NORD®
National Organization
for Rare Disorders

January 27, 2023

Senate Telehealth Working Group
House Telehealth Caucus
Washington, DC 20510

Attn: Gabrielle Schechter, Office of Senator Brian Schatz
Crozer Connor, Office of Congressman Mike Thompson

RE: Input for the CONNECT for Health Act of 2023

Dear Members and Staff of the Senate Telehealth Working Group and House Telehealth Caucus,

On behalf of the over 25 million Americans living with a rare disease, the National Organization for Rare Disorders (NORD) welcomes the opportunity to provide feedback on the request for information on the 2023 version of the Creating Opportunities Now for Necessary and Care Technologies (CONNECT) for Health Act.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare 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.

In the United States, a rare disease is defined as any disease, disorder, illness, or condition affecting fewer than 200,000 people.[1] Unfortunately, there are often very few specialists who have expertise in any given rare disease. As a result, patients frequently travel significant distances, often across state lines, to see a medical specialist qualified to provide appropriate treatment for their condition. In a survey of rare disease patients conducted by NORD in 2019, 40% of respondents reported traveling 60 miles or greater to see a medical specialist with expertise in their rare condition.[2]

While rare disease patients faced serious barriers to care even before the COVID-19 pandemic, these barriers increased significantly within the rare disease community as the pandemic shocked the U.S. and global health care systems. In a survey of rare disease patients and caregivers conducted by NORD in the summer of 2020, 79% of respondents reported experiencing a canceled medical appointment due to

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[1] Orphan Drug Act, P.L. 97-414, as amended. https://www.fda.gov/industry/designating-orphan-product-drugs-and-biological-products/orphan-drug-act-relevant-excerpts

[2] NORD Report, *Ensuring Access to Telehealth for Rare Diseases.* October 15, 2020. https://rarediseases.org/wp-content/uploads/2020/10/NRD-2098-RareInsights-Telehealth-Report-1.pdf

COVID-19.[3] Fortunately, 88% of survey respondents reported being offered a telehealth appointment, and 92% who accepted the offer of a telehealth visit reported having a positive experience with telehealth.[4] Looking ahead, many patients and providers have signaled that they appreciate and have benefitted from the expanded use of telehealth and want to see its permanent integration into our health care system.

NORD is grateful that with the passage of H.R. 2617, the Consolidated Appropriations Act, 2023, policymakers have taken action to extend certain Medicare telehealth flexibilities afforded under the public health emergency (PHE) through the end of 2024 and numerous reports are in development to inform future telehealth legislation and policy. Still, there is clearly more that must be done to ensure all patients have equal and effective access to telehealth services. Our comments are built around NORD's Telehealth Principles which were developed in 2020 and are aimed at improving telehealth access for rare disease patients.

Recommendations for the CONNECT for Health Act of 2023

1. **Fully remove all originating site and geographic restrictions on telehealth in the Medicare program.**
   During the PHE, Medicare expanded the list of originating sites where a patient can be physically located while receiving telehealth services. This flexibility has enabled rare disease patients who, for a variety of reasons, including being immune compromised, benefited from being able to see a medical professional from the convenience and safety of their home. These flexibilities also enabled access to telehealth services for Medicare beneficiaries who are not located in a rural Health Professional Shortage Area or in a county outside of a Metropolitan Statistical Area – requirements for telehealth eligibility prior to the PHE. While this provision has been extended to the end of 2024, it remains a temporary flexibility and many Americans will lose access to telehealth services should the policy be allowed to lapse. Removing geographic site restrictions is particularly important for rare disease patients, who may live in an area with ample access to health care professionals and still lack access to a provider with experience treating their condition.

