



August 12, 2020

The Honorable Robin Kelly
United States House of Representatives
2416 Rayburn House Office Building
Washington, D.C. 20510

Dear Representative Kelly:

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) is pleased to formally endorse H.R. 7078, the Evaluating Disparities and Outcomes of Telehealth During the COVID-19 Emergency Act.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. We believe that all individuals with a rare disease should have access to quality and affordable health care that is best suited to their medical needs.

Typically, rare disease patients receive care in hospitals, health centers, and doctors' offices. Due to the specialized nature of the treatment that many rare disease patients require, this often necessitates traveling significant distances, even across state lines, to obtain such care. In the face of the COVID-19 pandemic, these patients are at higher risk if they were to leave their homes and travel to their usual health care facilities. Therefore, patients and physicians are increasingly utilizing telehealth as a way to keep rare disease patients healthy in the midst of this crisis.

While NORD is grateful that the barriers that have previously resulted in reduced telehealth utilization have been temporarily removed during the COVID-19 public health emergency, it is critical that patient choice and data drive future permanent decisions on telehealth. The expansion of telehealth has enormous potential to permanently improve access to quality health care for patients with rare diseases, if appropriately implemented. The Evaluating Disparities and Outcomes of Telehealth During the COVID-19 Emergency Act would require Federal and state governments collect and analyze data on the impact of telehealth on utilization, health outcomes, and spending during the COVID-19 pandemic. This data and analysis is necessary to guide future regulatory and legislative decisions to ensure that through telehealth, high quality care is provided, positive health outcomes are achieved and fraud is prevented.

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NORD believes that the Evaluating Disparities and Outcomes of Telehealth During the COVID-19 Emergency Act would help ensure the lessons learned from the rapid increase in telehealth utilization can be applied to the future, helping rare disease patients access via telehealth quality health care services. NORD is grateful for your efforts to address this important issue and urges its swift consideration. If you have any questions or need further information, please contact Heidi Ross, NORD's Director of Policy at (202) 588-5700.

Sincerely,

A handwritten signature in black ink that reads "Heidi Ross". The signature is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

Heidi Ross
Director of Policy

A decorative graphic at the bottom of the page consisting of numerous teardrop-shaped elements. Most are light blue, but one in the center is a light orange color. They are arranged in a roughly circular pattern, resembling a stylized sunburst or a cluster of cells.

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