



Alone we are rare. Together we are strong.®

February 21, 2024

The Honorable Rhonda Fields  
Chair, Senate Committee on Health & Human Services  
Colorado General Assembly  
200 E Colfax Avenue  
Denver, CO 80203

The Honorable Joann Ginal  
Vice Chair, Senate Committee on Health & Human Services  
Colorado General Assembly  
200 E Colfax Avenue  
Denver, CO 80203

Dear Chair Fields and Vice Chair Ginal,

On behalf of the one-in-ten individuals in Colorado living with one of the over 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your consideration of SB24-141 during your committee's hearing on February 22. SB24-141, if passed, would allow out-of-state healthcare providers to provide services through telehealth to patients located in Colorado, making it possible to improve patient access to medical specialists using telehealth. NORD urges you to support SB24-141 and pass it favorably out of your Committee.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare 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. We believe that all individuals with a rare disease should have access to quality and affordable health care that is best suited to meet their medical needs.

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In the United States, a rare disease is defined as any disease, disorder, illness, or condition affecting fewer than 200,000 people.<sup>1</sup> 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.<sup>2</sup>

While rare disease patients faced serious barriers to care even before the COVID-19 pandemic, these barriers increased significantly within the rare disease community as the pandemic shocked the U.S. and global health care systems. In a survey of rare disease patients and caregivers conducted by NORD in the summer of 2020, 79% of respondents reported experiencing a canceled medical appointment due to COVID-19.<sup>3</sup> 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.<sup>4</sup> 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.

SB24-141 would streamline the process for providers in other states to obtain the approval to provide telehealth services to patients in Colorado. SB24-141 provides out-of-state health-care providers with the ability to register with an authority in Colorado, then be granted permission to provide telehealth services to patients within the state. This would not only expand access to out-of-state medical specialists for individuals with diagnosed rare diseases living in Colorado,

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<sup>1</sup> 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>

<sup>2</sup> 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>


<sup>3</sup> 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](https://rarediseases.org/wp-content/uploads/2022/10/NRD-2061-RareInsights-CV19-Report-2_FNL.pdf)

<sup>4</sup> Ibid.

but also to diagnostics, potentially cutting down the often-extensive diagnostic odyssey patients go through to obtain an accurate diagnosis.

Once again, on behalf of the Colorado rare disease community, we thank you for your consideration of SB24-141 and urge its swift passage. For any questions, please feel free to contact Lindsey Viscarra at [lviscarra@rarediseases.org](mailto:lviscarra@rarediseases.org)

Sincerely,



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