



The National Patient Organization Dedicated to Advocacy, Education and Research for Primary Immunodeficiency Diseases

January 28, 2019

Chairman Terry Kilgore
Pocahontas Building
900 E. Main Street
Richmond, VA 23219

RE: Support of HB2515 / SB1596

The Immune Deficiency Foundation (IDF) **supports HB2515 / SB1596**, which would require any carrier issuing a health plan to count any payments made by a person or on a person's behalf when calculating the enrollee's overall contribution to any out-of-pockets maximum or any cost-sharing requirement under the carrier's health plan.

IDF is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases (PI) through advocacy, education and research. People with PI are born with part of the body's immune system missing or functioning improperly which leads to an increased vulnerability to infections, which can be recurrent, unusually severe, or won't clear up. Fortunately, most people with PI can live healthy productive lives if they receive lifelong immunoglobulin infusion treatments. However, immunoglobulin costs, on average, \$7,500 to \$10,000 per month, and there is no generic form of this lifesaving treatment.

To help temper these high prescription costs, many individuals living with PI receive co-pay assistance for their specialty medication. Many of those receiving assistance enroll in the co-pay assistance programs offered by the manufacturer that produces their specialty medication. This assistance is extremely helpful to those who would be required to pay their entire annual deductible or out-of-pocket maximum in the beginning of their plan year. The amount covered by these programs is intended to be counted toward the individual's deductible or out-of-pocket maximum, decreasing the amount of money one must spend before their benefits kick in for the year.

Recently, we have seen a rise in health plans instituting co-pay accumulator programs. These programs are a health insurance benefit design option in some plans that stipulate that payment from these manufacturer assistance programs are not to be counted toward individuals' deductibles or out-of-pocket maximums, thus eliminating any long-term benefit to the patients. While they would stave off high costs of medications in the short-term, once the limit for the co-pay program has been reached, the beneficiary would then have to pay their full deductible or out-of-pocket maximum for the year before their benefits would begin to cover their medical costs.

Instead of allowing manufacturer assistance programs to alleviate the financial burden of high cost specialty medications, co-pay accumulator programs ensure that the burden is merely postponed. This is not fair to patients who rely on these expensive specialty medications in which there is no generic equivalent. It also unfair that the insurer receives double payment, once from the assistance program and again from the patient since the assistance payment cannot be applied to the deductible.

In addition to the financial burden these programs pose to individuals with rare and chronic diseases like PI, another concern is that many plan changes are implemented with little to no notification to the beneficiary. Virginians do not discover their co-pay assistance did not count toward their annual deductible or out-of-pocket maximum until they arrive at the pharmacy counter, and are expected to pay the full cost of the drug. Often, these individuals must walk away without their needed medication because they cannot afford it.



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This is not acceptable for the thousands of Virginia residents suffering from chronic diseases, including PI. This bill will provide essential protections to ensure patients can both afford and stay stable on their medications. **We ask for your support on HB2515 / SB1596 to protect all Virginians, including those with PI, from unnecessary and burdensome prescription medication costs.**

Sincerely,

A handwritten signature in blue ink that reads 'Lynn H. Albizo'.

Lynn Albizo
Senior Director of Public Policy
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