



September 29, 2021

The Honorable Stephen A. Huffman
Chair
Senate Health Committee
1 Capitol Square, Ground Floor
Columbus, OH 43215

Re: Support for House Bill 122

Dear Chairman Huffman,

On behalf of the 1-in-10 individuals in Ohio 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 122 (H.B. 122) and urges you to swiftly advance it out of the Health Committee. H.B. 122 would make permanent important provisions related to telehealth that will allow the rare disease community to maintain 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. As a result of the COVID-19 pandemic, many of 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 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 Ohio has increased flexibility around telehealth during the pandemic to meet the needs of the rare disease community; however, it is critical moving forward that robust access to telehealth be maintained. To guide NORD's policy and advocacy work on telehealth,

¹ NORD. Ensuring Access to Telehealth for Rare Diseases. Accessed 3/23/21.
<https://rarediseases.org/wpcontent/uploads/2020/10/NRD-2098-RareInsights-Telehealth-Report-1.pdf>



our organization has developed a set of [telehealth principles](#). Please see below for a summary of our principles as it relates to H.B. 122:

- **All patients should have equal and effective access to telehealth services.** H.B. 122 supports access to and reimbursement for telehealth services from a robust set of health care providers, regardless of a patient or providers geographic location. It also allows Ohio health care professionals to provide telehealth services to a patient that is out of state if permitted by the laws of the state where the patient is located.
- **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.** H.B. 122 ensures coverage and patient cost-sharing parity exists for both in-person or remote visits. It also requires that health plans not impose patient cost-sharing when telehealth is utilized for preventative health care services.
- **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 HIPAA compliant and/or Food and Drug Administration approved or cleared. H.B. 122 provides that all technology be compliant with state and federal laws that protect patient information. H.B. 122 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 H.B. 122 will benefit the rare disease community in Ohio 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 Annissa Reed at Areed@rarediseases.org.

Sincerely,

Annissa Reed

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

Tiffany Sammons

Tiffany Sammons
Volunteer State Ambassador
Ohio Rare Action Network