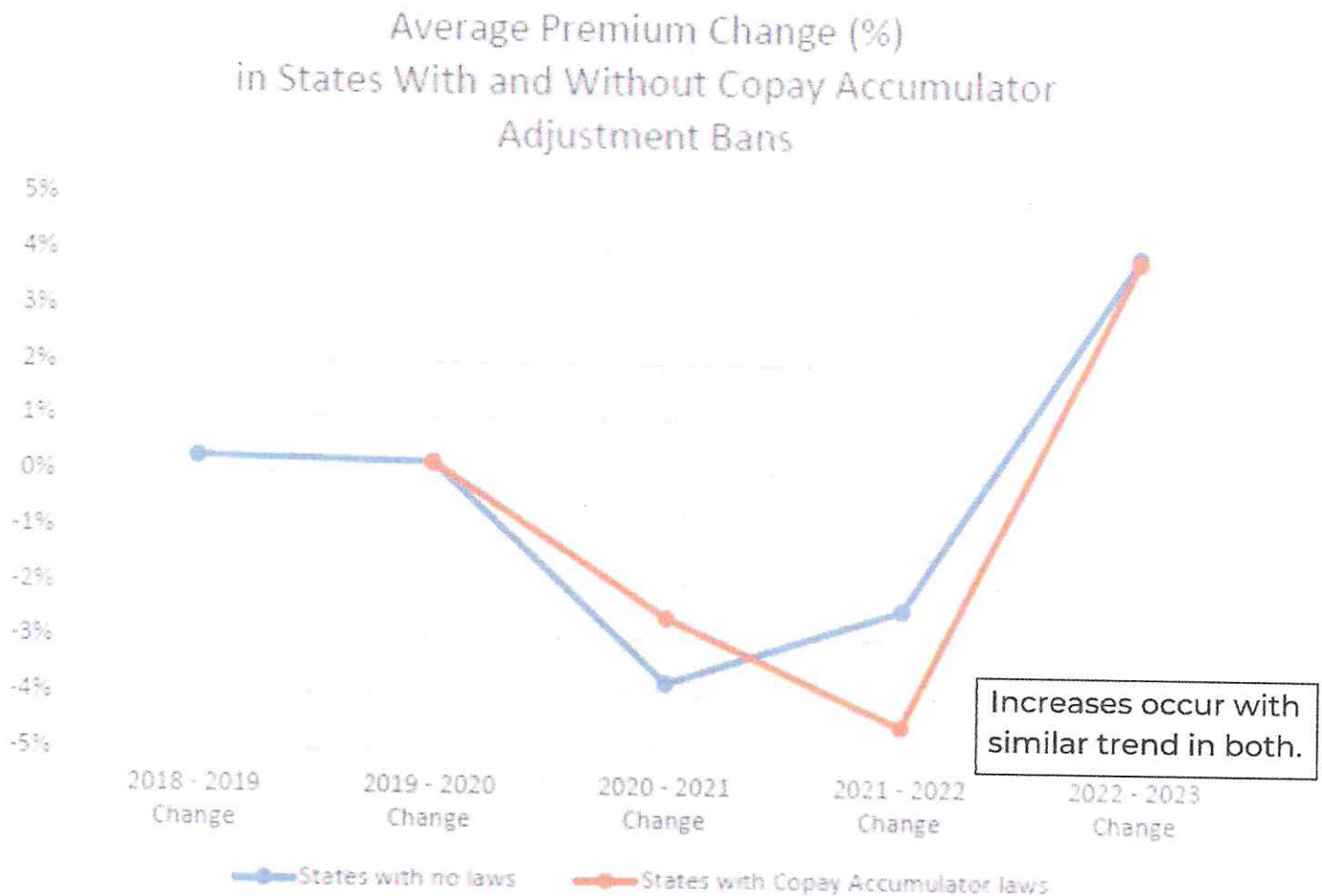
States	2018	2019	2020	2021	2022	2023
Arizona	\$516	\$471	\$441	\$431	\$430	\$411
Illinois	\$486	\$478	\$471	\$471	\$418	\$411
Virginia	\$535	\$555	\$521	\$477	\$320	\$311
West Virginia	\$545	\$596	\$478	\$453	\$382	\$414
Georgia	\$483	\$487	\$463	\$471	\$344	\$411
Arkansas	\$364	\$378	\$365	\$394	\$347	\$410
Connecticut	\$545	\$475	\$570	\$580	\$481	\$411
Kentucky	\$422	\$460	\$471	\$476	\$387	\$410
Louisiana	\$474	\$454	\$500	\$545	\$541	\$581
North Carolina	\$627	\$618	\$558	\$516	\$304	\$311
Oklahoma	\$659	\$696	\$601	\$554	\$438	\$510
Tennessee	\$743	\$548	\$511	\$466	\$311	\$411
Delaware	\$589	\$684	\$548	\$540	\$548	\$510
Maine	\$588	\$544	\$513	\$440	\$427	\$410
New York	\$505	\$569	\$610	\$597	\$592	\$410
Washington	\$336	\$406	\$391	\$388	\$396	\$310
Alabama	\$558	\$546	\$553	\$590	\$597	\$567
Alaska	\$726	\$702	\$724	\$675	\$712	\$762
California	\$430	\$439	\$430	\$426	\$417	\$482
Colorado	\$470	\$488	\$358	\$351	\$350	\$350
District of Columbia	\$324	\$393	\$414	\$413	\$307	\$428
Florida	\$466	\$477	\$468	\$457	\$456	\$471
Hawaii	\$438	\$493	\$474	\$478	\$484	\$469
Idaho	\$478	\$495	\$520	\$485	\$481	\$425
Indiana	\$339	\$339	\$387	\$421	\$395	\$397
Iowa	\$713	\$762	\$742	\$523	\$502	\$484
Kansas	\$518	\$552	\$502	\$491	\$450	\$471
Maryland	\$487	\$419	\$397	\$347	\$328	\$336
Massachusetts	\$316	\$332	\$343	\$363	\$309	\$417
Michigan	\$381	\$383	\$360	\$347	\$340	\$362
Minnesota	\$385	\$326	\$309	\$307	\$327	\$335
Mississippi	\$519	\$521	\$487	\$459	\$448	\$461
Missouri	\$509	\$499	\$483	\$479	\$442	\$473
Montana	\$525	\$561	\$483	\$471	\$433	\$477
Nebraska	\$767	\$838	\$721	\$689	\$595	\$550
Nevada	\$432	\$410	\$374	\$393	\$383	\$386
New Hampshire	\$475	\$402	\$405	\$357	\$309	\$323
New Jersey	\$413	\$352	\$392	\$405	\$424	\$441
New Mexico	\$414	\$365	\$345	\$399	\$399	\$445
North Dakota	\$377	\$457	\$383	\$491	\$497	\$475
