



NORD[®]
National Organization
for Rare Disorders

December 10, 2019

The Honorable Lamar Alexander, Chairman
United States Senate
Committee on Health, Education, Labor & Pensions
Washington, D.C. 20510

The Honorable Patty Murray, Ranking Member
United States Senate
Committee on Health, Education, Labor & Pensions
Washington, D.C. 20510

The Honorable Frank Pallone, Chairman
United States House of Representatives
Committee on Energy and Commerce
Washington, D.C. 20515

The Honorable Greg Walden, Ranking Member
United States House of Representatives
Committee on Energy and Commerce
Washington, D.C. 20515

Dear Chairman Alexander, Ranking Member Murray, Chairman Pallone, and Ranking Member Walden,

On behalf of the 25 to 30 million Americans with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for working to find common ground on a solution to surprise medical billing.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the over 290 organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Patients across the country are suffering from what are referred to as "surprise medical bills." To be exact, recent polling indicated that 67 percent of Americans are worried about surprise medical bills and whether they will be able to afford such expenses.¹ Further, according to 2017 data on large employer plans, surprise bills result, on average, 18 percent of the time after trips to the emergency room and 16 percent of the time following in-network, in-patient hospital stays.²

Particularly for rare disease patients, emergencies can be frequent and confusing. At these times, individuals do not have the time, or perhaps even the capacity, to ensure they are being treated at an in-network facility by an in-network provider. Consequently, NORD strongly supports action on surprise medical billing.

NORD supports a legislative solution to surprise medical billing that holds patients harmless, protects them from balance billing, and only holds them accountable for the equivalent in-network cost sharing amounts. Rare disease patients need action now. NORD is appreciative of your efforts to produce a bipartisan, bicameral solution to this problem in a timely manner.

¹ Pollitz, Karen. "An Examination of Surprise Medical Bills and Proposals to Protect Consumers from Them." Peterson-Kaiser Health System Tracker, October 16, 2019. <https://www.healthsystemtracker.org/brief/an-examination-of-surprise-medical-bills-and-proposals-to-protect-consumers-from-them/>.

² Ibid.

NORD looks forward to reviewing the legislative text for the revised Lower Health Care Costs Act and providing more detailed feedback, but encourages both Committees to continue their important progress for the sake of all patients, including the rare disease community.

All individuals with a rare disease should have access to quality and affordable health care that is best suited to their medical needs. NORD looks forward to working with Congress to ensure the end of surprise medical billing by the end of this year. For questions regarding NORD or the above comments, please contact me at rshe@rarediseases.org or 202-545-3970.

Sincerely,

A handwritten signature in black ink that reads "Rachel Sher". The signature is written in a cursive, flowing style.

Rachel Sher
Vice President, Policy and Regulatory Affairs