NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

March 13, 2025

The Honorable Joseph Cervantes, Chair
Senate Judiciary Committee
New Mexico State Senate
490 Old Santa Fe Trail
Santa Fe, NM 87501

The Honorable Antonio Maestas, Vice-Chair
Senate Judiciary Committee
New Mexico State Senate
490 Old Santa Fe Trail
Santa Fe, NM 87501

Dear Chair Cervantes, Vice-Chair Maestas, and Members of the Senate Judiciary Committee:

On behalf of the one-in-ten Americans living with one of the over 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your consideration of SB 46. SB 46, if passed, would allow New Mexico to join the Interstate Medical Licensure Compact (IMLC), an agreement between participating U.S. states to work together to significantly streamline the medical licensing process for physicians who want to practice in multiple states, therefore making it possible to improve patient access to medical specialists using telehealth. NORD urges you to support SB 46 and pass it favorably out of this Committee.

With a more than 40-year history, NORD is the leading and longest-standing patient advocacy organization for the more than 30 million Americans living with a rare disease. An independent 501(c)(3) nonprofit, NORD is dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 355 patient organization members, is committed to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. NORD believes that all individuals with a rare disease should have access to high quality, affordable health care that is best suited to meet their medical needs.

In the United States, a rare disease is defined as any disease, disorder, illness, or condition affecting fewer than 200,000 people.[1] Unfortunately, there are often very few specialists who have expertise in any given rare disease. As a result, patients frequently travel significant distances, often across state lines, to see a medical specialist qualified to provide appropriate treatment for their condition. In a survey of rare disease patients conducted by NORD in 2019, almost 40% of respondents reported traveling 60 miles or greater to see a medical specialist with expertise in their rare condition.[2] Furthermore, in a survey of rare disease patients and

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[1] Orphan Drug Act, P.L. 97-414, as amended. https://www.fda.gov/industry/designating-orphan-product-drugs-and-biological-products/orphan-drug-act-relevant-excerpts

[2] NORD Report, *Ensuring Access to Telehealth for Rare Diseases.* October 15, 2020. https://rarediseases.org/wp-content/uploads/2020/10/NRD-2098-RareInsights-Telehealth-Report-1.pdf

caregivers conducted by NORD in the summer of 2020, 79% of respondents reported experiencing a canceled medical appointment due to COVID-19.[3] Fortunately, 88% of survey respondents reported being offered a telehealth appointment, and 92% who accepted the offer of a telehealth visit reported having a positive experience with telehealth.[4] Looking ahead, many patients and providers have signaled that they appreciate and have benefitted from the expanded use of telehealth and want to see its permanent integration into our health care system.

As mentioned previously, rare disease patients are often required to travel long distances, including across state lines, to access necessary and appropriate medical care. Currently, many state's licensure laws create barriers to care by limiting providers ability to see patients across state lines. This not only complicates access for patients but also creates additional burdens for clinicians who want to see out-of-state patients who lack access to appropriate care closer to home. This barrier to care can prove insurmountable for some due to the significant costs associated with travel and lodging, among other expenses.

SB 46 would streamline the process for physicians in other states to obtain licensure in New Mexico, allowing those health care providers to see patients located in New Mexico via telehealth. This would not only expand access to out-of-state medical specialists for individuals with diagnosed rare diseases living in New Mexico, but also to diagnostics, potentially cutting down the often-extensive diagnostic odyssey patients go through to obtain an accurate diagnosis. In passing SB 46, New Mexico would join 40 other U.S. states, the District of Columbia, and the Territory of Guam as participants in the Interstate Medical Licensure Compact.

Once again, on behalf of the New Mexico rare disease community, we thank you for your consideration of SB 46 and urge its swift passage. For any questions, please feel free to contact me at lviscarra@rarediseases.org.

Sincerely,

Lindsey Viscarra
State Policy Manager, Western Region
National Organization for Rare Disorders

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[3] NORD Report. *COVID-19 Community Follow-Up Survey Report.* August 4, 2020. https://rarediseases.org/wp-content/uploads/2022/10/NRD-2061-RareInsights-CV19-Report-2_FNL.pdf

[4] Ibid