

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

April 3, 2017

Senator Kelvin Atkinson, Chairman Senate Committee on Commerce, Labor and Energy

## Testimony RE: Support for SB 436 – Prohibition of certain discriminatory designs for prescription drug benefits in health benefit plans

For the record, my name is Lynn Albizo and I am the Director of Public Policy for the Immune Deficiency Foundation (IDF). I am here to testify on behalf of IDF and ACT for Nevada, a diverse coalition of patient organizations committed to ensuring more equitable, affordable and accessible health insurance coverage for those Nevadans living with chronic illnesses.

Founded in 1980, the Immune Deficiency Foundation (IDF) has been dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiencies (PI) through advocacy, education and research. People with a PI are born with part or all of the body's immune system missing or functioning improperly which leads to an increased vulnerability to infections that can be recurrent, unusually severe, or won't clear up. You may recall the "boy in the bubble" who had virtually no immune system - the severest form of a primary immunodeficiency disease. Fortunately, for many of our patients there is a treatment that when taken for the **rest of their lives**, they can live normal, healthy and productive lives. The only viable treatment option available to many patients with PI, is the infusion of immunoglobulin (Ig), a blood plasma product that helps prevent frequent and/or severe infections. Ig replacement therapy is lifesaving and requires life-long infusions. It is also expensive, costing on average of \$7,500 to \$10,000 per month.

**IDF** enthusiastically supports SB 436 which will allow individuals living with chronic and rare diseases including those with PI access to lifesaving treatments that they otherwise could not afford. This bill would require that at least 25 percent of the plans offered by insurers at each coverage level be a flat dollar co-pay option for all prescription medications including those on specialty tiers. In addition, the co-payment rates must be reasonably graduated and proportionately related in drug formulary tier levels. In whole, it will ensure that patients have options when searching for health insurance that will allow them to afford to access necessary high cost medicines.

Health plans are structuring their pricing using a specialty tier co-insurance model that, in many cases, forces patients to pay 20 to 50 percent or more of the cost of treatment instead of a fixed co-pay. In recent years, there has been a steady increase in the use of this co-insurance cost-shifting to sick patients who require expensive specialty drugs. The financial burden on patients and families increases the likelihood that many patients will forego care. In fact, according to IDF's 2014 Health Insurance Survey of patients with PI, approximately one-third (1/3) of patients reported that they had skipped treatments because they could not afford the out-of-pocket costs required by payers. They literally put their lives at risk because of they couldn't afford the high cost of their treatment.

<sup>&</sup>lt;sup>1</sup> Immune Deficiency Foundation, (2014) National Health Insurance Survey. Unpublished data

The practice of cost shifting through the use of high coinsurance for specialty medications discriminates against patients who rely on these medications including those with PI who have no alternate treatment. Those of us who are the sickest should not be financially penalized disproportionately from those who are less sick.

People who rely on expensive specialty drugs, such as Ig replacement therapy, to treat chronic conditions face incredible out-of-pocket expenses that often cost more than their mortgage. Patients who forego treatment create *significantly more costs to the healthcare system than if they would have received their original treatment.* Non-adherence to medication regimens not only has a direct impact on health and disease progression – it contributes direct annual costs of an additional \$100 billion to the US healthcare system. Indirect costs exceed \$1.5 billion annually in lost patient earnings and \$50 billion in lost productivity.<sup>2</sup>

Many medicines used to treat chronic diseases are breakthrough treatments that often prevent disability, save and improve lives, and allow patients to function and remain in the workforce. Unfortunately, certain insurer practices threaten to put medications financially out of reach for many Nevada residents as they shift astonishing costs to consumers. These practices go against the basic premise of insurance and are causing commercially insured patients to underutilize treatments or go without their treatments entirely.

SB 436 will prohibit current discriminatory health plan design practices by providing an option for a co-payment to be applied to entire drug benefit, including specialty medications. In 2015, Colorado and Montana began employing this similar standard in order to ensure that consumers have insurance options that will allow them to access the treatment they need. The Colorado standard was developed as the result of a Colorado Division of Insurance bulletin finding that certain cost-sharing structures for prescription drug benefits may constitute a prohibited practice and discriminates against those with chronic conditions. The Colorado requirements included standards similar to those in SB 436. Data from a review of those plans sold on their health insurance exchange by the Moran Company showed:

- Copay-only plans did not have universally or significantly higher premiums than plans that incorporated copays and coinsurance
- Cost-sharing for other benefit categories in copay-only plans did not appear to be appreciably higher than in plans that were not designed to meet the copay-only requirement
- The copay-only requirement did not appear to negatively affect the number of issuers participating in plans offered in the state<sup>4</sup>

The data shows that requiring insurers to offer these options is not likely to have significant fiscal impact.

We urge you to pass SB 436 and provide patients reliant on high cost medications an option for insurance that they can afford and that meets their medical needs.

<sup>&</sup>lt;sup>2</sup> Goldman D.P., et al. (2004). Pharmacy benefits and the use of drugs by the chronically ill. JAMA., 291(19): 2344- 2350

<sup>&</sup>lt;sup>3</sup> Colorado Division of Insurance, Bulletin NO. B-4.82

<sup>&</sup>lt;sup>4</sup> The Moran Company. "Complete Findings from Colorado Insurance Landscape Analysis 2016". 2016.