

# **Separating Fact From Fiction: Copay Accumulators**

**South Carolinians Need You  
to Support H.3618**

**SCHBDAC**

The South Carolina Hemophilia and Bleeding  
Disorders Advocacy Coalition

The South Carolina Hemophilia and Bleeding Disorders Coalition asks for South Carolina lawmakers to support **H. 3618**, Sponsored by Representative Henegan. Join 19 states to ensure all copays or coinsurance payments count toward patients' annual health plan cost-sharing requirements. For more information contact Sue Martin at [Sue.Martin@bda-sc.org](mailto:Sue.Martin@bda-sc.org)

# Protecting Patient Assistance

## South Carolina Must Act Now

### Pass H.3618



**PATIENTS** in South Carolina often rely on copay assistance to afford their medications. However, health insurers and pharmacy benefit managers (PBMs) are using the assistance to reduce their own costs while placing an extreme financial burden on patients, often forcing them to forgo the treatment they need.



**SOUTH CAROLINA** must ensure that patient assistance goes to patients, not insurers. Stop our insurance companies from double-dipping and receiving two deductibles.



**COPAY ASSISTANCE** is provided by drug manufacturers, charitable foundations and other third parties to help patients pay for their prescriptions, enabling them to afford medications that they would otherwise wouldn't have access to.



**COPAY ACCUMULATORS** are programs through which health plans and pharmacy benefit managers (PBMs) prevent copay assistance given to patients from counting towards their deductible and maximum out-of-pocket spending. As a result, insurers receive more than their fair share for each prescription, first from patients' copay cards and again from patients' out-of-pocket funds once the copay card is maximized and their deductible is deemed to have not been met.



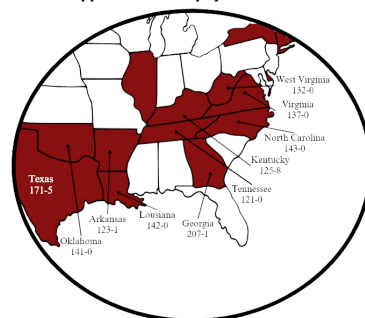
**INSURERS** are preventing access to medications that for many patients are the only available option to treat their disease.



**ACTION** is needed to protect patient assistance by banning the use of copay accumulators and requiring health insurers and PBMs to apply any amount paid, regardless of the source, to the patient's deductible or out-of-pocket maximum.

**A total of 19 states and Puerto Rico have already banned copay accumulators. South Carolina must act next to protect the most vulnerable patients.**

Support for "All Copays Count"



The South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition is a coalition of community-based bleeding disorders national and state organizations and patient advocacy groups from across the state concerned about the devastating impact that the use of copay accumulators has on the most vulnerable patients, including underinsured individuals and patients with chronic conditions who rely on multiple medications to manage their illness. The SCHBDAC mission is to empower the Hemophilia and Bleeding Disorders Community in South Carolina to speak to public and private decision-makers about improving Access to Quality and Affordable Health Care and Treatment.



# ENSURE ALL COPAYS COUNT FOR SOUTH CAROLINA PATIENTS

## WHAT IS A COPAY?

- A copay, copayment or coinsurance is a **dollar amount set by a health plan that a patient must pay out of pocket** to access a covered medical service or prescription medication.
- Copay or coinsurance payments typically count towards the patient's annual insurance deductible or cost-sharing requirements.

## WHAT IS COPAY ASSISTANCE?

- Copay assistance is often available to insured patients who are having **trouble accessing their medicine because of a high out-of-pocket or cost-sharing** requirement for **covered medicines**.
- Patients or their healthcare providers may seek approval for copay assistance from a drug manufacturer, assistance foundation, church or other nonprofit organization.
- Patients who qualify for copay assistance use it to help cover their required copay or coinsurance payments until their health plan's deductible or out-of-pocket (OOP) maximum is met.
- When patients use copay assistance, their pharmacy uses those payments to cover the cost of the medicine and the **health plan is not responsible for reimbursing the pharmacy for it**.
- Copay assistance is different from a pharmacy discount card, which changes the patient's cost for a medicine based on a rate negotiated by the discount company.

