



March 2, 2020

The Honorable Anna Eshoo
Chairwoman
House Energy and Commerce Subcommittee on
Health
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Brett Guthrie
Ranking Member
House Energy and Commerce Subcommittee
on Health
2125 Rayburn House Office Building
Washington, DC 20515

Dear Chairwoman Eshoo and Ranking Member Guthrie,

The National Organization for Rare Disorders (NORD) thanks you for holding this important hearing titled, “The Future of Telehealth: How Covid-19 Is Changing the Delivery of Virtual Care.” This topic is extremely important to rare disease patients who have relied 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 during this public health emergency and urges Congress to take the steps necessary to fully and permanently integrate telehealth into our 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 affordable 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. This results in significant missed time away from school, work and family, travel costs, and disruptions to everyday life.

Given the challenges often encountered trying to attend routine health care appointments, it is not surprising that the response of the rare disease community to increased access to telehealth services has been overwhelmingly positive. In the summer of 2020, NORD surveyed over 800 rare disease patients about their telehealth experience. The survey results revealed that 79% of respondents had experienced a canceled medical appointment as a result of the COVID-19 pandemic.¹ 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

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

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. Even with these 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 adjusted their licensure requirements. However, as of today, six states have let those waivers expire and more are set to expire this month, 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 urges this Committee to support the inclusion of Rep. Latta's and Rep. Dingell's [TREAT Act](#) (H.R. 708), which provides for universal reciprocity for state licensure for the duration of the COVID-19 public health emergency, into the current COVID-19 relief package.

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. 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.
- 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. Patient choice must be preserved; 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, provisions that have been championed by several members of this Subcommittee. NORD also urges swift consideration of the provisions included Rep. Kelly's [Evaluating Disparities and Outcomes of Telehealth During COVID-19 Emergency Act of 2020 \(H.R. 7808 in the 116th Congress\)](#), which required federal

² Ibid.

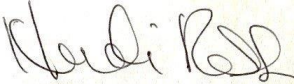
³ Ibid.

and state governments to collect and analyze data from Medicare and Medicaid on the impact of telehealth on utilization, health outcomes, and spending during the COVID-19 pandemic once the public health emergency declaration has expired.

The future of telehealth is an issue that is top of mind for many organizations, and NORD is working with numerous other patient 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.

Thank you for the opportunity to submit this statement to the Committee; we look forward to working with Congress to ensure that telehealth is adequately enshrined as an option for patients in the future. If you have any questions, please do not hesitate to reach out to Heidi Ross at HRoss@rarediseases.org.

Sincerely,

A handwritten signature in black ink, appearing to read "Heidi Ross", is written over a light yellow rectangular background.

Heidi Ross, M.P.H.