Ohio	\$371	\$380	\$373	\$375	\$375	\$413
Oregon	\$414	\$443	\$446	\$437	\$444	\$462
Pennsylvania	\$575	\$484	\$459	\$455	\$390	\$433
Rhode Island	\$311	\$336	\$332	\$349	\$361	\$379
South Carolina	\$530	\$552	\$509	\$476	\$444	\$496
South Dakota	\$521	\$557	\$593	\$618	\$601	\$626
Texas	\$434	\$444	\$432	\$436	\$424	\$461
Utah	\$550	\$542	\$486	\$472	\$456	\$471
Vermont	\$505	\$622	\$662	\$669	\$749	\$641
Wisconsin	\$569	\$597	\$491	\$457	\$429	\$456
Wyoming	\$865	\$865	\$881	\$791	\$762	\$802



## True Facts: Current data shows there is no evidence that Co-Pay Accumulator bans will increase premiums.

Previously, opponents have claimed that there will be a raise in premiums if Co-Pay Accumulator bans are passed. While it's true that healthcare premiums continue to increase, there is no evidence and correlation between passage of bans and trend.

- Fortunately, we now have data from several data sources on premiums from the 21 states and Puerto Rico that have passed Co-Pay Accumulator bans. The data doesn't substantiate those concerns. [1] See the charts and studies below.
- Global Healthy Living Foundation's analysis shows that despite what insurers and pharmacy benefit managers say, protecting patient assistance programs has not increased the cost of health insurance: <https://ghlf.org/copay-assistance-protection/>
- The AIDS Assistance's 2023 study shows Co-Pay Accumulator laws are not increasing average benchmark premiums in states that passed CAAP laws (at least for the first 16 of the 21w/ existing bans). And in fact, in several states average premiums declined (presumably due to better medication adherence):[The-AIDS-Inst.-Copay-Assistance-Does-Not-Increase-Premiums.pdf](#)



[1] <https://www.kff.org/affordable-care-act/state-indicator/marketplace-average-benchmark-premiums/?activeTab=graph&currentTimeframe=0&startTimeframe=10&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>