## WHY IS COPAY ASSISTANCE NEEDED?

- **Annual health insurance premiums averaged \$22,463 for family coverage in 2022, up 43 percent in the last decade** and projected to rise another 5.6 percent this year.
- On top of that, South Carolina patients are also responsible for paying out of pocket for a rising share of any medical services or medications their health plan approves for coverage.
- Until patients reach their annual deductible or OOP maximum – **as much as \$9,100 for individuals and \$18,200 for families** – they may be responsible for paying for all amounts at the pharmacy counter before their insurance plan starts sharing the costs for the covered drugs.
- Patients managing complex or chronic conditions often face **steep out-of-pocket costs to meet their annual \$\$\$\$ deductible** early each year due to their need for multiple medications.
- With deductibles rising twice as fast as wages and far outpacing inflation, patients may lean on copay assistance to help them afford their insurer's annual cost-sharing requirements.
- Copay assistance programs were born out of necessity to fix a confusing health benefits design trend that makes it financially difficult for patients to afford their prescription medications due to **up-front cost-sharing requirements year after year**.

## HOW DO COPAY ACCUMULATORS AFFECT SOUTH CAROLINA PATIENTS?

- Copay accumulator adjustment programs implemented by health plans in recent years allow patients to utilize copay assistance but **no longer apply those dollars toward the patient's deductible** and cost-sharing requirements for their covered treatments.
- Oftentimes, patients are unaware their health plan includes a copay accumulator program, as the notification **language is often buried or misleadingly worded** in the plan's legalese.
- **Patients are caught by surprise** when they learn their copay assistance dollars have run out but were not applied to their deductible, so to continue on their prescribed drug, their health plan requires them to pay out of pocket for the full cost of the medicine until they reach their deductible again. This forces many to abandon the treatments that would keep them healthy and productive.
- **If a patient's prescribed medicine is denied coverage by the health plan, the patient is responsible for all costs.** Patients may seek to access medicines through several paths:
  - Either the medication is on their health plan's "preferred list" and is approved for coverage;
  - The health plan requires patients to go through a "utilization review" process, such as prior authorization and/or step therapy protocols, before being considered for coverage; or
  - Their doctor appeals the health plan's denial on the basis that the medication is medically necessary to improve or stabilize the patient's health and well-being. **However, health plans deny those appeals about 2/3 of the time, according to the latest data.**

# Misconceptions about Copay Assistance

## 1 Copay Assistance Steers Patients from Generic to Brand Name Drugs

- Nothing about the availability and use of patient assistance allows patients to “disregard formularies and lower cost alternatives”. Patients are still required to go through a health plan’s utilization management practices, which can include prior authorization, step therapy, and quantity and dosage limits. Patient assistance only comes into play after a health plan has determined that the drug in question is appropriate and will be covered. Patient assistance only affects how a drug will be paid for, not whether it will be paid for. **A study from IQVIA of claims data from 2013-2017 shows that 99.6% of copay assistance was used for treatments without generic alternatives, so there is no inherent incentive to choose brand name over generic.** For example, bleeding disorders patients utilize complex biologic therapies that have no generic or biosimilar alternatives.
- Nearly all manufacturer patient assistance programs are for brand name drugs that have no generic or cheaper alternative. Patient assistance, therefore, is a necessary tool to mitigate the effect of health plans placing specialty drugs on the highest cost formulary tier.
- The available therapies are all expensive and serve a very small population size. Patients with chronic diseases are motivated to find the drug most likely to treat their disease effectively, not the most expensive therapy available.
- Copay assistance only becomes a factor for a medication once an insurance company has granted approval for the patient to utilize that medication.

## 2 Insurers and PBMs Never See the Money from the Copay Assistance

When insurers exclude copay assistance payments from counting toward a patient’s deductible and out-of-pocket maximum, it is the insurer who is effectively paid twice. First, the copay assistance money covers what the patient owes out-of-pocket at the pharmacy. Then, because the insurer decides not to count the copay assistance payments, the insurer tells the patient (by way of the pharmacy) that the deductible has not been met. At this point, the patient has to either pay hundreds or thousands of dollars for their prescription or go home empty handed.

## 3 Premiums Will Go Up if Insurers and PBMs Ensure that All Copays Count

- In examining the justifications for rate changes in states that have enacted legislation, such as Virginia and Arizona, to ensure that all copays count, insurers gave no clear evidence that issuers were using copay accumulators to justify a rate increase. If copay accumulators are a factor in the issuers’ rate determination, it is not clearly evident in their descriptions.
- Insurers have not brought forward rate changes in plans crediting the implementation of accumulator adjustment programs as a reason for premium decreases. If accumulator adjustment programs are not decreasing premiums, then there is no reason to believe that restricting them would cause premium increases.
- Copay assistance keeps the patients adherent to their treatment and out of the emergency department, which ultimately can help to control costs for the broader healthcare system.

