



April 16, 2021

The Honorable Jake Chapman
President
Iowa Senate
256862 Fox Ridge Ln
Adel, IA 50003

The Honorable Brad Zaun
President Pro Tempore
Iowa Senate
7032 Holcomb Ave
Urbandale, IA 50322

Re: Support for House File 431

Dear President Chapman and President Pro Tempore Zaun,

On behalf of the 1-in-10 individuals in Iowa with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to express our support for House File (HF 431) and urges you to bring it to a vote in the Senate before the end of session. This legislation, which would greatly help increase access to telemedicine for rare disease patients and providers by allowing audio-only services, passed the House unanimously in February and now awaits consideration in the Senate.

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 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, but for some, access to broadband or video devices remains a challenge.

¹ 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>



To that end, NORD is grateful that the Iowa House of Representatives has approved HF 431, which will enable the use of audio-only telehealth services. This legislation aligns with [NORD's telehealth principles](#) to ensure access and patient choice remain front and center for telehealth post-pandemic. For example, our first principle states that *“all patients should have equal and effective access to telehealth services.”* One way to ensure this remains true is by allowing for audio-only telehealth services to ensure all patients have access to their providers regardless of broadband connection or access to a video device.

In conclusion, NORD believes HF 431 will benefit the rare disease community in Iowa and is pleased to support this important legislation. NORD thanks you for your consideration and urges you to swiftly move this bill through the Senate before the end of session. If you have any questions or need further assistance, please contact Alyss Patel at Apatel@rarediseases.org.

Sincerely,

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

CC: House Human Resources Committee