ENSURING ACCESS TO TELEHEALTH FOR RARE DISEASES

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The National Organization for Rare Disorders (NORD®) is the leading independent advocacy organization representing over 25 million Americans affected by a rare disease. NORD is committed to the identification, treatment and cure of the more than 7,000 rare diseases, of which approximately 90% are still without an FDA-approved treatment or therapy.

NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 37 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research and providing patient and family services for those who need them most. NORD is also home to over 300 disease-specific patient and family services for those who need them.

For the more than 25 million Americans with rare and undiagnosed diseases, having consistent access to health care providers is critical to their immediate and long-term health. Throughout the coronavirus pandemic, nearly 8 in 10 rare disease patients experienced canceled medical appointments. Fortunately, during this time period, telehealth emerged as an increasingly common way for people to safely access medical care without risking exposure to the virus. Going forward, the majority of rare disease patients say that they want the option of telehealth for their medical appointments.

For many rare diseases, there are only a handful of specialists nationwide, or even worldwide, who have expertise in that condition. As a result, patients often are forced to travel long distances to access their treating providers. Such travel involves significant expenses, time off from work and logistical challenges. For rare disease patients who are immunocompromised, it may not even be safe for them to travel these distances.

Recent surveys conducted by the National Organization for Rare Disorders (NORD) found that out of over 800 rare disease patients and caregivers, more than 83% had been offered a telehealth visit during the COVID-19 pandemic by their health provider and, of those who were offered a visit, 88% accepted. Out of all patients who reported having had a telehealth visit, 92% described it as a positive experience, and 70% of respondents would like the option of telehealth for future medical appointments.

NORD has been hard at work finding ways to ensure that people with rare diseases have continued access to telehealth throughout the pandemic and beyond. Further, as part of our efforts to advance understanding of the rare disease patient experience through data under our RareInsights® initiative, we analyzed findings from NORD’s recent research, including our Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up survey and two COVID-19 Community surveys, in conjunction with publicly-available data, to better understand and quantify the opportunities of telehealth.

**ABOUT RAREINSIGHTS®**

RareInsights® is a NORD initiative to expand public knowledge of rare diseases and translate that knowledge into real-world solutions for patients and families. Through this initiative, NORD is commissioning and undertaking a broad range of projects to collect and analyze empirical data for next-generation advocacy that is patient-centered and data-driven. Information is shared with the community in a variety of accessible formats, including reports, white papers, infographics, fact sheets, and more.

**RARE DISEASE PATIENT EXPERIENCE**

Why is access to telehealth so critical for people with rare diseases? First, patient safety is an acute concern. Many individuals living with rare diseases are immunocompromised, putting them at greater risk for complications from COVID-19 and other illnesses.

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2 Ibid. 3 Ibid. 4 Ibid. 5 Ibid. 6 Ibid.
Second, in the case of many rare diseases, there few providers who are experts in the disease and there can be a significant distance between where a patient lives and where their health care provider practices, leaving patients and often their family caregivers no choice but to take time off work to travel to see that provider. NORD’s recent Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up survey found that 62% of patients have been prevented from attending work and 26% of children have missed school as a result of their rare disease.¹ Thirty-nine percent of patients travel at least 60 miles to receive medical care.² The burden of travel is so great that 17% have moved (or are considering relocation) to be closer to treatment to manage their rare diseases over the long-term.³

These concerns and challenges have been highlighted by the hundreds of rare disease patients and caregivers who have told NORD about the positive impact that telemedicine has had on their lives during the pandemic, who have told NORD about the positive impact that telemedicine has had on their lives during the pandemic, and where their health care provider practices, leaving patients and often their family caregivers no choice but to take time off work to travel to see that provider. NORD’s recent Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up survey found that 62% of patients have been prevented from attending work and 26% of children have missed school as a result of their rare disease.¹ Thirty-nine percent of patients travel at least 60 miles to receive medical care.² The burden of travel is so great that 17% have moved (or are considering relocation) to be closer to treatment to manage their rare diseases over the long-term.³


62% of patients have been prevented from attending work due to their rare disease.⁴

26% of children have missed school as a result of their rare disease.⁴

39% of patients travel at least 60 miles to receive medical care.⁵

Eighty-eight percent of rare disease patients would consider using an investigational treatment.⁶

Policy Developments

In response to the call from the rare disease community reflected in our surveys, NORD’s policy team went right to work advocating for immediate access to telehealth in the context of the COVID-19 public health emergency.

While the concept of telehealth is not a new development, telehealth visits accounted for less than 0.01% of total health care visits across the US before the COVID-19 public health emergency declaration.⁷ By mid-April, that number had increased to 69%.⁸ According to data from the Centers for Medicare & Medicaid Services (CMS), prior to the pandemic, 14,000 beneficiaries received a Medicare telehealth service each week, yet more than 10.1 million beneficiaries utilized telehealth between mid-March and early-July.⁹

In response to the pandemic, starting in early March, the federal government took important steps to temporaril...
Currently, the Trump Administration, Congress and state governments are trying to decide which changes to telehealth should be made permanent beyond the COVID-19 public health emergency. Taking our cue from rare disease patients and providers, NORD drafted telehealth principles to shape our support or opposition to the numerous permanent changes being considered. We also joined forces with 34 other patient organizations to release coalition telehealth principles to guide policymakers seeking to ensure millions of patients with pre-existing and chronic conditions can continue to safely access appropriate telehealth services during and after the COVID-19 public health emergency. NORD has endorsed certain federal legislation\textsuperscript{14,15,16} and has been tracking and engaging on more than 80 bills around the country related to COVID-19.

\textit{Read NORD’s policy statements related to COVID-19.}

\textbf{WHAT CAN YOU DO TO HELP?}

Many telehealth improvements are time-limited to the COVID-19 public health emergency declaration, however, our continued advocacy can help on this issue so that the positive changes that we have seen during the pandemic will endure after it ends. \textbf{Share your COVID-19 telehealth experience with NORD and/or send a message to your Senators and Representative asking them to protect rare disease patients in the next coronavirus relief package.} Together, we can fight to ensure that telehealth opportunities are equally and appropriately available to the benefit and not detriment of rare disease patients.