## 4 Patients Should Have “Skin in the Game”

- This is an inaccurate claim directed at patients managing complex chronic and rare diseases. Pointing back to the shift in benefit design with high deductibles and high coinsurance, insurers have forced patients to put more and more skin in the game; and with copay accumulator adjustment programs, they are putting patients’ lives on the line. Furthermore, copay assistance is a finite amount of money; when the assistance runs out during the plan year the patient is responsible for any remaining cost-sharing.
- This statement ignores the enormous - and often lifetime - costs that patients with chronic disease bear, not to mention the premiums they pay for their insurance coverage and the myriad other challenges that come with living with a chronic condition.
- US Courts have sided with patients by overturning rules allowing for the implementation of the copay accumulators; *HIV AND HEPATITIS POLICY INSTITUTE et al., v. UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES et al.*

# Misconceptions about Copay Assistance

## 5 There is No Reason for Health Care Providers to Weigh-In on this Issue

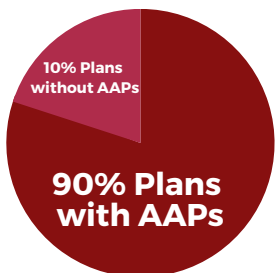
- Health care providers care about the health of their patients. Adherence is a crucial aspect of ensuring that their patients are healthy. Without copay assistance, patients could discontinue their treatment which would lead to negative health outcomes.
- Also, insurers and PBMs have expressed a desire to implement accumulator adjustment programs on the medical benefit, along with the pharmacy benefit. To implement the programs on the medical benefit, insurers and PBMs have, or are considering, requiring a health care provider to disclose patient information about copay assistance to the insurers and PBMs. Asking physicians to report on the amount their patients receive in copay assistance will put them in an ethically objectionable position. As such, reporting this information would likely harm the patient as well as the doctor-patient relationship, and would be unethical under AMA guidelines.

## 6 If a drug maker's product doesn't get favorable tier placement, drug makers give copay coupons to patients in order to incentivize patients to remain on the company's drug with the lower OOP cost.

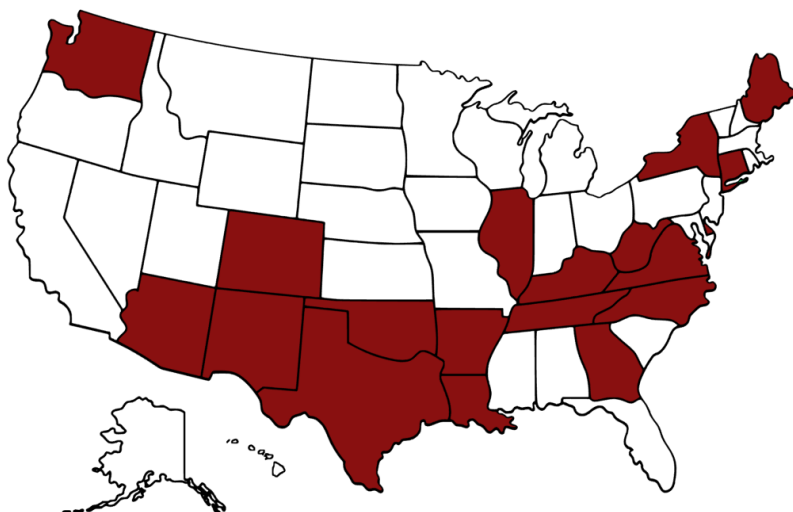
- One of the more persistent battles that patient advocacy groups wage is the discriminatory practice by health plans of placing most or all specialty drugs on the highest cost-sharing tier of the formulary. This placement often requires patients to meet an expensive coinsurance requirement rather than a flat and/or cheap copayment. This disproportionately impacts patients with high-cost chronic diseases – the most vulnerable patients in the health care system. The availability of patient financial assistance is one way of mitigating this destructive practice.
- The opposition likes to describe copay assistance as “coupons” because for other products, coupons can guide decision-making on behalf of the consumer. However, coupons for other products do not have other stakeholders (i.e. insurers and pharmacy benefit managers) within the process like there is with medications. There is no one in the aisle of the grocery store telling a consumer that they have to first purchase the store-brand product before using their coupon on the brand name product. Unlike coupons, copay assistance are real funds being transferred from one party to another.



**6 in 10 Adults in South Carolina have a chronic condition.**



**4 out of 5 SC Marketplace Plans have AAPs**



**As of June 2023, 19 states have banned copay accumulators:** Arizona, Arkansas, Colorado, Connecticut, Delaware, Georgia, Illinois, Kentucky, Louisiana, Maine, New Mexico, New York, North Carolina, Oklahoma, Tennessee, Texas, Virginia, Washington, and West Virginia, as well as Puerto Rico.