2. **Provide incentives for states to facilitate broader access to telehealth services with out-of-state providers.**
   As mentioned previously, rare disease patients are often required to travel long distances, including across state lines, to access necessary and appropriate medical care. Currently, many states' licensure laws create barriers to care by limiting providers ability to see patients across state lines. This not only complicates access for patients, but also creates additional burdens for clinicians who want to see out-of-state patients who lack appropriate care closer to home. For

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[3] NORD Report. *COVID-19 Community Follow-Up Survey Report.* August 4, 2020. https://rarediseases.org/wp-content/uploads/2022/10/NRD-2061-RareInsights-CV19-Report-2_FNL.pdf

[4] Ibid.

example, NORD recently heard from a physician in New York who provides highly specialized care for children and adults with a rare disorder characterized by behavioral challenges and intellectual disability. During the pandemic, state-level telehealth waivers allowed him to see patients who had previously been unable to seek his expert care due to the distance from their home state. Additionally, he was able to observe the behavior of patients who he typically only saw in the office in a home setting, an activity that can be very helpful when evaluating children with this condition. However, as states have returned to pre-COVID telehealth policies, he can no longer see several of his patients who live in other states via telehealth in their home setting. Stories like these are far too common among patients and providers in the rare disease community.

Solutions like the Interstate Medical Licensure Compact, while helpful in streamlining state licensure for physicians in participating states, are often not sufficient to meet rare disease patients and their providers' needs. For many rare diseases, there may be only one expert nationwide in any given condition. It is not practical, or at this time even possible, for a physician to be licensed in all 50 states, even if their expertise and care are needed by a few patients in each state. Patients and families should not be forced to travel long distances or even relocate to obtain necessary medical care. We urge Congress to take steps to incentivize states to facilitate access to out-of-state providers when specialized care isn't available nearby.

3. **Fully remove distant site provider list restrictions to allow CMS to determine which providers enrolled in Medicare can provide telehealth services when clinically appropriate.**
   Many rare disease patients have extremely complex medical needs which necessitate care from providers other than those on the distant site provider list. Allowing other providers, such as speech, occupational, and physical therapists to provide appropriate care via telehealth would expand access to those providers for Medicare beneficiaries who may not otherwise be able to see them.

4. **Allow CMS to cover audio-only telehealth services when clinically appropriate.**
   When considering how to expand access to telehealth services, we cannot ignore the fact that one in five American households do not have internet access.[5] Ninety-seven percent of Americans, however, own a cell phone.[6] Audio-only telehealth services have proved to be useful for providers to complete visits with patients who live in areas with limited broadband services and/or don't have access to audio-visual capable devices. While audio-only care is not appropriate in all circumstances, Congress should give CMS the authority to determine which audio-only services must be available on a code-by-code basis.

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[5] National Telecommunications and Information Administration. *Switched Off: Why Are One in Five U.S. Households Not Online?* October 4, 2022. https://ntia.gov/blog/2022/switched-why-are-one-five-us-households-not-online

[6] Ibid.

5. **<u>Regularly collect and analyze data related to patient outcomes, including continuity of care and treatment adherence, for Medicare and Medicaid beneficiaries with chronic or rare conditions who utilize telehealth services.</u>**
   A key position within NORD's telehealth principles is that decisions around telehealth should be driven by data. Several Congressionally requested reports are in development that would analyze telehealth access, utilization, cost and health outcomes, but NORD would encourage Congress to request these reports also include information and analysis examining continuity of care and treatment adherence for Medicare and Medicaid beneficiaries with chronic or rare conditions before and after implementation of telehealth flexibilities under the PHE. A lack of transportation, unstable housing, inaccessible infrastructure, incompatible work or school schedules, difficult financial situations, and other factors can impact an individual's ability to reliably attend medical appointments and adhere to a treatment regimen. When visits can be attended at home or in another remote location, patients are able to attend visits they otherwise may have missed, enabling better management of chronic or rare health conditions.

6. **<u>Ensure telehealth fraud and abuse policy is informed by data and does not unnecessarily burden patient access.</u>**
   Recognizing that Congress has directed the Secretary to conduct a study on program integrity related to telehealth services under Medicare Part B, and that a recent report released by the Office of the Inspector General (OIG) found that 99.98% of providers billed Medicare correctly during the telehealth surge of 2020[7], we urge Congress to base future telehealth fraud and abuse policy on the available data.

