

# Written Testimony Of Amy Niles Chief Mission Officer, Patient Access Network Foundation 1032 15<sup>th</sup> Street NW, Suite 413 Washington DC 20005

For the Maryland House Health and Government Operations Committee Bill Hearing

Regarding House Bill 1246, Health Benefit Plans - Calculation of Cost Sharing Contribution – Requirements

## February 27, 2025

Chair Pena-Melnyk, Vice Chair Cullison, and members of the House Health and Government Operations Committee, The Patient Access Network Foundation (PAN Foundation), appreciates the opportunity to submit testimony in **support with amendment** for **House Bill 1246**, **Health Benefit Plans - Calculation of Cost Sharing Contribution – Requirements.** 

As a leading charitable foundation and healthcare advocacy organization, the PAN Foundation is dedicated to accelerating access to treatment for those who need it most and empowering patients on their healthcare journeys. We provide critical financial assistance for treatment costs, advocate for policy solutions that expand access to care, and deliver education on complex topics—all driven by our belief that everyone deserves access to affordable, equitable healthcare.

Since 2004, our financial assistance programs have helped more than 1.2 million people to start or stay on life-changing treatment. In addition, we've achieved major policy victories that increase access to care, mobilized patient advocates to call for change, and educated people nationwide on critical healthcare-related topics. We're committed to working towards a future where equitable health outcomes are a reality for all.

# **Independent Charitable Patient Assistance Foundations**

The PAN Foundation is one of nine national independent charitable foundations providing financial assistance to patients living with life-threatening, chronic, and rare diseases for their out-of-pocket prescription medication costs. Collectively the nine charitable organizations provide assistance through more than 200 disease funds.

All patient assistance programs are not the same. Independent charitable foundations are unique and operate differently from manufacturer patient assistance programs.

- Charitable patient assistance programs provide financial assistance to the underinsured, including people with federal insurance such as Medicare beneficiaries. For Medicare beneficiaries, foundations are a critical safety net, since people with federal insurance cannot seek financial assistance directly from pharmaceutical programs, due to the anti-kickback statute. This safety net is critical for Medicare beneficiaries who cannot afford the out-of-pocket costs associated with the prescription drugs and for whom programs, like those offered by the PAN Foundation, are a true lifeline to better health.
- Like other foundations, the PAN Foundation operates under guidance and an advisory opinion issued by the U.S. Department of Health and Human Services' (HHS) Office of Inspector General (OIG). The U.S. Department of Health and Humans Services Office of Inspector General (OIG) advisory opinions outline how independent charitable patient assistance foundations can operate while ensuring compliance with federal laws, regulations, and guidelines. In 2007, the PAN Foundation received its original OIG Advisory Opinion stating that we can provide cost-sharing assistance to Medicare Part D patients. PAN received an OIG Modification Letter in 2015 acknowledging our compliance with key disease fund requirements.

## How does PAN provide assistance?/Notification to patients

The PAN Foundation's standardized application process makes sure every patient has the same experience. We process applications on a first-come, first-served basis to ensure eligible patients have an equal opportunity to receive assistance and prevent preferential treatment to any individual or groups of individuals using a specific drug or product. Our standardized application process also prevents referral sources or donor interests from influencing eligibility or enrollment. Patients—or their provider or pharmacy—can apply for a grant either online or over the phone.

To be eligible for a PAN Foundation grant, a patient must:

- o Be getting treatment for the disease named in the disease fund.
- Have health insurance that covers their qualifying medication or product. (Note: health insurance requirements vary by disease fund).
- o Be prescribed a medication listed as covered in the disease fund being applied for.
- Have an income that falls at or below a percentage of the federal poverty level specified by the disease fund.
- o Reside and receive treatment in the United States or U.S. territories.

The amount of assistance varies by disease fund, and at PAN, we offer assistance through more than 90 disease funds.

At PAN, it takes under 10 minutes to complete the application and, once submitted, as a result of automated verification and eligibility, patients find out immediately if they are approved. At that point, an official welcome letter and PAN Foundation identification card is sent to the patient via email or by mail within 10-14 business days after approval. This letter indicates the amount of assistance awarded, the eligibility period, what the grant can be used for, and the

requirements that the patient must submit claims every 120 days through their eligibility period. If claims are not submitted within this timeframe, they may be disenrolled.

### **Copay Accumulators**

Individuals living with serious, chronic health conditions often require ongoing and continuous access to treatment. And yet, these individuals often face multiple barriers to the therapies they need to treat their conditions, such as prior authorization and step therapy that limit or delay access to specialty medications. In recent years, many health insurers have shifted more financial responsibility onto patients with chronic illnesses by increasing deductibles, raising copayments, expanding drug formulary tiers, and increasing the patient's share of the cost of medications. For many disease states there are no lower-cost treatments or generic equivalent treatments available. As a result, copay assistance — whether from a charitable foundation or manufacturer - has become a necessity for many patients to be able to afford their lifesaving or life-extending medicines. Unfortunately, many insurers are taking this assistance intended for patients and not counting it towards a patient's deductible and out-of-pocket maximum. This it yet another barrier for patients and can result in unexpected bills that could reach into the thousands of dollars.

The PAN Foundation has long advocated for all copay assistance to count toward a person's deductible and out-of-pocket costs. Copay accumulator policies subvert the benefit of copay assistance, thereby discriminating against people living with chronic conditions.

When copay assistance is not counted toward a patient's deductible and out-of-pocket costs, the patient alone is left responsible for paying what is often an exorbitant amount in out-of-pocket costs that can inhibit access to a needed prescription medication. This means that the insurer is often accepting payments above and beyond the maximum cost sharing requirement, as the dollars from third-party payments are not counted towards the calculation of the patient's deductible or annual out-of-pocket maximum. Pharmacy Benefits Managers are potentially collecting the payments twice - once via copay assistance, and again when the patient requires other care, or when their copay assistance runs out and they need to get their prescriptions refilled assuming they can afford to do so.

Twenty-one states, DC and Puerto Rico have already acted to protect patients. These states have used their authority to block accumulator adjustor policies in state exchanges and certain private health insurance plans they regulate. Although not all patients are protected by these laws these state actions are helping millions of patients. The PAN Foundation urges you to add Maryland to this list of twenty-one states in adopting these patient protections.

## **Support for HB 1246 With Amendment**

HB 1246 importantly requires health plans to count the value of copay assistance toward patient cost-sharing requirements. Adoption of the bill would bring much-needed relief to financially vulnerable individuals by ensuring that all payments—whether they come directly out of a patient's pocket or with the help of copay assistance—count towards their out-of-pocket costs.

However, we are concerned with Section 1.(c) of the bill regarding notification requirements. As stated above, independent charitable foundations are very different from pharmaceutical assistance programs and should not be treated the same. Notification of the recipient of the amount and duration of the grant is provided by charitable foundations. The PAN Foundation believes this provision is an unnecessary additional compliance burden. As mentioned previously, charitable foundations like the PAN Foundation adhere to applicable local, regional and federal requirements, such as those required by the OIG. We encourage the committee to craft a solution that benefits patients without creating an unnecessary burden on charitable foundations or regulators.

The PAN Foundation urges the Committee to remove the burdensome and unnecessary notification requirements and adopt HB 1246 to allow copay assistance in its variety of forms to count toward patient cost-sharing requirements.

Thank you for the opportunity to submit this testimony; please don't hesitate to contact me at <a href="mailes@panfoundation.org">aniles@panfoundation.org</a> if you would like further information on the issues raised.