



May 16, 2017

The Honorable Morgan Griffith
2202 Rayburn House Office Building
Washington, DC 20515

RE: *Support for H.R. 1703, the “Medical Product Communications Act of 2017”*

Dear Congressman Griffith,

The Dystrophic Epidermolysis Bullosa Research Association of America (debra of America) is the only U.S. nonprofit providing all-inclusive support to the Epidermolysis Bullosa (EB) community by engaging in two initiatives in parallel. We fund innovative research for a treatment and a cure and provide free programs and services for those with EB. We call EB “the worst disease you’ve never heard of”—it is a rare connective tissue disorder with many genetic and symptomatic variations that affects 1 out of every 20,000 births in the U.S.

We, and other members of the Rare Disease community, often find ourselves with few, if any, treatment options. In fact, of the more than 7,000 rare diseases, very few have FDA approved treatment options. According to Global Genes, a leading rare disease patient and organizational advocacy group, only five percent of rare diseases have a FDA approved treatment. While we would like nothing more than to see that landscape change, now most rare disease patients, including those with EB, are receiving off-label treatments out of necessity—if they are lucky. With 1 in 10 Americans suffering from a rare disease, H.R. 1703 has the potential to improve treatment options for a large number of patients. We want to thank you for your leadership on this issue and introducing H.R. 1703.

Off-label use is often considered the standard of care for many rare diseases and their respective patients; therefore, it is imperative that more comprehensive information pertaining to off-label use be shared in a way that can best benefit patients, potentially providing more treatment options. This sharing of this comprehensive information would potentially provide more treatment options from off-label usage. Currently, the FDA’s determination of “intended use” negatively impacts scientific exchange of information that could be beneficial or even potentially life-changing to patients. We believe H.R. 1703 appropriately balances patient safety while providing patients and their physicians access to appropriate, evidence-based information used to make informed treatment choices.

Dystrophic Epidermolysis Bullosa Research Association of America, Inc.

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debra of America ♦ 75 Broad Street, Suite 300 ♦ New York, NY 10004 ♦ (P) 212-868-1573 ♦ (F) 212-868-9296 ♦ debra.org



The undersigned organizations thank you for your commitment to this issue and stand ready to help you advance the Medical Product Communications Act of 2017.

Sincerely,

Association for Creatine Deficiencies
Bridge the Gap-SYNGAP Education and Research Foundation
Choroideremia Research Foundation
Dystrophic Epidermolysis Bullosa Research Association of America, Inc.
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