



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

February 27, 2020

Chairwoman Shane Pendergrass
Health and Government Operations Committee
Room 241, House Office Building
Annapolis, MD 21401

RE: Immune Deficiency Foundation Support of HB 1359

Dear Chair Pendergrass,

The Immune Deficiency Foundation (IDF) supports the introduction of legislation which would ensure appropriate, common sense guardrails are applied to step therapy to help patients receive the most effective treatments as quickly as possible.

IDF is dedicated to improving the diagnosis, treatment and quality of life of people affected by primary immunodeficiencies (PI) through fostering a community empowered by advocacy, education and research. There are more than 400 of these rare, chronic disorders in which part of the body's immune system is missing or functions improperly. These diseases are caused by hereditary or genetic defects and are not contagious. Some disorders present at birth or in early childhood, but anyone can be affected, regardless of age or gender. In Maryland, it is estimated there are 4,600 people are diagnosed with PI but many more go undetected.

IDF's patient surveys show that many people with PI struggle with a number of comorbid conditions including asthma, arthritis and various other autoimmune and digestive diseases. Fortunately, individuals with PI can live healthy productive lives if they receive appropriate treatment for their PI and other conditions. However, many people in the PI community experience difficulties accessing the needed treatments and navigating the complicated insurance system when they are denied coverage for the therapies their provider has determined can best treat their conditions.

HB 1359 will address the challenges faced by individuals with PI by offering a clear path to appeal the step therapy process and providing certain circumstances when an individual and physician could override a health plans' step therapy protocol. While the step therapy law that passed in 2014 was a step in the right direction by incentivizing insurers to establish online processing for overriding protocols, barriers for patients to access necessary treatments still remain. In addition, on a regular basis IDF receives calls from patients who are denied treatments based on the cost of the therapy, rather than the medical indication. Streamlining the process, ensuring that protocols are based upon widely accepted clinical guidelines and ensuring patients on a therapy are not required to switch when their contract renews are essential to supporting individuals with PI. Having a strong step therapy law will help ensure many people with PI live healthy and productive lives.

We urge the committee to vote favorably on HB 1359 to ensure that patients with PI and other chronic conditions are able to access the therapies they require without unnecessary barriers and delays.

Sincerely,

A handwritten signature in blue ink that reads 'Jamie N. Sexton'.

Jamie N. Sexton, JD
Government Relations Manager