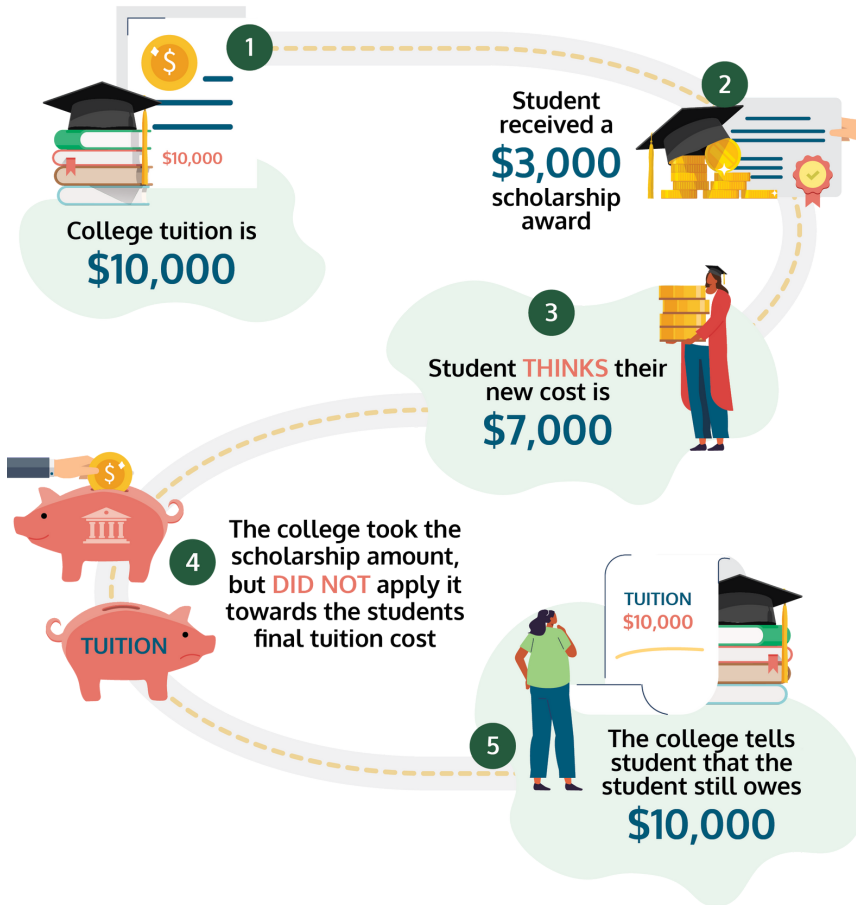
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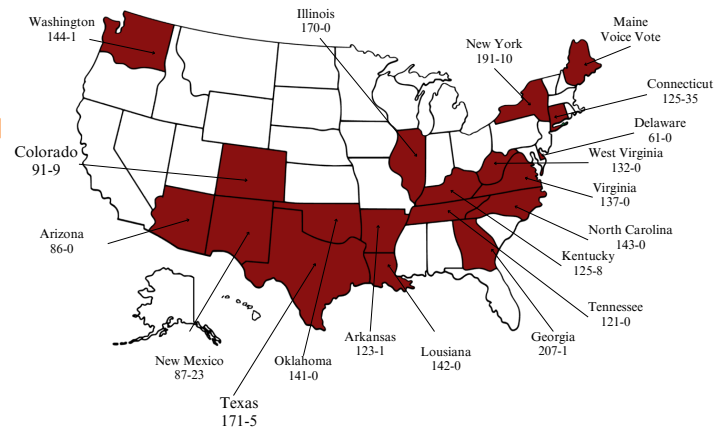


# Copay Accumulator Practices are **DETRIMENTAL** to Patient Treatment, Access, Affordability, and Care

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



## Near Unanimous Support for "All Copays Count"



Legislation has been passed in **19 states** by a vote total of **2,431 in support** to only **93 opposed**.



The average annual cost of clotting factor therapies for a person with severe hemophilia is roughly **\$300,000**

