Dear Ms. Matthews,

I am not a patient. I don't have a rare disease. I do not see specialized physicians. However, I am an advocate on behalf of the millions of people affected by pemphigus and pemphigoid. They are more than patients, caregivers, and physicians: they are my family.

These diseases do not simply affect one person's life. Rare diseases in general impact the lives of family and friends with degraded social experiences. Rare diseases impact the medical and research communities with underfunded challenges to better treatments and cures. Rare diseases impact business and industry with lost man-hours because patients need to make numerous trips to see doctors, and in some instances, "hide" from coworkers.

The truth of living with a rare disease is as damaging as the disease -- or treatments. The late Canadian Federal Finance Minister Jim Flaherty was rumored to be an alcoholic or suffering from cancer. He had bullous pemphigoid and the treatments caused him to gain weight and lose sleep. Rock band Blondie stopped touring after co-founder and guitarist Chris Stein was diagnosed with pemphigus vulgaris in 1983 and wanted to hide from the public eye. An anonymous former world-champion body builder dropped out of competition to hide their pemphigus vulgaris from the world.

Ms. Matthews, I am writing to express my concern over Section 14(B) of the individual market model, and Section 15(B) of the small group model. Both would exclude “benefits provided out-of-network” from the annual limit. Not only is this inconsistent with statutory language provided in PPACA Section 1302(c) because it could make out-of-pocket protection more or less illusory in light of well-documented concerns with narrow networks, it hurts patients and their families who have yet to be diagnosed, or treat those who have been diagnosed. What's worse is the NAIC’s language could be interpreted by plans to exclude benefits covered through an appeal or exception process. This would be a step backward from current practice.

If you or a loved one depended on this type of coverage, would these proposed changes help or hinder access to care, and improve or damper quality of life?

The rare disease community relies on out-of-network physicians and the annual limitations protect families from having to choose between treatment drugs and the baby's diapers. What NIAC is considering could penalize the rare diseases community. The current NAIC drafts would erode one of the ACA’s most important consumer protections — the annual limit on out-of-pocket spending.

I ask you, no, I implore you to keep the drafts open for discussion in light of my concerns -- and those of the rare disease community.

Thank you.

Noelle Madsen
Patient Services Coordinator

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