



April 14, 2022

The Honorable Neal Foster
Co-Chair
Alaska House Finance Committee
120 4th St., Room 421
Juneau, AK 99801

The Honorable Kelly Merrick
Co-Chair
Alaska House Finance Committee
120 4th St., Room 421
Juneau, AK 99801

Re: Support for House Bill 265

Dear Chairman Foster and Chairwoman Merrick,

On behalf of the 1-in-10 individuals in Alaska with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to express our support for House Bill 265 (HB 265) and urges you to swiftly advance it out of the House Finance Committee. HB 265 makes explicit that providers may deliver telehealth services without an in-person exam if the provider's license is in good standing. This bill will also allow out-of-state providers not licensed in Alaska to render telehealth services to patients referred by someone licensed in Alaska, or under a federal or tribal health care program, which will allow the rare disease community to maintain access to much-needed providers and care.

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.

Typically, people with rare disorders 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. Even prior to the COVID-19 pandemic many patients struggled to access necessary specialists, but during the pandemic the difficulty that patients encountered while trying to access medical care increased significantly. In a survey of rare disease patients and caregivers conducted by NORD in the summer of 2020, 79% of respondents reported that they had experienced a



canceled medical appointment due to COVID-19. Fortunately, 88% of survey respondents also reported being offered a telehealth appointment, and 92% who accepted the offer of a visit said it was a positive experience. Looking ahead, many patients and physicians have signaled they appreciate and have benefited from the expanded use of telehealth and want to see its continued use even after the pandemic subsides.

NORD is grateful that Alaska increased flexibility around the utilization of telehealth during the pandemic to meet the needs of the people with rare, serious, and chronic health conditions. However, it is critical that access and patient choice related to telehealth access remain a priority to state policymakers moving forward, as outlined in [our organization's telehealth principles](#). Please see below for a summary of our principles as it relates to HB 265:

- **All patients should have equal and effective access to telehealth services.** HB 265 supports access to and reimbursement for telehealth services regardless of a patient or providers geographic location. It also allows out-of-state health care professionals to provide telehealth services to Alaska-based patients. This would be a significant benefit to the rare disease community, as there are often a limited number of health care providers with expertise in an individual's rare disease and those experts may not be located in Alaska.
- **Patients and their providers should be able to make a choice on the location and type of care they received that is in the best interests of the patient.** Moreover, HB 265 also aligns with NORD's principle for equal and effective access to telehealth by allowing for audio-only coverage with in-network providers, which helps maintain patient access to telehealth services where patients face challenges accessing broadband or utilizing visual technology.

In conclusion, NORD believes HB 265 will benefit the rare disease community in Alaska and is pleased to support this important legislation. If you have any questions or need further assistance, please contact Ruby Dehkharghani at rdehkharghani@rarediseases.org.

Sincerely,

Ruby Dehkharghani

Ruby Dehkharghani
Policy Analyst
National Organization for Rare Disorders