



April 28, 2021

The Honorable Deb Patterson  
Chair  
Senate Committee on Health Care  
900 Court St. NE, S-215  
Salem, Oregon 97301

**RE: Support for House Bill 2508**

Dear Chair Patterson,

On behalf of the 1-in-10 individuals in Oregon with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to share our support for House Bill 2508 (HB 2508) and urges you to swiftly advance it out of your committee. HB 2508 passed the House on April 14 and would permanently implement important provisions and flexibilities related to telehealth that will allow the rare disease community to maintain access to much-needed health care 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 2020 NORD survey, 79% of respondents reported that they had experienced a cancelled 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 was a positive experience<sup>1</sup>. Looking ahead, many patients and physicians have signaled they appreciate the recently expanded use of telehealth and look forward to its continued use even after the pandemic subsides as it brings great value to the rare disease community.

NORD is grateful that Oregon has increased flexibility around telehealth during the pandemic to meet the needs of the rare disease community, however, it is critical moving forward that access and patient choice remain a priority as outlined in our [organization's telehealth principles](#). Please see below for a summary of our principles as it relates to HB 2508:

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



- **All patients should have equal and effective access to telehealth services.** HB 2508 supports access to and reimbursement for telehealth services regardless of a patient or providers geographic location. Additionally, this bill would increase equal and effective access to telehealth by ensuring access to auxiliary aids and service accommodations to enrollees that may need it, as well as providing culturally and linguistically appropriate services as needed.
- **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.** HB 2508 expands patient choice as it allows for telehealth services through different technologies including audio-only and audio-visual communications. The bill also includes specific provisions to increase patient and provider choice in a future state of emergency. Additionally, the bill prohibits health insurance plans from discriminating against originating sites for reimbursement purposes and ensures payment parity exists for both in person or remote visits.
- **Transparency around privacy protections and cost sharing must be established and preserved.** NORD believes patients should be confident that the technology they use to receive their care are HIPPA compliant and/or Federation and Drug Administration approved or cleared. However, we support these standards being waived as outlined in HB 2508, in the case of a future state of emergency as declared by the Governor to increase access to needed care in a timely manner for rare disease patients.

In conclusion, NORD believes HB 2508 will increase telehealth benefits for the rare disease community for years to come and is pleased to support this important legislation. NORD thanks you for your consideration and urges you to swiftly move this 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  
State Policy Manager, Western Region  
National Organization for Rare Disorders