March 26, 2020

The Honorable Gary R. Herbert
Governor of Utah
350 North State Street Suite E220
State Capitol, PO Box 142220
Salt Lake City, UT 84114-2220

Dear Governor Herbert:

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) asks that as you work to address the COVID-19 crisis within your state, you modify state licensure requirements for health care providers to enable those providers that are licensed and in good standing with one state to provide commiserate medical services across state lines. Reducing the barriers associated with licensure is critically important to help protect the ability of rare disease patients to access their health care providers via telemedicine services while the threat of COVID-19 remains.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the 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.

Typically, rare disease patients receive care in hospitals, health centers, and doctors’ offices. Often, due to the specialized nature of the care rare disease patients require, this necessitates traveling across state lines to obtain such care. However, their underlying conditions often leave rare disease patients immune-compromised, putting them at high risk of contagion and serious illness. In the face of the COVID-19 pandemic, these patients are at higher risk if they were to leave their homes and enter these facilities for their medical care. Therefore, patients and physicians are increasingly looking to utilize telemedicine as a way to keep themselves healthy in the midst of this crisis.

On March 13, 2020, the Secretary of Health and Human Services, Alex Azar, issued a blanket waiver permitting physicians participating in Federal health care programs to receive payment for telemedicine services in states where they do not hold a license during the COVID-19 emergency. However, states still govern whether or not a health care provider is allowed to practice medicine if they are not licensed in that specific state. Additionally, on Tuesday, March 24th, Secretary Azar sent a letter to all Governors, requesting, among other things, you “allow health professionals licensed or certified in other states to practice their professions in your state, either in person or through telemedicine.” Fortunately, numerous states have already modified their state licensure requirements enabling physicians to practice across state lines.
NORD urges you utilize your authority to reduce licensure barriers to care and take maximum advantage of the flexibility provided by the federal government to ensure rare disease patients have access to critical telemedicine services during this extraordinary time. Thank you very much for your consideration of our views.

If you have any questions or need further information, please contact Rachel Sher, NORD’s Vice-President of Policy and Regulatory Affairs at (202) 588-5700.

Sincerely,

Peter L. Saltonstall  
President and CEO

Marshall Summar, M.D.  
Chairman, Board of Directors  
Director, Rare Disease Institute