



Alone we are rare. Together we are strong.®

January 9, 2024

The Honorable Annette Cleveland
Chair, Senate Health & Long Term Care Committee
J.A. Cherberg Building
304 15th Ave SW
Olympia, WA 98501

The Honorable June Robinson
Vice Chair, Senate Health & Long Term Care Committee
J.A. Cherberg Building
304 15th Ave SW
Olympia, WA 98501

Dear Chair Cleveland, Vice Chair Robinson and Members of the Health & Long Term Care Committee,

On behalf of the one-in-ten individuals in Washington living with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your consideration of SB 5821. SB 5821, if passed, would permanently lift the sunset clause on the “established relationship” definition for audio-only telehealth, allowing an audio-visual encounter to establish the patient-provider relationship to enable subsequent audio-only visits. NORD urges you to support SB 5821 and pass the bill favorably out of this 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 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. For example, a 2020 GAO

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>

analysis found that Washington had just three medical geneticists per 500,000 population.² As a result, patients frequently travel significant distances, sometimes even across state lines, to see a medical specialist qualified to provide appropriate care and treatment for their condition. In a survey of rare disease patients conducted by NORD in 2019, almost 40% of respondents reported traveling at least 60 miles to see a medical specialist with expertise in their rare condition.³ Additionally, lack of accessible transportation, significant costs associated with travel, and other logistical challenges can serve as insurmountable barriers to appropriate care for some rare patients. The burden of travel is so great that 17% of survey respondents had relocated or were actively considering relocating to be closer to care.⁴

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-19.⁵ 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.⁶ 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.

Taking our cue from rare disease patients and providers, NORD developed a set of [Telehealth Principles](#) in 2020 to guide our engagement on telehealth policy moving forward. The first of these four principles states that all patients should have equal and effective access to telehealth services. This includes ensuring patients in both rural and urban areas can benefit from telehealth services. Audio-only telehealth services have proved to be useful for providers to complete visits with patients who live in areas with limited broadband services and/or don't have access to audio-visual capable devices. As patients who live in these areas are also more likely to have to travel long distances to obtain specialty care, it is particularly important that patients can establish the provider-patient relationship without an in-person visit. Allowing an audio-visual telehealth encounter to establish the patient-provider relationship to enable

² Government Accountability Office. (2020). *Information on Genetic Counselor and Medical Geneticist Workforces*. GAO Publication No. 20-593. Washington, D.C.: U.S. Government Printing Office. Retrieved from <https://www.gao.gov/assets/gao-20-593.pdf>.

³ 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>

⁴ *Ibid.*

⁵ 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

⁶ *Ibid.*

subsequent audio-only visits will help ensure rare disease patients across Washington have access to the best care available for their condition, regardless of where they live in the Evergreen state.

Once again, on behalf of the Washington rare disease community, we thank you for your consideration of SB 5821 and urge its swift passage. For any questions, please feel free to contact Lindsey Viscarra at lviscarra@rarediseases.org.

Sincerely,



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