October 22, 2014

RE: Draft Individual Market Health Insurance Coverage Model Regulation and the Draft Small Group Market Health Insurance Coverage Model Regulation

Submitted via email to: Jolie Matthews (jmatthews@naic.org)

Dear Ms. Matthews:

The Immune Deficiency Foundation (IDF) is the national patient organization, founded in 1980, dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency (PI) disease through advocacy, education, and research. On behalf of the thousands of patients we represent, we are writing to express our concern regarding NAIC’s September 30, 2014 versions of the Draft Individual Market Health Insurance Coverage Model Regulation and the Draft Small Group Market Health Insurance Coverage Model Regulation (Draft Models).

Primary Immunodeficiency represents a group of more than 200 related, rare genetic diseases. The defining characteristic throughout each of the 200 different PI conditions is that the immune system is malfunctioning resulting in a decreased ability to fight off infection. Infections can affect organ function, and autoimmune diseases are common. Throughout their lives, people with PI are more susceptible to infections, endure chronic diverse health problems and often develop serious and debilitating illnesses.

There are approximately 250,000 people diagnosed with primary immunodeficiency diseases in the United States. Treatments are diverse and can include prophylactic antibiotic therapy, bone marrow transplantation, enzyme replacement, interferon gamma and antifungals. Many patients diagnosed with PI require lifelong treatment with immunoglobulin replacement therapy to replace missing or improperly functioning antibodies needed to fight infection.

The consumer protections created by the Affordable Care Act (ACA) included a requirement that, as of January 1, 2014, individual and small group plans limit enrollees’ annual out-of-pocket (OOP) cost-sharing to maximum levels defined by the statute.¹ This is critical to our patients, as immunoglobulin replacement therapy can cost thousands of dollars per treatment. We are concerned that the Draft Models’ proposed implementation of the OOP provision will undermine the ACA’s protection for patients such as ours, with ongoing and expensive healthcare needs.

Specifically, section 14(B) of the Draft Model pertaining to the individual market and section 15(B) of the Draft Model pertaining to the small group model would permit health insurers to exclude from the annual limit “benefits provided out-of-network.”

We object to this proposed language for two reasons. First, it is inconsistent with ACA section 1302(c)(3)(B), which provides that the only exceptions to cost-sharing are “premiums, balance billing amounts for non-network providers, or spending for non-covered services.”

¹ ACA § 1302(c)(1).
language allows the exclusion of balance billing amounts, but those are simply the difference between the billed amount and the contracted amount. The statute draws no distinction between cost-sharing for in-network services and cost-sharing for out-of-network services.

Despite the protections initially afforded by the statute, we realize that the implementing regulations by the Department of Health and Human Services (HHS) unfortunately allow exclusion of amounts paid by enrollees for services provided by out-of-network providers. This interpretation by the agency essentially equates balance billing with cost-sharing and, in our view, fails to appreciate the difference between the two concepts. Further, in supporting this decision in the final regulation, HHS pointed to research showing that health spending “generally” occurs in network. While that may “generally” be true, it is not true of our patient population in which our patients often have no other option but to seek treatment out of network, given that the nearest immunologists may be in another state.

Despite the regulatory setback by HHS, the agency further noted that “nothing in this proposal explicitly prohibits an issuer from voluntarily establishing a maximum out-of-pocket limit applicable to out-of-network services, or a state from requiring that issuers do so.” Thus, a model by NAIC that includes out-of-network spending in the annual maximum would not be inconsistent with federal regulation and would afford appropriate protections to vulnerable patients.

Second, the proposed language may make the ACA’s out-of-pocket protection meaningless in light of the rise of narrow networks. For those with conditions that require specialty care, it may not be an option to stay in network to obtain the needed medical treatment, especially as networks are predicted to become narrower. And, our patients require such specialty care for survival. According to our patient survey of individuals using immunoglobulin replacement therapy, access to specialty providers is critical for PI care.

- While most patients with PI that have used immunoglobulin therapy rely on a primary care doctor as their main source of health care, the vast majority report also having a specialist responsible for the management and treatment of their PI condition. Among patients who had another doctor who was responsible for treatment and management of their primary immunodeficiency disease, over three-quarters (78%) said they saw an immunologist to treat their PI. In addition, 11% saw an allergist, 10% a hematologist, 5% a pulmonologist, 4% an infectious disease doctor, and 3% saw an ENT specialist. Another 8% had another type of doctor to treat their PI.

- Moreover, in addition to their primary doctor and the doctor most responsible for the treatment of their immune deficiency disease, more than four out of five patients with PI (82%) saw at least one other specialist during the past year. Between one-quarter and one-third of patients with PI saw a hematologist (35%), dermatologist (30%), ENT specialist (28%) pulmonologist (27%), or an immunologist (26%) other than their primary care doctor and the one responsible for the management of their condition. Twenty-two

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2 Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 FR 12834 (February 25, 2013).
3 Id.
percent saw another allergist or cardiologist. One in seven patients with PI (16%) have seen an endocrinologist in the past year, while others report seeing an infectious disease specialist (13%), gastroenterologist (12%), rheumatologist (5%) or neurologist (3%) in the past year. Only 18% of patients saw none of these specialists unless they were their primary care doctor or the one responsible for the treatment of their immune deficiency disease.

Even in cases where a specialist is available within the network, a patient may not be able to correctly identify any in-network provider. Indeed, a recent study assessing network adequacy in six states found that “insurers and state officials alike reported consumer and provider confusion about which plan networks included which providers[.]” It is unreasonable to penalize patients for seeking care outside their networks when the information needed to seek care inside their networks is not readily available.

For these reasons, we urge NAIC to rewrite its Draft Models so that patients are not penalized for seeking the care they need outside of today’s narrow networks. On behalf of patients with primary immunodeficiency diseases, I want to thank you for your consideration of our views. Please feel free to contact me if I can provide additional information or answer any follow-up questions.

Sincerely,

Marcia Boyle
President and Founder
Immune Deficiency Foundation

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