



April 22, 2021

The Honorable David Bentz
Chair
House Health and Human Development Committee
411 Legislative Ave
Dover, DE 19901

Re: Support for House Bill 160

Dear Chairman Bentz,

On behalf of the 1-in-10 individuals in Delaware with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to thank you for introducing House Bill 160 (HB 160) and express support for this important legislation. Temporarily expanded access to telehealth services during the COVID-19 pandemic has been critical for rare disease patients to maintain their health. HB 160 would streamline existing telehealth law and make permanent many of the changes that permitted this expanded access, enabling continued use of much-needed telehealth services during and after the COVID-19 pandemic. HB 160 would also help increase access to telehealth for the rare disease community by allowing coverage for audio-only telehealth services and adopting the language necessary for Delaware to join the Interstate Medical Licensure Compact, which would increase access to physicians across state lines. While NORD is supportive of HB 160, we would urge some small modifications be made to the legislation to ensure robust patient access to telehealth services is maintained before it is voted on by the full Delaware House of Representatives.

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, however, this often necessitates traveling significant distances, even across state lines, to obtain such care. During the COVID-19 pandemic, these patients are often 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 canceled medical appointment as a result of the COVID-19 pandemic. Fortunately, 88% of survey respondents also reported being offered a telehealth appointment amid this crisis, and 92% who accepted the offer of a visit said it was a



positive experience.¹ 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 Delaware has increased access to telehealth during the pandemic to meet the needs of Delaware's rare disease community. Many of HB 160's provisions align with our [organization's telehealth principles](#). For instance, HB 160 aligns with NORD's principle that states "all patients should have equal and effective access to telehealth services" by entering Delaware into the Interstate Medical Licensure Compact, which establishes a streamlined process for providers who want to practice in multiple states. The rare disease community would benefit from Delaware 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 Delaware. In addition, HB 160 also aligns with NORD's principle for equal and effective access to telehealth by allowing for audio-only service when there are access challenges to broadband or visual technology, which helps maintain patient access to telehealth services.

However, NORD urges you to consider certain modifications to further align with NORD's principle that "patient and providers should be able to make a choice on the location and type of care needed." Specifically, we urge slight modifications to Section 4, §6001 (3) which defines an "originating site" and §6005 (a)(4) which states an exception to the in-person requirements.² HB 160 defines an originating site as "a site in Delaware at which a patient is located at the time of health-care services are provided to the patients by means of telemedicine or telehealth" unless insurers and providers agree to an alternative site arrangement deemed appropriate. NORD recommends clarifying that a patient's home is guaranteed to be an originating site in addition to any other alternative site arrangements agreed upon by a provider and insurer.

Lastly, NORD is pleased to see the bill include exceptions to the requirement for an existing provider-patient relationship before receiving telehealth services to support patient and provider choice. NORD urges you to consider amending the bill to ensure that the "circumstances which make it impractical for a patient to consult with the health-care provider in-person prior to the delivery of telemedicine services" consider distance, patient mobility challenges, and lack of diagnosis as justifiable reasons for not seeing a provider in-person first before utilizing telehealth services.³ Unfortunately, it takes an average of 5-7 years for a rare disease patient to get an accurate diagnosis, and the intervening years often leave patients engaging with a variety of specialists. Telehealth can effectively reduce the burden of this diagnostic odyssey without needing to first establish an in-person patient-provider relationship.

¹ NORD. Ensuring Access to Telehealth for Rare Diseases. Accessed 4/21/21.

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

² <https://legis.delaware.gov/BillDetail?LegislationId=58579>

³ <https://legis.delaware.gov/BillDetail?LegislationId=58579>



In conclusion, NORD believes HB 160 will benefit the rare disease community in Delaware and is pleased to support this important legislation with the above-listed modifications. If you have any questions or need further assistance, please contact Annissa Reed at Areed@rarediseases.org.

Sincerely,

Annissa Reed

Annissa Reed
Eastern Region, State Policy Manager
National Organization for Rare Disorders

CC: House Health and Human Development Committee