Call to Action for HB 1604 Talking Points

**Phone Call Script:***"My name is [Your Name] from [your city/county], and I am a [patient/parent/community member] affected by/with [your bleeding disorder]. House Bill 1604 protects those with [your bleeding disorder] and those with chronic diseases who rely on copay assistance for our life-saving medications that have no generic alternatives. I urge [Legislator’s Name] to* ***vote YES on HB 1604.****"*

**Email Script**

Dear Senator [insert name],

My name is [name] and I live [city/county/identify your district]. [Tell your story - talk about your/family member’s bleeding disorder, how they are affected, a little history about your type of bleeding disorder, what you use for treatment, things they couldn't do if you didn't’ have access to treatment, a significant occurrence when treatment was really important/life-saving]

*Example:* The main management of [my bleeding disorder] is done through expensive medications which addresses our reduced or inability for the blood to clot. With access to treatment, [i/my children/my family member] can lead a very normal and active life. Without access, [we] would all face serious bleeding complications and an increased risk of death. Our medication is *thousands of dollars* per dose and our family bill is *over a million per year.* [If you know these numbers, add them here] To access our medication, our family relies on insurance copay assistance at the start of each year when our family must meet our deductible and out-of-pocket maximum in full with the first distribution of medication. This situation not only rings true for those with expensive bleeding disorder medications, but also chronic medical issues that require expensive medications in which there does not exist a cheaper alternative such as a generic drug. The copay assistance programs are offered by each of the medication manufacturers since there is no alternative.

The CAAPs are harmful as they prevent copay assistance from counting toward a patients’ deductibles or out-of-pocket maximums and make it harder for patients to afford their medications. In copay maximizers, plans say that a covered drug is not an EHB and that patient protections do not apply. Insurers literally “double dip” and not only get the copay assistance but then would be able to tell beneficiaries that they still owe the full amount (as it wouldn’t “count”), doubling their copay intake. We all know the costs associated with those who cannot afford their medications — increased ER visits, long term complications, and missed days off work/school. CAAPs also disproportionately impact those who are low income or persons of color. They erode the ACA minimum standards and protections against high OOP costs for people with pre-existing conditions.

There are currently only [21 states, DC, and Puerto Rico](https://urldefense.com/v3/__https%3A/allcopayscount.org/state-legislation-against-copay-accumulators/__;!!FlTQaCg!lq-zUDqhRo8fSvGKfitXd8MxnN49D3R5E9zkfYmdJMR8YFXOdsRB4bMYEE2xB0wCW4xgHFYU9wvFV_VFE24tBBk$) have laws on the state level that address this issue. Sixteen more have legislation introduced at the state level this year including Indiana. I feel that ensuring that Hoosiers like my family are protected on the state level is incredibly important. This is not only for us in the bleeding disorder community but those with other costly chronic health conditions such as cancer, MS, HIV/AIDS, arthritis, lupus, and other rare chronic diseases who like us meet our deductible within the first month or so or quickly achieve their OOP Maximum.

This Bill protects patients by ensuring any payments made on their behalf count toward their out-of-pocket costs. I ask you to support HB 1604!

Respectfully,

[Name]

[Address]

**Key Concerns:**

* About 55% of the bleeding disorders community has private coverage through work or the Marketplace.
* Due to the high, life-long costs of bleeding disorders care, out-of-pocket (OOP) expenses are extremely high even for those with good insurance. A person’s drug costs can be as much as $500,000 per year and so we hit the OOP max each year – which can up to $9,200 for individuals and $18,400 for families in 2025.
* Many people use copay assistance programs to afford their cost-sharing and stay on treatment. But that lifeline is fraying due to health insurer/PBM practices (copay accumulator adjusters and maximizers) that disallow copay assistance from counting toward patient cost-sharing.
* The HB 1604 is bipartisan legislation that bans these abusive practices and ensures that patients can access their medication.
* We ask Members of Congress to co-sponsor this legislation to “make all copays count.”

**Your Action Steps:**

* **Call & Email Legislators**
* **Encourage Others to Speak Out**
* **Stay Informed & Engaged**