   Oversight is undeniably important when expanding access to new care modalities, however, policies that implement provisions such as in-person visit requirements can create needless barriers when applied to certain types of care. This is especially relevant to rare disease patients, who often live far from health care providers with expertise in their condition, making in-person visits difficult or even prohibitive, ultimately resulting in suboptimal health outcomes. These requirements can not only make it difficult for diagnosed patients to see experts familiar with their condition, but also prevent patients from obtaining a timely and accurate diagnosis. For example, an in-person visit is largely unnecessary for a genetic counseling consultation but may prevent patients in areas with genetics workforce shortages from accessing essential genetic testing and an accurate diagnosis. Fraud and abuse prevention should be informed by the data outlined in the recent OIG report and the pending Secretary's report on telehealth and program integrity and targeted to realize the benefits of telehealth services while minimizing risk in an efficient and effective manner.

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[7] U.S. Department of Health and Human Services, Office of the Inspector General. *Medicare Telehealth Services During the First Year of the Pandemic: Program Integrity Risks.* September, 2022. OEI-02-20-00720

7. **Develop guidance for providers and telehealth platform developers on how to make telehealth accessible for patients with disabilities.**
   Telehealth has played an important role in making health care accessible for people with disabilities, but discrimination and other problems can prevent people with disabilities from fully accessing that care. We recommend that CMS utilize Section 504 of the Rehabilitation Act and the Americans with Disabilities Act electronic and information technology standards to provide guidance to providers and platform developers on how to ensure that telehealth platforms are accessible for people with disabilities. This may include incorporating communication aids, allowing a support person to join the appointment, budgeting additional time, sending materials for review prior to the appointment, and more.

8. **Provide for a National Academies of Medicine (NAM) report on the barriers that prevent rare disease patients from accessing specialty medical care and the opportunities for telehealth and other emerging technologies to address these barriers.**
   Rare disease patients face several barriers to accessing the medical care they need. This can manifest through limitations imposed by insurance coverage, physical distance to appropriate specialty care, fragmented state licensure laws, inaccessibility of transit, and more. For many rare disease patients, even obtaining a correct diagnosis can take years, often due to inadequate access to providers with the expertise necessary to ascertain an accurate diagnosis. The genetics workforce shortage, for example, can delay the genetic testing a patient needs in order to be diagnosed. Ten U.S. states have fewer than three genetic counselors per 500,000 residents, and medical geneticists are even more scarce. New technologies, including telehealth and e-consults, present an opportunity for patients who live in areas without access to these providers to be seen sooner and cut down delays to treatment. Congress should provide for a NAM report to identify rare disease patients' greatest barriers to care and make recommendations on how to mitigate said barriers.

9. **Add a finding stating telehealth should be a decision made between patients and providers.**
   NORD recommends adding a finding stating that the decision to utilize telehealth as a care modality should be made by a patient and their provider, based on what is in the best interest of the patient. Increasingly, we are hearing from patients who are being pushed to in-person medical appointments not out of medical necessity, but rather due to circumstances related to state licensure requirements, ability of providers to charge facility fees, or providers preferred use of in-house ancillary services, such as laboratory services. Patient and provider choice of health care setting to achieve optimal health outcomes is critical and patients should not be pushed to or away from telehealth by their health plans or providers for non-medical reasons.

NORD applauds the Senate Telehealth Working Group and the House Telehealth Caucus for the continued commitment to improving telehealth access for patients across the country and is grateful for this opportunity to provide input on this important legislation. We are hopeful that the CONNECT for

Health Act of 2023 will make great strides toward our common goal of achieving equal and effective access to telehealth for rare disease patients and Americans across the board. If you have any additional questions, please contact Allison Herrity at aherrity@rarediseases.org.

Sincerely,

Allison Herrity, MPH
Policy Analyst
National Organization for Rare Disorders