

ONE HUNDRED FOURTEENTH CONGRESS
Congress of the United States
House of Representatives
COMMITTEE ON ENERGY AND COMMERCE
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WASHINGTON, DC 20515-6115
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Minority (202) 225-3641

June 17, 2016

Ms. Marcia Boyle
President and Founder
Immune Deficiency Foundation
110 West Road
Towson, MD 21204

Dear Ms. Boyle:

Thank you for appearing before the Subcommittee on Health on May 17, 2016, to testify at the hearing entitled "The Obama Administration's Medicare Drug Experiment: The Patient and Doctor Perspective."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and (3) your answer to that question in plain text.

To facilitate the printing of the hearing record, please respond to these questions with a transmittal letter by the close of business on July 1, 2016. Your responses should be mailed to Graham Pittman, Legislative Clerk, Committee on Energy and Commerce, 2125 Rayburn House Office Building, Washington, DC 20515 and e-mailed in Word format to graham.pittman@mail.house.gov.

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,



Joseph R. Pitts
Chairman
Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment

Attachment — Additional Questions for the Record

The Honorable Leonard Lance

As Chair of the Congressional Rare Disease Caucus, I am particularly concerned about those patients with rare diseases, a vulnerable population that already experience lengthy journeys to accurate diagnosis, only to be presented with limited therapeutic options – if any – for effective treatment.

These same at-risk patients have great difficulty locating providers who can appropriately treat their rare and complex disease. To equate their medical condition with one that has multiple therapies available puts their access to these providers at risk.

Further, as we look to encourage the adoption of personalized medicine, Congress has taken particular care to recognize that a “one-size-fits-all” approach does not respect the acute needs of rare disease patients and other unique populations.

1. Ms. Boyle, can you elaborate on the struggles rare disease patients and their families must endure and the unique needs of this population that CMS must keep in mind?
2. Have you heard of these concerns from the patients in your organization? Can you comment on the impact of any potential delay or interruption in treatment for these patients?

The Agency fails to recognize the reality that, for some conditions, there is no appropriate alternative treatment other than an orphan drug. The Proposed Rule all but acknowledges its disproportionate impact on beneficiaries with rare disorders in its discussion of budget neutrality and acknowledgement that the Model would shift Part B drug payments from specialists (treating the majority of rare disorders) to primary care providers, without furthering CMS’ stated goal of encouraging use of lower-cost treatment options.

3. Can you speak to the impact of having to switch physicians for the rare disease patients you represent?