



March 18, 2022

The Honorable Mary Daugherty Abrams
Chair
Senate Public Health Committee
Legislative Office Building
Room 3000
Hartford, CT 06106-1591

Re: Support for Senate Bill 375

Dear Chairwoman Daugherty Abrams,

On behalf of the 1-in-10 individuals in Connecticut 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 375 (SB375) and urges you to swiftly advance it out of the Joint Committee on Public Health. SB375 would extend the expansion of telehealth services until June 30, 2024, which would 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 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 experience¹. 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 Connecticut 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 related to telehealth access remain a priority as outlined in



[our organization's telehealth principles](#). Please see below for a summary of our principles as it relates to SB375.

- **All patients should have equal and effective access to telehealth services.**

SB375 supports access to and reimbursement for telehealth services regardless of a patient or providers geographic location. It also allows out-of-state healthcare professionals to provide telehealth services to Connecticut-based patients. On February 10, 2022, a bill (H.B. 5046) was introduced for Connecticut to join the Interstate Medical Licensure Compact (IMLC); the rare disease community would benefit from Connecticut joining the Interstate Medical Licensure Compact, 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 Connecticut.

- **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, SB375 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.

- **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 is HIPPA compliant and/or Federation and Drug Administration approved or cleared. SB375 provides that all technology be compliant with state and federal laws that protect patient information. SB375 also provides important transparency into patient costs for telehealth visits, requiring a provider to obtain a patient's consent before billing for the cost of providing telehealth services.

In conclusion, NORD believes SB375 will benefit the rare disease community in Connecticut 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