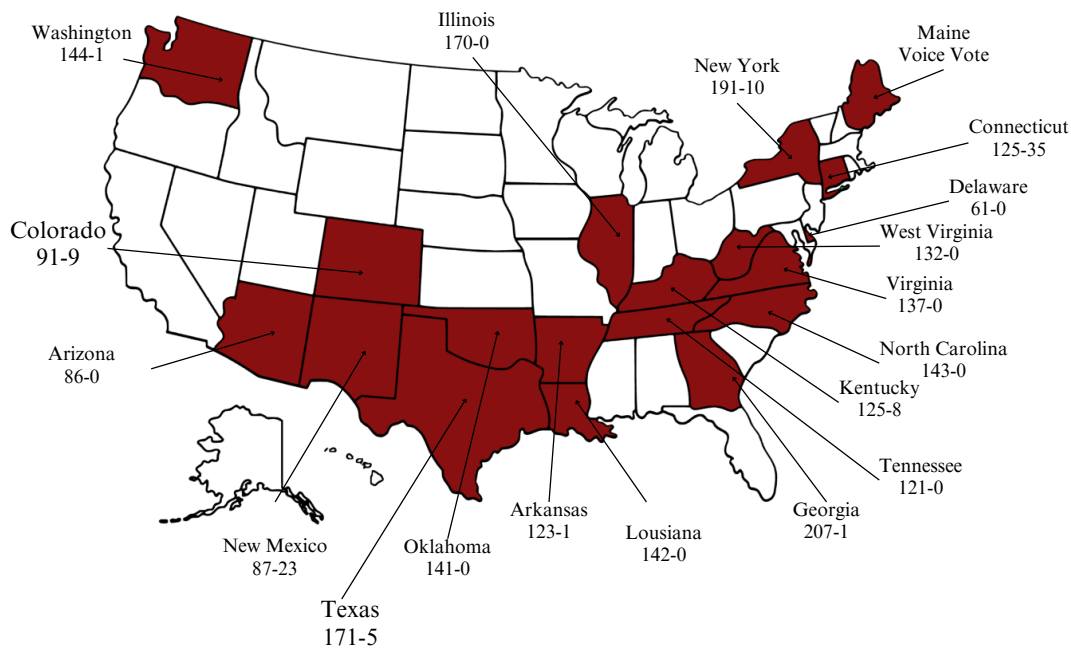
## Facts About Bleeding Disorders

- There are currently **no generic prescription drugs available for bleeding disorders** (hemophilia, von willebrand disease, platelet disorders, etc.)
- The Average Out-Of-Pocket cost for clotting factor for a person living with severe hemophilia is roughly \$300,000/year.<sup>1</sup>
- The average hemophilia patient incurs tens of thousands of dollars in medical expenses monthly.
- Adult Patients living with vonWillebrand Disease have 3 options available to them currently when it comes to prescription drugs, none of these are generic.
- Preventative care treatment (prophylactic treatment with clotting factor) is effective in reducing total bleeding, and target joint bleeding, thus **preventing patients from seeking care in the Emergency Department or Hospital settings**.
- Mortality rates and hospitalization rates for bleeding complications from hemophilia were **40% lower** among people who received care in hemophilia treatment centers than among those who did not receive this care.<sup>2</sup>

1 **Hemophilia.org** <https://www.hemophilia.org/advocacy/state-priorities/patient-out-of-pocket-expenses>

2 **CDC.org** <https://www.cdc.gov/ncbddd/hemophilia/data.html>

# Near Unanimous Support for “All Copays Count”



## Bill Sponsor and Cosponsors

Rep. Patricia Henegan [D]Primary HD-054  
Rep. Robert Williams [D]Cosponsor HD-062  
Rep. Ivory Thigpen [D]Cosponsor HD-079  
Rep. John King [D]Cosponsor HD-049  
Rep. Wendell Jones [D]Cosponsor HD-025  
Rep. Rosalyn Henderson-Myers [D]Cosponsor HD-031  
Rep. Roger Kirby [D]Cosponsor HD-061  
Rep. Chandra Dillard [D]Cosponsor HD-023  
Rep. Annie McDaniel [D]Cosponsor HD-041  
Rep. Stewart Jones [R]Cosponsor-HD-014  
Rep. Richard Yow [R]Cosponsor HD-053  
Rep. Jermaine Johnson [D]Cosponsor-HD-080  
Rep. Beth Bernstein [D]Cosponsor-HD-078  
Rep. Heather Bauer [D]Cosponsor-HD-075  
Rep. Gilda Cobb-Hunter [D]Cosponsor-HD-066  
Rep. Elizabeth Wetmore [D]Cosponsor-HD-115  
Rep. William Wheeler [D]Cosponsor-HD-050  
Rep. David Weeks [D]Cosponsor-HD-051  
Rep. Cody Mitchell [R]Cosponsor-HD-065

### Will sign on to Cosponsor in January

Rep. Tommy Pope [R]Cosponsor-HD-047  
Rep. Neal Collins [R]Cosponsor-HD-005



# Fall Advocacy Summit

ACCESS TO CARE & TREATMENT

November 10th-11th, Greenville, SC

**SCHBDAC**

The South Carolina Hemophilia and  
Bleeding Disorders Advocacy Coalition

