



April 15, 2021

The Honorable David Wilson  
Chair  
Senate Health and Social Services Committee  
State Capitol Room 121  
Juneau, AK 99801

**Re: Support for Senate Bill 78**

Dear Chairman Wilson,

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 Senate Bill 78 (SB 78) and urges you to swiftly advance it out of the Health and Social Services Committee. SB 78 would increase access to telehealth for the rare disease community by permitting providers in good standing to provide telehealth services without first conducting an in-person visit and ensures the amount providers are charging is reasonable and consistent with in-person fees. Telehealth during the COVID-19 pandemic has been critical for rare disease patients in order to maintain their health and NORD is grateful that SB 78 would make these changes permanent, enabling access to much-needed telehealth services during and after the COVID-19 pandemic.

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. 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, rare disease patients 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. In the face of the COVID-19 pandemic, these patients are at higher risk if they were to leave their homes and travel to their usual health care facilities. In a summer 2020 NORD survey, 79% of respondents reported that they had experienced a canceled medical appointment as a result of the COVID-19 pandemic. Fortunately, 88% of survey respondents also reported being offered a telehealth appointment in the midst of this crisis, and 92% who accepted the offer of a visit said it was a positive experience<sup>1</sup>. Looking ahead, many patients and physicians have signaled they

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<sup>1</sup> NORD. Ensuring Access to Telehealth for Rare Diseases. Accessed 4/14/21.

<https://rarediseases.org/wpcontent/uploads/2020/10/NRD-2098-RareInsights-Telehealth-Report-1.pdf>



appreciate and have benefited from the expanded use of telehealth and want to see its continued use even after the pandemic subsidies.

NORD is grateful that Alaska has increased access to telehealth during the pandemic to meet the needs of Alaska's rare disease community—and SB 78 would make permanent several important telehealth provisions that align with [our organization's telehealth principles](#):

- **All patients should have equal and effective access to telehealth services.** SB 78 supports equal and effective access to telehealth services by allowing providers to treat patients through telehealth without first conducting an in person visit. In addition, it allows providers in good standing in another jurisdiction to provide telehealth in the state, helping rare disease patients and providers who may seek or provide care across state lines.
- **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.** SB 78 ensures that the amount charge by a provider for telehealth must be “reasonable and consistent with ordinary fees” and cannot be more than 5 percent above the ordinary fee. This helps to not make in-person or telehealth more appealing than another and keep the choice of care received in the best interest of the patient. However, NORD prefers payment parity exists for telehealth and in-person visits, but appreciates that SB 78 does not structure reimbursement in a way that tips the scale in either direction.

In conclusion, NORD believes SB 78 will benefit the rare disease community in Alaska and is pleased to support this important legislation. NORD thanks you for your consideration and urges you to support and swiftly move this bill through your committee. If you have any questions or need further assistance, please contact Alyss Patel at [Apatel@rarediseases.org](mailto:Apatel@rarediseases.org).

Sincerely,

Alyss Patel  
Western Region, State Policy Manager  
National Organization for Rare Disorders

CC: Senate Labor and Commerce Committee