NORD®
National Organization
for Rare Disorders

April 28, 2021

The Honorable Lloyd Doggett
Chair, Subcommittee on Health
House Ways and Means Committee
2307 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Devin Nunes
Ranking Member, Subcommittee on Health
House Ways and Means Committee
1013 Longworth Building
Washington, D.C. 20515

Dear Chairman Doggett and Ranking Member Nunes,

The National Organization for Rare Disorders (NORD) thanks you for holding today's hearing titled, "Charting the Path Forward for Telehealth." This topic is extremely important to rare disease patients who have relied extensively on telehealth services during the COVID-19 pandemic to manage their often-complex health conditions from the safety of their homes. NORD is grateful for the efforts of Congress and the U.S. Department of Health and Human Services to enable broad telehealth access for patients on Medicare during this public health emergency and urges Congress to take the steps necessary to integrate telehealth fully and permanently into Medicare and our broader health care system.

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. This includes robust access to telehealth services in a post-pandemic world.

Due to the nature of their conditions, rare disease patients often struggle to find health care providers with expertise in their disease(s). Traveling hundreds and sometimes thousands of miles across state lines for a routine medical appointment is not uncommon for an individual with a rare disease and their caregiver. In fact, a 2020 NORD survey of over 800 rare disease patients and caregivers found that almost 40% of rare disease patients traveled more than 60 miles to receive their medical care.[1] This often results in significant burdens for both patients and their caregivers, including missing work, time away from family, and travel-related complications and costs.

Given these challenges, it is not surprising that the response of the rare disease community to increased access to telehealth services has been overwhelmingly positive. NORD's 2020 survey results revealed that 79% of respondents had experienced a canceled medical appointment as a result of the COVID-19 pandemic, but 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

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[1] https://rarediseases.org/wp-content/uploads/2020/10/NRD-2098-RareInsights-Telehealth-Report-1.pdf

it was a positive experience.[2] 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, with 70% of respondents would like the option of telemedicine for every appointment in the future.[3]

While federal and state governments quickly adapted to the COVID-19 pandemic by expanding telehealth access to patients, many of the waivers that have made this expansion a success are temporary and tied to emergency declarations. As we slowly inch closer to the end of this pandemic, and as the Committee considers the future of telehealth, NORD believes that the following fundamental principles should permeate these discussions to ensure patient needs are at the forefront of telehealth policy decisions:

- All patients should have equal and effective access to telehealth services.
- Patient choice must be preserved; patients and their providers should be able to make a choice on the location and type of care they receive that is based on what is in the best interests of the patient; and patients should not be pushed to or away from telehealth by their health plans or providers.
- Transparency around privacy protections and cost-sharing must be established and preserved.
- Data should drive decisions on telehealth.

In furtherance of these principles, NORD is supportive of legislative efforts that will permanently end geographic and originating site requirements under Medicare, allow for additional health care providers to utilize telehealth services to meet with their patients and expand the types of health care services that can be done via telehealth. Furthermore, NORD supports legislative efforts to require robust data collection from Medicare and Medicaid programs to analyze the impact of expanded telehealth access on utilization, health outcomes and health equity. Therefore, NORD has formally endorsed H.R. 1332, the Telehealth Modernization Act and well as the soon-to-be reintroduced CONNECT for Health Act and urges their swift consideration by the Ways and Means Committee.

Even with waivers in place, some rare disease patients have continued to struggle to see their out-of-state health care providers because states have not uniformly adjusted their licensure requirements, creating a patchwork of requirements that have been difficult for patients and providers to navigate. Within the first few months of the pandemic, all states used waivers to adjust their licensure requirements to some degree. However, numerous states have let those waivers expire[4], leaving an increasing number of patients unable to see their out-of-state health care providers via telehealth even as the threat of COVID-19 persists. Therefore, NORD

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[2] Ibid.

[3] Ibid.

[4] https://www.fsmb.org/siteassets/advocacy/pdf/state-emergency-declarations-licensures-requirementscovid-19.pdf

supports the passage of the TREAT Act (H.R. 708), which provides for universal reciprocity for state licensure for the duration of the COVID-19 public health emergency. While this legislation has been referred to the Energy and Commerce Committee for consideration, NORD encourages the members of this Committee to cosponsor this important legislation and push for its inclusion in any health care package moving through Congress.

The future of telehealth is an issue that is top of mind for many organizations, and NORD is working with numerous other patient advocacy groups to ensure that any permanent changes to telehealth policy are done with patient needs in mind. To this end, last year, the Partnership to Protect Coverage coalition, which consists of some of the largest patient advocacy organizations in the country, released coalition principles for telehealth. NORD and these other patient advocacy groups, which represent tens of millions of Americans with acute and chronic conditions, stand ready to provide valuable insight to this Committee for the purposes of expanding telehealth permanently in a manner that truly benefits patients.

This pandemic has laid bare many challenges in our society, but NORD is hopeful that telehealth can continue to be a way to reduce some of the burdens that rare disease patients and their caregivers face. NORD looks forward to working with the Ways and Means Committee to ensure that telehealth is appropriately and permanently integrated into Medicare and the broader health care system to help meet the needs of rare disease patients. If you have any questions, please do not hesitate to reach out to Heidi Ross at HRoss@rarediseases.org.

Sincerely,

Heidi Ross

Heidi Ross, M.P.H.
Director of Policy
National Organization for Rare Disorders